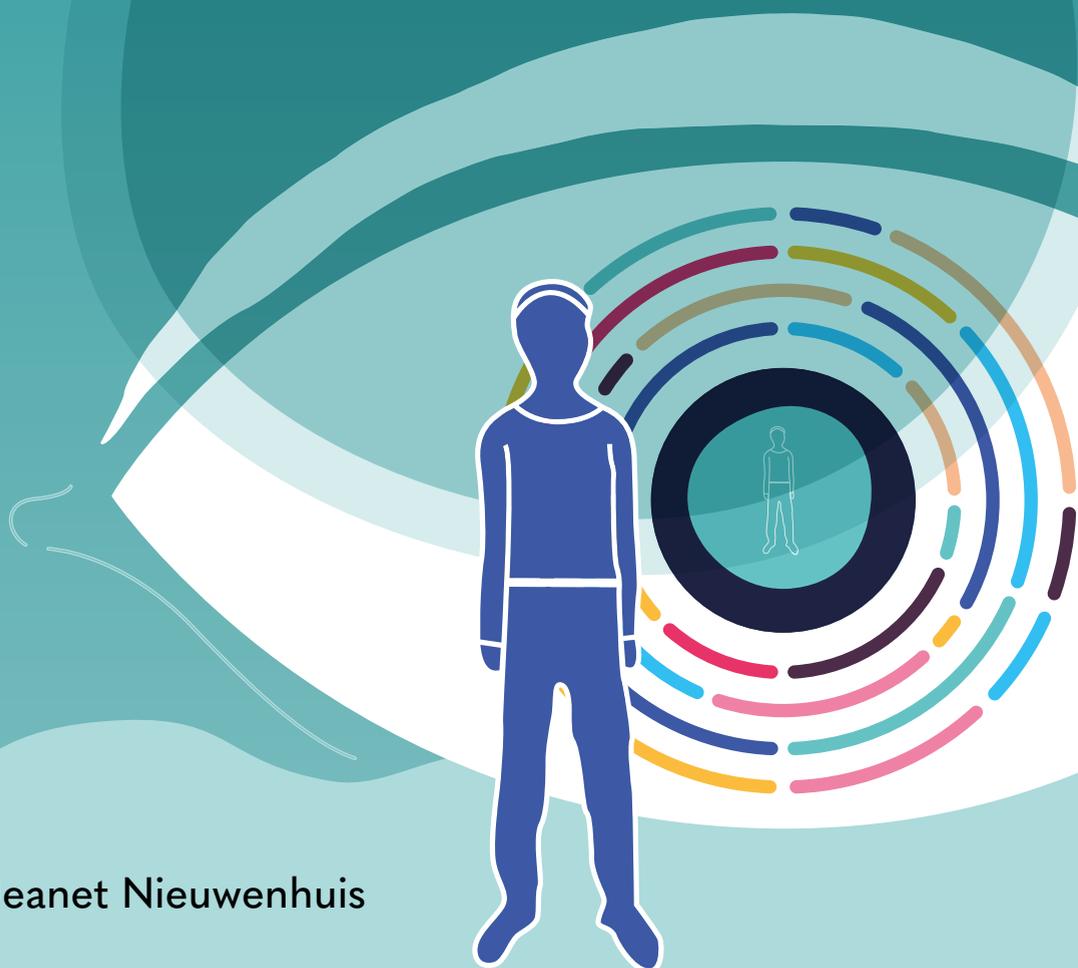# A blind spot?

Screening for mild intellectual disabilities
and borderline intellectual functioning
in psychiatric patients in specialized
mental health care in the Netherlands:
prevalence and associations

Jeanet Nieuwenhuis

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**GGNet**   ERASMUS UNIVERSITEIT ROTTERDAM

# Een blinde vlek?

Screening op licht verstandelijke beperkingen en zwakbegaafdheid bij psychiatrische patiënten in de gespecialiseerde geestelijke gezondheidszorg in Nederland: prevalentie en associaties

# A blind spot?

Screening for mild intellectual disabilities and borderline intellectual functioning in psychiatric patients in specialized mental health care in the Netherlands: prevalence and associations

**PROEFSCHRIFT**

Ter verkrijging van de graad van doctor aan de
Erasmus Universiteit Rotterdam
op gezag van de rector magnificus
Prof.dr. A.L. Bredenoord
en vervolgens besluit van het College voor Promoties.

De openbare verdediging zal plaatsvinden op
dinsdag 20 september 2022 om 13:00 uur.

door
**Janna Grietje Nieuwenhuis**
geboren te Renkum

**Erasmus University Rotterdam**

**Promotoren**
Prof. dr. C.L. Mulder
Prof. dr. H.L.I. Nijman †
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Prof. dr. H.C.M. Didden

**Copromotor**
Dr. E.O. Noorthoorn

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# Ruimte scheidt de lichamen, niet de geesten

Diderius Erasmus (filosoof)

Chapter

# General introduction

**1**

# Introduction

This introductory chapter will start with an explanation of the term Intellectual Disability (ID), definitions of Mild Intellectual Disability (MID) and Borderline Intellectual Functioning (BIF), and also the description of the term "Licht Verstandelijke Beperking" as used in the Netherlands. Followed by, in short, the associations between psychiatric disorders and the prevalence of "Licht Verstandelijke Beperking (LVB)" and ID in different populations. Next, screening and diagnosing of ID in clinical psychiatric practice, aetiology of ID, changing perspectives on ID and psychiatry over time are discussed, followed by three vignettes from my daily clinical practice at VGGNet. Finally, the aims and structure of the thesis are described.

Patients inspired me to start this PhD project. Together with my colleagues, we started the SCIL project in GGNet to improve the recognition, screening, and diagnosis of "Licht Verstandelijke Beperking" in clinical practice in general mental health care. The project was named after the recently developed SCreener Intelligence Learning disability (SCIL;1). After a local audit, evidence suggested underdiagnosis in the number of patients with the MID/BIF. We wanted to close this gap. We did this by using the SCIL for estimating the prevalence of MID/BIF and factors associated with MID/BIF in general psychiatry, as described in this PhD thesis. With the SCIL project in GGNet, we also wanted to make our mental health trust more aware of and responsive to LVB related needs. As we know from daily clinical practice at VGGNet, an expertise centre of GGNet (a Mental Health Trust in the East of the Netherlands for patients with psychiatric problems and LVB), these patients can be treated very well. Apart from the patients (some of them described in the vignettes below), three other factors motivated me to start this PhD project:

1.  the lack of international research on the subject of the prevalence of MID and BIF in general psychiatry;

2.  possibilities for research in this area after the publishing of the SCreener Intelligence Learning disability (the SCIL) and finally;

3.  the recently published research in ID and Psychiatry of colleagues in the Netherlands (2,3).

## 1.1 Intellectual Disability

### 1.1.1 Intellectual Disability Internationally

In the last few decades, many terms and definitions have been used to refer to intellectual disability (ID), such as mental retardation, mental handicap, intellectual disabilities, and learning disabilities. According to the WHO, the use of terminology varies between countries, with the term mental retardation being the most used in 2007 (76.0%), followed by intellectual disabilities (56.8%), mental handicap (39.7%), and mental disability (39.0%) (4).

More recently, in psychiatry, internationally, there are currently three closely aligned definitions of Intellectual Disability (5):

(1) The first definition is the American Association on Intellectual and Developmental Disabilities (AAIDD). The AAIDD definition is: "significant limitations characterize intellectual disability in both intellectual functioning (reasoning, learning, problem-solving) as well as adaptive behaviour, as expressed in everyday conceptual, social, and practical adaptive skills. This disability originates before age 18". Recently this has been changed in the age of 22.

(2) The second definition, closely aligned with the previous one, is that proposed in the DSM-5 by the American Psychiatric Association (APA, 2013), which is that "intellectual disability (intellectual developmental disorder) is a disorder with its onset during the developmental period that includes both intellectual and adaptive behaviour deficits in conceptual, social, and practical domains".

(3) The third definition is found in the ICD-11 (World Health Organization, 2018): "disorders of intellectual development are a group of aetiologically diverse conditions originating during the developmental period characterized by significantly below average intellectual functioning and (approximately less than the 2.3 rd. percentile, see figure1), based on appropriately normed, individually administered standardized appropriately normed and standardized tests adaptive behaviour that are approximately two or more standard deviations below the mean are not available, diagnosis of disorders of intellectual development requires greater reliance on clinical judgment based on appropriate assessment of comparable behavioural indicators."

In all these three definitions, the emphasis is on significant deficits in intellectual functioning, adaptive behaviour, and age of onset during the developmental period (6). The causative relationship between intellectual functioning and adaptive behaviour is debated among clinicians and researchers. Both can be seen as two different constructs, but without a doubt, intelligence and adaptive functioning have a strong correlation (7).

With the introduction of DSM-5 in 2017, the dominant classification used in the Netherlands, a sub-classification system based on the person's needs for support rather than the individual's intelligence quotient (IQ) level, was introduced. IQ numbers were left out. ID is usually classified according to the severity of the cognitive impairment, together with adaptive functioning in conceptual and social domains, in mild, moderate, severe and profound. In clinical practice, an IQ score can still be a helpful guideline.

These changes reflect a better understanding of intelligence and adaptive behaviour (8,9). To date, the support programs for the very heterogeneous population of people with MID or BIF seem to be suboptimal, indicating that more differentiation is required in the services offered to these individuals.

### 1.1.2 Mild Intellectual Disability

In DSM 5, MID covers people with a mild intellectual impairment with difficulties in adaptive functioning in such a way that this leads to failure to meet developmental and sociocultural standards of personal independence and social responsibility. Although IQ figures are officially left out, in daily clinical practice, this still corresponds with a Total Intellectual Quotient (TIQ) in the range of 50-70, so 2.3 standard deviations lower than the standard score of 100 points (See figure 1). Without continued support, the deficiencies in adaptability limit functioning in one or more aspects of daily life, including communication, participation in social life, school or professional functioning and personal independence at home or social environment. This disorder is seen as a neurobiological developmental disorder starting before 22 years.

### 1.1.3 Borderline Intellectual Functioning (BIF)

BIF has always been a problematic concept that has changed in both name and IQ boundaries. Since the introduction of DSM 5, BIF is just a descriptive V-code that can be used when there is a reason for care or when treatment or prognoses are influenced negatively by the BIF. Former IQ ranges (70-85) are left out, but a careful assessment of intellectual and adaptive functions and their discrepancies is needed, especially when there is a mental disorder. Historically BIF started as a sub-type of ID (formerly mental retardation or intellectual disability) but morphed into its current status when the IQ ceiling for ID was changed from minus one standard deviation (85)

to minus two standard deviations (70). It has been suggested that, as people with BIF often have adjustment problems, the BIF category should be elevated to the status of a formal psychiatric disorder (10). In my opinion, by making it a disorder, clinicians would take it more seriously into account when devising a treatment plan.

Figure 1: Normal Standard Distribution and standard IQ Scores

**IQ Scale with percentiles**



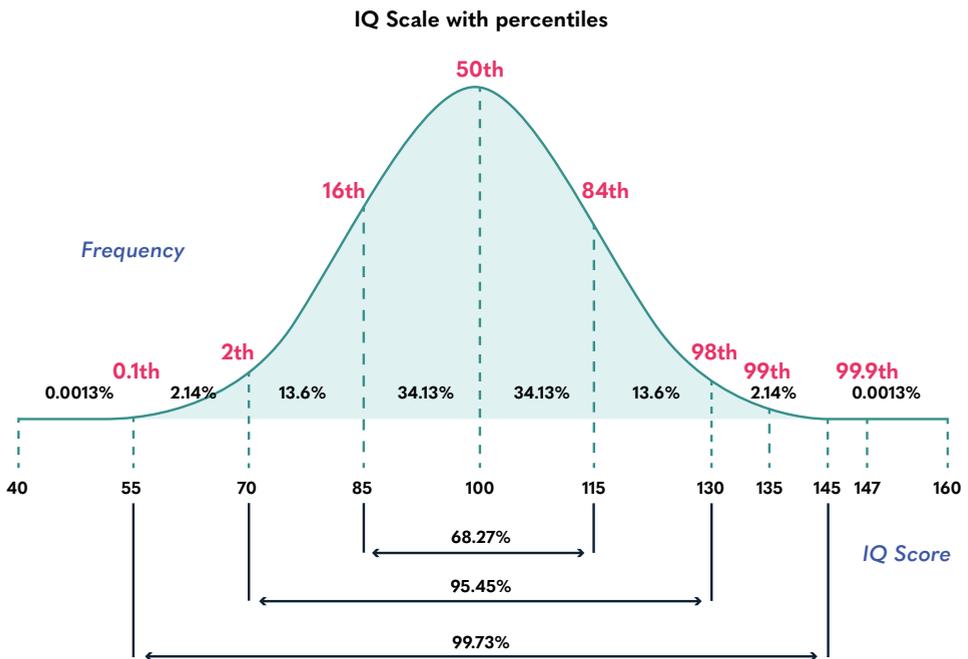Figure 1. The normal curve of the distribution of intelligence in the general population. The intelligence quotient (IQ) is a score derived from one of the standardized tests designed to assess human intelligence. The median raw score of the normative sample is defined as an IQ of 100; each standard deviation up or down equals 15 points. By this definition, approximately two-thirds of the population scores and an IQ between 85-115.

### 1.1.4 Licht Verstandelijke Beperking (LVB)

In the Netherlands, in contrast to many other countries, policymakers and clinicians in mental health care use the term "Licht Verstandelijke Beperking" (LVB). It can be translated as "Slightly Limited Ability". In detail, it covers not only people who have an IQ score in the range of 50-70 (MID) but also an IQ score of 70-85 with additional problems such as problems in self-sustainability and those who need professional support (BIF). Thus, in the Netherlands, although sometimes confusing, we often use LVB as a broad definition. Although the use of this term and definition is still under debate, there is agreement among professionals in mental health care about the vulnerability of BIF patients, especially because of today's complex and digital society. Often BIF remains unnoticed by others and by the people themselves and can easily lead to an accumulation of problems (11). This vulnerability means that these BIF persons often fall under the definition of "Licht Verstandelijke Beperking".

Nouwens et al. 2017 (12) concluded that individuals referred to an organization that offers long-term inpatient/outpatient care for people with ID can be separated into five categories. These categories differ significantly in individual and environmental characteristics and care needs. For example, he concluded that people with MID experienced fewer problems such as personal, environmental and parental (e.g. financial and mental health) problems than those with BIF who suffer more from poverty in the family of origin, sexual and physical abuse, externalizing problem behaviour, having multiple judicial contacts, and addiction problems.

### 1.1.5 MID/BIF and Psychiatric Problems

People with MID/BIF frequently suffer from psychiatric problems and vice versa. Matson et al. (13) concluded that although ID has been a topic of considerable interest since the inception of the mental health field, this has not been the case concerning co-occurring psychopathology. Instead, for many years, professionals and researchers did not believe that these two phenomena could both be present in the same person. Although research on this topic is growing, especially in the field of autism spectrum disorders (ASS;13) and post-traumatic stress disorder (PTSD;14), there is a lack of recently published reviews that cover an overview of studies into the comorbidity of patients with MID/BIF in general psychiatry or ID services. Below, we present a summary of the results of recent studies.

Firstly, two studies were carried out in patients treated within ID services; Morgan et al. (15) cross-linked the Western Australian intellectual disability register with a register of psychiatric diagnoses among people with ID (IQ below 74). Overall, they found that 31.7% of people with an ID also had a psychiatric disorder. Schizophrenia, but not

bipolar disorder and unipolar depression, were significantly overrepresented among individuals with an IQ below 74. Next, Bhaumik et al. (2008) did a cross-sectional study on all adults with ID (IQ below 70) using records of specialist services in the U.K. They came to a similar percentage as Morgan et al. (15), in effect, that psychiatric disorders such as schizophrenia and depression were present in 33.8 % of adults with ID (16).

Secondly, two studies concerning BIF in the general population; McManus et al. (17), used the Adult Psychiatric Morbidity Survey of people with BIF (IQ 70-79) who were living in private households and who had the cognitive and verbal ability to participate in a general household survey. This study showed that adults with BIF face high mental health morbidity, poorer general health, and many limitations in their daily lives. A quarter of people (24%) with a Verbal IQ of less than 80 had a common mental disorder such as an anxiety disorder or depression, compared with 17% of the adult population as a whole. Rates of severe mental illnesses, such as psychotic disorder and bipolar disorder, were about twice as high in people with intellectual impairment as in the general population. Women with intellectual impairment were about three times more likely to test positive for PTSD (15%) than women in the population as a whole (5%).

Next, Hassiotis et al. (18), using British national surveys of psychiatric morbidity data to establish the prevalence of psychosis and psychotic symptoms, concluded that the BIF group were more than twice as likely to have probable psychosis (OR 2.3) and to report hallucinations (OR 2.9).

Thirdly, concerning ID (IQ 50-70) in the general population, in 2017, Hughes-McCormack published the first whole country study in Scotland and found that ID was strongly associated with having a psychiatric disorder (odds ratio =7.1 (95% CI 6.8–7.3). Also, general health was substantially poorer in people with ID (19).

Lastly, in a study in a military population with BIF, Gigi et al. (20) used data from the Israeli army. They retrieved social and clinical characteristics of 76,962 adolescents with BIF and compared their social functioning, psychiatric diagnoses and drug abuse with those of 96,580 adolescents with an average IQ. The results demonstrated that the BIF group had more often a poor social functioning than the control group (OR=1.9, 95%CI=1.85–1.94). Individuals with BIF were 2.37 times more likely to have a psychiatric diagnosis (95%CI=2.30–2.45) and 1.2 times more likely to use drugs (95%CI=1.07–0.35) than those with an average IQ.

Although different in populations and methodology, all these studies worldwide showed that people with ID (including BIF) compared with the general population were at higher risk of developing severe and often long-lasting psychiatric, social and physical problems. Despite these outcomes and the clearly increased risk for mental health problems in people with MID/BIF, surprisingly, no study was found about the prevalence of MID/BIF in general psychiatry.

### 1.1.6 Prevalence of "Licht Verstandelijke Beperking" in the Netherlands

Depending on the definitions and methods used, estimates of the prevalence of "Licht Verstandelijke Beperking" in the general population in the Netherlands vary greatly.

About one-third of these individuals also have social self-sustainability problems and in obtaining access to the same care as people with intellectual disabilities. In the Sociaal Cultureel Planbureau (2018) report, the prevalence of people with MID and those with BIF who rely on the support and therefore meet the Dutch definition "Licht Verstandelijke Beperking" was estimated at 1.1 million (with a confidence interval ranging from 0,8 to 1,4 million), which is about 6,4 % of the total Dutch population. Nevertheless, these estimates are surrounded by some uncertainty (21).

## 1.2 Recognition, screening and diagnosing of ID in psychiatric clinical practice

### 1.2.1 Recognition of ID

Recognition starts simply with the awareness and interest of the clinician (Chaper2).

It is difficult to rely only on the patient's appearance or the language used during first contact. Therefore, these patients do not seem to differ significantly from those with average intelligence. Even for a trained clinician, recognizing ID is difficult at first sight. Patients often present as 'streetwise', and we know that language and understanding do not always match. Clinicians usually do not ask the patient to repeat what the clinician has explained to them, although this could make clear what the patient has understood or not. This can be the first sign of ID. In the first contact with a patient, clinicians do not usually ask about their school level and working career. It can be essential to check for actual possession of school or professional qualifications. To assess intelligence based on actual diplomas is quite complicated because there have been enormous changes in the education system in the Netherlands in the last 50 years, with an overwhelming amount of different certificates as a result. In the education and training of all mental health professions, more attention could be paid to learning to obtain a good personal history, which can provide a wealth of information, not only about the level of education and cognitive function but also about the patient's emotional level, attachment and adaptive functioning.

## 1.2.2 Screening for intellectual disability

It can be very time-saving to assess intelligence using a screening tool, and it is less time-consuming than administering a full Intelligence test like the WAIS, the gold standard (22), or a functional assessment described in DSM 5 and ICD 11.

Apart from the Screener Intelligence and Learning disability (SCIL) (1) which we will discuss later, other screening instruments can be used, including the Hayes Ability Screening Index (23), the Learning Disability Screening Questionnaire (LDSQ; 24, 25) and the Learning Disabilities in the Probation Service (LIPS; 26). Only the Hayes Ability Screening Index has been translated and validated for the Netherlands. All these instruments provide us with an estimation of an IQ in the range 50-70; however, these instruments have not been validated in Severe Mentally Ill (SMI;27) patients. The SCIL was inspired and developed to screen for MID and BIF, involving a broader IQ range (IQ 50-85).

**The Screener Intelligence and Learning problems (SCIL)**

The recently developed SCIL (28) is a handy instrument and easy to use in clinical practice, screening for an IQ level in the range of 50-85, covering both MID and BIF, so the broader group of patients with LVB. It takes just about 15 minutes to administer the SCIL.

In all of our studies presented in this thesis, we used the SCIL to detect patients suspected of having MID/BIF by using two different cut-off points. The SCIL is a test consisting of 14 questions, including educational level and small tasks intended to provide an overall insight into a patient's cognitive and adaptive abilities. It was developed specifically to detect MID/BIF in individuals in various settings, such as (mental) healthcare or social-service settings and police stations and shelters for the homeless.

The SCIL was validated in an adult sample recruited in a Dutch organisation ('De Borg'), providing services for clients with educational and or social problems and often additional psychiatric problems. Scores on the SCIL were compared with test results obtained with the WAIS-III. The reliability of the SCIL as expressed in Cronbach's alpha was good (0.83), and the AUC-value was 0.93, which is excellent. With 19 or lower as a cut-off score, the SCIL accurately classified 82% of people with MID/BIF. Of the ten people without MID/BIF, 9 (89%) were classified correctly as not having MID/BIF. Following the SCIL manual, administering the SCIL requires no specific clinical skills or training.

Recently, in 2019, the SCIL had been validated in SMI patients treated in FACT teams (29). The Cronbach's alpha of the SCIL in that sample was 0.73. The AUC value for detecting MID/BIF was 0.81 and 0.81 for detecting MID, with percentages of correctly classified subjects of 73% and 79%, respectively. The SCIL has been translated into English, Spanish (Mexican) and German, and translation in Swedish is in preparation.

In our studies (except the first study described in chapter 2), we used two cut-off scores: 19 and 15. A SCIL score of 20 or higher implies no MID/BIF; 19 and lower implies being suspected of having MID/BIF. The cut-off point of 15 and below indicates suspected MID.

### 1.2.3 Adaptive Functioning

Adaptive functioning is defined as a person's ability to function effectively in the world. Problems in the adaptive functioning show to what extent MID/BIF hinders daily life. If no lasting support is provided, many people with MID/BIF will experience problems in one or more aspects of everyday life (30,31). In DSM-5, having problems in adaptive functioning is a conditio-sine-qua-non for diagnosing MID or BIF. Recently, screening tools have been developed to screen easily and quickly for daily clinical practice.

The ADaptive Ability Performance Test (ADAPT;31) is a hetero-anamnestic instrument completed by, e.g. a caregiver and is already validated. Results suggest that the ADAPT is a valid instrument for measuring adaptive skills in individuals with ID. The reference values may be used to estimate the level of ID and the intensity of support needed.
The SCreener Adaptive Functioning (SCAF;32) is currently under development in the Netherlands, and results are expected at the end of 2022. The SCAF is a self-reporting instrument for 16 years of age and above.

Both instruments give another perspective of the patient themselves (SCAF) and caregivers (ADAPT) and complement each other. These instruments map conceptual, social and practical functioning and can contribute in the future to the determination of cognitive impairment in clinical practice.

### 1.3 Aetiology of Intellectual Disability

### 1.3.1 Genetic factors

Several factors are important in the aetiology of ID, including genetic factors. Family and population studies of intelligence show high heritability, but no reliable literature exists on the heritability of ID itself. Genetic studies have been complicated for a long time by ID's extreme clinical and genetic heterogeneity. Recently, progress has

been made using different next-generation sequencing approaches in combination with new functional readout systems. This approach has provided novel insights into ID's biological pathways (33). Especially the 'de Novo genetic mutations' constitute a significant cause of severe ID. By contrast, more common and complex forms of inheritance are expected to underlie the milder forms of ID. At present, however, much less is known about the genetics underlying these mild forms of ID. It has been estimated that mutations in more than 1000 different genes may cause intellectual disability. Knowledge about psychiatric symptoms caused by genetic syndromes that frequently occur in the context of genetic abnormalities, such as Fragile X, 22 Q 11.2 Deletion Syndrome, Smith-Magenis, CHARGE syndrome, is increasing (34).

### 1.3.2 Other causes of ID

Apart from genetic causes, several other biological, demographic, social and psychological factors also have been associated with ID.

The older age of pregnancy of both parents increases the possibility of ID for the offspring (35), but also the very young age of the mother (36).

In addition, premature birth, perinatal infections, hypoxia, and problems during the pregnancy and delivery can cause ID (35, 37) as well as extreme malnutrition during and after pregnancy (37).

The risk of ID also increases when the mother uses alcohol, which can cause Foetal Alcohol Spectrum Disorders (FASD;38). FASD is an umbrella term for a range of congenital disabilities caused by prenatal exposure to ethyl alcohol. This damage leads to lifelong physical, behavioural, and cognitive disabilities. Depending on the nature and severity of the damage, the following diagnoses under the FASD umbrella can be given: foetal alcohol syndrome (FAS), partial foetal alcohol syndrome (pFAS), alcohol-related neurodevelopmental problems (ARND), alcohol-related congenital disabilities (ARBD), or neurobehavioral disorder-prenatal alcohol. The estimated prevalence regarding all levels of FASD in populations of younger school children may be as high as 2–5% in the US and some Western European countries (39). During pregnancy, tobacco, drugs or other toxic substances, including some types of medication, can also cause brain damage in the unborn child leading to ID (40).

Social, demographic and other biological factors related to ID include teenage pregnancy, educational level and work of the parents, health and mental health of the parent, and socio-economic factors such as poverty, deprivation, and ethnicity play an essential role (41, 42, 43).

As mentioned above, people with ID are more vulnerable to developing severe psychiatric problems. Furthermore, people with severe psychiatric (including addiction) problems are also at risk of developing a lower IQ and becoming intellectually disabled.

Figure 2: Possible risk factors for developing ID during pregnancy
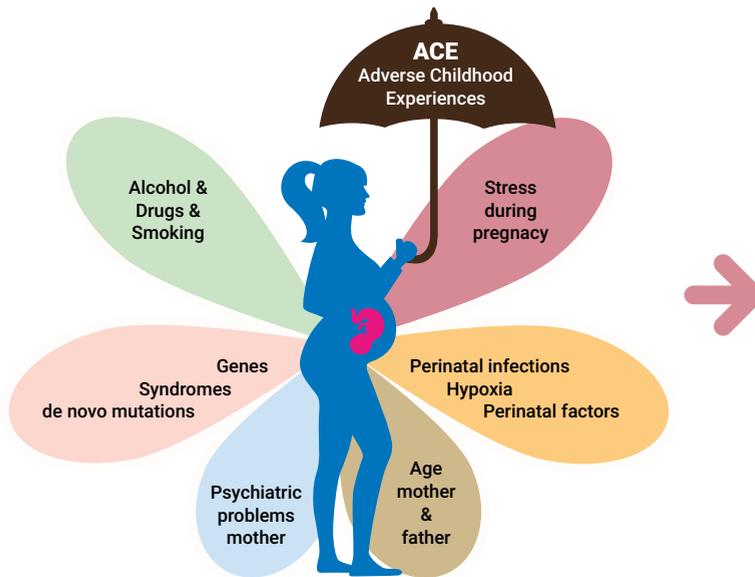


*The arrow on the right refers to the next figure on page 21.*

### 1.3.3 Heterogeneity of ID phenotype

As mentioned above, all different aetiologic causes cause a myriad of diversity in the genotype and phenotype of MID/BIF from birth onwards. Often there are also neurological and physical problems and other comorbid disorders. Individuals with MID/BIF are at increased risk of growing up in an environment where they are confronted with accumulating negative experiences that threaten their development and increase their vulnerability (41, 44). They often encounter repeated broken relationships, multiple moves between foster homes, problems in attachment, childhood and adult exploitation, neglect, abuse, bullying, (sexual) harassment and many other traumatic experiences in childhood and later on. These Adverse Childhood Experiences (ACE) cause (further) psychosocial problems and brain structure damage (44, 45). Stress also

has an (in)direct toxic effect on the development of the brain and the development of psychiatric disorders (45).

Individuals with MID/BIF are frequently confronted with inappropriate access to services or lack of support (8) and are at higher risk of becoming homeless (46) and abusing alcohol, tobacco and drugs. Healthcare workers often do not notice MID/BIF, and treatment programs are usually not tailored to these individuals (47). In addition, MID/BIF youngsters are at risk of developing anti-social and delinquent behaviour (48). In adults, behaviour disorders are the most common psychiatric disorders in people with ID (16), and adults with ID are overrepresented in prison (49, 50) and forensic psychiatric clinics (51). In figure 3, we summarise the possible risk factors (as mentioned above) for developing psychiatric disorders in a person with ID.

Figure 3: Possible risk factors for developing psychiatric disorders in a person with ID
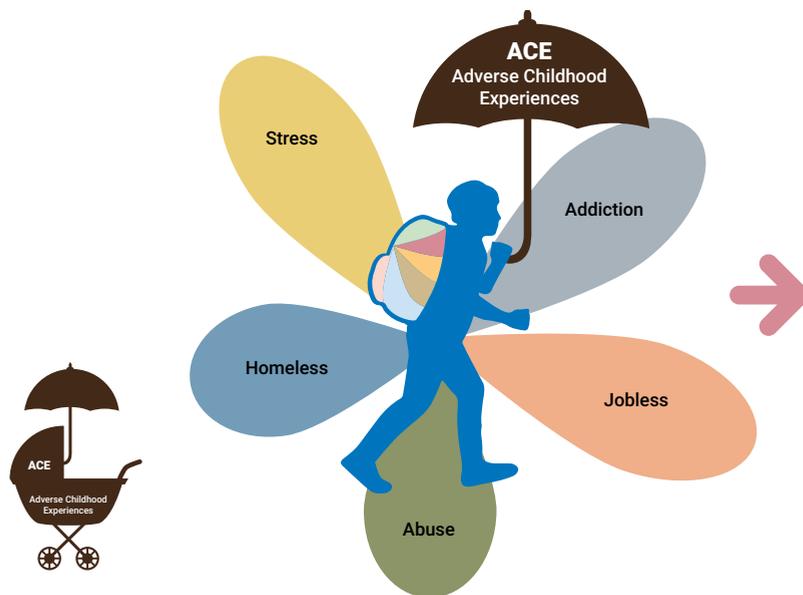


*The arrow on the right refers to the next figure on page 152.*

**1.4 Changing perspectives on Intellectual Disability and Psychiatry over time**

In the Middle Ages, the group of people with psychiatric problems and ID were seen as "idioten, zotten, gekken, dwazen or dollen" ("idiots, fools, crazy, madmen or lunatics"), sometimes living in monasteries but without possibilities for improvement (52). Only since the end of the 19th century were specialised institutions for people with ID funded (53). Before, people with ID, mental problems, criminals, beggars etc. were isolated from society in workhouses (tuchthuizen or later in, so-called Interneringshuizen), where they were put to work (54). People with the most severe psychiatric problems who were also dangerous were sent to secure asylums (Dolhuizen or Gestichten). In 1841, the so-called Krankzinnigenwet (law for the mentally ill) was introduced as a new mental health law regulating involuntary admissions and treatment to improve human dignity (54). In 1844, the Inspectie Voor het Krankzinnigenwezen (Commission for care providers for mentally ill patients) was set up, and two state inspectors were appointed to supervise this Krankzinnigenwet, which resulted in an improvement of the circumstances and daily activities (the so-called "gekkenwerk") (54, 55). In 1871, the Dutch Association for Psychiatry was established to give psychiatry a scientific foundation. Since the introduction of the Krankzinnigenwet, intellectual disability and mental illness were seen as a disease or disorder that could be treated or at least handled in the context of a psychiatric hospital.

*1.4.1 Development of IQ tests*

During the early 1900s, the French government asked psychologist Binet to help decide which pupils were most likely to experience difficulties in school. The government had passed laws requiring that all French children should attend school. Therefore, it was essential to find a way of identifying children who would need specialized assistance. Binet and his colleague Theodore Simon began developing questions that focused on areas not explicitly taught in schools, such as attention, memory, and problem-solving skills. This first intelligence test, referred to today as the Binet-Simon Scale, became the basis for the intelligence test (52). Specialised (practical) teaching methods adapted to the student's intellectual abilities were developed. The American psychologist Lewis M. Terman (1877-1956), a Professor at Stanford University, built upon Binet's early work, renaming the scale the Stanford–Binet Test of Intelligence (Terman, 1916). Terman, strongly influenced by the burgeoning eugenics movement of the late nineteenth and early twentieth centuries, emphasised the danger that "high-grade defectives" presented to society. Eugenic societies sprang up over much of the Western world, with pressure placed upon parents of people with an intellectual disability to discourage their marriage and procreation. Some just recently repealed sterilization laws were enacted in many countries, including Canada, the United States, Sweden, and France.

The net effect of the eugenics movement was a rapid increase in the numbers of people who were institutionalised across the Western world (52).

After introducing the Leerplichtwet (law for compulsory schooling) in 1901, the number increased rapidly to 95 schools for "zwakzinnigen" in 1934. Public schools for intellectual disabled were usually called Volksscholen, located in working-class neighbourhoods with many children from poor social backgrounds (53).

In 1926, Dr Willem Matthias van der Scheer (1882-1957) introduced "actievere therapie" (active therapy) in the Netherlands, based on the idea of activating the healthy part of a patient by re-education. That mental illness resulted from bad habits or inappropriate behaviour, and good housing and hygiene were thought to contribute to a decent life (54).

From the mid-twentieth century onwards, several significant advances were made in defining and classifying intellectual disabilities (52). From both operant and cognitive psychological perspectives, the research results demonstrated the learning potential of people with an intellectual disability. Since 1921 the AAIDD has published definitions of intellectual disability. The fourth and fifth revisions edited by Heber (1959, 1961) significantly included impairments in adaptive behaviour in addition to "sub-average general intellectual functioning", which was the main factor in an earlier edition (55).

Intelligence tests were introduced in the Netherlands, like many other European countries. However, care and treatment of people with ID and psychiatric problems became further separated in the 50s and 60s of the last century. Institutions for patients with ID and General Mental Health Care were separately commissioned. Between 1960 and 1970, people with ID possessed possibilities to be developed. The aim was to live a life as normally as possible. Parents were encouraged to send their child at as young an age as possible to a specific institute (54).

The proclamation by the United Nations in 1971 of the Declaration of the Rights of Mentally Retarded Persons (United Nations, 1971) provided an impetus for countries to re-examine their laws to ensure that the rights of people with an ID were being safeguarded (52, 55). A decade later, de-institutionalisation and participation in the community were introduced, incorporating small-scale housing facilities and the right to education and basic necessities of life and financial support (53, 54).

Recently, the 2019 report "Interdepartementaal Beleidsonderzoek (IBO) Voor Mensen met een licht verstandelijke beperking" illustrated the realisation of society and government that this part of the population includes a large and diverse group of people (here assessed as 1.1 million people). Policymakers realised that: "These people often have trouble in daily life to understand information, performing tasks such as finding a house or running a household, which is not recognised enough because usually ID is invisible". Several recommendations for improving care for people with ID were given (55).

## 1.5. Vignettes

Within the Mental Healthcare Trust GGNet in the East of the Netherlands, VGGNet is a Centre of Expertise for patients with MIF/BIF and complex psychiatric and often additional social problems. Working as a psychiatrist at one of the VGGNet outpatient clinics, patients often told me about their long treatment histories, both inside and outside mental health care. Their stories made me curious and inspired me to start this PhD.

*Patient Mieke* [1] is a 44-year-old female, single, living at an apartment in a 24/7-hours ID care service, who was admitted to the VGGNet outpatient clinic because she was recently diagnosed with a non-epileptic seizure disorder. She went to a school for deaf and hard of hearing children in her childhood because she only started talking after the age of six.
Her parents neglected their children. For many years she was homeless and had several involuntary admissions to a psychiatric hospital because of auto-aggression and suicide attempts. She was secluded frequently, and she received high doses of medication. She would say: "I was just a zombie". She received day-treatment for her Borderline Personality Disorder for many years without good results. At the age of 38, an IQ test was done with a Total IQ outcome of 61. She was then referred to live in a care institution for the mentally disabled.

When re-diagnosed at the VGGNet outpatient clinic, she was diagnosed with autism spectrum disorder (ASD) and mild depression. Comorbid hypothyroidism was also treated. Sedative medication was tapered and stopped, and her work and daily life became more structured and transparent and were adapted to her level of functioning. She and the staff took part in psycho-education training about autism. They got explanations about her disharmonious IQ profile and limited adaptive function,

―――――
[1] All names are fictional

resulting in the team placing fewer demands on her. They also understood her inability to cope with emotions better because she functioned emotionally at a much lower developmental level than indicated at first sight.

These interventions were tailor-made in collaboration between her and the staff of the ID care service where she lived. She was discharged from mental health care after two years of treatment with only one tablet of anti-depressant medication.

*Patient Patrick*, a 64-year-old male, was married and living independently with his wife. They had one adult daughter and one grandchild living in the same city. He was admitted to the outpatient clinic because he had frequent outbursts of aggression. When he was 18 years old, he was admitted involuntarily several times to a psychiatric clinic because of severe depression and alcohol abuse. There were also more extended periods when he received no services assistance and drank alcohol excessively. He had a bad relationship with mental healthcare workers, and in the past, a psychiatrist diagnosed him as "a psychopathic narcissist ". Only at the age of 62 an IQ test was done with the outcome of a Total IQ of 56.

Meanwhile, he used medication to not relapse into alcohol abuse. His request for help was, "I want to spend some good years together with my grandson". When asked about his daily life, he dared to confess that he and his wife were illiterate. No healthcare worker had ever asked before. Their daughter took care of all their finances and administration. This created stress and sometimes irritation because they depended heavily on the benevolence of their daughter. This also interfered with family relations. At the end of the first interview, the Trauma Screenings Questionnaire was administered. Then he dared to disclose for the first time that he had been physically abused for years by the director of the children's home where he lived from the age of 7 until 13. He had never talked before about these traumatic events. Finally, he was diagnosed with Post-Traumatic Stress Disorder (PTSD) and a sleeping disorder, in addition to his ID. It turned out that restless legs caused by long-term alcohol abuse were the cause of his sleep disturbances and were treated with proper medication prescribed by the general hospital. After successful Exposure Therapy treatment, anti-depressive medication, and Cognitive Behavior Therapy, his self-esteem improved. These treatments were adapted to his limited comprehension and low literacy. Home care and financial support were advised, but the couple did not accept this. After three years, Patrick could be dismissed from the outpatient clinic. Patrick had no aggressive outbursts any longer, could enjoy relationships and was still sober. Next to the adapted treatment, success factors were the administration of the TSQ by which the PTSD became clear, taking his sleep complaints seriously, and treating the couple with respect without any enforced imposition.

*Patient Johan*, a 42-year old male, was married and lived with his wife and two children - boys of 8 and 10 years old. They received support for taking care of the children. He worked as a truck driver at least 60 hours a week. He was referred to the outpatient clinic of VGGNet because of marriage problems caused by the obsessive watching of porn and sex movies. When a developmental anamnesis was administered, it turned out that he had had a difficult life; his father was an alcoholic who had terrorised the family, and there had been emotional neglect. When he was 14 years old, he left his family after a fight with his father and became homeless. Later he slept in his car, drove without a licence, had a job intermittently, used cannabis and twice he was involved in an accident caused by drunk driving. After the last accident, when he was 17 years old, a social worker visited him in a general hospital. From then on, J. fared better: he received support with daily living tasks, he met his wife, who had average intelligence, and got a job. They had two children, both with a rare genetic metabolic disorder, ADHD and an ID. This caused the couple much distress. A social worker from the organisation MEE[2] who supported the parents in taking care of the two children suspected Johan of having an ID and referred him to VGGNet. An IQ test was done, and it turned out to be a Total IQ of 78. After re-diagnosing, it turned out that Johan not only had BIF but that he was sexually abused by his neighbour at the age of 12-14 and had PTSD and ADHD. In the past, Johan was treated by a sexologist without positive results. He probably did not dare to speak about his sexual abuse, and the BIF stayed unnoticed because Johan used much streetwise language. Together with his wife, he received tailor-made psycho-education about ADHD and BIF. He was treated with ADHD medication with good results. He was advised to cut his work hours to reduce the overloading and stress caused by work, but he did not accept this advice. The couple got extra support for the weekends when the children could stay in a specialised centre. Johan received EMDR treatment with good results. He was discharged from mental health care after 1.5 years of treatment.

These three vignettes illustrate the long treatment histories both inside and outside the mental health services of patients with ID and the often-complex relationships with mental healthcare workers, and periods of not receiving any care. They also illustrate the often late or very late recognition and diagnosing of MID/BIF, which seem to have contributed to the poor results during previous treatments. Especially in patients with an IQ of 70 and lower, psychiatric disorders can be expressed in different ways, such as complaints about somatic symptoms, pseudo-epilepsy, and behaviour that is hard to understand (see Chapter 2).

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[2] MEE is the cooperative association of 20 regional co-organisations. They aim to work towards an inclusive society.

One of the vignettes also illustrated that coercive measures are frequent in MID/BIF patients, and therefore these patients can be easily traumatised (see Chapter 3). All vignettes illustrate that neglect, abuse, addiction and trauma are common phenomena (see Chapter 6), and these patients get quickly involved in aggression and judicial problems (see Chapter 5). In addition, genetic factors can also play a role. Finally, being illiterate is more common than health care workers realise. Saying that you do not understand the practitioner and are Illiterate is very embarrassing and often not disclosed. All patients told us that it was the first time a developmental anamnesis was administered and a TSQ screening for PTSD. At VGGNet, they felt understood, not least by adapting language and speed of communication to their emotional and social developmental level, being treated with respect, and by making a personalised treatment plan tailored to the level of adaptive functioning and daily concerns. In consultation with the ID service or WMO [3] care, sources of stress such as work, finances, administration and parenting problems were reduced to achieve lasting treatment results; tuned with the patient and significant others, to their capabilities, in their own environment with a maximum of personal control.

Based on the literature and the case vignettes described above, we have c to study the estimated prevalence of MID/BIF and factors associated with having MID/BIF in psychiatric patients.

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[3] Wet Maatschappelijke Opvang

**1.6 Aims and content of the thesis**

As mentioned above, there is a lack of knowledge on the prevalence of MID/BIF and factors associated with having MID/BIF in psychiatric patients. Therefore, we aimed to answer the following research questions:

1. What is the estimated prevalence of patients suspected of MID/BIF using the SCIL as a screener on admission wards? (Chapter 3)

2. Are patients screened positive for MID/BIF with the SCIL more often subjected to coercive measures than patients who screened negative? (Chapter 3)

3. What is the estimated prevalence of patients suspected of having MID/BIF in different mental health care settings using the SCIL as a screener? (Chapter 4)

4. What percentage of patients who screened positive for MID/BIF is suspected of having cognitive decline, using the SCIL as a screener? (Chapter 4)

5. Are patients who screened positive for MID/BIF using the SCIL as a screener more often engaged in aggressive incidents than patients not suspected of having MID/BIF? (Chapter 5)

6. Do patients suspected of MID/BIF more frequently experience trauma and have Post-Traumatic Stress Disorder (PTSD) symptoms compared to patients not suspected of having MID/BIF? (Chapter 6)

7. Finally, we tried to answer the research question: what is the association between the level of psychiatric symptoms and the scores on the SCIL? (Chapter 7)

## Content of the thesis:

- Chapter 1 provides a general introduction to the thesis.

- Chapter 2 describes how mental health professionals can recognise and diagnose low intellectual functioning in psychiatric patients.

- In Chapter 3, the results of a study are described in which we screened for MID/BIF in patients admitted to two psychiatric wards and investigated the use of coercive measures. We hypothesised that patients who screened positive for MID/BIF would be more often confronted with coercive measures than patients who screened negative.

- Chapter 4 aimed to establish the prevalence of MID/BIF in a cross-sectional study in mental health care settings with increasing levels of care using the SCIL as a screener. In addition, we estimated the percentage of cognitive decline patients who screened positive for MID/BIF.

- In Chapter 5, we addressed the research question of whether patients with MID/BIF differed in causing aggressive incidents as compared to patients not suspected for MID/BIF in an inpatient setting. We hypothesised that patients who screened positive for MIF/BIF would be involved in more aggressive incidents than patients not suspected for MID/BIF.

- Chapter 6 established the prevalence of trauma and its association with screening positive for MID/BIF in seriously mentally ill (SMI) outpatients in a cross-sectional study conducted in two mental health trusts in the Netherlands (GGZ Oost Brabant and GGNet). We hypothesised that patients suspected of MID/BIF would more frequently have experienced trauma and be more frequently suspected of having Post-Traumatic Stress Disorder (PTSD) symptoms than patients not suspected of MID/BIF.

- In Chapter 7, we tried to answer the research question of whether the severity of psychiatric symptoms impacts the scores on the SCIL.

- Finally, in Chapter 8, we summarized and discussed the findings of the studies described in the previous chapters.

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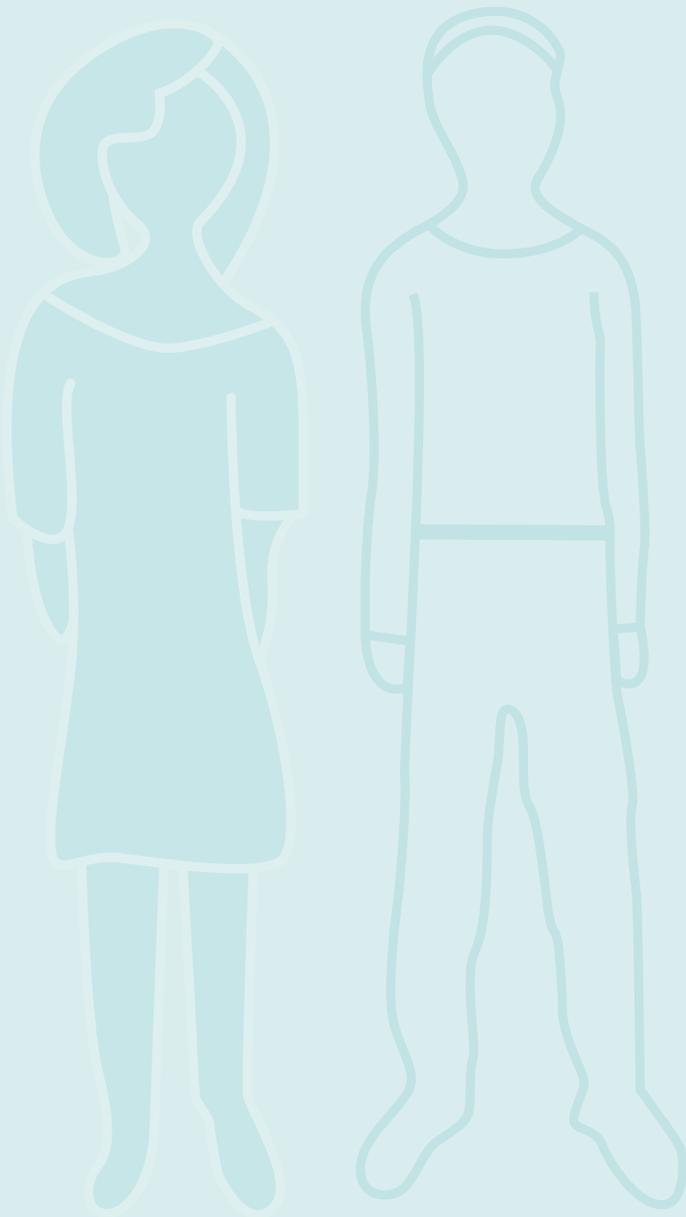
Chapter

**2**

# Recognizing and diagnosing the intellectual problems in patients with Mild Intellectual Disabilities and Borderline Intellectual Functioning

# Abstract

**Background.** The assessment of intelligence is of great importance for matching treatment, and this is not easy, even for experienced therapists.

**Purpose.** to teach practitioners to identify and diagnose lower intelligence and give them a general idea of the methodology and pitfalls in diagnosing psychiatric disorders in patients with Mild Intellectual Disorder and Borderline Intellectual Functioning.

**Method.** Discuss various screening instruments commonly used in the Netherlands in conjunction with the subsequent diagnostics.

**Results.** Using screening and diagnostics on intelligence and adaptive functioning to arrive at a more integrative psychiatric diagnosis with attention to emotional and, consequently, social functioning. One should be aware of some pitfalls in psychiatric diagnostics.

**Conclusion.** Psychiatrists and clinicians should be aware of Mild Intellectual Disorder and Borderline Intellectual Functioning. They should assess the patient's overall functioning and know which follow-up steps are necessary for a proper diagnostic process of Mild Intellectual Disorder and Borderline Intellectual Functioning and the associated psychiatric disorders.

# Introduction

Recognizing and diagnosing intellectual problems in patients with Borderline Intellectual Functioning (BIF) and Mild Intellectual Disabilities (MID) has until recently received little attention in the training of psychiatrists and psychiatry in general. The subject of intelligence was often seen as the domain of psychologists and orthopedagogues. There was little or no attention paid to the recognition of low intelligence, nor specific diagnostics of intellectual functioning in psychiatric disorders, and adapted or specific treatment possibilities for MID/BIF patients in the basic training for psychiatrists. It is possible that the separation of care for patients with psychiatric problems and mental disability in the 1970s led to a loss of attention and knowledge on both sides. In addition, it seems negative perceptions and prejudices play an essential role in the lack of attention paid to this significant patient group in psychiatry.

In DSM 5, MID covers people with a mild intellectual impairment with difficulties in adaptive functioning in such a way that this leads to failure to meet developmental and sociocultural standards of personal independence and social responsibility. Although IQ figures are officially left out, in daily clinical practice, this still corresponds with a Total Intellectual Quotient (TIQ) in the range of 50-70. Without continued support, the deficiencies in adaptability limit functioning in one or more aspects of daily life, including communication, participation in social life, school or professional functioning and personal independence at home or social environment. This disorder is seen as a neurobiological developmental disorder starting before 22 years.

BIF has always been a problematic concept that has changed in both name and IQ boundaries. Since the introduction of DSM 5, BIF is just a descriptive V-code that can be used when there is a reason for care or when treatment or prognoses are influenced negatively by the BIF. Former IQ ranges (70-85) are left out, but a careful assessment of intellectual and adaptive functions and their discrepancies is needed, especially when there is a mental disorder.

# Purpose

With this article, I aim to ensure that mental health practitioners recognise MID/BIF in their patients at an earlier stage, diagnose MID/BIF and learn the basic steps in the diagnostics of this specific group. The aim is that this group of patients is no longer excluded based on reluctance or prejudice but that a correct diagnosis offers appropriate treatment within the mental health services. Intelligence has a significant influence on symptom presentation. As a result, diagnoses can easily be missed or incorrectly made, especially when a disharmonious intelligence profile or an IQ below 70 is present. Patients with MID/BIF often do not or insufficiently benefit from the regular diagnostic and treatment services in mental health, while the training of clinicians and some adjustment of treatment programs could help a large group of patients, especially those with a BIF, quite significantly. In this article, I describe how MID/BIF can be determined. Screening instruments or questionnaires for detecting MID/BIF are easily applicable. This article discusses the basic principles for further diagnostics in general terms for disorder-oriented diagnostics. In addition to relevant recent articles on the subject, I have made use of various (teaching) books such as the "Diagnostic Manual - Intellectual Disability" (DM-ID; Fletcher et al. 2017), The "Handbook of LVB and Psychiatry" (Didden et al. 2016), The book "Behandeling van patiënten met een laag IQ in de GGZ" (Wieland et al. 2017), and the "Handbook of emotional development and intellectual disability" (De Bruijn et al. 2016).

**Recognition and screening**
Recognizing MID/BIF simply begins with the clinician being aware of it. It is difficult to determine this by the appearance of the patient or the language used during initial contact. Patients often do not differ from moderately intelligent or highly gifted patients in these areas. Even for trained practitioners, recognition is complex. Patients often present themselves as "streetwise", while we know that language use and understanding often do not match. Clinicians do not usually ask the patient to recount the conversation in their own words, a process in which it becomes clear what they have understood. This can provide the first clue to MID/BIF. Also, in the first contact, they often do not ask about their school career, and if they do, they do not ask enough about the actual possession of certificates, which is a problem. If they do, they do not ask about the actual possession of school or job achievements, which is complicated by the enormous changes in education over the past 50 years. In addition, it is important to be able to make an estimation of intelligence based on the mentioned certificates. In their specialist training, psychiatrists are not usually taught to take a good personal history or (hetero) developmental anamnesis, which can provide a wealth of information about the level of cognitive functioning and emotional development and adaptive development skills.

**Intelligence**

It is very valuable to use a screening instrument as a standard administration to estimate intelligence. There are various screeners on the market, such as the Hayes Ability Screening Index (Hayes 2000), but these only give an indication for an IQ of 50-70 and are usually not validated for patients with a severe psychiatric disorder (SMI) (Delespaul et al. 2013). The SCreener Intelligence and Learning Problems (SCIL; Nijman et al. 2018) is a helpful screening instrument to indicate MID/BIF (IQ 50-85). The SCIL consists of 14 items across the four domains: schooling, social contacts, school skills, and language comprehension. This instrument indicates both MID and BIF at two different cut-off points. The overall sensitivity and specificity is 82% and 89%, respectively. In patients with SMI, the sensitivity is 67% and the specificity 81% (Seelen et al. 2019). The taking takes only fifteen minutes. The patient must concentrate sufficiently during the test. Preferably after training, any professional discipline may administer the SCIL. If the test score is low, the next step may be to take an intelligence test or conduct a biography and or (hetero-)developmental anamnesis.

**Adaptive functioning**

Adaptive functioning is defined as the ability of a person to function effectively in the world. When no ongoing support is provided, the person will experience problems in one or more aspects of daily life. Adaptive functioning shows how this cognitive functioning hinders daily life (Tassé et al., 2012). At this moment, there are no good validated screening instruments on the Dutch market. Two instruments currently under development in the Netherlands are the Screener Adaptive Functioning SCAF; Moonen & Verstegen 2006) and the ADaptive ADAPT (Jonker et al., 2016). Both instruments map conceptual, social and practical functioning and may in the future contribute to the determination of MID/BIF, but the validation process of these instruments is currently still ongoing. In DSM-5, problems in adaptive functioning are stated as a factor for determining MID or BIF.

**Diagnostics**

Every good diagnosis begins with observation. When collecting the patient from the waiting room, there are frequently peculiarities in appearance and motor skills. Understanding what is going on with the patient (symptom picture) in conjunction with the origin/cause (pathogenesis) and the (social) context in which facilitating and obstructing factors play a role form an indispensable whole, especially in patients with (mild) intellectual impairment. The diagnostics must clarify whether the behaviour or complaints are about a disorder or mainly have coping or (mal)adaptive behaviour as a reaction to the context. With the classification based only on phenomenology according to the DSM, a serious problem arises with patients with an IQ below 70.

The lower the IQ, the less reliable the DSM classification becomes. This also applies to the retarded group with a disharmonious (low) intelligence profile. In order to get a better understanding, it is advisable to use the Diagnostic Manual - ID for patients with an IQ below approximately 70. This diagnostic manual is structured analogously to the DSM but provides additional criteria to arrive at a correct classification. In patients with a (mild) intellectual disability, it is not only important to gain insight into emotional development, in addition to the cognitive and adaptive functioning, in order to be able to make DSM diagnosis but also in order to arrive at an integrative diagnosis (Došen et al. 2008). This requires the clinician also to assess the emotional and related social developmental level. This takes time but provides crucial starting points for targeted treatment.

**Emotional functioning**

As far as emotional development is concerned, one can roughly place patients with an IQ of 50-70 in emotional functioning at the developmental age of 6-12 years and with an IQ of 70-85 at the developmental age of 13-17 years of age. Došen states (De Bruijn et al., 2017) that a discrepancy between emotional and cognitive development can make someone vulnerable to behavioural problems and psychiatric disorders. Knowledge of emotional development is essential for recognizing the origin of the problem and the diagnosis. The level of emotional development can say a lot about basic emotional needs, reaction patterns and behaviour. It offers important clues for treatment and can prevent the patient from being overloaded not so much cognitively but emotionally and therefore cannot benefit from treatment. To gain insight into emotional development, one can use several developmental scales. The most common is the Emotional Research Scale – Revised 2 (Morisse & Došen 2016) administered by trained academics. This assessment adheres to five developmental stages over thirteen domains, which are portrayed hetero-anamnestically and discussed with the patient for their own recognition. This results in an easy-to-read profile and offers starting points for support.

**Pitfalls**

Psychiatric disorders in persons with MID/BIF manifest themselves more in problematic behaviour and somatic problems, such as abdominal pain in a depressive disorder. Patients are not always able to articulate feelings and complaints. The clinician will always have to verify whether the patient knows and understands the language used; for example, an apparently common word such as 'gloom' is regularly found to be unknown to patients. On the other hand, symptom presentation is strongly influenced by emotional development, which is often lower than expected relative to cognitive development. This may originate in neurological, syndromic problems but can also be

a consequence of stress and trauma in childhood. A significant proportion of these patients live in less favourable socioeconomic conditions. Adaptive or maladaptive behaviour or coping in response to overload and stress is then confused for symptoms of a disorder. An established diagnosis of bipolar disorder or a personality disorder can simply disappear after adapting the guidance and support needs. It is questionable whether a personality disorder diagnosis can be made in these patients, given the level of emotional functioning. With a diagnosis such as schizophrenia, there may be such a low level of emotional functioning that fantasy and reality are not separated, and therefore there is no formal delusional disorder. It would be beyond the realms of this article to discuss all the regularly occurring pitfalls, but if the patient does not improve enough with treatment, renewed diagnosis is of great importance. In specialist centres such as VGGNet, the most frequently observed psychiatric disorders among MID/BIF patients referred to the centre are Depressive disorders, Developmental disorders and PTSD.

## Conclusion

Given the high prevalence of MID/BIF in mental health (Nieuwenhuis et al., 2017; 2019), psychiatrists and other clinicians must accurately establish a patient's cognitive functioning, which should be a standard part of the descriptive diagnosis. In addition, it is essential to arrive at an integrated diagnosis including biosocial aspects and form a picture of emotional and adaptive functioning. The treatment must fit in with this. With an IQ below 70, one should use Diagnostic Manual-ID since the DSM classification is not sufficiently reliable. Given the complexity of diagnostics, one can opt for referral or cooperation with specialist MID/BIF centres.

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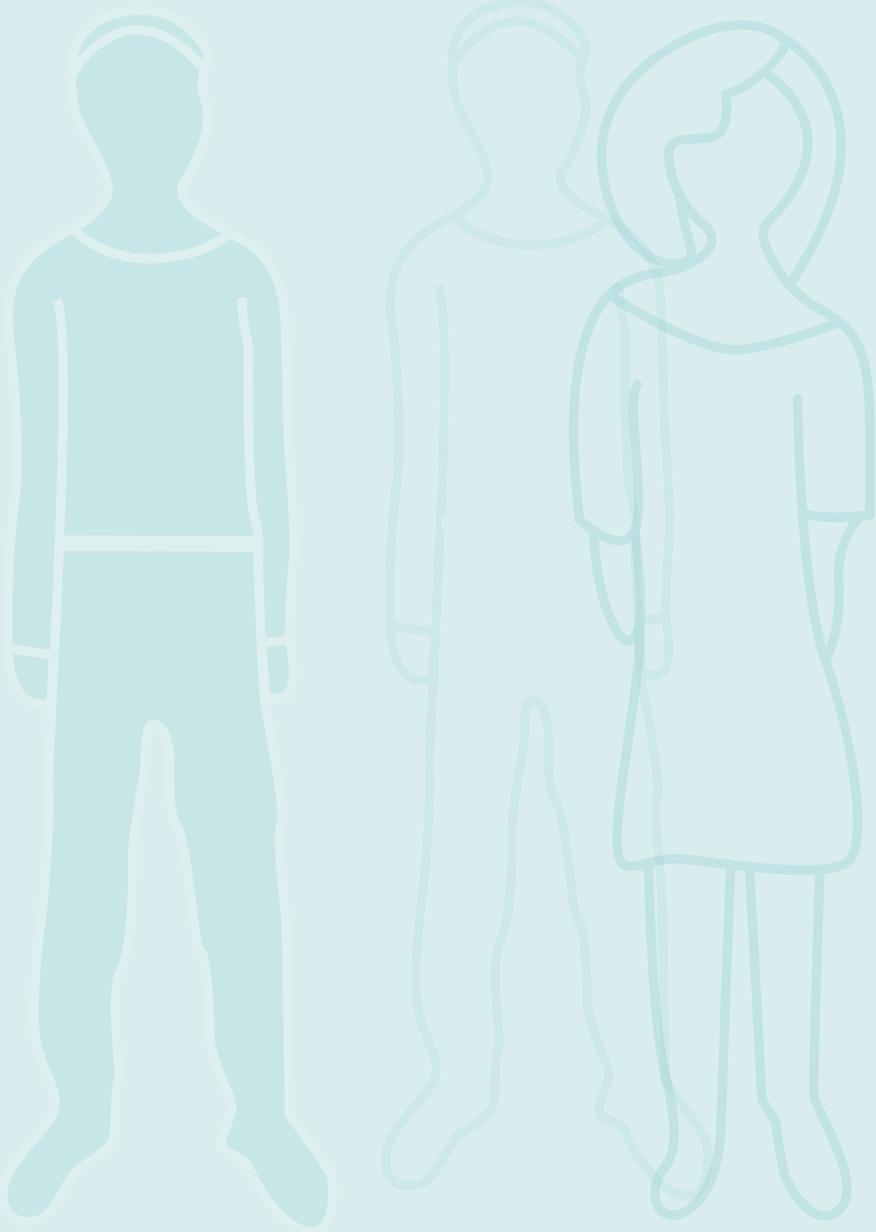
Chapter

# 3

# A blind spot? Screening for Mild Intellectual Disability and Borderline Intellectual Functioning in admitted psychiatric patients: prevalence and associations with coercive measures

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# Abstract

**Background.** Failure to detect psychiatric patients' intellectual disabilities may lead to inappropriate treatment and greater use of coercive measures.
Aims. In this prospective dynamic cohort study, we screened for intellectual disabilities in patients admitted to psychiatric wards and investigated the use of coercive measures with these patients.

**Methods.** We used the Screener for Intelligence and Learning disabilities (SCIL) to screen patients admitted to two acute psychiatric wards and assessed patient characteristics and coercive measures during their stay and over the last 5 years.

**Results.** Results on the SCIL suggested that 43.8% of the sample had Mild Intellectual Disability or Borderline Intellectual Functioning (MID/BIF). During their current stay and earlier stays in the previous 5 years, these patients had an increased risk of involuntary admission (OR 2.71; SD 1.28 – 5.70) and coercive measures (OR 3.95, SD 1.47 - 10.54).

**Conclusions.** This study suggests that functioning on the level of MID/BIF is very prevalent in admitted psychiatric patients and requires specific attention from mental health care staff.

# Introduction

Many individuals with Mild Intellectual Disability and Borderline Intellectual Functioning (MID/BIF; IQ between 50 and 84) have difficulties in society and may also have problems with adaptive behaviour (1, 2). Mild Intellectual Disability (MID; IQ between 50 and 70) is generally detected early in life, unlike Borderline Intellectual Functioning (BIF; IQ between 71- 84), which is more often unknown to an individual, his/her family, or others (3). Thirty-one percent of adolescents with BIF have been estimated to have poor social functioning, as well as other problems (4).

According to the definitions and methods used, estimates of the prevalence of MID/BIF in the general population vary greatly. In Western countries, the population prevalence of Mild Intellectual Disabilities (MID) is estimated to be 0.7-1.3% (5, 6). On the basis of the normal distribution of intelligence in the general population, 2.14 % would have an IQ in the 50- 70 range (MID) and 13.59 % in the 71-84 range (BIF).

The prevalence of MID/BIF does not seem to have been studied extensively in psychiatric adult patients, with the exception of some studies in MID patients (7, 8) or BIF patients (9), it is thus unknown in people with severe mental illness treated in inpatient and outpatient settings, and often seems to go unrecognized (9, 10). Such unawareness is likely to result in inadequate treatment, more lengthy hospital stays, more use of coercive measures, and poor outcome (8, 11). Due to patients' lack of ability to verbalize their feelings and emotions, the difficulties they experience may be expressed more often in acting-out behaviour and somatic complaints. These can be wrongly interpreted, leading to false diagnoses and treatments (8). There are various special considerations that have to be taken into account in assessing and classifying psychiatric disorders in adults with MID, including among others associations between comorbid conditions and a patient's communicative limitations; a patient's impaired capacity for providing consent; an assessor's response style; and an assessor's use of information from multiple sources (12).

Although it is not known why MID/BIF is poorly recognized, it is probably due to problems in communication, such as verbal handicaps and poor vocabulary. It may also be due partly to "streetwise" presentation on the part of various individuals or to socially acceptable answers that conceal intellectual shortcomings (1). The clinical presentation of symptoms in patients with MID/BIF may also differ from that in patients with a normal IQ.

If clinicians knew the prevalence of MID/BIF in everyday psychiatric practice, they might be aware of the need to diagnose it and to take account of any intellectual disabilities in their patients. However, validated tests for assessing IQ are time-consuming—a problem that led to the development of the Screener for Intelligence and Learning disabilities (SCIL), a short 14-item questionnaire that provides global insight into a patient's cognitive abilities and assesses the risk for MID/BIF.

In this study, we, therefore, determined the percentage of patients suspected of having a MID/BIF according to the SCIL in patients admitted to two wards for acute psychiatry in two different general hospitals. Second, we checked whether MID/BIF was documented in medical charts. Third, we compared the demographic and psychiatric characteristics of the SCIL-positive and the SCIL-negative patients. Finally, we investigated the number of involuntary admissions and coercive measures in the SCIL-positive and the SCIL-negative patients.

## Methods

**Design and setting**
This prospective dynamic cohort study involved patients admitted to two acute psychiatric wards in general hospitals located in a catchment area with 300,000 inhabitants in the eastern Netherlands. The study was conducted and reported in accordance with the STROBE guidelines for reporting observational studies (13).

**MID/BIF screening using the SCIL**
A test consisting of 14 questions and minor tasks, the SCIL is intended to provide global insight into a patient's cognitive abilities. It was developed specifically to detect MID/BIF (IQ 50-84) in people in various social-service and health-care settings and in jails, police stations, and homeless settings. It was validated in an adult sample consisting of 318 participants from social workplaces, probation services, organizations that provide support to clients with (intellectual) disabilities living in the community, and also treatment facilities for addiction care and mental health problems by comparing the scores on the SCIL with test results obtained on the WAIS-III (14 - 16). The reliability of the SCIL expressed in Cronbach's alpha was good (0.83 in the sample of 318 adult subjects). The AUC- value was high (0.93 in the adult sample). With 19 or lower as a cut-off score, the SCIL accurately classified 82% of people with MID/BIF. Similarly, about 9 out of 10 people without MID/BIF (89 %) were correctly classified as having no MID/BIF (15, 16).

The SCIL identifies two categories: SCIL positive, i.e., patients with a high risk of having MID/BIF; and SCIL negative, i.e., those patients with low risk. No specific professional degree is required to administer the SCIL. Before administering it, the nurses who participated in the current study received two hours of training, after which they first assessed 8 patients under supervision before performing assessments on their own.

**Patients**
All patients admitted for more than 6 days between June 15, 2014, and June 14 2015, were eligible for the study. The SCIL was administered by nurses who were not involved in treating these patients. The exclusion criteria were a patient's lack of command of Dutch or his or her lack of cooperation. To engage in the test, patients also had to be able to concentrate for at least 20 minutes, an ability that was determined by the nurses. If the patient showed acute psychotic or an otherwise severely disordered mental state, the SCIL was not administered until recovery allowed the patient to concentrate.

**Chart information**
The following was extracted from digital medical charts: basic demographic data, such as age, gender, marital status, ethnic background, and psychiatric diagnosis (DSM-IV-TR, as assessed by the psychiatrist on the ward); and information on admission history, previous voluntary or involuntary admissions, and current or previous coercion. The medical charts were also read by a research assistant (a psychologist). For the latter, there were three reasons: to confirm the information in question, to screen for any IQ data, and to screen the biography for any information on MID/BIF such as diplomas and broken school careers.

**Coercive measures**
Coercive measures were rated prospectively during the current hospital stay by means of the Argus rating scale (17), a short instrument covering all coercive measures such as seclusion, restraint, and enforced medication. The psychologist also read the medical charts to check the Argus figures for any involuntary admissions or coercive measures in the past five years.

**Analyses**
As appropriate, chi-square statistics or a Student's t-test was used to test the differences between three groups: not assessed with the SCIL, SCIL-positive, and SCIL-negative. Similarly, for all patients, SCIL positive or otherwise, odds ratios were calculated for 1.) patient characteristics, 2.) admission history, and 3.) having experienced coercive measures (as measured on the Argus rating scale (17)) during the current hospital stay

or during hospital stays in the previous five years. The significance level for the analyses was set at an α of 0.05. The analyses were performed with SPSS version 20.

## Results

**Demographic and psychiatric characteristics**
In the 12-month inclusion period, 314 patients were admitted for longer than 6 days, 208 of whom (66.2%) could be examined using the SCIL. In 106 patients, it was not possible to administer the SCIL, mostly because patients were discharged before the assessment could be completed (N=49), but also because they had insufficient command of Dutch (N=20), refused to participate (N=6), or because very severe psychiatric symptoms were revealed during the test (N=2). 29 patients were not assessed because staff had no time to gather data. Table 1 contrasts the patient characteristics of three groups of patients: those for whom it was not possible to obtain a score on the SCIL, those with a positive SCIL, and those with a negative SCIL.

Table 1: Comparisons between patients with no SCIL, SCIL-negative patients, and SCIL-positive patients

| | No SCIL | SCIL negative | SCIL positive | SCIL positive versus SCIL negative | | Difference between all groups | Difference between SCIL-positive and SCIL-negative patients |
|---|---|---|---|---|---|---|---|
| | | | | OR | 95% CI OR | | |
| N | 106 (33.8%) | 117 (56.3%) | 91 (43.8%) | | | | |
| Age | 43.08 | 43.95 | 44.45 | | | - | - |
| Male | 49.1% | 41.0% | 37.4% | | | | |
| Female | 50.9% | 59.0% | 62.6% | 1.16 | 0.66 - 2.04 | - | - |
| No partner | 64.2% | 53.0% | 68.1% | | | | |
| Partner | 35.8% | 47.0% | 31.9% | 0.53 | 0.30 - 0.93 | - | + |
| Western descent | 83.0% | 96.6% | 93.4% | | | | |
| Non-western descent | 11.3% | 2.6% | 6.6% | 0.37 | 0.09 - 1.54 | ++ | - |
| Unknown | 5.7% | 0.9% | 0% | | | | |
| Diagnosis | | | | | | | |
| No diagnosis* | 4.8% | 8.5% | 12.1% | 1.47 | 0.59 - 3.63 | ++ | - |
| Anxiety disorder | 5.8% | 9.4% | 8.8% | 0.93 | 0.36 - 2.41 | - | - |
| Depression | 24.0% | 44.4% | 28.6% | 0.50 | 0.28 - 0.89 | ++ | + |
| Bipolar disorder | 8.7% | 8.5% | 17.6% | 2.28 | 0.98 - 5.34 | - | - |
| Psychotic disorders | 27.0% | 16.2% | 20.9% | 1.36 | 0.67 - 2.75 | - | - |
| Schizophrenia | 11.5% | 4.3% | 4.4% | 1.03 | 0.27 - 3.95 | + | - |
| Drug-abuse disorder | 17.3% | 8.5% | 7.7% | 0.89 | 0.33 - 2.41 | + | - |
| Personality disorder** | 33.3% | 26.5% | 33.3% | 1.36 | 0.75 - 2.48 | - | - |
| Developmental disorder | 11.4% | 4.3% | 14.3% | 3.73 | 1.27 - 10.89 | - | + |
| IQ data in charts | 11.3% | 11.8% | 22.1% | 2.12 | 0.98 - 4.57 | - | - |
| Total IQ (score and N=) | 86 (5) | 89 (11) | 69 (13) | | | | |

*:   No diagnosis was found in the medical chart.

**:  any personality disorder present.

OR = odds ratio, - = no significant difference, + = significant difference, *P*<0.05, ++ = significant difference, *P*<0.01.

Ninety-one patients of the 208 patients who were screened with the SCIL (43.8%) were found to be SCIL positive. A higher number of patients in the SCIL-positive group than in the SCIL-negative group (OR=0.53, SD=0.30 - 0.93) had no partner. Fewer were diagnosed with depression (OR=0.50, SD=0.28 - 0.89). As may be expected, developmental disorders were more common in the SCIL-positive patients (OR=3.73, SD=1.27 - 0.89).

After comparing patients with no SCIL, the non-responders with those who were SCIL positive and those who were SCIL negative, the responders, we found that non-responders contained significantly more patients in three groups: those of non-Western descent (chi-square=7.84, $P$=0.02), those with drug-abuse disorder (chi-square=5.56, $P$=0.02), and those with schizophrenia (chi-square=5.51, $P$=0.02). It is likely that the options for assessing these patients had been impaired by language and attention problems.

The medical charts showed earlier documentation of intellectual impairment in only a minority of the 91 SCIL-positive patients (22.1 %). Even though IQ was documented in only a small number of patients, the mean IQ in the SCIL-positive group (N=13) was 69, compared to 89 (N=11) in the SCIL-negative group.

**Coercive measures**
With respect to coercive experiences, SCIL-positive patients had a higher risk of being admitted involuntarily (OR=2.71, SD=1.28 - 5.70, $P$<0.05). Their medical charts also reported a higher number of past involuntary admissions (OR=2.20, SD=1.12 - 4.32, $P$<0.01) and showed that patients who tested SCIL positive had had a higher risk of undergoing coercive measures (i.e., seclusion, restraint and forced medication) (OR=3.95, SD=1.47 - 10.54, $P$<0.01). Table 2 presents the outcomes for a number of coercion-related items in all SCIL groups.

Table 2: Use of coercive measures in patients with no SCIL, in SCIL-negative patients, and in SCIL-positive patients

| | No SCIL | SCIL negative | SCIL positive | SCIL positive versus SCIL negative | | Difference between all groups | Difference between SCIL-positive and SCIL-negative patients |
|---|---|---|---|---|---|---|---|
| | | | | OR | 95% CI OR | | |
| N | 106 (33.8%) | 117 (56.3%) | 91 (43.8%) | | | | |
| Currently involuntary admitted | 20.8% | 11.1% | 25.3% | 2.71 | 1.28 - 5.70 | + | + |
| Admitted involuntarily in the last 5 years | 35.8% | 15.4% | 28.6% | 2.20 | 1.12 - 4.32 | ++ | + |
| Coercion* during current stay | 4.7% | 3.4% | 7.7% | 2.35 | 0.67 - 8.30 | - | - |
| Coercion* in the last 5 years | 19.8% | 5.1% | 17.6% | 3.95 | 1.47 - 10.54 | ++ | ++ |
| Ever admitted involuntarily | 40.6% | 23.1% | 37.4% | 1.99 | 1.08 - 3.63 | + | + |
| Ever experienced coercion* | 22.6% | 7.7% | 23.1% | 3.60 | 1.56 - 8.31 | ++ | ++ |

*: coercion = seclusion, restraint and forced medication.

OR = odds ratio, - = no significant difference, + =significant difference, *P*<0.05, ++ =significant difference, *P*<0.01.

## Discussion

Approximately 40% of recently admitted psychiatric patients were at risk for having MID/BIF as assessed on the SCIL. Only in 22.1% of the SCIL-positive group did the medical charts show an earlier diagnosis of MID/BIF. A SCIL-positive patient was more likely than a SCIL-negative patient not to have a partner and not to have been diagnosed with depression. SCIL-positive patients were more likely to have been admitted involuntarily and to have been subjected to coercive measures in the past.

If, as we assume, SCIL-positive patients are at a high risk of having MID/BIF, the prevalence of MID/BIF is much higher in the current study than in the general population. The prevalence of MID/BIF in our patients was comparable to that in an

unpublished study on patients treated in Assertive Community Treatment teams, which found a prevalence of MID/BIF as high as 59%. The study in question had assessed MID/BIF using a Dutch Intelligence Test (GIT; 18). Another study in ACT teams in Ontario, Canada, estimated MID to be 9-11% (19). We found no other studies that assessed both MID and BIF in psychiatric patients.

Our finding that fewer SCIL-positive patients than SCIL-negative patients had a depressive disorder contrasts with a study showing that affective disorder is one of the commonest disorders in people with MID (8). As we also know from the Diagnostic Manual—Intellectual Disability (DM-ID) (20), there may be differences between the clinical presentation of symptoms in patients without intellectual problems and the presentation in the patients with MID (and often BIF) we know in clinical practice. When depressed, adults with MID have been noted to have higher rates of conduct problems, social withdrawal and irritable mood (8). In the same study, a developmental disorder was diagnosed in 11.4% of the SCIL-positive group, against 4.5% in the negative group. These findings are confirmed in studies by Prasher et al. (21) in which an Autism Spectrum Disorder was associated with MID. In our SCIL-positive sample, we note the modest number of patients diagnosed with a substance use disorder (SUD). A study across several samples by Duijvenbode et al. (22) showed that the prevalence of SUD with MID/BIF varied very widely (0.5-21% or more).

Our results also show that, in the past, SCIL-positive patients had had more involuntary admissions than SCIL-negative ones and had experienced more coercive measures. This is a remarkable finding. Coercive measures may obstruct recovery and even result in iatrogenic PTSD (23). People with MID/BIF have reduced coping skills and easily react with verbal aggression, and, in circumstances, they cannot oversee, with abject behaviour or refusal behaviour. In the context of admission wards with large numbers of severely disordered patients, their inability to cope may even increase impairing diagnosis and the identification of treatment that will meet their needs. To prevent coercion, MID/BIF patients treatment should thus be adapted to their intellectual capacities and to their ability to understand their environment.

## Strengths and Limitations

**Strengths**

To our knowledge, this is the first prevalence study on MID/BIF in a relatively large sample of acutely admitted psychiatric patients. Even though the assessments were performed on acute psychiatric wards, we were able to include a substantial number of patients (66.2%). In such a setting, this is a very reasonable response rate (24). As the data were gathered in two psychiatric wards in general hospitals, our findings have validity for clinical practice. Because there were no specific selection criteria for admission to these wards, these findings may be a good overall reflection of psychiatric patients admitted in the Netherlands.

**Limitations**

The first limitation is that the SCIL is a screener instrument for assessing MID/BIF that was not followed by a fully validated IQ test, such as the WAIS, and then -as might be preferred- by a second test for emotional and adaptive functioning.

The second limitation is that we do not know what causes a SCIL-positive result: it may result from cognitive decline, psychiatric disease or symptoms, or from long-term psychiatric medication. Nevertheless, whatever the origin of the intellectual impairment, our study shows that a high proportion of patients who are admitted in the acute phase of psychiatric disease appear to function at the level of MID/BIF and that their treatment and handling should be adapted to their specific abilities and care needs. To what extent the intellectual impairment with which they present is an inborn defect or the effect of cognitive decline or is a subject for further research.

A third possible limitation is that there may have been a selection bias involving patients with schizophrenia, drug abuse and those of non-western descent.

Finally, no structured interview was used to establish the DSM-IV-TR diagnosis.

## Recommendations for clinical practice and research

To assess their earlier intellectual aptitude, we recommend that all patients admitted are interviewed with regard to their school career, diplomas, and employment. To understand the impairments of a patient with MID/BIF, clinicians have to adapt their communication and attitude. This can help to avoid coercion and can also support the recovery process.

Although the SCIL is not a cognitive test in the narrower sense, and although many skills required to perform the small tasks in the SCIL are learned in early life, we do not yet know the influence of psychiatric symptoms on the SCIL test result. We, therefore, recommend further research on the association between SCIL findings, psychiatric symptoms, medication, and drug use or drug abuse that possibly results in cognitive decline. As well as examining intellectual capacities with an intelligence test, one might consider other assessments of adaptive functioning and social-emotional development. Finally, we recommend that the current study is repeated in first referral patients, Functional Assertive Community Treatment (FACT) patients, and long-stay patients.

## Conclusions

Overall, we feel it is fair to assume on the basis of our results that MID/BIF is present in a substantial proportion of admitted psychiatric patients and that such a diagnosis may often be overlooked in the acute phase of psychiatric disease. Due not only to the relatively high number of patients with a suspected MID/BIF but also to the substantial lack of information on education and employment history in their biographies, we recommend that all patients referred to mental health treatment should first be interviewed on their school career, diplomas, and employment history. This will provide an impression of formal intellectual functioning.

It is also important to gain an impression of a patient's intellectual capacities -by using the SCIL, for example- and of their social function skills and adaptive behaviour. Examination of the patient's intellectual capacities through an intelligence test might also be considered. Failure to identify a MID/BIF may represent an additional risk with regard not only to involuntary admission but also the use of coercive measures that may lead to iatrogenic damage. The need to identify this particular patient group at an earlier point in treatment is an important challenge in mental healthcare.

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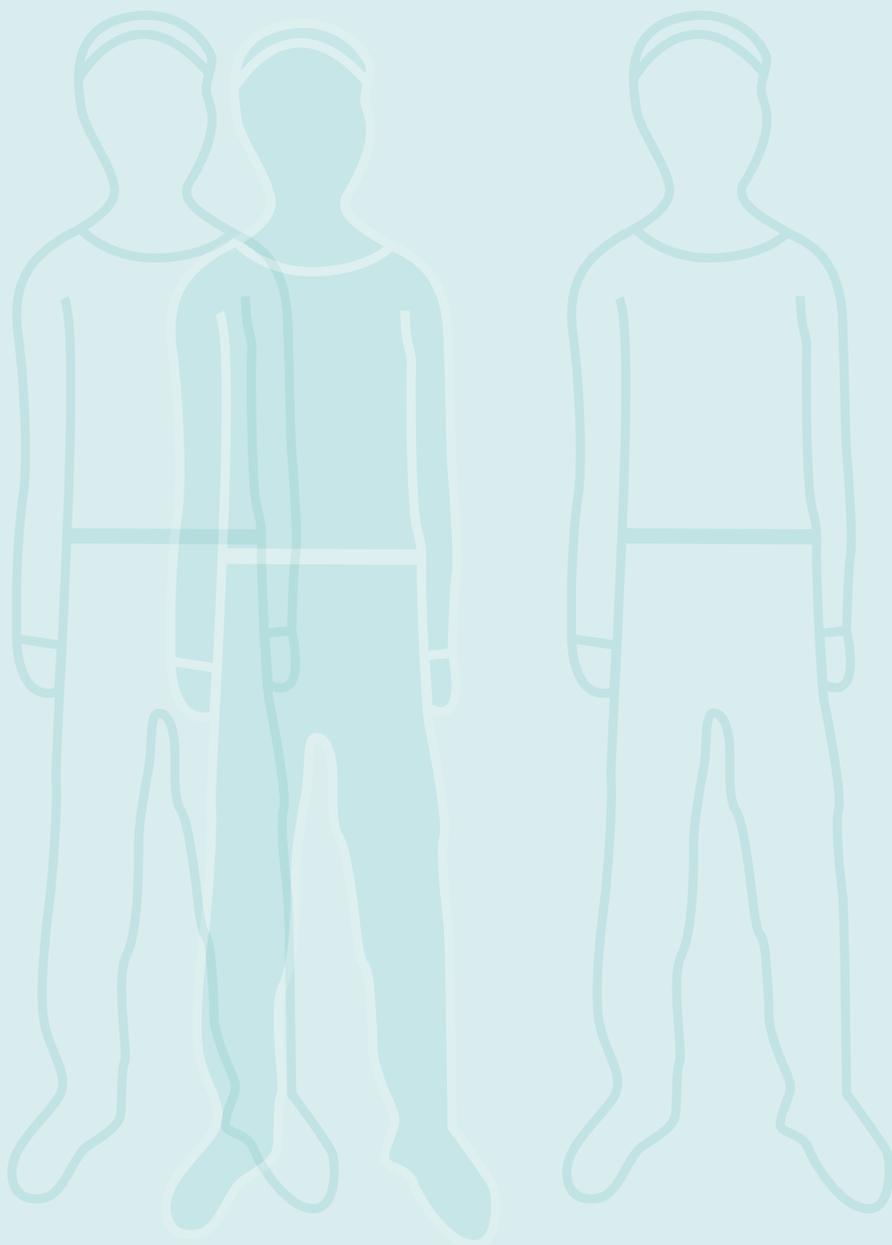
Chapter

**4**

# Increased prevalence of Intellectual Disabilities in higher intensity mental health settings

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# Abstract

**Background.** It has been suggested that people with intellectual disabilities have a higher likelihood to develop psychiatric disorders and that their treatment prognosis is relatively poor.

**Aims.** We aimed to establish the prevalence of intellectual disability in different mental health care settings and estimate the percentage of cognitive decline. We hypothesised that the prevalence of intellectual disabilities increases with the intensity of care.

**Method.** A cross-sectional study was conducted in different settings in a mental healthcare trust in the Netherlands. We used the Screener for Intelligence and Learning disabilities (SCIL) to identify suspected Mild Intellectual Disability (MID) or Borderline intellectual functioning (BIF). We identified patients with high education and low SCIL-scores to estimate which patients may have had cognitive decline.

**Results.** We included 1213 consecutive patients. Over all settings, 41.4% of participating patients were screened positive for MID/BIF, and 20.2% screened positive for MID only. Prevalence of suspected MID/BIF increased by setting, from 27.1 % in out-patient settings, 41.9% in Flexible Assertive Community Treatment (FACT) teams and admission wards, to 66.9% in long-stay wards. Only 85 (7.1%) of all patients were identified as possibly having a cognitive decline. Of these, 25.9% were in long-stay wards and had a diagnosis of schizophrenia or substance use disorder.

**Conclusions.** Low intellectual functioning is common in Dutch mental health care settings. Only a modest number of patients were identified as suffering from cognitive decline rather than suspected MID/BIF from birth. Therefore we recommend improved screening of psychiatric patients for intellectual functioning at the start of treatment.

**Keywords.** Intellectual disability; community mental health teams; outpatient treatment; SCIL; in-patient treatment.

## Prevalence of intellectual disability in mental health care

In the Netherlands, as in many other European countries, care and treatment of people with Intellectual Disability (ID) and psychiatric problems became separated from psychiatric care for those without ID in the 1950s and 1960s. Institutions for patients with ID and general mental health were separately commissioned by different funding streams in the Netherlands, and since then, each institution's knowledge of the other was diminished over the years. As we know from two previous studies (1, 2, 3), the prevalence of Mild Intellectual Disability (MID) or Borderline Intellectual Functioning (BIF) is much higher in general) mental healthcare as may be expected from the prevalence estimations in the general population. This finding was remarkable, given the background of developing separate intellectual disability services alongside standard psychiatric care in the Netherlands. In the study, more than 40% of psychiatric in- and out-patients screened were suspected of having MID/BIF, using the SCreener for Intelligence and Learning disability (SCIL, 4). The study validated the SCIL against the WAIS (5) in participating patients with severe mental illness (SMI). In the Netherlands, the SCIL is a widely accepted Screener used in psychiatric and forensic settings.

The population prevalence of Mild Intellectual Disabilities (MID) is estimated to be 0.7 ± 1.3% in Western countries (6, 7). On the basis of the normal distribution of intelligence in the general population, 2.1% would have an IQ in the 50-70 range (MID) and 13.6% in the 71-84 range (BIF). Possibly, persons with MID/BIF have a higher likelihood of requiring psychiatric care, and relatively often, this need for care may be long-term and intense.

## Improper diagnoses may lead to developing SMI

For a number of decades, there has been an awareness in psychiatry that patients with schizophrenia, substance and alcohol abuse and bipolar disorder are at risk of developing cognitive decline (8, 9). So in the assessment of intellectual impairment, cognitive decline needs to be ruled out. To our knowledge, there are no studies examining the prevalence of MID/BIF in general psychiatry, correcting for possible impaired cognitive functioning, either at birth or acquired in childhood or after 18 years of age.

## Aims of this study

This study investigated intellectual disability and its possible association with cognitive decline in different general mental health care settings, each providing an increasingly longer-term treatment. When MID/BIF is not properly identified by clinicians, this may lead to missed, improper or false diagnosis and treatment (10), followed by a longer history in psychiatry, lower quality of life, worse functioning, and possible higher care costs (11). As such, these patients may develop SMI (12). SMI patients may be defined as having one or more psychiatric disorders (psychosis, severe depression, personality disorders and bipolar disorders, perhaps in combination with several other disorders), together with social-functioning problems for at least two years (13). Clinical treatment of schizophrenia, mood disorders and personality disorders is different when a patient has an intellectual disability (14). Treatment for addiction is also different in a number of aspects if an intellectual disability has to be taken into account (15, 16). A clear diagnosis at an early stage is therefore important in preventing long-term care dependency.

The aim of this study was to investigate the prevalence of a possible MID/BIF and possible cognitive decline in different mental healthcare settings in the Netherlands. In addition, we investigated the association between MID/BIF and patient characteristics such as age, gender, diagnosis and global functioning. Our hypothesis was that lower intellectual functioning is associated with a higher prevalence of SMI, a more chronic disease course, higher care intensity, and worse functioning.

## Method

The study was conducted and reported in accordance with the Strengthening the Reporting of Observational Studies in Epidemiology guidelines for reporting observational studies (17). Screening of potential Intellectual Disabilities was done from May 2014 until January 2019. All patients at participating wards or care centres were asked to join the study. We used consecutive sampling, thus asking all new patients to participate; all participants provided informed consent. This allowed for non-response analysis, adding to the clinical validity of the findings (18).

## Setting

We collected a consecutive sample of patients treated with four different types of care in a mental health care Trust in the east of the Netherlands, covering a catchment area of 630.000 inhabitants. This Trust covers all specialised mental health care in the catchment area with an annual total of about 18.000 out-patient referrals and approximately 2500 inpatient referrals, of which approximately 200 patients reside in long-stay wards. It is a standard mental health trust, of which the Netherlands has 24. The four types of care included were:

a) Out-patient clinics, where patients were referred to after having been treated with insufficient effect by a general practitioner, community nurse or psychologists.

b) Flexible assertive community treatment (FACT) teams, specialising in daily (out-patient) support and treatment for patients with SMI. In the Netherlands, FACT teams are multidisciplinary out-patient teams with between eight and ten professionals, such as a psychiatrist, a psychologist, several nurses and social workers, in general, taking care of 200 patients with SMI (19).

c) General admission wards, admitting both first-onset patients and patients referred from FACT teams or out-patient clinics. In addition, patients at these wards were eligible for the study when at least six days on the ward.

d) Long-stay wards, providing residential care for patients with SMI. The teams at these wards have a similar setup as the FACT teams. Patients all have a long history of receiving professional support and treatment, primarily in the FACT teams.

Patients were excluded if they had an inadequate grasp of the Dutch language, lack of cooperation, or an inability, in the assessor's opinion, to concentrate for at least 20 minutes to engage in the test as outlined in the instruction (20).

## Measures

MID/BIF screening with the SCIL. We used the SCIL to detect patients suspected of MID or BIF (20). The SCIL was first used in several published studies in forensic psychiatry in the Netherlands (21). Translation for use in English is in preparation. The SCIL comprises 14 questions, including educational level and small tasks that are intended to provide an overall insight into a patient's cognitive abilities (20). It was developed specifically to detect MID/BIF (IQ 50-85) in people in a range of settings, such as healthcare or social-service settings, police stations and shelters for the homeless. The SCIL adds to other screeners for intellectual disability, such as the Hayes Ability Screening Index (22), because it screens for BIF in addition to MID.

The SCIL was validated in an adult sample by comparing the scores obtained with test results from the WAIS-III. The reliability of the SCIL, as expressed in Cronbach's alpha, was good (0.83 in 318 adults). The area under the curve value was 0.93, which is excellent. With $\leq$19 as a cut-off score, the SCIL accurately classified 82% of people with MID/BIF. Of the ten people without MID/BIF, nine (89%) were classified correctly as having no MID/BIF. In accordance with the SCIL manual, administering the SCIL requires no specific clinical skills.

Recently, the SCIL had been validated in patients with SMI in FACT teams (3). The Cronbach's alpha of the SCIL in that sample was 0.73. The area under the curve value was 0.81 for detecting MID/BIF and 0.81 for detecting MID, with percentages of correctly classified subjects of 73% and 79%, respectively. We used two cut-off scores: 19 and 15. Scoring >19 implied no MID/BIF, and scoring $\leq$19 implied suspected MID/BIF. The cut-off point of $\leq$15 implies a MID (20). In the following descriptions, we use two cut off points, 19 for MID or BIF and 15 for MID only.

*Cognitive decline*. The SCIL does not distinguish between impaired intellectual functioning caused by cognitive decline and intellectual disability from birth. To detect a potential cognitive decline after 18 years of age, we verified the patient's school reports and qualifications in their medical file. We categorised the school qualifications into four education levels which are related to estimated IQ (WAIS) levels. For this, we identified the educational attainment of the participants. We categorised > 60 different educational data and certificates into four categories. By accessing publically available information, we estimated and verified the content of the educational data and certificates to WAIS levels. Two team members coded the school certificates and obtained consensus in a final listing.

Education level 4 corresponds to an estimated IQ outcome on the WAIS of >120, level 3 to an IQ of 110-120, level 2 to an IQ of 85-110, and level 1 to an estimated IQ of 50-85. We compared these levels with SCIL outcomes. An educational level of 2, 3 and 4 with a current SCIL of <19, implying low intellectual functioning after reasonable educational attainment, may suggest cognitive decline. Patient characteristics of patients with a possible cognitive decline were compared to the patient characteristics of all other patients in the sample. We performed this comparison to understand whether the patient characteristics associated with intellectual disability were the same as those associated with cognitive decline.

*Demographic and medical information.* The following information was extracted from digital medical notes: age, gender, psychiatric diagnosis (DSM-IV-TR, as assessed by the psychiatrist) and Global Assessment of Functioning (GAF) score. In all samples, we included retrospective file information from the five years before the SCIL was conducted. A maximum of four primary DSM diagnoses were included.

*Statistical Analyses.* We calculated the odds ratios when comparing groups to understand the extent of differences between groups. Where appropriate, differences between groups were tested by means of t-tests or χ2-tests. An alpha of 0.001 was used because of the large numbers in the study. Missing values were recorded and reported where they may be expected to have an effect on the findings.

*Ethics.* Ethical approval for the study was provided in 2014 by the ethical board of the University of Twente, Enschede, The Netherlands. All procedures performed in the current study were in accordance with the Helsinki Declaration of 1975, as revised in 2008, and with comparable ethical standards. Data were analysed on the basis of fully anonymised data that allowed none of the cases to be traced to an individual.

# Results

*Patients*. We asked 1616 consecutive patients to participate; we got a SCIL score in 1213 cases (75.1%). The response did not vary greatly across settings. At the out-patient clinics, the response rate was 71.3%, followed by the FACT teams with 72.9%. At the long-stay wards, the response rate was 75.8%, whereas, at the general admission wards, it was 79.2%. We included 313 patients from out-patient services, 291 patients from FACT teams, 452 patients from admission wards, and 157 patients from long-stay wards. Patients in the out-patient services were significantly younger than in the admission wards, the FACT teams and the long-stay wards. The long-stay wards had admitted more male patients.

*SCIL scores across the settings.* Table 1 presents the distribution of SCIL categories across the four examined settings. The results show that overall, 41.4% of the 1213 included patients showed a SCIL score of $\leq$19 (corresponding to suspected MID/BIF), and 20.2% had a SCIL score of $\leq$15 (corresponding to likely MID). Of the 313 general outpatients interviewed, 27.2% had a SCIL score of $\leq$19 (suspected MID/BIF), and 10.2% a SCIL of $\leq$15 (MID). The 291 patients interviewed at FACT teams showed a significantly higher prevalence of suspected intellectual disabilities; 41.2% of the FACT patients had a SCIL score of $\leq$19, and 20.6% had a SCIL score of $\leq$15. Of the 452 patients interviewed at regular admission wards, 42.5% had a SCIL score of $\leq$19 (suspected MID/ BIF) and 19.0% had a SCIL score of $\leq$15 (suspected MID). The 157 patients at the long-stay ward had the highest prevalence of positive SCIL scores; 66.9% had a SCIL of $\leq$19; 42.7% had a SCIL score of $\leq$15. This increase is also reflected in differences in odds' ratios over the four settings, with the out-patient services at the lower end (SCIL $\leq$19 odds ratio 0.43; SCIL $\leq$15 odds ratio 0.37) and the long-stay wards at the higher end (SCIL $\leq$19 odds ratio 3.35; SCIL $\leq$15 odds ratio 3.67).

Table 1: Distribution of MID/BIF as identified by SCIL scores and patient characteristics across settings

| | Totals | Out-patient services | Admission wards | FACT Teams | Long stay inpatient wards | P |
|---|---|---|---|---|---|---|
| N | 1616 | 439 | 571 | 399 | 207 | |
| Response | 1213 (75.1%) | 313 (71.3%) | 452 (79.1%) | 291 (75.0%) | 157 (75.8%) | |
| Mean age (SD) | 43.1 (11.8) | 39.3 (10.8) | 43.9 (12.3) | 46.5 (10.9) | 45.3 (13.3) | <0.001 |
| Gender — Male | 790 (48.9%) | 200 (45.9%) | 270 (47.3%) | 177 (44.4%) | 143 (69.1%) | <0.001 |
| Female | 826 (51.1%) | 239 (54.4%) | 301 (52.7%) | 222 (55.6%) | 64 (30.9%) | |
| Educational level — Low | 823 (61.7%) | 227 (59.4%) | 276 (60.5%) | 198 (60.4%) | 122 (72.6%) | 0.020 |
| High | 511 (31.6%) | 155 (40.6%) | 180 (39.5%) | 130 (39.6%) | 46 (27.4%) | |
| Not assessed | 282 (17.4%) | 57 (12.9%) | 115 (20.1%) | 71 (17.8%) | 39 (18.9%) | <0.001 |
| **SCIL outcome** | | | | | | |
| % No SCIL | 403 (24.9%) | 126 (28.7%) | 119 (20.8%) | 108 (27.1%) | 50 (24.2%) | 0.024 |
| **Intellectual Functioning** | | | | | | |
| % SCIL negative (>19) | 711 (58.6%) | 228 (72.8%) | 260 (57.5%) | 171 (58.8%) | 52 (33.1%) | <0.001 |
| % SCIL positive (≤19) | 502 (41.4%) | 85 (27.2%) | 192 (42.5%) | 120 (41.2%) | 105 (66.9%) | |
| BIF | OR | 0.43 | 1.07 | 0.99 | 3.35 | |
| | 95% CI OR | 0.33 – 0.57 | 0.85 – 1.36 | 0.76 – 1.30 | 2.35 – 4.78 | |
| SCIL positive / SCIL negative | P | <0.001 | 0.551 | 0.505 | <0.001 | |
| **Mild intellectual Disability** | | | | | | |
| % SCIL >15 | 968 (79.8%) | 281 (89.8%) | 366 (81.0%) | 231 (79.4%) | 90 (57.3%) | <0.001 |
| % SCIL ≤15 | 245 (20.2%) | 32 (10.2%) | 86 (19.0%) | 60 (20.6%) | 67 (42.7%) | |
| SCIL ≤15 / SCIL >15 | OR | 0.37 | 0.89 | 1.03 | 3.67 | |
| | 95% CI OR | 0.25 – 0.55 | 0.66 –1.19 | 0.75 – 1.43 | 2.57 – 5.24 | |
| | P | <0.001 | 0.240 | 0.448 | <0.001 | |
| **Cognitive decline** | | | | | | |
| High educational level and high SCIL or | 1128 (93.0%) | 303 (96.8%) | 420 (92.9%) | 270 (92.8%) | 135 (86.0%) | <0.001 |
| High educational level with low SCIL | 85 (7.1%) | 10 (3.2%) | 32 (7.1%) | 21 (7.2%) | 22 (14%) | |
| OR SCIL in line with educational level / | OR | 0.36 | 1.02 | 1.04 | 2.57 | |
| SCIL not in line with educational level | 95% CI OR | 0.18 – 0.71 | 0.65 – 1.60 | 0.63 – 1.74 | 1.53 – 4.31 | |
| | P | <0.001 | 0.513 | 0.481 | <0.001 | |

*Diagnosis.* When we investigated the differences in diagnosis between those assessed with the SCIL and those who were not (because they did not want or could not participate), we observed no significant differences in diagnoses between patients (Table 2).

When we investigate the differences between the various SCIL groups we did assess, we found that the diagnoses schizophrenia (odds ratio 2.41, 95% CI=1.81 - 3.22, *P*<0.001), substance use disorder (odds ratio 1.84, 95% CI=1.33 - 2.54, *P*<0.005), and intellectual disability (odds ratio 7.11, 95% CI=4.25 - 11.88, *P*<0.001) were significantly more prevalent in patients with a SCIL score of ≤19. The same diagnoses were also more prevalent in patients with a SCIL of ≤15 (Schizophrenia odds ratio 2.93, 95% CI=2.14 - 4.01, *P*<0.001; substance use disorder odds ratio 1.70, 95% CI=1.18 - 2.45, *P*<0.05, intellectual disability odds ratio 5.05 95% CI=3.32 - 7.69, *P*<0.05). Patients more frequently had a GAF score <45 if they had a SCIL score of ≤19 (odds ratio 1.68, 95% CI=1.32 - 2.14, *P*<0.001) and or a SCIL of ≤15 (odds ratio 1.97, 95% CI=1.48 - 2.63, *P*<0.001).

Patients with a SCIL score of ≤19 were significantly less diagnosed with anxiety disorder (odds ratio 0.58, 95% CI=0.41 - 0.82, *P*<0.001), depression (odds ratio 0.47, 95% CI=0.36 - 0.61, *P*<0.001) and personality disorder (odds ratio 0.69, 95% CI=0.54 - 0.87, *P*=0.002). When we compare the above diagnoses in patients with a SCIL score above or below 15, the outcomes were nearly the same (odds ratios of 0.63; OR=0.45 and OR=0.59 respectively).

**Table 2: Distribution of patient characteristics and diagnosis in patients not assessed with the SCIL, patients with SCIL scores above and below 19 (Borderline Intellectual Functioning and Mild Intellectual Disability) and above and below 15 (Mild Intellectual Disability)**

a   Significant difference between SCIL positive and SCIL negative (BIF) *P*<0.001 one-sided chi-square.

b   Significant difference between SCIL below 15 and above 15 (MID) *P*<0.001 one-sided chi-square.

c   Column percentage (% response in patients over the whole group).

d   Row percentage (distribution of the various SCIL groups over the 1213 responders).

e   The GAF scores were not administered in 63 (4.5.%) out of 1616.

| | N | Below Borderline Intellectual Functioning/Mild Intellectual Disability | | | | | Mild Intellectual Disability | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | % No SCIL | % SCIL negative (>19) | % SCIL positive (≤19) | SCIL positive/SCIL negative OR | 95% CI OR | % SCIL >15 | % SCIL ≤15 | SCIL <15/SCIL >15 OR | 95% CI OR |
| N | 1616 | 403 | 711 | 502 | | | 968 | 245 | | |
| Response | 1213 (75.1%)[c] | 302 (24.9%)[d] | 533 (43.9%)[d] | 378 (31.2%)[d] | | | | 245 | | |
| Mean age (SD) | | 44.9 (11.7) | 42.1 (11.5) | 43.1 (12.4) | | | 42.2 (11.6) | 43.9 (12.7) | | |
| Gender Male | 790 (48.9%) | 193 (47.9%) | 336 (47.3%) | 261 (52.0%) | 0.83 | 0.66 - 1.04 | 462 (47.7%) | 135 (55.1%) | 0.74 | 0.56 - 0.99 |
| Female | 826 (51.1%) | 210 (52.1%) | 375 (52.7%) | 241 (48.0%) | | | 506 (52.3%) | 110 (44.9%) | | |
| Educational level [ab] Low | 823 (61.7%) | 124 (68.9%) | 321 (46.5%) | 378 (81.6%) | 0.20 | 0.15 - 0.26 | 502 (54.4%) | 197 (84.9%) | 0.21 | 0.15 - 0.31 |
| High | 511 (31.6%) | 56 (31.1%) | 370 (53.5%) | 85 (18.4%) | | | 420 (46.6%) | 35 (15.1%) | | |
| Not assessed | 282 (17.4%) | 122 (30.2%) | 20 (2.8%) | 39 (7.8%) | | | | | | |
| Diagnosis | | | | | | | | | | |
| Adjustment disorder | 63 (3.9%) | 11 (2.7%) | 31 (4.4%) | 21 (4.2%) | 0.96 | 0.55 - 1.69 | 42 (4.3%) | 10 (4.1%) | 0.94 | 0.47 - 1.90 |
| Anxiety disorder [ab] | 239 (14.8%) | 124 (17.4%) | 124 (17.4%) | 55 (11.0%) | 0.58 | 0.41 - 0.82 | 153 (15.8%) | 26 (10.6%) | 0.63 | 0.41 - 0.99 |
| Depression [ab] | 481 (29.8%) | 127 (31.5%) | 252 (35.4%) | 102 (20.3%) | 0.47 | 0.36 - 0.61 | 311 (32.1%) | 43 (17.6%) | 0.45 | 0.32 - 0.64 |
| PTSD diagnosis | 301 (18.6%) | 77 (19.1%) | 125 (17.6%) | 99 (19.7%) | 1.15 | 0.86 - 1.54 | 180 (18.6%) | 44 (18.0%) | 0.96 | 0.67 - 1.38 |
| Bipolar disorder | 163 (10.1%) | 31 (7.7%) | 73 (10.3%) | 59 (11.8%) | 1.16 | 0.81 - 1.67 | 109 (11.3%) | 23 (9.4%) | 0.96 | 0.88 - 1.05 |
| Psychotic disorders | 266 (16.5%) | 65 (16.1%) | 111 (16.6%) | 90 (17.9%) | 1.18 | 0.87 - 1.60 | 148 (15.3%) | 53 (21.6%) | 1.53 | 1.07 - 2.17 |
| Schizophrenia [ab] | 341 (21.1%) | 101 (25.1%) | 99 (13.9%) | 141 (28.1%) | 2.41 | 1.81 - 3.22 | 153 (15.8%) | 87 (35.5%) | 2.93 | 2.14 - 4.01 |
| Developmental disorder | 213 (13.2%) | 49 (12.2%) | 97 (13.6%) | 67 (13.3%) | 0.97 | 0.69 - 1.36 | 135 (13.9%) | 29 (11.8%) | 0.83 | 0.54 - 1.28 |
| Drug-abuse disorder [ab] | 227 (14.0%) | 54 (13.4%) | 79 (11.1%) | 94 (18.7%) | 1.84 | 1.33 - 2.54 | 124 (12.8%) | 49 (20.0%) | 1.70 | 1.18 - 2.45 |
| Personality disorder [ab] | 669 (41.4%) | 186 (46.2%) | 309 (43.5%) | 174 (34.7%) | 0.69 | 0.54 - 0.87 | 409 (42.3%) | 74 (30.2%) | 0.59 | 0.44 - 0.79 |
| Intellectual Disability [ab] | 136 (8.4%) | 35 (8.7%) | 19 (2.7%) | 82 (16.3%) | 7.11 | 4.25 - 11.88 | 49 (5.1%) | 52 (21.2%) | 5.05 | 3.32 - 7.69 |
| GAF score <45 [abc] | 564 (36.3%) | 147 (37.5%) | 208 (30.9%) | 209 (42.9%) | 1.68 | 1.32 - 2.14 | 300 (32.6%) | 117 (48.8%) | 1.97 | 1.48 - 2.63 |
| Assessed | 1616 (100%) | 403 (100%) | 711 (100%) | 502 (100%) | | | 968 (100%) | 245 (100%) | | |

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When examining the distribution of diagnoses over the four settings, we observed some diagnoses such as anxiety disorders and depression occurring more in the out-patient services and the admission wards, while others, such as psychotic disorders, schizophrenia, substance use disorders or a GAF <45 occurred more in the FACT teams and the long-stay wards (Table 3).

*Cognitive decline.* Of the total of 1213 included patients, only 85 (7.1%) had a high education level (levels 2-4) corresponding with a low SCIL score. In contrast to this, in patients with a SCIL score of ≤19, 81.6% had a low educational level (level 1). In patients with a SCIL 15 or lower, as many as 84.9% had a low educational level (Table 4). We could not clearly identify the educational level of 308 patients (27.3%) without suspected cognitive decline (N=1128). In the patients with possible cognitive decline (a high education level and low SCIL), education levels could not be verified in only four patients (4.7%).

Patients on the long-stay wards were more likely to have a patient history associated with cognitive decline (odds ratio 2.57, *P*<0.001) than patients from the out-patient services, who were the least likely group to show evidence of cognitive decline (odds ratio 0.36, *P*<0.001). Figure 1 provides a summary of the proportions of the various SCIL groups (no ID. suspected BIF and MID) and the proportions of patients with possible cognitive decline over the wards.

Figure 1: Prevalence of MID, BIF/MID and suspected cognitive decline in the four studied settings of psychiatric care
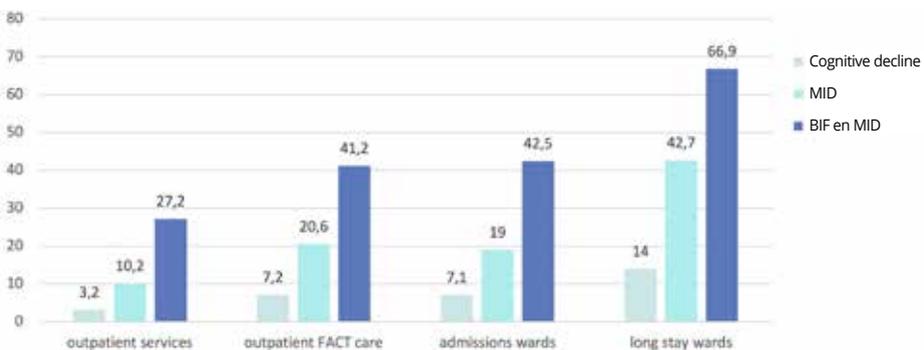
Table 3: Diagnostic characteristics of patients with a high educational level but low SCIL score (likely cognitive decline rather than ID from birth)

| | Low educational level and low SCIL or high educational level and high SCIL | High educational level and low SCIL | SCIL in line with educational level/SCIL not in line with educational level | | P |
|---|---|---|---|---|---|
| | | | OR | 95% CI OR | |
| N | 1128 | 85 | | | |
| % | 92.9% | 7.1% | | | |
| Educational level not | 308 (27.3%) | 4 (4.7%) | | | |
| Diagnosis | | | | | |
| Adjustment disorder | 49 (4.3%) | 3 (3.5%) | 0.80 | 0.25 - 2.64 | 0.498 |
| Anxiety disorder | 168 (14.9%) | 11 (12.9%) | 0.85 | 0.44 - 1.63 | 0.382 |
| Depression | 335 (29.7%) | 19 (22.4%) | 0.68 | 0.40 - 1.15 | 0.093 |
| PTSD diagnosis | 208 (18.4%) | 16 (18.8%) | 1.02 | 0.58 - 1.80 | 0.512 |
| Bipolar disorder | 117 (10.4%) | 15 (17.6%) | 1.85 | 1.03 - 3.34 | 0.038 |
| Psychotic disorders | 188 (16.7%) | 13 (15.3%) | 0.90 | 0.49 - 1.66 | 0.441 |
| Schizophrenia | 214 (19.0%) | 26 (30.6%) | 1.88 | 1.16 - 3.06 | 0.009 |
| Developmental disorder | 156 (13.8%) | 8 (9.4%) | 0.64 | 0.31 - 1.37 | 0.162 |
| Drug-abuse disorder | 153 (13.6%) | 20 (23.5%) | 1.96 | 1.15 - 3.33 | 0.012 |
| Personality disorder | 454 (40.2%) | 29 (34.1%) | 0.77 | 0.48 - 1.22 | 0.159 |
| Intellectual Disability | 95 (8.4%) | 6 (7.1%) | 0.83 | 0.35 - 1.94 | 0.426 |
| GAF score <45 | 377 (34.9%) | 40 (48.8%) | 1.77 | 1.13 - 2.78 | 0.009 |
| Outpatient wards | 303 (26.9%) | 10 (11.8%) | 0.36 | 0.18 - 0.71 | 0.001 |
| Admission wards | 420 (37.2%) | 32 (37.6%) | 1.02 | 0.65 - 1.60 | 0.513 |
| FACT teams | 270 (23.9%) | 21 (24.7%) | 1.04 | 0.62 - 1.74 | 0.481 |
| Long stay inpatient wards | 135 (12.0%) | 22 (25.9%) | 2.57 | 1.53 - 4.31 | 0.001 |

*Diagnosis and Cognitive decline.* In patients with possible cognitive decline, schizophrenia (odds ratio 1.85, 95% CI=1.03 - 3.34, *P*=0.009), and a GAF score below 45 (odds ratio 1.77, 95% CI=1.13 - 2.78, *P*=0.009) were significantly more often associated with the cognitive decline group (Table 4).

Table 4: Distribution of diagnosis over settings

| Diagnosis | | Out-patient clinics | Admission wards | FACT teams | Long stay wards | P |
|---|---|---|---|---|---|---|
| Adjustment disorder | 63 (3.9%) | 18 (4.1%) | 30 (5.3%) | 10 (2.5%) | 5 (2.4%) | 0.106 |
| Anxiety disorder | 239 (14.8%) | 87 (19.8%) | 88 (15.4%) | 47 (11.8%) | 17 (8.2%) | <0.001 |
| Depression | 481 (29.8%) | 161 (36.7%) | 231 (40.5%) | 81 (20.3%) | 8 (3.9%) | <0.001 |
| PTSD diagnosis | 301 (18.6%) | 68 (15.5%) | 141 (24.7%) | 83 (20.8%) | 9 (4.3%) | <0.001 |
| Bipolar disorder | 163 (10.1%) | 20 (4.6%) | 77 (13.5%) | 54 (13.5%) | 12 (5.8%) | <0.001 |
| Psychotic disorders | 266 (16.5%) | 13 (3.0%) | 131 (22.9%) | 70 (17.5%) | 52 (25.1%) | <0.001 |
| Schizophrenia | 341 (21.1%) | 3 (0.7%) | 91 (15.9%) | 115 (28.8%) | 132 (63.8%) | <0.001 |
| Developmental disorder | 213 (13.2%) | 58 (13.2%) | 65 (11.4%) | 62 (15.5%) | 28 (13.5%) | 0.314 |
| Drug-abuse disorder | 227 (14.0%) | 20 (4.6%) | 92 (16.1%) | 54 (13.5%) | 61 (29.5%) | <0.001 |
| Personality disorder | 669 (41.4%) | 188 (42.8%) | 232 (40.6%) | 187 (46.9%) | 62 (30.0%) | <0.001 |
| Intellectual Disability | 136 (8.4%) | 5 (1.1%) | 47 (8.2%) | 45 (11.3%) | 39 (18.8%) | <0.001 |
| Low GAF | 564 (36.3%) | 56 (14.4%) | 257 (45.6%) | 123 (31.2%) | 128 (62.1%) | <0.001 |

# Discussion

Intellectual functioning (ID) appears to be a factor that commonly remains unnoticed (1, 2) but is important in the treatment and recovery of psychiatric patients. We found that a strikingly high number of 41.4% of patients across the four investigated care settings showed a high probability of MID or BIF. This is significantly higher than the prevalence expected in the population but in keeping with the few existing previous smaller studies (1, 2, 3). The prevalence increased with the intensity level of the mental health care provided (lowest in out-patient settings, highest in long-stay wards). These findings are in line with a recent forensic sample showing prevalence rates of as high as 60% (23). Importantly, in this study, the SCIL findings were validated with concurrent WAIS outcomes. A recently published retrospective study by Smits et al. (24) showed that patients in FACT teams with possible BIF can benefit more from treatment when professionals know about their lower cognitive level. This same study showed that possible MID patients, in contrast, did not benefit from a different approach and hardly recovered.

Considering our current findings, although we did not examine causality, we have to consider the possibility that not recognising ID in patients at an early stage may lead to poorer treatment outcomes. Only 7.1% of all included patients showed evidence suggesting cognitive decline since adulthood, which is a lower percentage than expected (5). Somewhat unsurprisingly, most of those patients were on long stay wards. A total of 72.6% of the patients of the long-stay ward turned out to have a low education level. This suggests that these patients may have already functioned at a lower intellectual level in their youth. However, it cannot be ruled out that current psychotropic medication influences the SCIL outcome. Long-term mental hospital stay, comorbid mental illness, and limited participation in society, especially of the patients at the long-stay inpatient wards, may also limit SCIL outcomes. Nevertheless, the SCIL is an instrument that has no time limit and deliberately assesses early school skills, making it less dependent on current social deprivation or medication effects than the WAIS.

After analysis of the existing evidence, we hypothesised that lower intellectual functioning is associated with more severe illness, a poorer prognosis and worse functioning. We know from several Intellectual Disability studies (25, 26) in patients with MID in the UK, the US and Finland that schizophrenia, psychotic disorders, aggression and alcohol and drug abuse are often reasons for hospital admission and long-term treatment. Looking at the distribution of diagnoses in the patients with a SCIL score of 19 and lower, schizophrenia (OR 2.41), substance use disorder (OR 1.84), and intellectual disability (OR 7.11) are significantly more often diagnosed than in patients with a SCIL of >20 and higher. In a review article on psychiatric disorders in ID, Morgan et al. (27) concluded that schizophrenia was overrepresented among patients with additional ID, especially in those in the borderline and MID range. In addition, Hassiotis et al. showed that patients with BIF are at high risk of developing psychotic symptoms (28). Our findings are in line with these ID studies and with more recent studies about schizophrenia in general psychiatry, which showed patients with schizophrenia might have a lower educational level because of preadolescent onset of the disease (29). A review article from Chapman and Wu (15) concluded that although the prevalence of alcohol and illicit substance use in the population in the USA is low, the risk of having a substance-related problem is comparatively high. Prevention and treatment programs for these individuals seem to fail. This emphasises the need to recognise ID in mental health settings early to optimise treatment for substance misuse for this patient group. Again, our results are in keeping with these findings. We did not find an increased association of developmental disorders with MID or BIF, despite our substantial sample size. In line with underreporting of intellectual disability, underreporting of developmental disorders cannot be ruled out, as was also shown in a recent study in a long-stay inpatient sample (30).

In the UK, The National Intellectual Disability Professional Senate defined modern specialist community health services for people with intellectual disability in 2015 (31). In the Netherlands, this patient group is too often not recognised enough, or MID/BIF may be cited as a reason to exclude such patients from treatment programs. UK studies have shown that, regardless of the method or model used, increasing knowledge, accessibility and collaboration of both mental health and ID services improves the functioning of patients with ID and decreases inpatients referrals (26). Healthcare providers should develop effective training packages regarding the treatment of ID in standard mental health care settings.

In summary, this study shows that there is a strong association between suspected MID/BIF, diagnoses such as schizophrenia and addiction, worse overall functioning and a long history of psychiatric care. The finding that high or low SCIL outcomes are associated with high or low educational attainment level suggests a pre-existing impaired intellectual level. The patient journey usually starts in outpatient services. Professionals' knowledge of the diagnostic process and treatments, adapted to the cognitive and intellectual needs of patients with BIF and MID, are important for the effectiveness of such treatments. In the Netherlands, the specific needs of patients with ID are often omitted from the training of professionals. We know that psychiatric patients with ID can significantly benefit from treatment. The literature confirms that patients with BIF/MID living in long-term residential facilities (30) who are re-diagnosed in a specialised centre for ID and psychiatry obtained not only other but also multiple diagnoses. The interference of the intellectual disability and its interconnection with a lower level of emotional maturity demands a thorough assessment. If not recognised, patients with possibly unidentified BIF and MID may end up being classed as having an SMI, and costs may rise rapidly because of failed treatment approaches. BIF/MID can thus become a significant risk factor for developing chronicity. Therefore, it is important to be aware of the intellectual functioning of each patient. We recommend screening patients for ID as far as practically possible as part of any assessment at the start of treatment.

Knowledge about the diagnostic process and effective treatment for patients with BIF and MID are important. We know that treatments are effective for psychiatric patients with ID. Patients who do not follow the expected path of recovery may benefit from input from ID specialists for a diagnostic re-assessment and specialised treatment plan.

A limitation of this study is that cognitive decline remains an estimation within all the patients assessed with the SCIL and based on educational level as documented in the medical file. Both SCIL scores and the categorisation of educational certificates into WAIS levels are estimates. Furthermore, intellectual ability may not necessarily be linked to academic achievements (32). In 27% of those patients with a SCIL outcome in line with the SCIL score and 5% of those with high education and low SCIL score, the educational level could not be verified from the medical file. Also, patients with preadolescent schizophrenia with very early cognitive decline were not detected in this study (29). Other factors, such as psychotropic medication, long-term institutionalisation, comorbid psychiatric illness and limited participation in society, may also have negatively influenced the outcomes of the SCIL.

The strengths of this study are the number of included patients and the high recruitment rate of 75%. To our knowledge, the prevalence of intellectual impairment and cognitive decline of psychiatric patients over different settings has not been studied before. Another strength is the use of the SCIL, as this instrument assesses BIF in addition to MID, adding to current knowledge that primarily focuses on the association of intellectual disability with psychiatric disorders. In conclusion, this study shows that 40% of patients in a general mental health trust in the Netherlands are suspected of a MID or BIF across different settings, which is far more than expected. Only 7% of those were assessed as having acquired cognitive decline since adolescence. The prevalence of suspected intellectual disability increased in settings providing increasingly more intensive and longer-term treatment. When intellectual disability is not properly identified by clinicians, it may lead to improper or false diagnosis and treatment, poorer functioning and perhaps higher care costs. We, therefore, recommend clinicians screen for intellectual functioning at the start of treatment and work together in a multidisciplinary way to prevent long-term care dependency.

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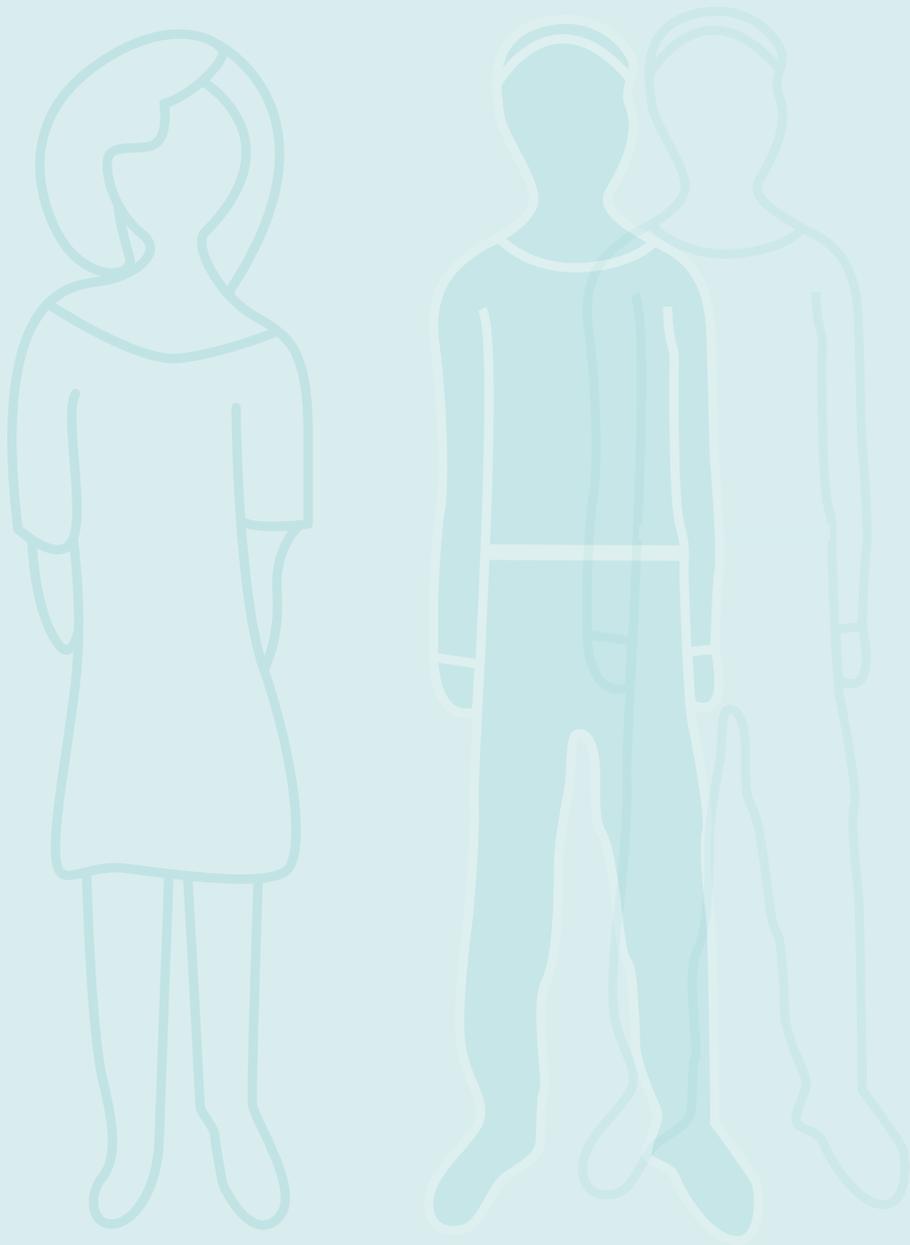
Chapter

**5**

# Aggressive behaviour of psychiatric patients with Mild and Borderline Intellectual Disabilities in general Mental Health Care

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# Abstract

**Purpose.** Little is known about the associations between mild intellectual disability (MID), borderline intellectual functioning (BIF) and aggressive behaviour in general mental health care. The study aims to establish the association between aggressive behaviour and MID/BIF, analysing patient characteristics and diagnoses.

**Method.** 1174 out of 1565 consecutive in-and outpatients were screened for MID/BIF with the Screener for Intelligence and Learning Disabilities (SCIL) in general mental health care in The Netherlands. During treatment, aggressive behaviour was assessed with the Staff Observation Aggression Scale-Revised (SOAS-R). We calculated odds ratios and performed a logistic and poisson regression to calculate the associations of MID/ BIF, patient characteristics and diagnoses with the probability of aggression.

**Results.** Forty-one percent of participating patients were screened positive for MID/BIF. Patients with assumed MID/BIF showed significantly more aggression at the patient and sample level (odds ratio (OR) of 2.50 for aggression and 2.52 for engaging in outwardly directed physical aggression). The proportion of patients engaging in 2-5 repeated aggression incidents was higher in assumed MID (OR=3.01, 95% CI=1.82 - 4.95) / MID/BIF (OR=4.20, 95% CI=2.45 - 7.22). Logistic regression showed that patients who screened positive for BIF (OR=2,0, 95% CL=1.26-3.17), MID (OR=2.89, 95% CI=1.87 - 4.46), had a bipolar disorder (OR=3.07, 95% CI=1.79 - 5.28), schizophrenia (OR=2.75, 95% CI=1.80 - 4.19), and younger age (OR=1.69, 95% CI=1.15 - 2.50), were more likely to have engaged in any aggression. Poisson regression underlined these findings, showing a SCIL of 15 and below ($\beta$=0.61, *P*<0.001) was related to more incidents.

**Conclusions.** We found an increased risk for aggression and physical aggression in patients with assumed MID/BIF. We recommend screening for intellectual functioning at the start of treatment and using measures to prevent and manage aggressive behaviour that fits patients with MID/BIF.

**Keywords.** General Mental Health Care, aggression, intellectual disability, SCIL, SOAS-R

# Introduction

Mild intellectual disability (MID) and borderline intellectual functioning (BIF) are highly prevalent in general mental health care but often stay unnoticed (1, 2). Our research group has previously shown that in the Netherlands, the prevalence of MID/BIF increases by setting, from 27% in outpatient settings, to 40% in Flexible Assertive Community Treatment (FACT) teams and admission wards, to 67% in long-stay wards (3). Furthermore, in the admissions wards, patients with MID or BIF were found to have increased risks of having been involuntarily admitted in the past (OR=2.71) and being subjected to coercive measures (OR=3.95) (1). Aggressive and dangerous behaviours are the main reason for involuntary admissions and seclusion in the Netherlands. The severity and dangerousness of disruptive behaviour perceived by treating staff influence the decisions to use restrictive measures (4). These measures are widely recognised as interventions that potentially have severe negative consequences for the patient, including trauma (5). Aggression is often called "challenging behaviour" (CB) in intellectual disability (ID) services, and the use of coercive measures also has a significant impact on staff and healthcare workers. On average, 62% of nurses in different countries indicate they have experienced physical violence over the course of a year (6). Health care workers (7, 8, 9) and workers in ID services (10, 11) experience psychological and emotional consequences of aggression such as post-traumatic stress, depression, and a negative impact on work functioning and job satisfaction.

From studies in institutions for people with ID (12, 13), we know that CB is a common problem. However, Bowring and colleagues (13) noted no agreed consensual, conceptual, or operational definition of CB. In population studies, considerable variation in CB prevalence is found (4%-22%, (14)). Communication problems, the severity of the ID, and psychopathology are associated with a higher risk of CB (14, 15, 16). In a large Dutch study of an inpatient ID service covering 421 patients, 20% of the patients involved in aggression incidents were responsible for 50% of the verbal and 80% of the physical, aggressive incidents (17). This study showed that the more severe the disability, the higher the possibility of repeated incidents in a single patient. Such patterns of incidence showing repetitive aggression in patients with more severe intellectual disability can also be expected to occur in general psychiatry.

A review of 424 studies conducted in general psychiatry in various settings across 11 countries showed that 32.4% of patients admitted to psychiatric facilities engaged in aggressive behaviour or violence and generated 182.8 events per 100 admissions (18). Studies also show that a small subgroup of patients is generally responsible for a large proportion of violent incidents (18, 19). Many previous publications have been single-

centre reports, making comparison and generalising conclusions difficult. One indirect measure of aggression that considers whole country data is the UK NHS staff survey. In 2019, 48% of the 1.1 million NHS staff participated in the survey. 14.7% of all respondents reported having personally experienced violence from patients, relatives, or public members. This figure rose to 20.2% in the staff working in mental health services and 34% in those working for the ambulance services. It decreased to as low as 5.5% in acute services and 7.5% in non-psychiatric community services. Five years trends are remarkably stable in all measured groups (20). Aggression and coercive measure are closely linked. Using whole country data, coercion figures were remarkably similar across four European countries (19). An analysis of Welsh coercion data from this study across all Welsh Health Boards demonstrated twice as many coercive measures when ID services are included (2013 total incidents, Wales: 3735) compared to when ID services are not included (2013 incidents without ID, Wales: 1886). The results also showed that the number of patients affected by coercive measures per 100 occupied bed days was not affected by adding the ID data, but the number of coercive measures was. This suggests that those patients with ID who were affected by coercive measures were coerced multiple times and more often than the non-ID population (21). This is similar to what we know from aggression data.

In a study on admission wards (1), we showed that patients with BIF/MID had an increased risk of involuntary admission (OR=2.71, SD=1.28 - 5.70) and coercive measures (OR=3.95, SD=1.47 - 10.54). These findings were confirmed in nationwide data gathered in 2014, where intellectual impairment also showed an association with increased risk of seclusion and other coercive measures (22). Internationally, there is evidence that patients with BIF/MID account for more and more prolonged seclusion and restraint events (2, 3).

Until now, however, the level of cognitive function has hardly been studied as a potential 'predictor' of aggression, although MID/BIF is much more prevalent in general mental health care than previously assumed (3). Therefore, in this study, we examined the associations between MID/BIF and aggressive behaviours in a sample of psychiatric inpatients and outpatients. We hypothesised that:

1. In mental health care services, patients suspected to have MID/BIF are more often engaged in aggression incidents.
2. Patients suspected to have MID/BIF are more often involved in outwardly directed physical aggression and have more incidents per person than patients not suspected to have MID/BIF patients.

## Method

**Setting**
We collected a consecutive sample of patients treated with four different types of care in a mental health care trust in the east of the Netherlands, covering a catchment area of 630.000 inhabitants. These four types of care concerned were:

1. Outpatient psychiatric clinics, in this context, are the services the general practitioner refers to patients for initial mental health care. This service provides acute crisis interventions, outpatient psychological and psychiatric treatment, and support.
2. Flexible Assertive Community Treatment (FACT) teams specialised in daily (outpatient) support and treatment for patients with serious mental illness (SMI). In the Netherlands, FACT teams are multidisciplinary outpatient teams with 8-10 professionals, such as psychiatrists, psychologists, nurses, and social workers, generally caring for 200 patients with SMI.
3. General admission wards admit first-onset patients and patients referred from FACT teams or outpatient clinics. Patients at these wards were eligible for inclusion in the current study when they resided on the ward for at least six days.
4. Long stay wards, providing residential care for patients with SMI. Patients all have a long history of receiving professional support and treatment, primarily in FACT teams.

The study was conducted and reported in accordance with the STROBE guidelines for reporting observational studies (23). Screening for potential ID and data collection for aggressive incidents was done from May 2014 until January 2019. All patients treated in participating settings were asked to join the study to screen for potential ID. Participants who agreed to participate provided written informed consent for this.

## Measures

The Staff Observation Aggression Scale-Revised (SOAS-R) was used to register aggression and is a widely used instrument to document the nature and severity of aggressive incidents. The SOAS-R records the following five aspects of aggressive incidents: (a) the apparent provocation, which led to the aggressive event, (b) the means used by the patient during the aggressive event, (c) the target of aggression, (d) the consequence(s) for the victim(s) of the aggression, and (e) the measures taken to stop the aggression, such as seclusion.

The inter-observer reliability of SOAS and SOAS-R aggression observations is acceptable, with a Cohen's kappa of 0.61 and 0.74, respectively, and a Pearson product-moment correlation coefficient between independent raters of 0.87 (24). The SOAS and SOAS-R severity scores correlate significantly with various other aggression measurement methods (i.e., correlations from 0.38 to 0.81) (25). The scale is quick to complete, and there is no need for staff to be trained to use it.

We used the SCreener for Intelligence and Learning disability (SCIL) to detect patients with MID or BIF (24, 25). Translation for use in English is in preparation. The SCIL is a test consisting of 14 questions, including educational level and small tasks intended to screen for patients' overall cognitive abilities (25). It was developed specifically to detect MID/BIF (IQ 50-85) in people in a range of settings, such as (mental) healthcare or social service settings and police stations and shelters for people experiencing homelessness. The reliability of the SCIL, as expressed in Cronbach's alpha in the initial validation study, was good (0.83 in 318 adult subjects). The AUC value for detecting MID/BIF was 0.93, which is excellent. With 19 or lower as a cut-off score, the SCIL accurately classified 82% of people with MID/BIF. Of the ten people without MID/BIF, 9 (89%) were classified correctly as having no MID/BIF. In accordance with the SCIL manual, administering the SCIL requires no specific clinical skills.

The SCIL has recently been validated in patients with SMI in FACT teams (26). The Cronbach's alpha of the SCIL in that sample was 0.73. The AUC value for detecting MID/BIF and MID was 0.81, with percentages of correctly classified subjects of 73% and 79%, respectively. We used two cut-off scores: 19 and 15. Above 19 implies no MID/BIF, and 19 and below implies a (suspected) MID/BIF. The cut-off point of 15 and below implies a (suspected) MID (27). In the following descriptions, we use two cut-off points, 19 for MID or BIF and 15 for MID only. The SCIL assessments used in the current study were performed between 2014 and 2018 (3). We included all SOAS-R incidents reported in routine care between 2014 and 2019.

Patients were excluded from screening for potential ID with the SCIL based on (1) an inadequate grasp of the Dutch language, (2) lack of cooperation, (3) an inability, in the assessor's opinion, to concentrate for at least 20 minutes in order to engage in the test as outlined in the instruction (27).

Nurses in inpatient and outpatient settings were trained to administer the SCIL. According to the questionnaire instructions, the SCIL was administered by a person not involved in the treatment. In the mental health trust where the study was carried out, the SOAS-R has been used since 2007 as a standard tool for nurses to log incidents and medical incident reports in inpatient and outpatient settings.

Demographic data and diagnosis were extracted from the electronic medical charts (EMC): age, gender, psychiatric diagnosis (DSM-IV-TR, as assessed by the psychiatrist), and Global Assessment of Functioning (GAF) score.

## Statistical analyses

At the level of the patient, we identified whether a patient had shown an aggressive incident and whether a patient had shown outwardly directed physical aggression incidents against persons (so not against themselves). The total number of SOAS-R incidents per patient reported between 2014 and 2019 was also counted. Differences in the number of incidents between patients with or without MID/BIF were tested using the Kruskal-Wallis rank order test because of extremely skewed frequencies. As mentioned earlier, the SCIL outcomes were categorised in scores of 19 and less, representing assumed MID/BIF and scores of 15 and less, representing assumed MID. BIF, MID and patient characteristics were cross-tabulated with having shown aggression incidents and physical aggression incidents against persons. We calculated chi-square statistics and Odds ratios to investigate the significance of the differences and the increased risk of showing (physical) aggression in relation to patient characteristics.

We also performed a logistic regression analysis to understand the association of these variables with having shown any aggression or physical aggression corrected for one another. A forward entry and backward deselection procedure were used. All variables selected from the EMC were entered in the analysis. Thus gender, age categories, diagnosis, MID or BIF as assessed with the SCIL. For the forward selection, variables with associations having a $P$-value of <0.2 were included in the logistic regression analysis, following the relevance criterion proposed by Hosmer and Lemeshow (28). These were entered in 3 blocks: the demographic variables, the diagnoses, and the response categories in the SCIL.

Next, Poisson regression was applied to the number of incidents as we may expect a skewed distribution, and the number of incidents represents a count. Before applying the regression, the distribution of the number of incidents was tested. We applied

forward entry and backward deselection to investigate which patient characteristics predicted the number of aggression incidents. We present the β, which as a rate ratio can be interpreted as a growth or downturn rate (29).

## Results

### SOAS-R score in general

In total, we found 1472 aggressive incidents in 196 (16.7%) of the 1565 patients. Most of the registered incidents occurred in inpatients. Only 36 outpatients were involved (18.3 % of the 196, 2.2% of the complete sample). Of the 196 patients with an incident of aggression, 47 were involved in one incident, 84 patients between two and five incidents, and 65 were involved in over six incidents. 23 (11.7% of 196) patients were responsible for 751 aggression incidents (51.0% of 1472). The mean number of incidents was 7.53 per patient, with a maximum of 78 incidents. Of the 1565 patients, 105 patients were engaged in 269 physical, outwardly aggressive incidents (18.3% of the 1472 incidents). Of these 105 patients, 46 were involved in one incident, 51 in between two and five, and 8 in over six physically aggressive incidents. 20 (7.4%) of these patients were responsible for 137 (50.9%) of the 269 incidents. Both analyses show that approximately 10% of the patients account for half of the aggression incidents.

### Sample and SCIL

We asked 1565 consecutive patients to participate. We obtained a SCIL score in 1174 cases (75.0%). 481 (41.0%) of the 1174 included patients showed a SCIL score of 19 and below (assumed MID/BIF). 239 (20.4%) showed a SCIL score of 15 and below (assumed MID). In the various settings, the response was comparable with 71.5% at the outpatient services, 73.1% at the FACT teams, 75.5% at the long-stay wards and 78.9% at the admission wards (3). The distribution of diagnoses was comparable in the participants compared to the non-responders, discarding selection bias by diagnosis.

### SOAS-R and SCIL score, univariate analyses

Table 1 presents the number of aggression incidents over the SCIL negative or positive groups for MID and BIF. It shows that the proportion of patients engaging in (repeated) violent behaviour, in general, is higher in patients assumed to have MID or BIF. Furthermore, the table indicates that outwardly directed physical aggression occurred more often in patients with assumed MID. The odds ratios show that these increase in the higher categories above two incidents per patient. In general, the odds ratios for MID are higher than those for BIF, implying that an increasing number of incidents is associated with BIF but even more frequent in MID patients (table 1.)

Table 1: BIF and MID compared to the number of aggression incidents

| | N | Aggression in general | | | | | Physical aggression | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | No Aggression | One incident | 2-5 incidents | > 5 incidents | P | No Aggression | One incident | 2-5 incidents | > 5 incidents | P |
| **SCIL** | | | | | | | | | | | |
| Above 19 / 19 and below (MID/BIF) | 693 / 481 | 636 (91.8%) / 385 (80.0%) | 18 (2.6%) / 20 (4.2%) | 19 (2.7%) / 51 (10.6%) | 20 (2.9%) / 25 (5.2%) | <0.001 | 665 (96.0%) / 432 (89.6%) | 13 (1.9%) / 24 (5.0%) | 12 (1.7%) / 23 (4.8%) | 3 (0.4%) / 2 (0.4%) | <0.001 |
| **OR** | | | | | | | | | | | |
| Category / else | | 0.24 (0.17 - 0.36) | 1.62 (0.85 - 3.11) | 4.20 (2.45 - 7.22) | 1.84 (1.10 - 3.35) | | 0.37 (0.22 - 0.59) | 2.74 (1.38 - 5.45) | 2.84 (1.40 - 5.78) | 0.96 (0.16 - 5.77) | |
| P | | <0.001 | 0.148 | <0.001 | 0.045 | | <0.001 | 0.004 | 0.004 | 0.965 | |
| **SCIL** | | | | | | | | | | | |
| Above 15 / 15 and below (MID) | 935 / 239 | 839 (89.7%) / 182 (76.2%) | 25 (2.7%) / 13 (5.4%) | 41 (4.4%) / 29 (12.1%) | 30 (3.2%) / 15 (6.3%) | <0.001 | 903 (96.6%) / 222 (92.8%) | 9 (0.9%) / 16 (6.7%) | 9 (3.8%) / 14 (5.9%) | 3 (0.3%) / 2 (0.8%) | <0.001 |
| **OR** | | | | | | | | | | | |
| Category / else | | 0.36 (0.24 - 0.51) | 2.09 (1.05 - 4.15) | 3.01 (1.82 - 4.95) | 2.02 (1.06 - 3.81) | | 0.46 (0.25 - 0.84) | 8.31 (3.51 - 19.67) | 6.40 (2.73 - 14.97) | 2.62 (0.43 - 15.77) | |
| P | | <0.001 | 0.037 | <0.001 | 0.0030 | | 0.013 | <0.001 | <0.001 | 0.292 | |

Table 2: Association between aggression BIF, MID and patient characteristics

| Predictors | | Aggression incidents | | | | | Physical aggression | | | | 95% CO OR |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | No Aggression | Aggression | P | OR | 95% CI OR | No Aggression | Aggression | P | OR | |
| N | | 1369 | 196 | | | | 1460 | 105 | | | |
| Age | | 43.3 | 42.3 | 0.29 | 0.00 | | 43.2 | 41.9 | | | |
| Age categories | 0 - 35 | 407 (29.7%) | 73 (37.2%) | 0.033 | 1.40 | 1.03 - 1.92 | 439 (30.1%) | 41 (39.0%) | 0.054 | 1.49 | 0.99 - 2.24 |
| | 36 - 59 | 840 (61.4%) | 101 (51.5%) | 0.009 | 0.67 | 0.49 - 0.90 | 887 (60.8%) | 54 (51.4%) | 0.059 | 0.68 | 0.46 - 1.00 |
| | 60+ | 122 (8.9%) | 22 (11.2%) | 0.179 | 1.29 | 0.79 - 2.09 | 134 (9.2%) | 10 (9.5%) | 0.906 | 1.04 | 0.53 - 2.05 |
| Gender | Male | 650 (47.5%) | 108 (55.1%) | 0.027 | 1.31 | 1.00 - 1.70 | 700 (47.9%) | 58 (55.2%) | 0.149 | 1.31 | 0.90 - 1.91 |
| | Female | 719 (52.5%) | 88 (44.9%) | | | | 760 (52.1%) | 47 (44.8%) | | | |
| SCIL Outcome | No SCIL | 248 (18.1%) | 43 (21.9%) | 0.217 | 0.86 | 0.60 - 1.25 | 363 (24.9%) | 28 (26.7%) | 0.341 | 0.90 | 0.58 - 1.42 |
| | SCIL | 1121 (81.9%) | 153 (78.1%) | | | | 1097 (75.1%) | 77(73.3%) | | | |
| SCIL Outcome | SCIL >19 | 637 (62.4%) | 56 (36.6%) | 0.000 | | | 665 (60.6%) | 28 (26.7%) | 0.000 | | |
| | SCIL 16 - 19 (BIF) | 202 (19.8%) | 40 (26.1%) | | | | 225 (20.5%) | 17 (16.2%) | | | |
| | SCIL ≤15 (MID) | 182 (17.6%) | 57 (37.3%) | | | | 207 (18.9%) | 32 (30.5%) | | | |
| Borderline Intellectual Functioning (BIF) | SKIL >19 | 637 (62.4%) | 56 (36.6%) | 0.000 | 2.49 | 1.83 - 3.39 | 665 (60.6%) | 28 (36.4%) | 0.000 | 2.52 | 1.61 - 3.95 |
| | SKIL ≤19 | 384 (37.6%) | 97 (63.4%) | | | | 432 (39.4%) | 49 (63.6%) | | | |
| Mild Intellectual Disability (MID) | SKIL >15 | 839 (82.2%) | 96 (62.7%) | 0.000 | 2.74 | 1.90 - 3.94 | 890 (81.1%) | 45 (58.4%) | 0.000 | 3.06 | 1.89 - 4.93 |
| | SKIL ≤15 | 182 (17.8%) | 57 (37.3%) | | | | 207 (18.9%) | 32 (41.6%) | | | |
| Diagnosis | | | | | | | | | | | |
| Anxiety | | 205 (15.0%) | 20 (10.2%) | 0.043 | 0.65 | 0.39 - 1.05 | 215 (14.7%) | 10 (9.5%) | 0.142 | 0.61 | 0.31 - 1.18 |
| Depression | | 429 (31.3%) | 39 (19.9%) | 0.001 | 0.54 | 0.38 - 0.79 | 449 (30.8%) | 19 (18.1%) | 0.006 | 0.50 | 0.30 - 0.83 |
| Bipolar | | 122 (8.9%) | 30 (15.3%) | 0.005 | 1.85 | 1.20 - 2.84 | 135 (9.2%) | 17 (16.2%) | 0.020 | 1.89 | 1.10 - 3.28 |
| Psychotic disorder | | 223 (8.9%) | 32 (16.3%) | 0.529 | 1.00 | 0.67 - 1.50 | 282 (19.3%) | 48 (45.7%) | 0.762 | 0.92 | 0.53 - 1.59 |
| Schizophrenia | | 256 (18.7%) | 74 (37.7%) | 0.000 | 2.64 | 1.92 - 3.63 | 239 (16.4%) | 16 (15.2%) | 0.000 | 3.52 | 2.35 - 5.28 |
| Developmental disorder | | 173 (12.6%) | 33 (16.8%) | 0.104 | 1.40 | 0.93 - 2.10 | 173 (12.6%) | 33 (16.8%) | 0.725 | 1.12 | 0.63 - 1.95 |
| Alcohol & drugs-abuse | | 171 (12.5%) | 45 (23.0%) | 0.000 | 2.09 | 1.44 - 3.02 | 188 (12.9%) | 28 (26.7%) | 0.000 | 2.46 | 1.56 - 2.89 |
| Personality disorder | | 570 (41.6%) | 73 (37.2%) | 0.243 | 0.83 | 0.61 - 1.13 | 610 (4.18%) | 33 (31.4%) | 0.037 | 0.64 | 0.42 - 0.98 |
| Low GAF | | 437 (31.9%) | 102 (52.0%) | 0.000 | 2.32 | 1.71 - 3.16 | 488 (33.4%) | 51 (52.4%) | 0.003 | 1.83 | 1.23 - 2.74 |

Table 2 presents the SCIL outcomes, patient characteristics, and aggression frequencies. A SCIL outcome 19 and below (assumed BIF or MID) was associated with more aggression in general (OR=2.50), as well as with more physical aggression (OR=2.52). A SCIL outcome 15 and below (assumed MID) was associated with more aggression in general (OR=2.74), as well as with more physical aggression (OR=3.06) (table 2).

**SOAS-R, SCIL score and patient characteristics, univariate analyses**
Gender showed no significant association between aggression in general or more physical aggression. Only middle age showed an inverse and significant association with aggression (OR=0.67, $P$=0.009). Diagnosis of bipolar disorder (OR=1.85, $P$=0.005), schizophrenia (OR=2.64, $P$<0.001), alcohol and drug abuse disorder (OR=2.09, $P$<0.001) and a low GAF (OR=2.32, $P$<0.001) were associated with an increased risk of aggression.

Schizophrenia (OR=3.52, $P$<0.001), drug abuse disorder (OR=2.46, $P$<0.001), and a low GAF (OR=1.83, $P$<0.003) were associated with an increased risk of physical aggression. Only depressive disorders (OR = 0.54, $P$=0.001) were associated with less aggression in general and less physical aggression (OR= 0.50, $P$=0.006).

**Logistic regression**
The logistic regression analysis showed that patients who screened positive for BIF (OR=2.00, $P$=0.003) or MID (OR=2.89, $P$<0.001) were more at risk of showing aggressive incidents, as well as the patients with the diagnoses bipolar disorder (OR=3.07, $P$<0.001), schizophrenia (OR=2.75, $P$<0.001), and a low GAF (OR=1.72, $P$=0.005). Logistic regression analysis with physical aggression as an outcome showed that patients with MID (OR=2.50, $P$<0.001), a bipolar disorder (OR=3.13, $P$=0.007) or schizophrenia (OR=4.04, $P$<0.001) were more at risk of showing aggressive incidents.

**Poisson regression**
These findings were underlined by the Poisson regression of the number of physical aggression incidents per patient. This showed anxiety disorder (β=0.62, $P$<0.001), bipolar disorder (β=1.63, $P$<0.001), schizophrenia (β=1.12, $P$<0.001), developmental disorder (β=0.69, $P$<0.001), drug abuse disorder (β=1.18, $P$<0.001) and a SCIL below 15 (β=0.61, $P$<0.001) were all related to more incidents.

In short, screening positive for BIF and MID were both associated with significantly more aggression, and this association appears to be somewhat stronger for MID. Bipolar disorder, developmental disorders, schizophrenia and drug abuse disorders are associated with higher aggression rates (table 3).

## Table 3: Multivariable association between predictors and aggression

| | Predictors | | Aggression incidents | | | | | Physical aggression | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | B | SE | sig | Ex (b) | 95% CI Ex (b) | B | SE | sig | Ex (b) | 95% CI Ex (b) |
| Univariable associations | Male Gender[1] | | 0.046 | 0.197 | 0.815 | 1.05 | 0.71 - 1.54 | 0.235 | 0.267 | 0.378 | 1.26 | 0.75 - 2.13 |
| | Age[2] | <35 | 0.324 | 0.341 | 0.342 | 1.38 | 0.71 - 2.69 | 0.721 | 0.485 | 0.137 | 2.06 | 0.79 - 5.32 |
| | | 35-59 | -0.248 | 0.325 | 0.445 | 0.78 | 0.41 - 1.47 | 0.134 | 0.470 | 0.776 | 1.14 | 0.45 - 2.87 |
| | Anxiety disorder[3] | | 0.366 | 0.303 | 0.288 | 1.44 | 0.79 - 2.61 | 0.191 | 0.444 | 0.668 | 1.21 | 0.51 - 2.89 |
| | Depressive disorder | | 0.255 | 0.266 | 0.338 | 1.29 | 0.76 - 2.17 | 0.135 | 0.377 | 0.721 | 1.14 | 0.55 - 2.39 |
| | Bipolar disorder | | 1.218 | 0.305 | <0.001 | 3.38 | 1.86 - 6.15 | 1.158 | 0.402 | 0.004 | 3.18 | 1.45 - 6.99 |
| | Psychotic disorder | | -0.367 | 0.286 | 0.200 | 0.69 | 0.39 - 1.21 | -0.428 | 0.387 | 0.269 | 0.65 | 0.31 - 1.39 |
| | Schizophrenia | | 1.122 | 0.263 | <0.001 | 3.07 | 1.84 - 5.14 | 1.337 | 0.338 | <0.001 | 3.81 | 1.96 - 7.39 |
| | Developmental disorder | | 0.735 | 0.276 | 0.008 | 2.08 | 1.21 - 3.58 | 0.475 | 0.386 | 0.218 | 1.61 | 0.75 - 3.43 |
| | Personality disorder | | -0.004 | 0.210 | 0.983 | 0.99 | 0.66 - 1.50 | -0.481 | 0.300 | 0.109 | 0.62 | 0.34 - 1.11 |
| | Alcohol and drug abuse disorder | | 0.643 | 0.240 | 0.007 | 1.90 | 1.19 - 3.05 | 0.703 | 0.308 | 0.022 | 2.02 | 1.11 - 3.69 |
| | Low GAF | | 0.596 | 0.194 | 0.002 | 1.81 | 1.24 - 2.68 | 0.264 | 0.260 | 0.311 | 1.30 | 0.78 - 2.17 |
| Final model | SCIL[4] | 16-19 | 0.716 | 0.239 | 0.002 | 2.07 | 1.30 - 3.31 | 0.379 | 0.333 | 0.254 | 1.46 | 0.76 - 2.80 |
| | | ≤15 | 1.115 | 0.228 | <0.001 | 3.05 | 1.96 - 4.75 | 0.986 | 0.295 | <0.001 | 2.68 | 1.50 - 4.78 |
| | Age | <35 | 0.562 | 0.199 | 0.005 | 1.75 | 1.18 - 2.59 | 0.632 | 0.257 | 0.014 | 1.88 | 1.14 - 3.11 |
| | SCIL score between 16 and 19 (BIF) | | 0.684 | 0.237 | 0.004 | 1.98 | 1.25 - 3.15 | | | | | |
| | SCIL score 15 and below (MID) | | 1.080 | 0.223 | <0.001 | 2.94 | 1.90 - 4.56 | 0.850 | 0.257 | <0.001 | 2.34 | 1.41 - 3.88 |
| | Bipolar disorder | | 1.075 | 0.279 | <0.001 | 2.93 | 1.69 - 5.05 | 1.102 | 0.364 | 0.001 | 3.22 | 1.58 - 6.58 |
| | Psychotic disorder | | -0.463 | 0.273 | 0.090 | 0.63 | 0.37 - 1.07 | | | | | |
| | Schizophrenia | | 0.954 | 0.219 | <0.001 | 2.59 | 1.69 - 3.99 | 1.370 | 0.268 | <0.001 | 3.93 | 2.33 - 6.65 |
| | Developmental disorder | | 0.616 | 0.261 | 0.018 | 1.85 | 1.10 - 3.09 | | | | | |
| | Alcohol and drug abuse disorder | | 0.560 | 0.231 | 0.015 | 1.75 | 1.11 - 2.75 | 0.638 | 0.286 | 0.026 | 1.89 | 1.08 - 3.32 |
| | Low GAF | | 0.602 | 0.194 | 0.002 | 1.83 | 1.25 - 2.67 | | | | | |

[1] Female gender was used as reference category.  [2] Elderly was used as reference category.
[3] No diagnosis was used as reference category.  [4] SCIL > 19 was used as reference category.

## Discussion

The current study indicates that patients with a (suspected) BIF or MID are more likely to display aggressive incidents than patients without ID. The odds ratios for aggression of any type and physical aggression toward others are 2.5 to 2.9, making it a highly significant finding. This is in line with other studies with people with ID showing that ID is associated with higher rates of aggression incidents (30, 31). Eight percent of patients without an ID had been engaged in aggressive incidents, keeping with previous Dutch data from international studies (19). However, in the BIF patient group, 20%, and in the MID patient group, 24% of patients showed aggressive incidents, roughly half of which were physical aggression. This represents a sizable contribution to the risk of being confronted with aggression in the wards.

Regarding the number of incidents per patient, about half of the patients involved in aggression incidents were involved in 2-5 incidents, and just a small group of patients were responsible for more than five incidents. This is in keeping with previous studies. For instance, Bowers et al. (6) found that on average, 45% of patients with violent behaviour were involved in more than one incident. In a study by Broderick et al. (32) in a Canadian multihospital state psychiatric system, just 1% of the study population participated in 28.7% of all violent assaults. Considering the current findings, it seems fair to conclude that earlier studies and reviews concerning aggression in mental health may have paid too little attention to the role of impairments in intellectual functioning as a potential determinant of aggressive behaviour. This was also recently concluded in Weltens et al.'s systematic review (33). However, Tsiouris et al. (34) reported in a large sample of persons with an ID that "impulse control, mood dysregulation and perceived threat appear to underlie most of the aggressive behaviours reported" across various settings. Another study in a Forensic Psychiatric Hospital (35) also concluded that chronic violent behaviour was associated with cognitive impairment or brain damage. In a study by Verstegen, a clear association between impulsivity and aggression was found (36). Our study confirmed that BIF/MID is an often unnoticed and undiagnosed factor that significantly contributes to physically aggressive behaviour, supporting our knowledge that patients with lower cognitive functioning, in general, may have more problems with impulse regulation.

Our findings suggest that specific patient characteristics increase the risk of being involved in aggressive incidents. These include young ages of up to 35 years, which is in line with other studies with inpatients and reviews in adult psychiatry and ID populations (6, 30). Other characteristics that showed an increased aggression risk were diagnosis of schizophrenia, harmful use of alcohol and drugs and bipolar affective disorder, and a GAF score below 45. The same patient characteristics were important when analysing only physical aggression incidents, showing that aggressive incidents per se appear to have similar patient risk factors. While this is one of the first comprehensive studies examining the association between ID and risk of aggression, schizophrenia and drug and alcohol use have commonly been associated with aggression in mental health care (6, 35, 36) and studies with people with ID. (12, 16, 30).

As we can learn from studies with people with ID based on interviews with people with intellectual disability (10, 37), people with ID often experience a lack of structure in their daily life, and staff may often place too many demands on them. This is coupled with the fact that these patients regularly have difficulty dealing with emotions, the complexity of social interaction, and other stressors. Challenging behaviour can also be related to a number of unmet needs that should be addressed, such as medical issues (e.g., pain) or communication difficulties, among others. It is also important to better understand patients' capabilities by staff and others - both in terms of their intellectual, emotional and adaptive skills. It may be helpful to offer patients counselling or training to better cope with emotions and impulses to help to reduce the occurrence of CB. Other potential ways forward are functional analyses of earlier CB and positive behaviour support for patients. The results of a large-scale meta-analysis indicated that in patients/clients with ID, behavioural treatments based on Function Analysis tend to be more effective than pharmacological interventions (38). Function Analysis derived from Behaviour Therapy to systematically identify the reinforcers of CB allows staff to mitigate the consequence and replace it with more prosocial behaviour (13, 39-42).

## Clinical implications

Earlier studies examining the associations between aggressive behaviour and patient characteristics focused on diagnoses, psychiatric history, staff training, restraint and workload, the interaction between patient and staff, care processes, and ward architecture and environment (32, 43). Based on the information from these studies, various suggestions and programs to reduce aggression were developed. We know from studies with people with ID that it is advisable to meet a person's needs better (e.g., engaging in appropriate support and communication, presenting information in

an accessible way, and approaching treatment from a biopsychosocial approach), all of which would likely result in fewer behaviours that challenge (44-47). Until now, mental health services seem to be frequently not equipped enough to meet those needs. The current study reminds us of the importance of the intellectual functioning of each individual patient in general psychiatry to prevent aggressive incidents, especially those responsible for a large number of incidents. In light of our findings, we recommend screening patients for ID as part of any assessment at the start of treatment in order to support the prevention of aggressive incidents in psychiatric care. The SCIL can be helpful in psychiatric care (29, 48) and give a quick first impression. Treatment and support to the needs can be adapted according to the SCIL category. As such, avoid over-demanding and stress. The staff's attitudes towards people with ID may also play a part in detecting and preventing aggressive incidents (49, 50).

## Recommendations

In mental health care, future studies should examine the causes and reasons for aggressive incidents in patients with MID/BIF and learn more about how these patients differ or resemble those in other studies with people/patients with ID. For example, we do not yet know much about the mental problems in the patient group with ID in mental health care and how this affects behaviour. We know from another of our studies (2) that patients with assumed ID frequently experience neglect and (sexual) abuse, but this is not recognised enough in mental health care. We also do not know the influence of social factors between patients within ward settings, as the current study did not look into that level of detail.

Next, intervention studies in patients with MID and BIF are needed in mental health care to study which measures (such as positive behaviour support (50, 51)) we know are helpful in ID care and preventing aggressive incidents. Cooperation with ID services can therefore be helpful. Attention to this vulnerable, large patient group in mental health is of great importance and should get more attention in the training of professionals.

## Limitations and strengths

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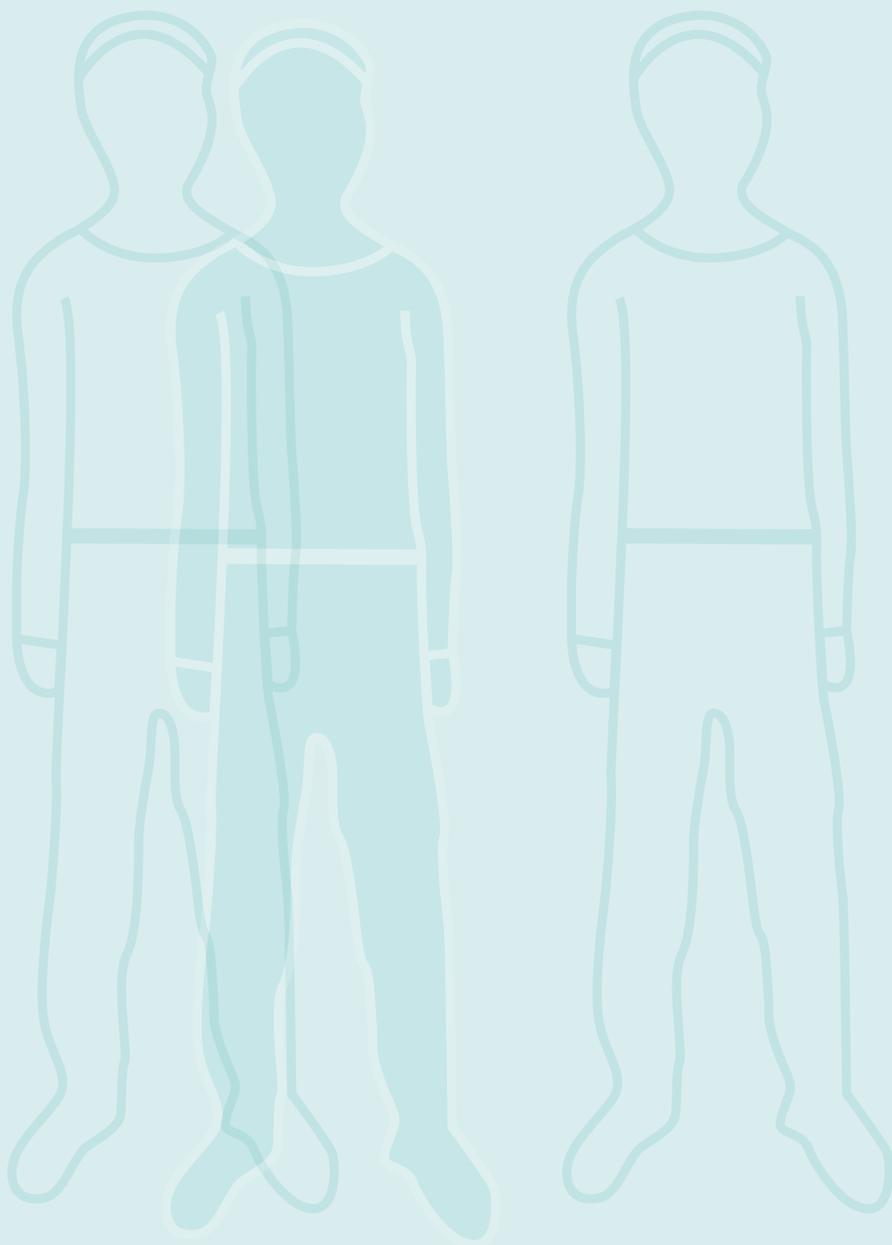
6

# Not recognized enough: the effects and associations of trauma and intellectual disability in severely mentally ill outpatients

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# Abstract

**Background.** Little is known about the association between trauma and intellectual disability in SMI patients.

**Aim.** To establish the prevalence of trauma and its association with intellectual functioning in SMI outpatients.

**Methods.** A cross-sectional study was conducted in two mental health trusts in the Netherlands. We used the Trauma Screening Questionnaire (TSQ) to screen for trauma and PTSD and the Screener for Intelligence and Learning disabilities (SCIL) for suspected MID/BIF. Chi-square and t-tests were used to test differences in outcome over patient characteristics. Post-hoc analysis was used to investigate gender differences between patients with and without MID/BIF on trauma and sexual trauma.

**Results.** Any trauma was found in 86% of 570 patients, and 42% were suspected for PTSD. The SCIL suggested that 40% had Borderline Intellectual Functioning (BIF), half of whom were suspected of having Mild Intellectual Disability (MID). These patients had had more traumatic experiences (1.89 in BIF, 1.75 in MID, against 1.41 in SCIL-negative patients). Female MID/BIF patients (61%) had experienced significantly more sexual abuse than male MID/BIF patients (23%).

**Conclusions.** Significantly more SMI outpatients who screened positive for MID/BIF reported having experienced traumatic events than those who screened negative. Rates of all trauma categories were significantly higher in the screen-positive group, who were also more likely to have PTSD. Sexual abuse occurred more in all females but the SCIL positive women are even more often victim. Clinical practice has to pay more attention to all of these issues, especially when they occur together in a single patient.

**Keywords.** Seriously mentally ill, Borderline intellectual functioning, Mild intellectual disability Trauma, Underreport, Post-traumatic stress disorder, Sexual abuse

## Introduction

Patients with severe mental illness (SMI) have often experienced traumatic events during their lifetime. In a review on SMI, Mauritz et al. (1) reported prevalence rates of 47% for physical abuse, 37% for sexual abuse and 30% for PTSD. In the general population these prevalence's are 21%, 23%, and 7%, respectively (1, 2). This review concluded that physical neglect, emotional abuse and neglect, and complex PTSD were all highly prevalent problems that had barely been examined in patients with SMI and may be overlooked in treatment (1, 3). In a representative sample of 2181 people interviewed by telephone in Florida, Breslau et al., 2011 (4) concluded that the lifetime prevalence of exposure to any trauma in the general US population was 89.6%. In the study by de Bont et al. (3), trauma exposure was reported to be 78.2% of the 2608 SMI patients with psychotic disorders. This study showed one subgroup of SMI patients - those with an intellectual disability - were even at greater risk for trauma. As our sample concerns SMI patients with or without MID/BIF we may expect similar findings.

In a recent study (5), we found on the basis of the Screener Intelligence Learning Disabilities (SCIL) that 43.8% of SMI patients admitted were suspected of MID/BIF. To our knowledge, there have been no studies on trauma or PTSD in SMI patients with MID/BIF. Only one study (6), in a sample of mostly first onset patients, showed that PTSD was nearly twice as common in MID patients (19.7%) and BIF patients (19.6%) than in those with no intellectual disability (10.4%). Intellectual disability can be divided into Mild Intellectual Disability (MID: IQ 50-70) and Borderline Intellectual Functioning (BIF: IQ 70-85). Apart from the IQ, also problems in adaptive function need to be taken into account when setting the diagnosis according to the DSM V criteria.

The clinical relevance of the distinction between MID and BIF was illustrated in the studies of Nouwens et al., who identified five patient profiles (7) and showed most unmet needs occurred in the BIF patients (8). From clinical practice, underlined by these studies, we know that especially BIF as a diagnosis may be missed because of their streetwise presentation and lowbrow appearance, while these patients lack sufficient coping strategies to deal with hassles in daily life. High levels of stress caused by these daily life problems are often an obstacle to profit from treatment. Patients with BIF may profit from the regular treatment if adapted in pace and language. Patients with MID need more treatment adjustments.

There is widespread violence, sexual and physical abuse against adult people with MID(9), and some studies have shown that non-SMI people with MID are particularly at risk for sexual violence and abuse (10, 11). A study by Lan-Ping –Lin et al. (12) showed an increased rate of sexual assault among people with all kinds of disabilities, but especially in those with an intellectual disability. Over half the reported sexual assaults were reported in the intellectually disabled, against one-third in those with chronic psychosis. Finally, a review (13) showed that the prevalence of PTSD in people with MID ranged from 2.5% to 60%, due possibly to the use of a wide variety of instruments and to their low psychometric quality. We, therefore, wished to establish the prevalence of trauma and PTSD in SMI patients who were either or not suspected of MID/BIF. Because the literature looks primarily into MID patients, we wanted to know whether the MID showed more trauma or PTSD than the BIF/MID group (13). For clinical practice, better empirical knowledge on the prevalence of PTSD in BIF or MID may contribute to improved diagnosis and treatment. The current study is an effort to provide some empirical findings in a naturalistic sample of SMI patients treated in the community.

## Methods

### 6.2.1 Settings and design

A cross-sectional study was conducted in SMI patients in four Flexible Assertive Community Treatment teams (FACT) in the eastern Netherlands (FACT teams North and South in Apeldoorn) and in the southern Netherlands (in Uden and Veghel). FACT teams are multidisciplinary outpatient teams with 8-10 clinicians (psychiatrist, psychologist, nurses and social workers), each usually treating about 200 SMI patients (14). The screening was done by the clinicians of the FACT teams asking their patients to fill out the self-report questionnaires described later, after informing them about the study. SMI patients were defined as having had one or more psychiatric disorders (psychosis, depression, personality, bipolar or several other disorders), combined with social-functioning problems, for at least two years (15, 16).

### 6.2.2 Patients

Over a period of approximately two years, from the end of 2015 until June 2017, all patients in the four FACT teams were screened for trauma and MID/BIF. Patients were excluded on the basis of (1) an inadequate grasp of the Dutch language, (2) uncooperativeness, (3) an inability, in the assessor's opinion, to concentrate for at least 20 minutes for purposes of engaging in the test as outlined in the instruction.

### 6.2.3 Measures

#### 6.2.3a Trauma Screening using the TSQ

PTSD comprises three symptom groups: re-experiencing, avoidance and hyperarousal. The Trauma Screening Questionnaire (TSQ) is a screener for Post-Traumatic Stress Disorder that consists of a 10-item symptom screening tool derived from the 17-item PTSD Symptom Scale (17). The TSQ items are answered by "yes" (symptom has been present for two weeks) or "no" (symptom is not present); the minimum score is zero, and the maximum score is 10. The items reflect the way patients themselves interpret the questions without predefined criteria. Sensitivity and specificity of the TSQ varied between 85 and 98%, depending on the severity of trauma and pre-existing psychiatric morbidity (17, 18). The reliability of the TSQ as expressed in Cronbach's alpha was good (0.85) (3). The TSQ cut-off score for having PTSD was found to be 6, which, in a study in psychotic patients, showed a sensitivity of 78.8%, and a specificity of 75.6%, with 44.5% correct positives and 93.6% correct negatives (3). The lower figure of correct positives can be explained by the low prevalence of PTSD diagnosis (18) and the complexity to de-entangle the symptoms of psychosis and trauma in psychotic SMI patients. While in that study, the TSQ was validated in psychotic SMI patients (3), it was not validated in patients with MID, maybe leading to some underreporting. Underreport, as the MID may not understand the question or the symptom stated due to their disability.

#### 6.2.3b MID/BIF screening using the SCIL

The SCIL is a test consisting of 14 questions and small tasks that are intended to provide an overall insight into a patient's cognitive abilities (19, 20). It was developed specifically to detect MID/BIF (IQ 50- 85) or suspected MID/BIF in people in a range of settings, such as healthcare or social-service settings, and also police stations and homelessness. The SCIL was validated in an adult sample by comparing the scores obtained with test results obtained by the WAIS (20). The reliability of the SCIL as expressed in Cronbach's alpha was good (0.83 in 318 adult subjects). The AUC- value was 0.93, which is excellent. With 19 or lower as a Cut-off score, the SCIL accurately classified 82% of people with MID/BIF. Of the ten people without MID/BIF, 9 (89%) were classified correctly as having no MID/BIF (20). According to the SCIL manual, administering the SCIL requires no specific clinical skills (19). Before administering it, the participating nurses received two hours of training, after which they first assessed eight patients under supervision before performing assessments on their own. We used the following cutoff scores: above 19 for no MID/BIF (SCIL negative); below 19 for MID/BIF (SCIL positive ); and 15 and below for MID.

### 6.2.3c Chart information

Basic demographic data such as age, gender and psychiatric diagnosis (DSM-IV-TR) were extracted from routine hospital information in digital medical charts. This information was added to the database containing the questionnaire findings.
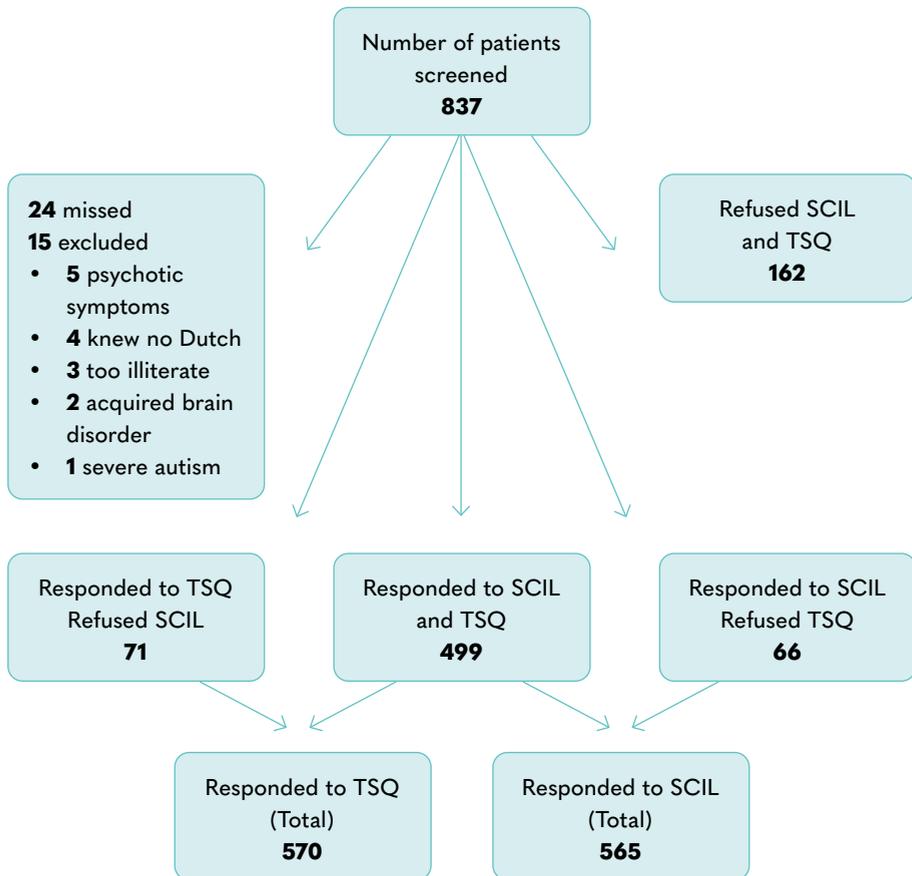
### 6.2.4 Analyses

Differences in patient compilation and scoring on these questionnaires were compared and tested using one-sided or two-sided chi-square or two-sided t-tests when appropriate. In all comparisons, we investigated possible selection bias by comparing patient compilation in non-assessed patients, SCIL-positive patients and SCIL-negative patients. As the purpose of these analyses is to seek confirmation of findings in former studies in MID/BIF, we used 1-sided chi-square when testing our assumptions on the associations between trauma and MID/BIF. For continuous variables such as age and number of traumas, we used the student t-test. We also performed a post hoc analysis on the differences regarding sexual trauma between men and women as well as within women, respectively, men over the various subgroups.

## Results

### 6.3.1 Sample

The flowchart (Fig 1) presents the response on the SCIL and the TSQ. Specifically, 565 patients (69%) were assessed using the SCIL, and 570 (69%) filled out the TSQ. SCIL interviews had not taken place in 24 cases, as patients had left care before they were able to concentrate for above 20 minutes. Fifteen patients were excluded; due to the severe anxiety or psychotic symptoms that were apparent during interview (5); due to their poor grasp of Dutch (4); and due to illiteracy (3); acquired brain disorder (2); and severe autism (1). In total, 39 were excluded, 162 (19%) refused, 137 (16%) were assessed using one of the questionnaires, and 499 (60%) were assessed using both. This accounts for the disparities in numbers in the various tables.

Figure 1: Flow chart

Number of patients screened
**837**

Refused SCIL
and TSQ
**162**

**24** missed
**15** excluded
- **5** psychotic symptoms
- **4** knew no Dutch
- **3** too illiterate
- **2** acquired brain disorder
- **1** severe autism

Responded to TSQ
Refused SCIL
**71**

Responded to SCIL
and TSQ
**499**

Responded to SCIL
Refused TSQ
**66**

Responded to TSQ
(Total)
**570**

Responded to SCIL
(Total)
**565**

*6.3.2 Patient characteristics within SCIL groups*

Table 1 shows that 40% of outpatients were suspected of MID/BIF and 20% were suspected of MID. The GAF score of the non-response group (no SCIL, mean 38.7) was lower than that of the group assessed by the SCIL (46.6, t=6.01, *P*< 0.01), suggesting that mental illness was more severe in the non-response group.

With respect to diagnosis, we found neither selective non-response nor any significant differences between the SCIL-positive and SCIL-negative patients. The only significant difference was the diagnosis of higher intellectual disability as a primary or secondary diagnosis in significantly more SCIL-positive patients (30.1% vs.6.6%, OR=5.91, *P*<0.001). Beside this obvious finding, SCIL-positive patients had a greater number of clinical diagnoses in only one disorder: Adjustment Disorder (10.7% vs. 5.9%, OR= 1.90, *P*<0.05). In the patients with a SCIL below 15, schizophrenia occurred more (37.8% vs. 26.4% OR=1.69, *P*<0.05 and Personality Disorder occurred less (17.8 vs. 28.3, OR=0.55, *P*<0.05). The clinically relevant cut-off score on the GAF (i.e., below 45) did not arise more frequently in the drop-out group (43% vs 51%, χ-square= 0.19).

| | % No SCIL | Below Borderline Intellectual Functioning / Mild Intellectual Disability | | | | Mild Intellectual Disability | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | % SCIL negative (>19) | % SCIL positive (≤19) | OR | 95% CI OR | % SCIL >15 | % SCIL ≤15 | OR | 95% CI OR |
| N | 272 | 340 | 225 | | | 474 | 91 | | |
| Age (mean) | 45.96 | 46.06 | 47.76 | | | 46.63 | 47.32 | | |
| Gender * Male / Female | 62.1 / 37.9 | 44.1 / 51.9 | 43.8 / 56.2 | 1.18 | 0.85 - 1.66 | 47.0 / 53.0 | 42.9 / 57.1 | 1.18 | 0.75 - 1.86 |
| Diagnosis | | | | | | | | | |
| Adjustment disorder [*a] | 5.5 | 5.9 | 10.7 | 1.90 | 1.02 - 3.54 | 8.2 | 5.6 | 0.66 | 0.25 - 1.71 |
| Depression [*b] | 8.5 | 13.3 | 12.0 | 0.89 | 0.53 - 1.48 | 13.9 | 6.7 | 0.44 | 0.18 - 1.05 |
| PTSD diagnosis | 8.1 | 6.5 | 10.7 | 1.72 | 0.94 - 3.15 | 8.2 | 7.8 | 0.94 | 0.41 - 2.17 |
| Bipolar disorder | 5.1 | 9.7 | 9.3 | 0.95 | 0.54 - 1.69 | 9.9 | 7.8 | 0.76 | 0.34 - 1.75 |
| Psychotic disorders | 12.5 | 14.5 | 15.1 | 1.05 | 0.66 - 1.69 | 14.1 | 17.6 | 1.31 | 0.72 - 2.39 |
| Schizophrenia [*b] | 21.3 | 27.7 | 28.9 | 1.05 | 0.73 - 1.54 | 26.4 | 37.8 | 1.69 | 1.06 - 2.72 |
| Developmental disorder | 11.0 | 9.4 | 5.8 | 0.58 | 0.30 - 1.15 | 8.0 | 7.8 | 0.97 | 0.42 - 2.24 |
| Drug-abuse disorder | 5.9 | 4.4 | 6.2 | 1.43 | 0.68 - 3.03 | 4.9 | 6.7 | 1.40 | 0.55 - 3.54 |
| Personality disorder [b] | 22.1 | 26.8 | 26.2 | 0.96 | 0.66 - 1.42 | 28.3 | 17.8 | 0.55 | 0.31 - 0.98 |
| Intellectual Disability [*ab] | 12.1 | 6.6 | 30.1 | 5.91 | 3.55 - 9.84 | 11.8 | 38.5 | 4.66 | 2.81 - 7.73 |
| GAF score [*] | 38.7 | 46.9 | 46.2 | | | 46.9 | 46.1 | | |

* Significant difference between no SCIL, SCIL positive and SCIL negative (BIF) $P<0.05$, one-sided chi-square.

a Significant difference between SCIL positive and SCIL negative (BIF) $P<0.05$ one-sided chi-square.

b Significant difference between SCIL 15 and below and above 15 (MID) $P<0.05$ one-sided chi-square.

*6.3.3 Trauma*

As table 2 shows, the prevalence of any trauma found using the TSQ in all subsamples (SCIL positive, SCIL negative and no SCIL) was nearly the same, with percentages between 80% and 90%. The number of traumas, however, was 1.49 in the no SCIL group against 1.89 in the SCIL-positive and 1.41 in the SCIL-negative group. In patients with a SCIL below 15, a mean of 1.75 traumas was observed. All these differences were significant. Analysis of trauma categories showed significant differences between the SCIL-positive and the SCIL-negative patients. Neglect was more prevalent in the SCIL-positive patients (57.1%) than in the SCIL-negative patients (45.3%), followed by physical trauma in 50.9%, sexual trauma in 43.9% and disaster in 37.9%. Physical trauma, neglect and disaster had occurred significantly more in the SCIL-positive group. We noted less sexual trauma in the "no SCIL" group.

For none of the TSQ items does table 3 show a difference between patients with MID and without MID. This lack of difference may have been due to the relatively small sample of MID patients, a suspicion that was confirmed by the relatively low odds ratios and relatively large confidence intervals. We observed that 43.2% of all patients assessed with the TSQ had over six trauma symptoms, which implies a possible PTSD. As table 3 shows, most PTSD symptoms occurred significantly more in the SCIL-positive patients, with the exception of bodily reactions when reminded of the trauma and of being startled by something unexpected. Only for heightened awareness of danger was the odds ratio reasonable (1.82; 1.26 - 2.61). The prevalence of a TSQ-score of 6 and higher (i.e., being suspected of having a PTSD) differed significantly between the groups (OR = 1.48, $P<0.05$, one-sided), with 43.2% in all patients, 37.6% in the SCIL-negative patients and 47.8 in the SCIL-positive patients.

Table 2: Trauma in patients with a SCIL score above 19 and below (BIF/MID) and above 15 and below (MID)

| | % All | % No SCIL | Below Borderline Intellectual Functioning/ Mild Intellectual Disability | | SCIL positive/ SCIL negative | | Mild Intellectual Disability | | SCIL ≤15/ SCIL >15 | |
| | | | % SCIL negative (>19) | % SCIL positive (≤19) | OR | 95% CI OR | % SCIL >15 | % SCIL ≤15 | OR | 95% CI OR |
|---|---|---|---|---|---|---|---|---|---|---|
| N | 570 | 71 | 287 | 212 | | | 414 | 85 | | |
| Any trauma | 85.1 | 88.4 | 84.0 | 86.8 | 1.25 | 0.75 - 2.08 | 85.0 | 85.9 | 1.07 | 0.55 - 2.09 |
| Number of trauma experiences *ab | 1.60 | 1.49 | 1.41 | 1.89 | | | 1.58 | 1.75 | | |
| Sexual trauma * | 39.7 | 27.0 | 36.5 | 43.9 | 1.36 | 0.95 - 1.95 | 39.8 | 38.8 | 0.96 | 0.59 - 1.55 |
| Physical trauma a | 42.0 | 41.9 | 35.1 | 50.9 | 1.92 | 1.33 - 2.76 | 40.5 | 48.2 | 1.37 | 0.86 - 2.19 |
| Neglect a | 50.4 | 44.7 | 45.3 | 57.1 | 1.60 | 1.12 - 2.92 | 49.0 | 56.5 | 1.34 | 0.84 - 2.16 |
| Experienced disaster a | 30.0 | 30.4 | 24.0 | 37.9 | 1.93 | 1.31 - 2.86 | 29.5 | 31.8 | 1.11 | 0.67 - 1.84 |

* Significant difference between no SCIL, SCIL positive and SCIL negative (BIF) $P<0.05$, one-sided chi-square.

a Significant difference between SCIL positive and SCIL negative (BIF) $P<0.05$. one-sided chi-square, or student t-test.

b Significant difference between SCIL below 15 and above 15 (MID) $P<0.05$, one-sided chi-square, or student t-test.

Table 3: Trauma Symptoms in patients with a SCIL score above 19 and below (BIF/MID) and above 15 or below (MID)

| Trauma symptoms | % All | % No SCIL | Below Borderline Intellectual Functioning/ Mild Intellectual Disability | | SCIL positive/ SCIL negative | | Mild Intellectual Disability | | SCIL ≤15/ SCIL >15 | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | % SCIL negative (>19) | % SCIL positive (≤19) | OR | 95% CI OR | % SCIL >15 | % SCIL ≤15 | OR | 95% CI OR |
| | | 71 | 287 | 212 | | | 414 | 85 | | |
| Thoughts or memories against will [a] | | 40.6 | 33.7 | 42.9 | 1.48 | 1.03 - 2.14 | 37.3 | 38.8 | 1.07 | 0.66 – 1.71 |
| Upsetting dreams [a] | | 46.4 | 37.6 | 49.8 | 1.64 | 1.14 - 2.35 | 42.6 | 43.5 | 1.04 | 0.65 – 1.66 |
| Feeling as if the event is recurring [a] | | 42.0 | 29.3 | 36.8 | 1.41 | 0.97 - 2.06 | 32.0 | 34.5 | 1.12 | 0.68 – 1.83 |
| Feeling upset by reminders of the event [a] | | 58.0 | 47.2 | 57.8 | 1.53 | 1.07 - 2.19 | 50.7 | 56.5 | 1.26 | 0.79 – 2.02 |
| Bodily reaction when reminded | | 36.2 | 37.5 | 37.4 | 0.98 | 0.69 - 1.44 | 38.4 | 32.9 | 0.78 | 0.48 – 1.29 |
| Difficulty falling or staying asleep | | 44.9 | 42.0 | 48.8 | 1.32 | 0.92 - 1.88 | 44.0 | 49.4 | 1.24 | 0.78 – 1.99 |
| Irritability [a] | | 41.2 | 35.1 | 42.5 | 1.37 | 0.95 - 1.97 | 38.5 | 37.2 | 0.95 | 0.59 – 1.53 |
| Difficulties concentrating * | | 27.0 | 36.9 | 44.3 | 1.36 | 0.95 - 1.95 | 40.1 | 40.0 | 0.99 | 0.62 – 1.60 |
| Heightened awareness of danger [a] | | 44.9 | 36.4 | 50.9 | 1.82 | 1.26 - 2.61 | 41.4 | 48.2 | 1.32 | 0.83 – 2.11 |
| Startled after something unexpected * | | 11.2 | 28.5 | 36.4 | 1.44 | 0.99 - 2.09 | 31.0 | 36.0 | 1.26 | 0.77 – 2.04 |
| Above six symptoms [a] | 43.2 | 40.6 | 37.6 | 47.8 | 1.48 | 1.03 - 2.12 | 40.6 | 47.1 | 1.30 | 0.81 – 2.08 |

* Significant difference between no SCIL, SCIL positive and SCIL negative (BIF) *P*<0.05, one-sided chi-square.

a Significant difference between SCIL positive and SCIL negative (BIF) *P*<0.05, one-sided chi-square.

b Significant difference between SCIL below 15 and above 15 (MID) *P*<0.05, one-sided chi-square.

### 6.3.4 Post Hoc analysis

Table 4 presents the analysis stratified by gender and shows some interesting differences with regard to gender and to SCIL-positive and SCIL-negative patients. In the men, there were no differences regarding any trauma or sexual trauma. In women, however, there was a slight but significant difference showing more any trauma (OR 2.01) in the SCIL-positive patients. More importantly, in SCIL-positive and SCIL-negative patients, stratified analysis showed an odds ratio above one between men and women. The odds were greater in the SCIL-positive patients (5.4) than the SCIL-negative patients (3.8). This implies that women had had more trauma than men, but also that this difference was greater in the SCIL-positive patients than in the SCIL-negative ones. We also observe a trend in the prevalence of sexual trauma in SCIL-positive women but not in SCIL-negative women (60.7 vs 51.4 OR = 1.46 $\chi$-square 2.8 $P$=0.062). Comparison of scores 15 and below showed no significant differences.

Table 4: Any trauma and sexual trauma in patients with a score above 19 and below 19 (BIF/MID) and above 15 and below 15 (MID)

| | | Below Borderline Intellectual Functioning/ Mild Intellectual Disability | | | | | Mild Intellectual Disability | | | |
| | | % No SCIL | % SCIL negative (>19) | % SCIL positive (≤19) | SCIL positive/ SCIL negative OR | 95% CI OR | % SCIL >15 | % SCIL ≤15 | SCIL ≤15/ SCIL >15 OR | 95% CI OR |
|---|---|---|---|---|---|---|---|---|---|---|
| **Men** | N | 71 | 287 | 212 | | | 414 | 85 | | |
| | Any trauma | 75.0 | 83.9 | 80.0 | 0.77 | 0.39 - 1.50 | 83.7 | 75.0 | 0.59 | 0.25 - 1.36 |
| | Sexual trauma | 7.0 | 21.5 | 23.2 | 1.09 | 0.59 - 2.04 | 22.7 | 19.4 | 0.82 | 0.34 - 2.00 |
| **Women** | N | 30 | 144 | 117 | | | 202 | 36 | | |
| | Any trauma [ab] | 96.7 | 84.0 | 91.4 | 2.01 [e] | 1.01 - 5.14 | 86.3 | 93.9 | 2.43 | 0.71 - 8.33 |
| | Sexual trauma [cd] | 54.8 | 51.4 | 60.7 | 1.46 | 0.89 - 2.39 | 56.1 | 53.1 | 0.88 | 0.47 - 1.64 |

* Significant difference between no SCIL, SCIL positive (BIF, below 19) and SCIL negative $P<0.05$, one-sided chi-square.

a Significant difference between SCIL positive (BIF, below 19) and SCIL negative $P<0.05$, one-sided chi-square.

b Significant difference between SCIL below 15 and above 15 (MID) $P<0.05$, one-sided chi-square.

c Significant difference between men and women on SCIL positive, below 19 (BIF) $P<0.05$, one-sided chi-square.

d Significant difference between men and women on SCIL below 15 (MID) $P<0.05$, one-sided chi-square.

e OR=(106/121)/ (10/23)=2.0149.

## Discussion

The main objective of this study was to establish the prevalence of trauma in SMI patients with and without MID/BIF. We found that 85.1% of these SMI outpatients had experienced one or more traumatic events; 43.2% of patients in the current sample were suspected of PTSD, with over six symptoms. Neglect and physical trauma were the commonest. Disaster or accident trauma was less frequent, while sexual trauma occurred primarily in women.

In the group of patients suspected of having MID/BIF, as many as 47.8% were screen-positive for PTSD, compared to 37.6% in the non-MID/BIF group. Analysis of the kinds of abuse we report in our study shows nearly the same outcome as shown in the review of Mauritz et al. (1). Most kinds of trauma are reported significantly more in the SCIL-positive group (table 2). Remarkably, the number of PTSD diagnoses (8.1%) was far lower than the number of patients suspected of PTSD as assessed by the TSQ, even after taking account of a corrective positive prediction of 44.5% (3). This implies that most PTSD diagnoses had not been documented in the patient files. The PTSD prevalence in MID/BIF patients reported in a review article by Mevissen and de Jong, 2010 (13) ranged between 2.5 and 60%. The prevalence we found thus lies in the upper range found in the review. As the TSQ is not validated in MID/BIF patients, it is conceivable that patients with a low score on the SCIL either do not properly understand what they have been asked or, due to their disability, do not recognize their symptoms. If so, this may have led to underreporting of PTSD symptoms in the SCIL-positive group. Another reason of lack of difference between the MID group and the group above 15 on the TSQ may have been due to the relatively small sample of MID patients, a suspicion that was confirmed by the relatively low odds ratios and relatively large confidence intervals.

Our findings are in line with both these studies. As expected, sexual trauma had occurred more in women, especially in the SCIL-positive (MID/BIF) group. More detailed examination of the gender differences in sexual trauma showed a significant difference between men (23.2%) and women (60.7%) in the SCIL-positive group, and also a significant difference between men and women on SCIL below 15 (19.4% - 53.1%). Women with BIF/MID are thus victims more often than men with BIF/MID. According to our findings, gender is more important in becoming a victim of sexual trauma. With regard to sexual trauma, the study by Murphy G, 2004 (21) showed that adults with MID were significantly less knowledgeable about almost all aspects of sex, having difficulty in distinguishing abusive relationships from consenting relationships. So this may even be an underestimation.

Our finding of more physical abuse in the SCIL-positive group is also in line with the literature on MID patients. In the study by Catani and Sossella, 2015 (22), physical and emotional child abuse was positively correlated with general traumatic events in adulthood. Childhood sexual abuse was related to the experience of intimate partner violence in adult life. Physical abuse, such as being badly beaten, was reported by a large number of participants (44.6%). At 50.9%, our findings of physical trauma are even higher than those reported by Catani and Sossella.

## Clinical implications

If we are to explain patients' underreporting of trauma and PTSD in SMI-including, to some extent, that by professionals-several factors should be considered. First, we know that many SMI patients present with a myriad of complaints that are initially hard to disentangle. For example, dissociation and psychotic symptoms can be signs not only of PTSD but also of schizophrenia. Comorbidity-such as substance abuse and depression, sexually aberrant behaviour or sexual problems-and somatic symptoms are often present. Another explanation may be that, out of fear of aggravating symptoms and causing a crisis, professionals hesitate to pay attention to past traumatic experiences. In this way, PTSD often seems to have been overlooked and left untreated (13).

Second, we need to keep in mind that using screeners remains an approximation of the clinical diagnosis. Especially in PTSD, the clinician may come to different conclusions than interview-based assessments (23, 24). Some authors dispute the validity of assessing PTSD in patients with psychosis (25).

Third, we know from the study by Mueser et al. (26) that PTSD in patients with SMI is associated with more severe symptoms, re-traumatization, worse functioning, and difficulties with interpersonal relationships. PTSD itself negatively affects the course of SMI. The study by McNeill et al. 2015 (27) also showed that patients with PTSD in SMI have increased avoidance coping, which leads to significant psychological distress and a more highly taxed psychiatric state. After stressful events, those with SMI and PTSD are at greater risk of engaging in life-endangering behaviours and are at a greater danger of attempting suicide than those with SMI alone (28). We found no literature on trauma and PTSD in SMI MID/BIF patients that also examined the subjects of wellbeing or mental state. As this may explain limited symptomatic recovery, it is relevant to future research.

Finally, as we know from the literature on PTSD in patients with MID, PTSD can present in different ways and be difficult to recognize. Flashbacks are sometimes falsely communicated as current experiences and thus diagnosed as schizophrenia (29). Whigham et al., 2011 (30) noted that, after trauma, MID patients could communicate reactions in various ways, either behaviorally (such as in challenging behaviour or acting out), through changes in physical health, or through changes or loss in daily skills. The authors also noted that the symptoms of trauma are mediated by the patients' developmental level. It is already known that people with MID/BIF tend to react with behaviour and coping styles that resemble a borderline personality disorder.

All these variations in the clinical presentation may thus confuse or impair interpretation of the TSQ findings in MID or BIF patients. Without adequate assessment and treatment, PTSD will lead to chronic and serious psychiatric problems, lower quality of life, and higher treatment costs. Despite initial criticism, SMI trauma treatment using Eye Movement Desensitisation Reprocessing (EMDR) and Cognitive Behavioural Treatment (CBT) in SMI patients has proven to be successful (31), even in patients with psychotic symptoms (32, 33). Case studies suggest positive treatment effects in PTSD for various treatment methods (34) in SMI. Both EMDR and CBT were proven effective in patients with MID (35, 36). These methods may therefore be effective in MID/BIF SMI patients. It is therefore very important for those in clinical practice to distinguish between patients with intellectual shortcomings and those without and to pay full attention to all categories of trauma.

## Strengths and limitations

One strength of the current study is that it covers consecutive data in a number of FACT teams over various centres. As the number of included patients was substantial, the results may be generalized to SMI patients as a whole. Apart from slightly lower GAF scores, there were no indicators of any selective response. An important limitation of the current study is that the MID subgroup was quite small. Some of the subgroup analyses concerned small numbers and may be investigated in future studies.

# Recommendations for clinical practice and research

Given the great impact of MID/BIF, trauma and PTSD on the course of Serious Mental Illness, we recommend that all patients who meet the SMI criteria are screened as early as possible in the treatment. The SCIL and the TSQ are both validated questionnaires that are short and easy to use (3, 17, 19, 20). If the outcome of these screening instruments is known, we recommend that PTSD be diagnosed using an appropriate questionnaire that takes account of the cognitive level of functioning. In people with MID, this may mean following the comprehensive guide to PTSD 2016 (36). For those with MID/BIF, it may mean using validated instruments or, where necessary and possible, referral to a specialized center for patients with SMI and MID/BIF. In the last few years, various screening instruments for PTSD in patients with MID/BIF have been validated, such as the LANTS (Lancaster and Northgate Trauma Scales) by Wigham, 2011 (37), and the IES-IDs (Impact of Event Scale - Intellectual Disabilities) by Hall J.C. et al., 2014 (38).

To minimize the number of potential blind spots regarding trauma, PTSD and intellectual functioning, we also recommend the following: If a patient's medical chart does not already contain relevant information on childhood or the past -particularly with regard to development, school career, family and social circumstances, and safety in relationships- it should always be collected.

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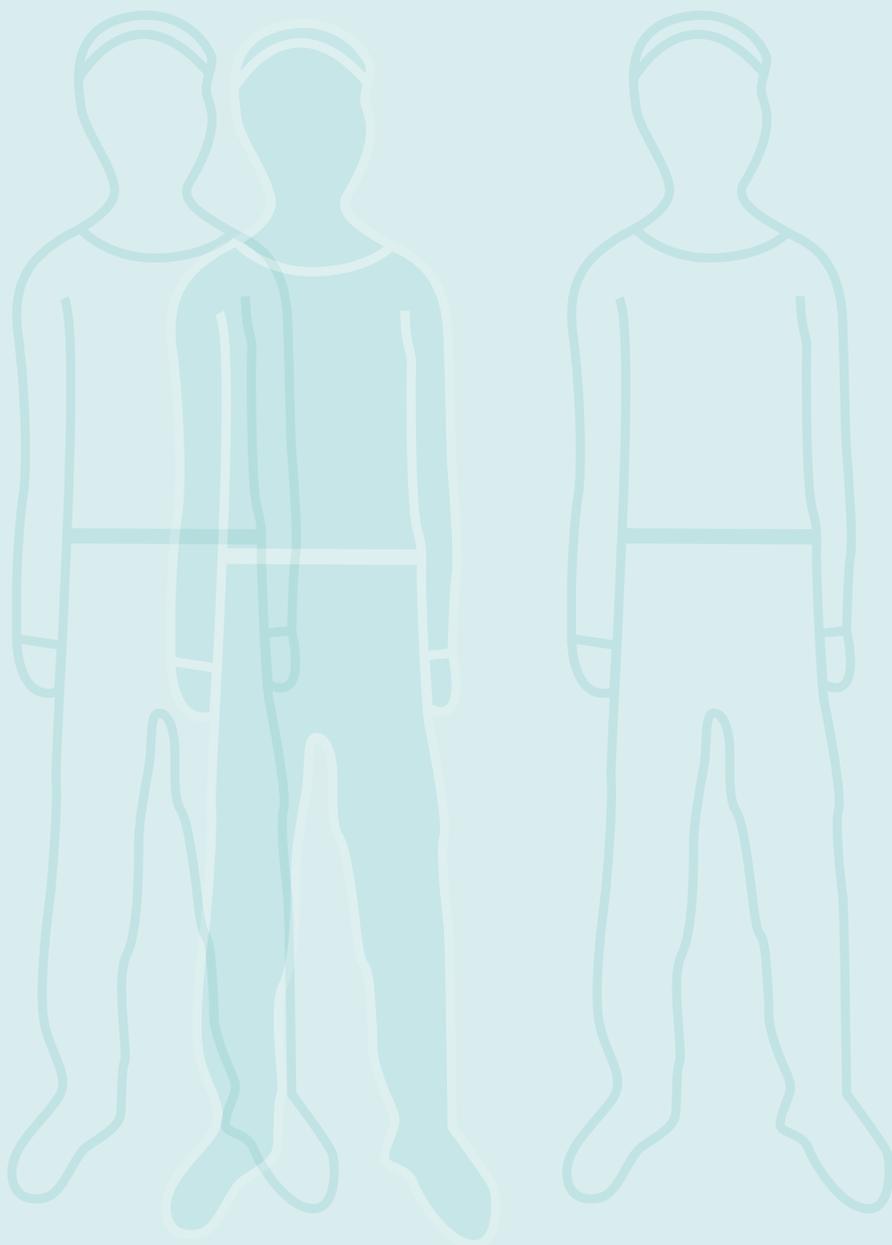
# Psychiatric symptoms influence the performance on the Screener Intelligence and Learning Disabilities in general mental health care in The Netherlands

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# Abstract

**Purpose.** A recently published study showed a 41% prevalence of mild intellectual disability (MID) and borderline intellectual functioning (BIF) in a large sample of Dutch psychiatric patients. This study aims to examine if the outcomes of the Screener for Intelligence and Learning Disabilities (SCIL) were affected by the severity of psychiatric symptoms during admission.

**Design.** The authors administered the SCIL and the Kennedy Axis V (domain psychological impairment) at two moments when patients were sufficiently stabilised and just before discharge.

**Findings.** A total of 86% of the respondents had the same outcome regardless of the time of administration. The Kennedy score correlated modestly with changes in the SCIL scores, suggesting that the severity of psychiatric symptoms just modestly affected the performance.

**Originality.** To the best of the authors' knowledge, there is no research concerning screening instruments on MID/BIF used at admission wards in Mental Health Care.

**Practical implications.** Recognising MID/BIF in mental health care is essential but challenging for clinicians. The authors concluded that screening with the SCIL allows clinicians to identify patients with MID/BIF at an early stage of their admission, which helps to individualise treatment and reduce the risk of aggression, coercive measures and prolonged admissions. However, the authors prefer to assess all patients on cognitive impairment as early as possible after referral at a more stable moment in time.

**Keywords.** SCIL, Acute psychiatric admission, Mental state, Intellectual performance, Screening, Borderline intellectual functioning, Mild intellectual disability

# Introduction

For professionals working in acute wards in general Mental Health Care, it is essential to have a reliable estimate of their patients' intellectual level of functioning. This allows the individualised provision of appropriate treatment. A recently published study showed a 41% prevalence of mild intellectual disability (MID) and borderline intellectual functioning (BIF) in a large sample of Dutch psychiatric patients (Nieuwenhuis et al., 2021a). This was far more than expected and previously recognised by the clinician. Completing a full IQ test during a short admission is rarely feasible and is of limited validity (Merz et al., 2021). In such cases, intellectual capacity may be estimated by using brief screening tools. One of these screening tools increasingly used in The Netherlands is the Screener for Intelligence and Learning disabilities (SCIL;Nijman et al., 2018; Kaal et al., 2015a). This is a test consisting of 14 questions and small tasks with high reliability in detecting MID and BIF (Kaal et al., 2015b). Patients screened suspected for MID/BIF by the SCIL, have been found to have an increased risk of being involuntary admitted (OR 2.71) and subjected to coercive measures (OR= 3.95) (Nieuwenhuis et al., 2017). A SCIL 19 and below (assumed BIF or MID) was associated with more aggression in general (OR=2.50). A SCIL 15 and below (MID) was associated with more aggression in general (OR=2.74) and with more physical aggression (OR=3.06) (Nieuwenhuis et al., 2022). A study in outpatient seriously mentally ill (SMI) patients showed that these patients also had more traumatic experiences (1.89 in BIF, 1.75 in MID, against 1.41 in SCIL-negative patients) and were also significantly more (OR=1.48, $P$ <0.05, one-sided), suspected of having PTSD (47.8%). Female MID/BIF patients had experienced significantly more sexual abuse (61%) than male MID/BIF patients (23%) (Nieuwenhuis et al., 2018). Also, in this study, the MID/BIF and being suspected of PTSD was often not recognised. All these studies show a high percentage of psychiatric patients functioning at a lower intellectual capacity than the practitioner estimated.

The SCIL was first used in several published studies in forensic psychiatry in the Netherlands (Kaal et al., 2015b). The SCIL was recently validated in SMI patients in functional assertive community treatment (FACT) teams Seelen (et al. 2019). The sample showed a Cronbach's alpha of 73. The area under the curve (AUC) value for MID/BIF as well as MID was 0.81, with percentages of correctly classified subjects of 73% (MID/BIF) and 79%, (MID), respectively. It is not clear whether the severity of psychiatric symptoms during admission impacts SCIL assessment results. Jonker et al. and Seelen-de Lang et al. showed an association of lower scores when assessing intellectual disability with having a co-morbid psychiatric disorder. Especially in patients on acute wards, we may expect current symptomatology to interfere with test outcome.

We, therefore, examined the influence of the severity of psychiatric symptoms on the SCIL assessment to determine an optimal time when such assessments should be conducted.

## Methods

### Participants
All patients admitted (N = 281) for more than six days to a High and Intensive Care (HIC) ward in Doetinchem (Eastern Netherlands) between 2017 and 2020 were eligible. We assessed patients with the SCIL and the Kennedy Axis V (Seelen-de Lang et al., 2019). The first SCIL assessment was along the instructions of the SCIL performed as soon as the patient was judged to be able to concentrate for at least 20 min (T1); the second (T2) was performed in the day(s) before discharge. The Kennedy Axis V was administered the same day as the SCIL in 92% of the cases. Cases were included when two assessments could be obtained, and the patient gave a valid informed consent.

The study was carried out and reported according to the strengthening the reporting of observational studies in epidemiology (STROBE) guidelines (Jonker et al., 2021). Medical Ethical approval was provided by the ethical board of the University of Twente, Enschede, The Netherlands. All patients gave informed consent.

### Assessments
We used the SCIL to screen for MID and BIF. The SCIL is a test consisting of 14 questions, including educational level and small tasks and takes about 15 min to administer. The reliability of the SCIL is good (Cronbach's alpha: 0.83). A score of 19 and lower implies positive screening for BIF; a score of 15 and lower implies MID (Nijman et al., 2018; Kaal et al., 2015b). The AUC value for predicting IQ scores of 84 or lower (i.e., MID/BIF) in adults was 0.93 when compared with the results of an IQ test (Merz et al., 2021). With 19 or lower as a cut-off score, the SCIL accurately classified 82% of people with MID/BIF (Kaal et al., 2015a, 2015b). The SCIL was recently also validated in SMI patients at FACT teams Seelen et al. 2019. That sample showed a Cronbach's alpha of 73. The AUC value for MID/BIF as well as MID was 0.81, with percentages of correctly classified subjects of 73% (MID/BIF) and 79% (MID).

The Kennedy Axis V (Kennedy, 2008) is a valid instrument to get a clinical impression of symptoms and functioning of the psychiatric patient in a hospital or home setting. Ratings for each of the seven domains can range from a low score of 5 (very dysfunctional) to a high score of 100 (no symptoms). The domain "psychological impairment" assesses

the severity of psychiatric symptoms (e.g. hallucinations, delusions, depressed mood, anxiety) and correlates well with the Global Assessment of Functioning (GAF). It will be used in this study as an indicator of the severity of psychiatric symptoms on admission.

Demographic data and diagnosis were extracted from the electronic medical charts (EMC): age, gender, psychiatric diagnosis (DSM-IV-TR, as assessed by the psychiatrist) and GAF score. We included these data to perform a non-response analysis.

**Analyses**
The stability of SCIL and Kennedy Axis V scores between T1 and T2 was compared by a simple Student t-test and by calculating the Pearson's R correlation coefficient between the total scores obtained at T1 and T2. The association of the Kennedys domain "psychological impairment" with changes in SCIL scores from T1 to T2 was analysed by calculating the correlation coefficient between the difference between SCIL total scores at T1 and at T2 and the Kennedy psychological impairment score on the first (T1) measurement.

## Results

A SCIL and Kennedy Axis V was obtained in 183 (65.1%) patients who consented to participate on average 19.3 days (Median 12.0, SD=21.7) after admission. Because of practical and logistical reasons, a follow-up interview could only be obtained in 43 (23% of the 183) patients. The reasons include the fact that many patients were discharged before they could be assessed for the second time. Others were not asked for permission to be interviewed at home before discharge, which is a requirement under Dutch privacy law. On average, T2 was 39.1 days after T1 (Median 25.0, SD=48.5 days). Importantly, there were no significant differences between the completers and non-completers in demographics, diagnoses, SCIL and Kennedy Axis V scores, apart from autism spectrum disorder, which was more common in the completer group (16.2% versus 8.3%, $P = 0.034$).

Forty-three patients (21 men and 22 women) with a mean age of 39 years (SD=11) completed the protocol. Among them, 19 (44%) had a diagnosis of schizophrenia, 7 (16%) had autism spectrum disorder, 6 (14%) had bipolar disorder, 5 (12%) had a psychotic disorder other than schizophrenia, 4 (9%) had depression or anxiety disorder, 1 (2%) had a drug abuse disorder and 1 (2%) had a post-traumatic stress disorder.

At the first and second assessments, the mean SCIL scores were 18.71, SD=5.75 and 19.01, SD=5.26 respectively; 51% had a score of 19 or lower (25% BIF, 26% MID). At T2, one patient moved from a SCIL score above 19 at T1 to 19 or lower, and five patients moved from 19 or lower to above 19. In one patient, the SCIL score improved by 8 points. In other words, 86% of patients received the same SCIL classification (in terms of screening positive/negative for MID/BIF), regardless of the administration time. When we look at the percentage agreement separately, BIF was classified in 76% as the same, while MID was the same in 86%. No BIF or MID was the same in 86% of cases.

Concerning mental state, the "Psychological impairment" scale showed a significant increase (Kennedy score T1 and T2, respectively: 40.44, SD=7.62 and 46.47, SD=10.48, paired t-tests; T1 = 42, T2 = 48; t = -3.4; $P$ <0.001). The correlation of the Kennedy score at T1 with the SCIL score was 0.37 ($P$ <0.001). At T2, this association increased slightly to 0.44 ($P$ <0.0001). The Kennedy scores at T1 did show a modest but significant correlation (r = -0.377, $P$ = 0.013) with the changes in SCIL scores from T1 to T2.

## Discussion

This study assessed the influence of the severity of psychiatric symptoms on assessment results of the SCIL, a screener for MID and BIF in patients admitted to an acute admission ward. We found a modest impact of the severity of psychiatric symptoms on the SCIL score. A possible learning effect of repeated assessment in a short time frame cannot be ruled out. The association of the Kennedy scores with the SCIL was slightly stronger at T2, than at T1, but in both measurement moments significant. For this reason, we recommend that, whenever possible, patients should be screened either when the severity of symptoms is relatively low (e.g. just after referral) or when the patient is at home.

As we can learn from a study by Wieland et al. (2020) and Kennedy (2008), it is difficult for clinicians to assess a person's intellectual capacity without measuring instruments. If the patient is admitted to an acute ward and the patient's intellectual capacity is unknown, the SCIL tests can be helpful to get a quick and easy first impression. Treatment and support of the patient can be adapted by practitioners and nurses to the findings. We advise reassessment when the severity of symptoms has decreased, which may be after a few weeks. From former studies, we know that screening with the SCIL can contribute to recognising patients with MID/BIF at an early stage of their admission, which helps to individualise treatment without overdemanding the patient and might reduce the risk of aggression, prolonged admissions and poorer outcome

(Seelen-de Lang et al.,2019; Nieuwenhuis et al., 2017). The SCIL is already translated into English, German, (Mexican) Spanish and translation in Swedish is in preparation, which offers international research on this topic in mental health care in future and can be beneficial in clinical practice.

A strength of the current study is the clinical validity of the assessments. It is a naturalistic study in the hectic of an acute admission ward. A reasonably representative sample of admitted patients could be included. An important weakness is the large dropout rate. A selection bias cannot be ruled out.

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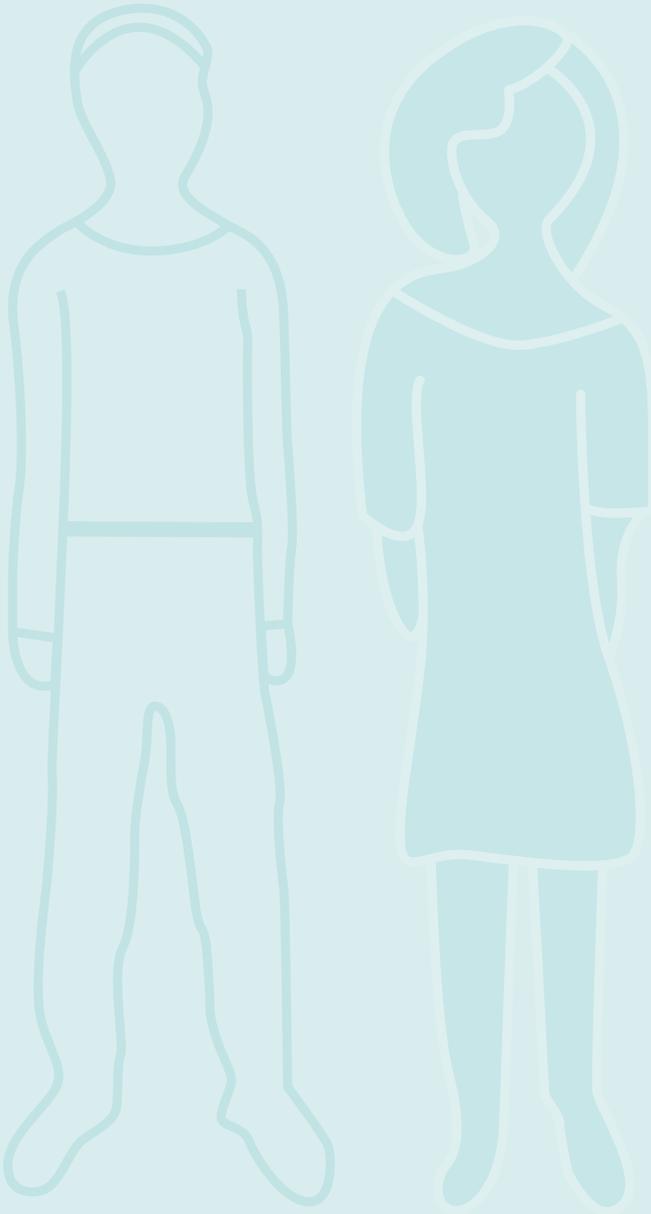
Chapter

**8**

# Summary and general discussion

**8.1 Introduction**

The purpose of this thesis was to investigate the prevalence of Mild Intellectual Disability (MID) and Borderline Intellectual Functioning (BIF) and to study the associations of MID/BIF with other mental health outcomes in different settings in general psychiatry. The prevalence of MID/BIF in general psychiatry in the Netherlands and most other countries was largely unknown until the start of the projects included in this thesis. In general, although the attention of this patient group is growing, MID/BIF often seems to go undetected and is not recognised in clinical practice. The results of the studies presented in this thesis attempt to contribute to an earlier recognition, leading to better treatment. In all studies presented in this thesis, we used the SCreener for Intelligence and Learning disability (the SCIL) to access intelligence in the range of an IQ of 50-85 (MID/BIF). The research questions addressed in the thesis were the following:

1.  What is the estimated prevalence of patients suspected of MID/BIF using the SCIL as a screener on admission wards? (Chapter 3)

2.  Are patients screened positive for MID/BIF with the SCIL more often subjected to coercive measures than patients who screened negative? (Chapter 3)

3.  What is the estimated prevalence of patients suspected of having MID/BIF in different mental health care settings using the SCIL as a screener? (Chapter 4)

4.  What percentage of patients who screened positive for MID/BIF are suspected of having cognitive decline, using the SCIL as a screener? (Chapter 4)

5.  Are patients who screened positive for MID/BIF using the SCIL as a screener more often engaged in aggressive incidents than patients not suspected of having MID/BIF? (Chapter 5)

6.  Do patients suspected of MID/BIF more frequently experience trauma and have Post-Traumatic Stress Disorder (PTSD) symptoms compared to patients not suspected of having MID/BIF? (Chapter 6)

7.  Finally, we tried to answer the research question: what is the association between the level of psychiatric symptoms and the scores on the SCIL? (Chapter 7)

These research questions were studied in five research projects, including observational and cross-sectional studies. This chapter will present a summary of the research presented in the thesis, discuss the findings, strengths and limitations, and the clinical implications, and finally present ideas for future research and suggestions for policymakers.

## 8.2 Summary of the findings

### *Chapter 1: General introduction*

Chapter 1 is a general introduction to the thesis. The chapter explains the term Intellectual Disability (ID), definitions of MID and BIF, and the Dutch term 'Licht Verstandelijke Beperking'. This is followed by addressing the association of MID/BIF with psychiatric disorders and the prevalence of 'Licht Verstandelijke Beperking' in the Dutch population. Recognition, screening and diagnosing of ID in clinical practice, the aetiology of ID, and changing perspectives on ID and Psychiatry over time are discussed, as well as three vignettes from my daily clinical practice. In the last paragraph, the aims and structure of the thesis are described.

### *Chapter 2: Recognising and diagnosing low intellectual functioning in Mental Health*

Chapter 2 is about awareness, recognising, and diagnosing MID/BIF in daily clinical practice, aiming to teach clinicians to detect and diagnose low intellectual functioning and give them a rough idea of the methodology and the pitfalls in diagnosing psychiatric disorders in this group of patients. Various screening instruments commonly used in the Netherlands are discussed in connection with the subsequent diagnostic procedures. Employing screening and diagnosing intelligence and adaptive functioning, a more integrative psychiatric diagnosis can be made with attention to the intellectual, emotional, and social level of functioning, possibly preventing a chronic course of the psychiatric disorder and offering a more tailor-made treatment.

### *Chapter 3: Screening for Mild Intellectual Disability and Borderline Intellectual Functioning in Admitted Psychiatric Patients: Prevalence and Associations with Coercive Measures*

In Chapter 3, a study was presented in which we screened for MID/BIF using the SCIL in patients admitted to two acute psychiatric wards. We investigated whether the use of coercive measures was higher for patients who screened positive for MID/BIF. We found that 43.8% of the sample screened positive for MID/BIF. During their current stay and earlier stays in the previous five years, these patients had a nearly three times increased risk of involuntary admission (OR 2.71) and four times more risk of being confronted with coercive measures (OR 3.95). The medical charts showed

earlier documentation of MID/BIF in only a minority (22.1%) of the 91 SCIL-positive patients. In the discussion, we stated that it was a remarkable finding that in the past, SCIL-positive patients have had more involuntary admissions than SCIL-negative ones and had experienced more coercive measures. We shared the opinion that coercive measures may obstruct recovery and even result in iatrogenic PTSD. We hypothesised that people with MID/BIF have reduced coping skills and quickly react with verbal aggression, and, in the circumstances, they cannot oversee abject behaviour, leading to involuntary admissions and easily coercive measures.

*Chapter 4: Increased prevalence of MID/BIF in higher intensity mental health settings*
Chapter 4 described an increased prevalence of MID/BIF in higher-intensity mental health settings. We also estimated the percentage of cognitive decline, investigating possible impaired cognitive functioning acquired after 18.

A cross-sectional study was conducted in settings with increasing levels of care within GGNet, a mental healthcare trust in the Netherlands. We asked 1616 consecutive patients to participate, of which 1213 (75.1%) did. We used the SCIL to screen for MID/BIF. We identified patients with a high level of education and low SCIL scores to estimate which patients may have had a cognitive decline.

Across all settings, 41.4% of participating patients were screened positive for MID/BIF. The proportion of patients who screened positive for MID was 20.2%. The prevalence of MID/BIF increased by level of care, from 27.1 % in outpatient settings to 41.9% in Flexible Assertive Community Treatment (FACT) teams and admission wards and 66.9% on the long-stay ward. Only 85 (7.1%) of all patients were identified as possibly having a cognitive decline based on their relatively poor performance on the SCIL compared to their educational level. Of these patients, 25.9% were in long-stay wards, and relatively often, these patients were diagnosed with Schizophrenia or Alcohol and Drug abuse disorder.
Based on the limited available data, we hypothesised that the prevalence of intellectual disabilities increases with the level of intensity of care in different mental health care settings. The reason could be that MID/BIF often goes unnoticed and untreated, as we discovered in the former study, making the treatment prognosis relatively poor. We also know from several studies that people with MID/BIF are more likely to develop psychiatric disorders.

We concluded that MID/BIF is common within GGNet, and the prevalence increased with the level of care. In addition, only a modest number of the patients were identified as suffering from cognitive decline. This study also showed a strong association

between suspected MID/BIF, diagnoses such as schizophrenia and addiction, worse overall functioning, and a long history of psychiatric care.

## Chapter 5: Aggressive behaviour of psychiatric patients with MID/BIF in general Mental Health Care

Chapter 5 established the association between aggression and MID/BIF in conjunction with patient characteristics and diagnoses. Empirical studies about the association between intellectual disabilities and aggressive behaviour in general Mental Health Care are still rare.

Aggressive behaviour during treatment was assessed with the Staff Observation Aggression Scale-Revised (SOAS-R). We calculated odds ratios and performed a logistic regression to calculate the associations of MID/BIF, patient characteristics, diagnoses, and aggression probability.

Forty-one percent of participating patients were screened positive for MID/BIF. Patients with assumed MID/BIF showed significantly more aggression at the patient and sample level (Odds Ratio of 2.50 for aggression and 2.52 for engaging in outwardly directed physical aggression, respectively).

The number of aggression incidents was significantly higher in assumed MID/BIF cases compared to patients who screened negative (OR MID 3.01, BIF 4.20). Furthermore, the outcomes indicate that outwardly directed physical aggression occurred more often in patients with assumed MID. The odds ratios of patients screened positive for MID increased significantly to 6.4 in the higher categories above two incidents versus OR 2.84 of patients screened positive for BIF. Finally, the logistic regression model showed that a combination of variables predicted aggression: screening positive for BIF (OR 2,0), MID (OR 2.89), having a diagnosis of bipolar disorder (OR 3.07), having the diagnosis of schizophrenia (OR 2.75), and younger age (OR 1.69).

## Chapter 6: The effects and associations of trauma and MID/BIF in severely mentally ill outpatients

In this cross-sectional study, we collaborated with colleagues of FACT teams from GGZ Oost-Brabant. We used the Trauma Screening Questionnaire (TSQ) to screen for trauma and PTSD and used the SCIL again to screen for MID/BIF. Post-hoc analysis was used to investigate gender differences between patients with and without MID/BIF regarding the prevalence of trauma.

In 570 patients, any trauma was found in 85.1% of the patients, and 43.2% screened positive for PTSD. The SCIL outcomes showed that about 40% screened positive for

MID/BIF, half of whom suspected MID. These patients had more traumatic experiences (the mean number of traumatic experiences was 1.89 in BIF, 1.75 in MID, against 1.41 in SCIL-negative patients). We concluded that significantly more SMI outpatients screened positive for MID/BIF reported having experienced traumatic events than those screened negative. Also, rates of trauma categories such as neglect and physical and sexual trauma were significantly higher in the screened positive, who were also more likely to have PTSD. Female MID/BIF patients (61%) had experienced significantly more sexual abuse than male MID/BIF patients (23%). Women who screened positive for MID/BIF were even more often sexually victimised.

Remarkably, the number of PTSD diagnoses reported in the electronic patient files of the patients (8.1%) was far lower than the number of patients suspected of PTSD as assessed by the TSQ. This implies that most PTSD diagnoses were not recognized or documented in the patients' files. In the discussion of this chapter, we paid attention to the possible different reasons explaining this gap.

### Chapter 7: Psychiatric symptoms influence the performance on the Screener for Intelligence and Learning Disabilities

Chapter 7 examined the influence of the mental state on the performance of the SCIL. The SCIL was initially validated in an adult sample in jails and institutions for people with psychiatric and forensic problems by comparing the scores obtained with test results obtained with the WAIS-III. It was developed specifically to screen for MID/BIF in people in various settings, such as healthcare or social-service settings, police stations, and shelters for the homeless.

In our study on a High Intensive Care admission ward, 43 patients participated. The SCIL and the Kennedy Axis V (psychological impairment scale) were administered after admission and stabilisation (19.3 days after admission (T1)) and before discharge (39.1 days after admission (T2)).

86% of patients had the same outcome on the SCIL regardless of administration time (correlation r=0.87). Kappa (degree of similarity corrected for the rarity of observation) was 0.722, indicating a good correlation. The Kennedy scores at T1 did show a modest but significant correlation (r=- 0.377, *P*=0.013) with the changes in SCIL scores from T1 to T2, suggesting that the severity of psychiatric symptoms only modestly affected the performance on the SCIL. We concluded that the SCIL could be used even in symptomatic patients, such as in the first weeks after admission to an acute ward, but it is preferable to screen when the severity of psychiatric symptoms is lower.

**8.3 General discussion**

The overall aim of the thesis was to investigate the prevalence and associations of MID/BIF with clinically significant problem areas such as coercive measures, aggression, trauma, and PTSD in patients in general psychiatry. These subjects have received little interest in the international literature and research. At the very least, we also wanted to investigate the usefulness of the SCIL in acutely admitted psychiatric patients.

*Prevalence of MID/BIF*
In short, there is a dearth of literature on the prevalence of MID/BIF in psychiatry patient samples. Before the start of the thesis, no prevalence studies were found addressing the prevalence of MID/BIF in general mental health care. Apart from our studies presented in this thesis, two recent studies have been done. First, a validation study by van Esch et al. (1) compared the SCIL to the gold standard (WAIS). In this study, 491 mentally ill detainees were included. The authors showed that the prevalence of MID/BIF as detected with the WAIS was high: the mean intelligence quotient (IQ) score was 82.6, and 60.3% could be classified as having an IQ < 85. These outcomes are in line with our prevalence study (Chapter 4), in which we found that patients in the long-stay intensive treatment setting - are reasonably similar to the population of van Esch, who screened positive on the SCIL for having MID/BIF - was 66.9%.

Second, in a not yet published replication study of our first study on a High Intensive Care ward at Mediant (2), trust in the most Eastern part of the Netherlands, we found nearly the same percentage of 43.6% MID/BIF. This study showed once again -as was shown in Chapter 4- that the prevalence of MID/BIF in a (locked) residential setting can be high. A recently conducted literature search yielded no other study results on this topic.

A remarkable finding in our prevalence study (Chapter 3) was that only one in five patients screening positive on the SCIL was reported as such using DSM categories in the electronic medical charts. Therefore, we suspect that lower intellectual functioning is a blind spot for clinicians. This was also found in a recent study by Wieland et al. (3), who found it hard for clinicians to recognise MID/BIF during an interview at the first referral at an outpatient clinic in clinical practice. Clinicians were asked beforehand to assess the intelligence level to be aware of intelligence as a possible co-morbid factor. They concluded that MID/BIF was frequently missed when no specific screener or assessment instrument of the intellectual capacities was used. Looking at possible reasons why clinicians do miss MID/BIF so frequently, clinicians could associate MID/BIF with people who have, for example, Down Syndrome and those who are visibly

disabled. In practice, however, MID/BIF is usually difficult to recognise. In addition, patients who already know themselves to be functioning at a lower cognitive level often try to hide their disability and use streetwise language. Another reason may be that MID/BIF is not seen as an important topic for clinical practice in training and education programs for clinicians.

Apparently, MID/BIF patients, in particular, seem to have an increased risk of ending up in the long-stay wards (Chapter 4). Apart from the fact that MID/BIF may be a possible blind spot for clinicians, one explanation could be that associations as described below lead to persistent wrong or missed diagnoses over time that may also overshadow intellectual functioning (4). When MID/BIF is missed, treatment may be less successful because prevailing therapeutic treatments are inappropriate since they are too difficult for these patients. However, when MID/BIF is known, these patients are often excluded a priori on the false assumption that this patient group cannot benefit from (psycho) therapy. Something that is less true (5, 6). Stress and overstretching of intellectual capacity and the level of emotional functioning are other important factors to take into account for achieving long-lasting recovery, as described in the Vignettes in Chapter 1.

*The SCIL in general psychiatry*
In one of our studies (Chapter 7), we added more information on the properties of the SCIL used in general psychiatry. Our study performed on an acute admission ward suggested that the severity of psychiatric symptoms only modestly affected the performance of the SCIL. The Kennedy Axis I (a measure of severity of psychiatric symptoms) showed only a modest correlation with the SCIL outcomes.

In 2019, a study by Seelen et al. with SMI outpatients treated in Dutch FACT teams showed a Cronbach's alpha of the SCIL of 0.73 (7). The AUC value for detecting MID/BIF was 0.81 and 0.81 for detecting MID, with percentages of correctly classified subjects (when using the advised cut-off scores) being 73% and 79%, respectively. This study concluded that the SCIL seems to be an appropriate screening tool for MID/BIF in SMI outpatient patients.

Finally, a study by van Esch et al. (1) showed that all psychometric properties could be classified as acceptable in applying the SCIL to mentally ill detainees. Cronbach's alpha coefficient for the total SCIL was 0.72, and the area under the receiver operating characteristics (ROC) curve was 0.84.

In conclusion, the SCIL seems to be an appropriate screening tool for detecting MID/BIF in severely mentally ill patients.

*Associations of MID/BIF with other mental health outcomes*

**MID/BIF and coercive measures**

We found a significantly higher risk of being confronted with coercive measures for the MID/BIF patient group (Chapter 3). Patients who screened positive for MID/BIF had roughly a three times higher chance of being admitted involuntarily and a nearly four times higher chance of being confronted with other coercive measures such as seclusion. We do not know of a similar study on mentally ill patients. A study by Massood et al. (8) showed that coercive measures dropped 50% after excluding ID services in Wales, showing that the risk of being confronted with coercive measures is higher in services for individuals with ID. Coercive measures can harm the patient's relationship with the health care worker and often constitute a traumatic experience, and it may also obstruct the individual patient's recovery and even result in iatrogenic PTSD (9).

**MID/BIF and aggression**

Investigating the association between MID/BIF and aggression was inspired by the findings above. In general, patients with MID/BIF have reduced coping skills, lower frustration tolerance, and quickly react with verbal aggression and abject or refusal behaviour. This is often defined as Challenging behaviour (10, 11). The severity and danger of disruptive behaviour as perceived by treating staff influence the decisions to use restrictive measures (12). The article by Kaunomäki et al. (13), describing an observational study on a Finnish psychiatric admission ward, also showed that the methods used for reducing the risk of aggressive behaviour were most frequently psychopharmacological or coercive measures.

We investigated the association between MID/BIF and aggressive behaviour in four different settings. Our study described in Chapter 5 showed that patients screened positive for MID/BIF have indeed an approximately 2.5 times higher risk of aggression and engagement in outwardly directed physical aggression as compared to those who were not suspected for MID/BIF. A SCIL score below 15 (MID) was even associated with about a three times higher chance of aggression. As far as we know, there are no other studies concerning MID/BIF in association with aggression in mental health care. This is in line with the outcomes of a recent review by Weltens et al. (14) about aggression in psychiatric wards, and they concluded that ID was not included as a risk factor for aggression.

One study that provides indirect evidence for increased aggression in patients with ID - assuming that aggression is often the reason for seclusion - is the study mentioned above by Masood et al. in 2016 (6). Their results showed that ID patients were more

frequently coerced than the non-ID population. This may indirectly indicate that aggression occurs more frequently in the MID/BIF patient group.

In a large Dutch study of an inpatient ID service covering 421 patients, 20% of the aggressive patients were responsible for 50% of the verbal and 80% of the physical aggressive incidents (15). The best predictor of aggressive behaviour was aggression early in treatment, followed by deficits in coping skills and impulsiveness.

We can learn how to prevent or manage incidents of aggression from methods used in services for intellectually disabled patients. In general, patients with MID/BIF can very well express what causes them stress, triggers anxiety and aggression, and what can help them prevent escalation and aggressive incidents (16, 17). This requires a personal and tailor-made crisis intervention plan that can be made in conjunction with the patient. Furthermore, it is important that staff and nurses are trained and have the knowledge and skills to understand the behaviour and emotional reactions of people with MID/BIF and not react to challenging behaviour by applying coercive measures immediately.

**MID/BIF and trauma**
We also studied the prevalence of trauma and PTSD in SMI outpatients with and without being suspected for MID/BIF (Chapter 6). In line with international literature (7, 18), our study found any trauma in 85.1% of 570 outpatients. In a review on trauma and PTSD in SMI patients, Mauritz et al. (18) reported population-weighted mean prevalence rates in SMI patients. For physical abuse this was 47% (range 25-72%), for sexual abuse 37% (range 24-49%), and for post-traumatic stress disorder (PTSD) this was 30% (range 20-47%). In line with studies on trauma, life events and PTSD in people with ID (19, 20), we found that patients suspected of MID/BIF had relatively more traumatic experiences (1.89 in BIF, 1.75 in MID, against 1.41 in SCIL-negative patients). Neglect and physical trauma were the most common. Sexual abuse occurred significantly more often in all SMI females, but the women who screened positive for MID/BIF were even more often victims of sexual abuse. We can learn from a recent review (20) in ID people that one in three adults with an intellectual disability suffers sexual abuse in adulthood. Subgroup analyses revealed that the prevalence of sexual abuse was higher in institutionalised individuals. As far as we know, there are no other studies done in SMI patients with MID/BIF looking at trauma. Our findings seem to be in line with the studies mentioned above carried out with people with ID, that trauma and sexual abuse are widespread phenomena.

Slightly higher than expected based on the mean prevalence of Mauritz et al. (18) study, 43.2% of patients in our study (Chapter 6) were suspected of having PTSD.

Importantly, in the electronic patient files, PTSD was underreported (8.1%). There may be several reasons for patients and staff underreporting trauma and PTSD: we know that many SMI patients present with a myriad of symptoms and complaints that are initially hard to disentangle. For example, dissociation and psychotic symptoms can be signs not only of schizophrenia but also of PTSD (21). Co-morbidity is often present, including substance abuse, depression, sexual problems, and somatic symptoms. Another explanation for not recognising PTSD may be that professionals hesitate to pay attention to past traumatic experiences out of fear of aggravating symptoms and causing a crisis (18). From the literature on PTSD in patients with MID, we also know that PTSD can present in different ways and can be challenging to recognise. Flashbacks are sometimes falsely communicated as current experiences and diagnosed as psychotic symptoms (21, 22). Whigham et al. (23) noted that MID patients could communicate reactions in various ways after trauma, either behaviourally (such as in showing challenging behaviour or acting out), through changes in physical health or changes or loss in daily skills.

People with MID/BIF tend to react to trauma with problematic behaviour, such as aggression and maladaptive coping styles, resembling a personality disorder (24). All these variations in clinical presentations may thus confuse and impair the interpretation of trauma (related) symptoms in MID/BIF patients. This may lead to an incorrect diagnosis and lack of specific treatment, possibly leading to a chronic course of the psychiatric illness (23, 24). This is illustrated by two recently published articles about adverse childhood experiences (25, 26), which underpin that toxic stress and PTSD in children cause huge downstream mental and physical health consequences throughout life.

In conclusion, in the studies presented in this thesis, we confirmed the hypotheses formulated in Chapter 1. We found a high prevalence of patients who screened positive with the SCIL, which mainly were not recognised before. In addition, we found significant associations between MID/BIF and an increased risk of coercion, aggression, and trauma.

Importantly, being screened positive on the SCIL and suspected of having MID/BIF is not the same as being diagnosed with MID/BIF. This is because the emotional development and the adaptive functioning of the patient are just as crucial in diagnosing MID/BIF (Chapter 2) and cannot be measured accurately by the SCIL.

The results of this thesis are brought together in a hypothetical conceptual model (see Figure 4)

Figure 4: Possible cause of chronicity in psychiatric care
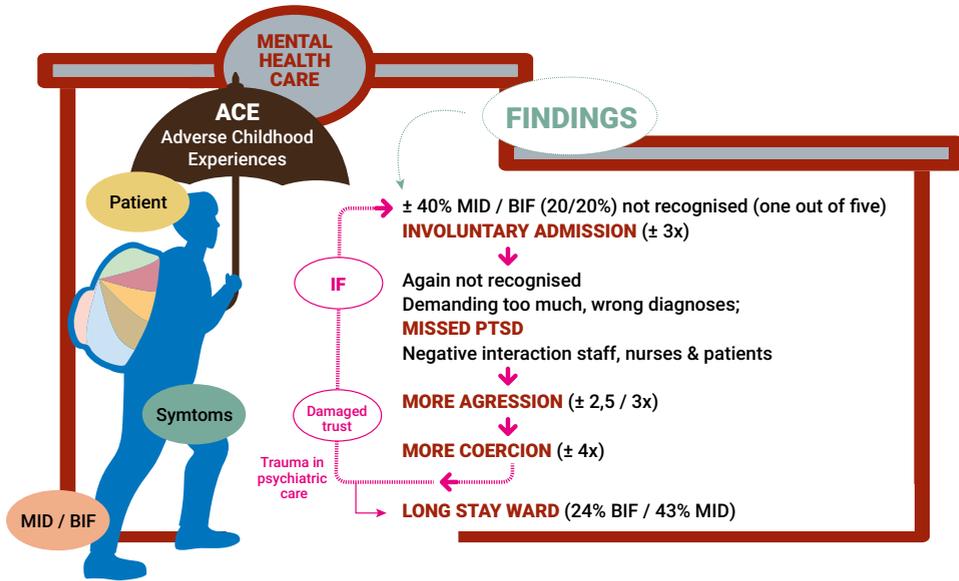


Hypothetical, theoretical model, combining the results presented in this thesis (in red colour) (MID = Mild Intellectual Disability, BIF = Borderline Intellectual Functioning, IF= if the patient did not recover or illnesses repeats). This model shows (following the pink arrows) 1. that failure to recognise Mild Intellectual Disability/Borderline Intellectual Functioning as a highly prevalent co-morbidity is a significant risk factor for 2. involuntary admissions, 3. missed PTSD, 4. aggression incidents and 5. coercive measures. Damaged trust and overdemanding in psychiatry are further stress-increasing factors that increase the chance of a circular process leading to re-admission (follow the arrows), becoming an SMI patient and ending up in a long-stay ward.

## 8.4 Strengths and limitations

*Strengths.* To our knowledge, this is the first thesis on the prevalence of MID/BIF and its associations with other mental health outcomes in relatively large patient samples in mental health care. We used documentation of coercive measures and incidents of aggression over a period of 6 years (which is a relatively long period) and used standardised and validated instruments for documenting these incidents (i.e., Argus for coercive measures and the SOAS-R for aggressive incidents). The data were gathered

in four different outpatient settings, two psychiatric wards in general psychiatric hospitals, four FACT teams (two from Oost Brabant, two from GGNet), and four long-stay settings. This wide variety of types and locations of psychiatric settings will have increased the generalizability of our findings.

*Limitations.* The first general limitation of the studies presented in this thesis is that we used a screening tool (The SCIL) for detecting MID/BIF and no specific assessment instruments to establish IQ. In addition, DSM classifications used in the present study were extracted from the patients' medical files and were not obtained through structured assessments.

Secondly, although we tried to estimate the percentage of cognitive decline and studied the influence of the level of psychiatric symptoms on SCIL performance, we have not studied other potential variables that could have influenced the performance of the SCIL. These include factors such as the use of (psychiatric) medication, social deprivation, stress etc. Unlike intelligence tests, there is no time pressure with the SCIL. In some items of the SCIL, however, e.g. the question about reading a quality newspaper, it is unlikely that the answer to this question is influenced by medication or stress.

Thirdly, we only had limited information on demographic and clinical characteristics in the studies presented here, which might have added information when analysing associations between SCIL scores and (health) outcomes. These include, for example, ethnic background and socioeconomic status. This may be important since we know, for example, that certain ethnic minority groups are more often confronted with coercive measures (27).

Fourthly, although the studies presented in this thesis were performed in several settings throughout the Netherlands, the generalizability to other regions and internationally remains unknown.

Fifthly, since all studies presented in the thesis used observational and cross-sectional designs, causality could not be established.

Lastly, although we proposed a conceptual model (Figure 4), more studies are needed to confirm or alter this model since very few studies have been done in this area.

## 8.5 Clinical implications

### Recognising MID/BIF

In line with the findings discussed in this thesis, we first propose screening for MID/BIF after every first referral to specialised mental health care (the S-GGZ). Screening with the SCIL at outpatient clinics, as conducted in the study and discussed in Chapter 4 shows that 27.2% of the patients screened positive for MID/BIF. In our opinion, such a high percentage warrants a systematic screening approach. Especially in light of the limited ability of practitioners to assess intelligence without a screening tool (4). Achieved education level (as an indication of MID/BIF) was not found in the medical files in 32% of our whole sample and 37% in the study of Seelen et al. (7). In addition to the fact that practitioners either do not ask for the level of education or do not write it down in the medical file, estimating intelligence based on diplomas is complicated. In addition, a diploma/achieved education level is certainly not always equal to intellectual functioning. So systematically screening with the SCIL is an important first step.

We propose that the SCIL should be administered in every referral to the specialised care of SMI patients, for example, to a FACT team, because of the high prevalence (of about 40%, Chapter 4) found. It takes just 15 minutes to administer the SCIL, and no specific professional degree is required to use the SCIL (28), although we know from the study by Seelen et al. (7) that it is advisable to train and perform the first eight SCIL assessments under supervision. Besides this, the SCIL is the only screening tool that also screens for BIF, and this is quite unique and important for clinical practice. Several studies showed that patients with BIF, even more so than patients with MID, face severe mental health and social problems and stress (29, 30). Diagnosing MID/BIF should no longer only be the task of the psychologists but also psychiatrists, and they should work together (Chapter 2). When using the SCIL, clinicians should be trained to communicate the outcome and know the next steps. A flow chart can be helpful (31) to decide what diagnostic steps could follow after a score of 19 or less on the SCIL. Firstly, a follow-up interview with the patient must take a personal history to obtain information about school career, achievements, work, etc. However, it is also important to understand possible adverse childhood experiences and emotional and social development. Secondly, a hetero anamnesis is essential as an additional source of information. Thirdly, an assessment with e.g. the WAIS can be considered as well as to perform e.g. the Schaal Emotioneel Onderzoek (SEO; 32). Fourthly, the SCreeener Adaptive Functioning (SCAF; 33) or the ADaptive Ability Performance Test (ADAPT; 34) can be applied. The SCAF is an auto-anamnestic screener for adaptive functioning (see also Chapters 1 and 2), and the ADAPT is a hetero-anamnestic instrument for measuring adaptive skills in people with intellectual disabilities and borderline

intellectual functioning. Treatment should be adapted to the level and possibilities of the patient. Here the "bronnenoverzicht" (35) and the "Handreiking LVB" (36) can be very helpful. Referral to a specialised centre in both psychiatry and ID may be considered if treatment results are not achieved. From the article by Smits et al. (37), we can learn that SMI patients treated in a FACT team who screened positive for PTSD as well as MID/BIF have poorer treatment results than those who were negative in these tests. This study also showed that patients suspected of MID do not make profit enough from treatment. Consultation or referral to a more specialised treatment centre should then be considered.

We know that psychiatric screening tools other than the SCIL are often not accurate in detecting the BIF patient group (35), which has consequences for the process of diagnosing psychiatric disorders. One way to go forward could be establishing an integrative diagnosis for ID patients. One example is given by Došen (38, 39). This diagnosis results from a multi-disciplinary diagnostic process in which biological, neurophysiologic, neuropsychological, personality, basic needs, interaction, existential and environmental aspects are considered.

The re-diagnosing of SMI patients with MID/BIF is important and can serve as a start to an integrative ID diagnosis and tailor-made treatment plan.

**Prevention of aggression**
Based on our finding that aggressive incidents occur more frequently in SMI patients screened positive for MID/BIF than those who screened negative (Chapter 5), we think it is important to prevent aggressive incidents specifically in the MID/BIF target group. In the article by Van den Boogaard et al. (40) about reducing aggression incidents in ID patients and co-occurring psychopathology, they concluded that focusing on interactions between clients and staff members might be an essential intervention starting point. This is because aggressive behaviour often results from interactions between the client, staff members, or other clients. Structured clinical assessment of aggressive behaviour can help devise and test the effects of interventions. The SOAS-R-ID seems to be a clinically helpful instrument and could help reduce the frequency of aggressive incidents (40).

Furthermore, we can learn from a recent meta-analysis about non-pharmacological interventions in adults with ID (41) that interventions such as Mindfulness and Cognitive Behaviour Therapy can effectively reduce challenging behaviour. These insights are probably also helpful in preventing or reducing aggressive incidents in SMI MID/BIF patients and are thus worth exploring.

**Trauma**

The high prevalence of trauma (85%) and assumed PTSD (47.8%) found in SMI patients who screened positive for MID/BIF (Chapter 6) justifies screening for trauma and PTSD as well. This could be done, for example, with the TSQ in every referred patient to specialised mental health care to minimise the number of potential missing diagnoses regarding PTSD and intellectual functioning, which was the case in our study. When a patient's medical chart does not already contain this relevant information, patient information should be collected about their childhood and development, school career, family and social circumstances, safety in relationships, and traumatic events (25, 26). If the TSQ indicates possible PTSD, the Diagnostic Interview Trauma and Stressors (DITS) is a critical, scientifically proven diagnostic instrument specially developed for MID/BIF patients in the Netherlands (42). In MID/BIF patients, extra attention should be paid to adverse life events that can be traumatic (43). Research on integrative trauma-sensitive work programs is promising in improving treatment results (44).

Lastly, my daily experience working in a specialised centre for MID/BIF SMI patients is that patients with MID/BIF and complex psychiatric disorders can profit very well from suitable treatments, as shown in the three vignettes (Chapter 1). These patients can recover both symptomatically and personally, but social recovery often becomes more complicated. This requires tailoring the social recovery interventions according to the specific adaptive skills and emotional developmental level and needs. Support from family and environment is often absent, as are other sources of support. Social recovery can be achieved with, e.g. adapted work or daytime activities and hobbies. Supported living in which the demands of everyday life do not overtax patients are necessary. Support with administration and finances is essential to reduce stress.

In sum, instead of an exclusion from different forms of treatment, this large patient group of SMI MID/BIF patients should be included and supported in society, in line with the United Nations Convention on Rights of Persons with Disabilities (CRPD; 45).

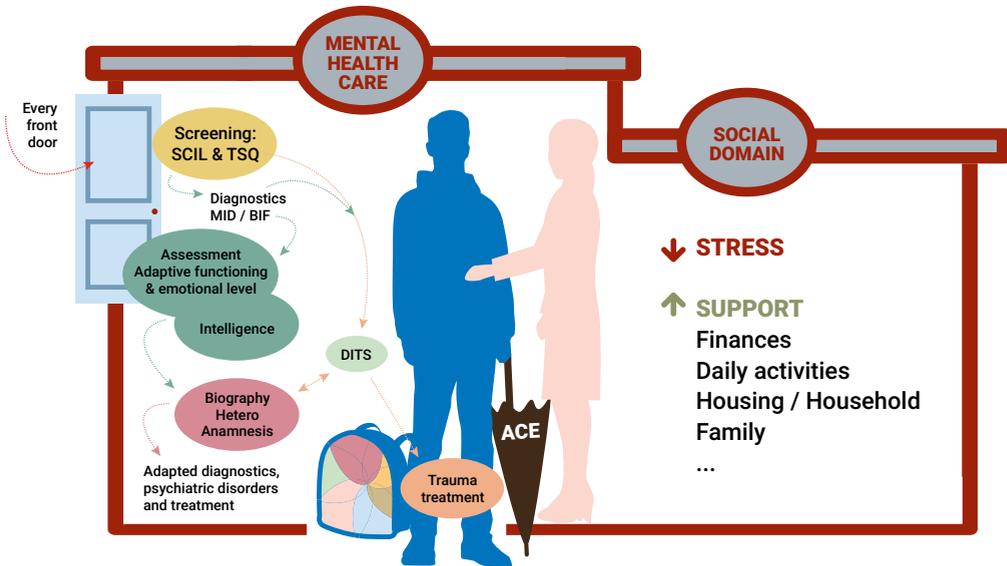Figure 5: Preventing chronicity in psychiatric care



Figure 5: shows a summary of the recommendations for clinical practice after referral to specialised mental health care, based on the findings described in this thesis (ACE =Adverse Childhood Experience(s), SCIL = Screener Intelligence Learning disability, TSQ =Trauma Screenings Questionnaire DITS = Diagnostisch Interview Trauma en Stressoren (Licht Verstandelijke Beperking))

## 8.6 Recommendations for future research

This thesis has shown that a large patient group with assumed MID/BIF is quite often not recognised as such in general psychiatry.
We have several recommendations for future research.
First, it seems worthwhile to begin researching the prevalence of MID/BIF at the general practitioner level in the "Praktijk Ondersteuning Huisartsen (POH) and Basis GGZ", which has not yet been done.

Second, it will be necessary to replicate our studies in the Netherlands and internationally to know more about the prevalence of MID/BIF in SMI patients and factors associated with MID/BIF, including aggression, trauma, and coercive measures.

Third, more research is needed on the validity of the SCIL in terms of the influence of psychiatric symptoms on the SCIL scores.

Fourth, the SCIL has already been translated into English, Spanish, and German, but as far as we know, these translations have not yet been validated.

Fifth, prospective studies are needed to investigate the effects of having MID/BIF in SMI patients on the long-term outcome of treatment.

Sixth, several other instruments used in mental health care for patients with ID should be validated in the SMI MID/BIF group. These include, for example, the HONOS-LD (46) and the tool "Mijn Positieve Gezondheid" (47). This tool assesses recovery in the six domains; body, daily activities, meaningful life, feelings and thoughts, quality of life and participation, as a measure of treatment and recovery outcome. Finally, prospective trauma treatment studies in patients with MID/BIF are needed to expand the range of interventions and better understand the effects of these interventions in the target group of MID/BIF SMI patients.

**8.7 Recommendations for future policy**

Approximately 1.1 million adults with MID/BIF meet the criteria of "Licht Verstandelijke Beperking" living in the Netherlands (48), and about 160.000 adults meet the criteria of SMI (49). This thesis has shown that probably 40% of SMI patients function on a level of MID/BIF, meaning that about 64.000 SMI patients could profit from treatments that take MID/BIF into account.

We know from the studies by McManus et al. (29) and Peltopuro et al. (30) that the use of mental health services does not appear to be commensurate with the higher level of need in MID/BIF SMI patients. This indicates that they are underserved compared with the rest of the population and may be due to a lack of professional awareness of their needs because services do not adapt enough to meet those needs or due to difficulties these individuals face in seeking treatment and support (29, 30).

In my opinion, recognising MID/BIF in mental health care requires a "delta plan" of action in which health insurers, politicians, the Nederlandse GGZ, Nederlandse Vereniging voor Psychiatrie but also Vereniging Gehandicaptenzorg Nederland will have to participate in addition to the patient, client and family councils. Far more attention should be paid to this subject in various professionals' education and training courses (doctors, nurses) concerning this patient group. This is necessary to improve the treatment outcomes and well-being of MID/BIF patients in the future. It is important that the Nederlandse

GGZ finds direct cooperation with the Vereniging Gehandicaptenzorg Nederland. I would recommend that Mental Health Care Trusts cooperate closely with local ID care services to profit from the knowledge and expertise of each other profession, treatment, and infrastructure to repair the historical fault of separation.

Studies in ID services, including patients with BIF, make clear that the prevalence of psychiatric disorders in these services is as high as the prevalence of MID/BIF in specialised mental health care (29, 50). These advancing insights require cooperation and additional finance and legalisation.

Specialised centres for mental health and ID care, such as VGGNet, are necessary to treat the most complex patients, cooperate, and develop or adapt existing guidelines and treatment programs. Several tools, instruments, and treatment programs have been developed for MID/BIF patients with psychiatric problems in the last few years. However, the current state of affairs shows that there is still a shortage of scientifically proven helpful instruments and treatment programs (35). I believe there is an urgent need to validate screening instruments, develop suitable (routine) outcome measurements, and stimulate research on genetics and medications in MID/BIF SMI patients. Furthermore, specialised MID/BIF centres in mental health services can also play a role in training and education programs for students in medicine, psychology, nursing, etc., and the advanced training of psychiatrists, GZ psychologists, and clinical psychologists. The aim could be to teach specific diagnostics and learn how to apply psychotherapy successfully. An internship in such a specialised centre or the ID services would be advisable in order to become more familiar with the problems of this group of patients, but also to understand each other's language and position better.

In addition, these centres can offer consultation in general mental health care and ID services and can give on-the-spot training. To expand the body of knowledge on both sides (ID services and mental health care), institutes such as the "Landelijk Kennis Centrum LVB" and Phrenos can play an essential role in building bridges between both fields.

Finally, the early prevention of adverse childhood experiences (ACE) and the recognition of MID/BIF are the critical factors in preventing long-lasting severe mental and physical health problems (25), including suicide ideations and attempts, drug abuse, and violence perpetration, and victimisation. This means that schools, supporting advice to babies and children, the general practitioner, youth services, and child and youth psychiatry should be more aware of the large and diverse group of people with ACEs and MID/BIF. There is still much to be gained!

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There is a crack
in everything,
that's how the
light comes in

Lennard Cohen

# Nederlandse samenvatting
## Summary in Dutch

## Portfolio

**Introductie**

Het doel van dit proefschrift was om de prevalentie van Licht Verstandelijke Beperking (LVB) en Zwakbegaafdheid (ZB) te onderzoeken en om de associaties van LVB/ZB met andere geestelijke gezondheidsuitkomsten in verschillende settings in de specialistische Geestelijke Gezondheidszorg (S-GGZ) te bestuderen. De prevalentie van LVB/ZB in de Geestelijke Gezondheidszorg (GGZ) in Nederland en de meeste andere landen was grotendeels onbekend bij de start van de studies die in dit proefschrift zijn opgenomen. Hoewel de aandacht voor deze patiëntengroep toeneemt, lijkt LVB/ZB in het algemeen vaak onopgemerkt te blijven in de GGZ en niet herkend te worden in de klinische praktijk. De resultaten van de in dit proefschrift gepresenteerde studies beogen bij te dragen aan een vroegere herkenning, met als doel een betere behandeling. In alle onderzoeken die in dit proefschrift worden gepresenteerd, is gebruik gemaakt van de Screener voor Intelligentie en Licht verstandelijke beperking (de SCIL) om (het vermoeden van) een intelligentie in de range van een IQ score tussen 50-85 (LVB/ZB) op te sporen.

De onderzoeksvragen die in dit proefschrift aan de orde kwamen waren als volgt:
1. Wat is de geschatte prevalentie van patiënten met een vermoeden van LVB/ZB, zoals gescreend met de SCIL (SCIL positief) op opnameafdelingen in de GGZ? (Hoofdstuk 3)
2. Worden patiënten die positief gescreend zijn op LVB/ZB met de SCIL vaker onderworpen aan dwangmaatregelen dan patiënten die negatief gescreend zijn? (Hoofdstuk 3)
3. Wat is de geschatte prevalentie van patiënten die verdacht worden van LVB/ZB in verschillende settings in de geestelijke gezondheidszorg met gebruik van de SCIL als screener? (Hoofdstuk 4)
4. Welk percentage van patiënten die positief gescreend zijn voor LVB/ZB gebruikmakend van de SCIL, wordt verdacht van cognitieve achteruitgang? (Hoofdstuk 4)
5. Zijn patiënten die positief screenen op LVB/ZB met gebruikmaking van de SCIL als screener vaker betrokken bij agressie incidenten dan patiënten die niet verdacht worden van LVB/ZB? (Hoofdstuk 5)
6. Ervaren patiënten met een vermoeden van LVB/ZB vaker trauma en hebben zij vaker Post Traumatische Stress Stoornis (PTSS) symptomen in vergelijking met patiënten zonder dit vermoeden op LBV/ZB? (Hoofdstuk 6)
7. Tenslotte hebben we getracht de laatste onderzoeksvraag te beantwoorden: wat is de associatie tussen de mate van psychiatrische symptomen en de scores op de SCIL? (Hoofdstuk 7)

Deze onderzoeksvragen werden bestudeerd in vijf onderzoeksprojecten, met behulp van observationele, cross-sectionele studies. Dit hoofdstuk geeft een samenvatting van het alle onderzoeken die in dit proefschrift worden beschreven.

**Algemene inleiding (hoofdstuk 1)**

Hoofdstuk 1 is een algemene inleiding waarin wordt begonnen met een uitleg van de term verstandelijke beperking (VB), het beschrijven van de definities van Licht Verstandelijke Beperking (LVB) en Zwakbegaafdheid (ZB), en tevens de beschrijving van de term "Licht Verstandelijke Beperking" zoals die specifiek in Nederland vaak wordt gebruikt. We vervolgen met de eerder gevonden associaties tussen psychiatrische stoornissen en LVB/ZB en de prevalentie in verschillende deel-populatis. We beschrijven screeningsinstrumenten voor het vaststellen van LVB/ZB, inclusief de SCIL en in het kort de diagnostiek van een VB in de klinische psychiatrische praktijk. Tevens komen de etiologie van een VB, veranderende perspectieven op VB, en de relatie tussen psychiatrie en VB door de tijd heen aan de orde. Ter illustratie volgen drie vignetten uit mijn dagelijkse klinische praktijk bij VGGNet (expertise centrum voor patiënten met een verstandelijke beperking en complexe psychiatrie binnen GGNet (Geestelijk Gezondheid Netwerk in Oost Nederland)). Tot slot worden de onderzoeksvragen en de opzet van het proefschrift beschreven.

Patiënten inspireerden mij om aan dit onderzoeksproject te beginnen. Samen met mijn collega's zijn we binnen GGNet het SCIL-project gestart om de herkenning, screening en diagnostiek van "Licht Verstandelijke Beperking" in de klinische praktijk van de GGZ te verbeteren. Het project werd vernoemd naar de toen recent ontwikkelde Screener voor Intelligentie en Licht verstandelijke beperking (SCIL). Na een eerste pilot bleek dat er sprake was van onderdiagnostiek van LVB/ZB in de klinische praktijk. Wij wilden deze onderdiagnostiek verminderen, te beginnen met het schatten van de prevalentie van LVB/ZB en factoren die hiermee zijn geassocieerd in de S-GGZ. Met het SCIL-project binnen GGNet wilden we ook onze organisatie meer bewust- en ontvankelijker- maken voor LVB/ZB-gerelateerde behoeften. Zoals we weten uit de dagelijkse klinische praktijk bij VGGNet, kunnen deze patiënten zeer goed behandeld worden. Naast de patiënten (waarvan sommige in de vignetten in hoofdstuk één worden beschreven), waren er nog drie andere factoren die mij motiveerden om dit PhD project te starten. Namelijk het gebrek aan internationaal onderzoek naar de prevalentie van LVB/ZB in de GGZ, de mogelijkheid om onderzoek te doen op dit gebied na de publicatie van de SCIL, en tenslotte recent gepubliceerde onderzoeken aangaande psychiatrische problematiek bij deze doelgroep in de GGZ van collega's in Nederland.

**Herkennen en diagnosticeren van laag intellectueel functioneren in de Geestelijke Gezondheidszorg (hoofdstuk 2)**

Hoofdstuk 2 gaat over bewustwording, herkennen en diagnosticeren van LVB/ZB in de dagelijkse klinische praktijk, met als doel clinici te leren laag intellectueel functioneren op te sporen, te diagnosticeren en hen een globaal idee te geven van de methodiek en de valkuilen bij het diagnosticeren van psychiatrische stoornissen bij deze groep patiënten. Verschillende in Nederland gangbare screeningsinstrumenten worden besproken in samenhang met de daarop volgende diagnostische procedures.

Door middel van screening en diagnostiek van intelligentie en adaptief functioneren kan een meer integratieve psychiatrische diagnose worden gesteld met aandacht voor het intellectuele, emotionele en sociale niveau van functioneren. Dit heeft meestal invloed op de symptoom presentatie, waardoor mogelijk een chronisch beloop van de psychiatrische stoornis kan worden voorkomen en een meer op maat gesneden behandeling kan worden geboden.

**Screening op Licht Verstandelijke Beperking en Zwakbegaafdheid bij opgenomen psychiatrische patiënten: prevalentie en de associatie met dwangmaatregelen (hoofdstuk 3)**

In hoofdstuk 3 wordt een studie gepresenteerd waarin we een screening hebben gedaan op LVB/VB met behulp van de SCIL bij patiënten die waren opgenomen op twee acute psychiatrische opname afdelingen. We onderzochten of het gebruik van dwangmaatregelen hoger was bij patiënten die positief scoorden op de SCIL. Wij vonden dat 43,8% van de steekproef van 208 patiënten positief scoorde voor het vermoeden van LVB/VB. Tijdens hun huidige verblijf en eerdere opnamen in de voorgaande vijf jaar hadden deze patiënten een bijna drie keer hoger risico op onvrijwillige opname (OR 2,71) en een vier keer hoger risico om geconfronteerd te worden met dwangmaatregelen (OR 3,95). De medische dossiers toonden eerdere documentatie van LVB/ZB bij slechts een minderheid (22,1%) van de 91 SCIL-positieve patiënten. In de discussie stellen wij dat het een opmerkelijke bevinding was dat SCIL-positieve patiënten in het verleden meer onvrijwillige opnames hebben gehad dan SCIL-negatieve en meer dwangmaatregelen hadden ondergaan. Wij delen de mening dat dwangmaatregelen herstel in de weg kunnen staan en zelfs kunnen leiden tot iatrogene PTSS. Wij formuleren de hypothese dat mensen met LVB/ZB verminderde copingvaardigheden hebben en sneller reageren met verbale agressie en in omstandigheden die zij niet kunnen overzien eerder reageren met agressief gedrag, hetgeen vaak leidt tot onvrijwillige opnames en dwangmaatregelen.

**Verhoogde prevalentie van LVB/ZB in settingen met een hogere zorgintensiteit in de Geestelijke Gezondheidszorg (hoofdstuk 4)**

Hoofdstuk 4 beschrijft een verhoogde prevalentie van LVB/ZB in instellingen voor geestelijke gezondheidszorg met een hogere zorgintensiteit. Ook werd een schatting gemaakt van het percentage cognitieve achteruitgang, waarbij gekeken werd naar mogelijk verminderd cognitief functioneren na het 18-de levensjaar.

Een cross-sectionele studie werd uitgevoerd in settingen met oplopende zorgniveaus binnen GGNet. Wij vroegen 1616 opeenvolgende patiënten om deel te nemen aan het onderzoek, waarvan er 1213 (75,1%) geïncludeerd werden. Wij gebruikten de SCIL om te screenen op LVB/ZB. We identificeerden patiënten met een combinatie van een hoog opleidingsniveau en een lage SCIL-score om in te schatten welke patiënten mogelijk een cognitieve achteruitgang hadden doorgemaakt.

Over alle settingen werd gemiddeld bij 41,4% van de deelnemende patiënten positief gescreend op LVB/ZB. Het aandeel patiënten dat positief werd gescreend voor LVB was 20,2%. De prevalentie van LVB/ZB steeg per zorgniveau, van 27,1% in ambulante poliklinische settingen tot 41,9% in Flexible Assertive Community Treatment (FACT)-teams en opnameafdelingen en 66,9% op de long-stay afdeling. Van slechts 85 (7,1%) van alle patiënten werd vastgesteld dat zij mogelijk een cognitieve achteruitgang hadden doorgemaakt op basis van hun relatief slechte prestaties op de SCIL in vergelijking met hun opleidingsniveau. Van deze patiënten verbleef 25,9% op long-stay afdelingen. Relatief vaak hadden deze patiënten de diagnose schizofrenie of stoornis in het gebruik van een middel.

Op basis van de beperkte beschikbare gegevens veronderstelden wij dat de prevalentie van VB toeneemt met het niveau van intensiteit van zorg in verschillende settingen binnen de geestelijke gezondheidszorg. Een verklaring zou kunnen zijn dat deze beperking in het voortraject vaak onopgemerkt en onbehandeld blijft, zoals we in de eerdere studie ontdekten, waardoor de behandelingsprognose in de loop van de tijd relatief slecht is. We weten ook uit verschillende (internationale) studies dat mensen met LVB/ZB een grotere kans hebben op het ontwikkelen van psychiatrische stoornissen.

Wij concludeerden dat LVB/ZB frequent voorkomt binnen GGNet, en dat de prevalentie toeneemt met de intensiteit van de zorg. Bovendien werd slechts bij een bescheiden aantal van de patiënten cognitieve achteruitgang vastgesteld. Deze studie toonde ook een sterke associatie aan tussen verdenking van LVB/ZB, diagnoses zoals schizofrenie en verslaving, slechter algemeen functioneren en een lange voorgeschiedenis van psychiatrische zorg.

**Agressief gedrag van psychiatrische patiënten met LVB/ZB in de specialistische Geestelijke Gezondheidszorg (hoofdstuk 5)**

In hoofdstuk 5 wordt de associatie tussen agressie en LVB/ZB in samenhang met patiënt kenmerken en diagnoses besproken. Empirische studies naar het verband tussen verstandelijke beperkingen en agressief gedrag in de GGZ zijn zeer schaars. In dit onderzoek werd agressief gedrag tijdens de behandeling beoordeeld met de Staff Observation Aggression Scale-Revised (SOAS-R). We berekenden odds ratio's en voerden een logistische regressie uit om de associaties van LVB/ZB, patiënt kenmerken, diagnoses, en de kans op agressie te kwantificeren.

Eenenveertig procent van de deelnemende patiënten werd positief gescreend op LVB/ZB. Patiënten met veronderstelde LVB/ZB vertoonden significant meer agressie zowel op individueel patiënt- als op groepsniveau (Odds Ratio van respectievelijk 2,50 voor agressie en 2,52 voor naar buiten gerichte fysieke agressie).

Het aantal agressie incidenten was significant hoger bij veronderstelde LVB/ZB patiëntengroep in vergelijking met patiënten die negatief screenden (OR LVB 3,01, ZB 4,20). Verder wijzen de uitkomsten erop dat naar buiten gerichte fysieke agressie vaker voorkwam bij patiënten met veronderstelde LVB. De odds ratio's van patiënten die positief werden gescreend op LVB (ten opzichte van de groep zonder LVB) waarbij er sprake is van herhaalde incidenten door dezelfde persoon, namen significant toe tot een OR van 6,4 in de categorieën van twee en meer incidenten, en een OR 2,84 van patiënten die positief werden gescreend voor ZB. Tenslotte bleek uit het logistische regressiemodel dat een combinatie van variabelen agressie voorspelde: positieve screening voor ZB (OR 2,0), LVB (OR 2,89), het hebben van een diagnose bipolaire stoornis (OR 3,07), het hebben van de diagnose schizofrenie (OR 2,75), en jongere leeftijd (OR 1,69).

**De effecten en associaties van trauma bij patiënten met een LVB/ZB en een ernstige psychiatrische aandoening (EPA) (hoofdstuk 6)**

In deze cross-sectionele studie werkten we samen met collega's van FACT-teams van GGZ Oost-Brabant. We gebruikten de Trauma Screening Questionnaire (TSQ) om te screenen op trauma en PTSS. We gebruikten de SCIL opnieuw om te screenen op LVB/ZB. Post-hoc analyse werd gebruikt om sekseverschillen te onderzoeken tussen patiënten met en zonder LVB/ZB wat betreft de prevalentie van trauma en seksueel misbruik.

Bij 570 patiënten werd een (of meerdere) trauma's gevonden (85,1% van de patiënten), 43,2% van de patiënten scoorde positief op het vermoeden van een PTSS. De SCIL-uitkomsten toonden aan dat ongeveer 40% positief screende voor LVB/ZB, waarvan de helft een vermoeden van LVB. Deze patiënten hadden meer traumatische ervaringen (gemiddeld aantal traumatische ervaringen was 1,89 bij ZB, 1,75 bij LVB, tegen 1,41 bij SCIL-negatieve patiënten). We concludeerden dat significant meer poliklinische EPA-patiënten die positief werden gescreend voor LVB/ZB rapporteerden traumatische gebeurtenissen te hebben meegemaakt dan degenen die negatief werden gescreend. Ook waren de percentages van trauma categorieën zoals verwaarlozing, fysiek en seksueel trauma, significant hoger bij de positief gescreende patiënten. Tenslotte hadden zij meer kans op het ontwikkelen van een PTSS. Vrouwelijke LVB/ZB patiënten (61%) rapporteerden significant meer seksueel misbruik ervaringen dan mannelijke LVB/ZB patiënten (23%).

Opmerkelijk was dat het aantal PTSS-diagnoses dat werd gerapporteerd in de elektronische patiëntendossiers (8,1%) veel lager was dan het aantal patiënten dat verdacht werd van PTSS na beoordeling met de TSQ. Dit impliceert dat de meeste patiënten met volgens de TSQ een vermoeden van een PTSS-diagnose, niet waren herkend of gedocumenteerd in de dossiers van deze patiënten. In de bespreking van dit hoofdstuk hebben we aandacht besteed aan de mogelijke verschillende redenen die deze discrepantie verklaren.

**De mogelijk invloed van psychiatrische symptomen op de uitkomsten van de Screener voor Intelligentie en LVB (hoofdstuk 7)**

In hoofdstuk 7 wordt het onderzoek naar de invloed van de psychische toestand op de prestatie van de SCIL besproken. De SCIL werd oorspronkelijk gevalideerd in een steekproef van volwassen in penitentiaire inrichtingen voor mensen met psychiatrische en forensische problemen. De verkregen scores op de SCIL werden vergeleken met testresultaten op de WAIS-III. De SCIL werd speciaal ontwikkeld om te screenen op LVB/ZB bij mensen in diverse settings, zoals de geestelijke gezondheidszorg of sociale dienstverlening, maar ook op politiebureaus en opvanghuizen voor daklozen.

Aan onze studie op een High Intensive Care opnameafdeling namen 43 patiënten deel. De SCIL en de Kennedy Axis V as I (psychologische stoornissen schaal) werden afgenomen na opname en stabilisatie (19,3 dagen na opname (T1)) en voor ontslag (39,1 dagen na opname (T2)).

86% van de patiënten had dezelfde uitkomst op de SCIL ongeacht het tijdstip van de afname (correlatie r=0,87). De Kappa (mate van overeenkomst gecorrigeerd voor de zeldzaamheid van de waarneming) was 0,722, wat duidt op een goede correlatie. De Kennedy scores op T0 vertoonden een bescheiden maar significante correlatie (r=-0.377, P=0.013) met de veranderingen in SCIL scores van T1 tot T2, wat suggereert dat de ernst van psychiatrische symptomen slechts een bescheiden invloed had op de prestaties op de SCIL. Wij concludeerden dat de SCIL zelfs kan worden gebruikt bij patiënten met psychiatrische symptomen, zoals in de eerste weken na opname op een acute afdeling, maar dat het de voorkeur verdient te screenen wanneer de ernst van de acute symptomen verminderd is.

**Algemene discussie (hoofdstuk 8)**

In hoofdstuk 8 worden de bevindingen, de sterke punten en beperkingen samengevat en de klinische implicaties besproken, in samenhang met recente literatuur en worden tenslotte ideeën voor toekomstig onderzoek en suggesties voor beleid op verschillende niveaus gepresenteerd.

Allereerst hebben we het belang benadrukt om na elke eerste verwijzing naar de gespecialiseerde geestelijke gezondheidszorg (de S-GGZ) te screenen op LVB/ZB. Screening met de SCIL op poliklinieken zoals uitgevoerd in het onderzoek en besproken in hoofdstuk 4 laat zien dat 27,2% van de patiënten positief screende op MID/BIF. Een dergelijk hoog percentage rechtvaardigt naar onze mening een systematische screenings-aanpak. Dit heeft ook te maken met de beperkte herkenning en documentatie van LVB/ZB in de praktijk. Daarnaast blijkt uit ons en ander onderzoek dat het bereikte opleidingsniveau (als indicatie voor LVB/ZB) bij ruim 1/3 van de medische dossiers niet aanwezig was. Tevens is het inschatten van intelligentie op basis van diploma's niet eenvoudig. Systematisch screenen met de SCIL lijkt dus een belangrijke eerste stap.
Verder stellen wij voor dat de SCIL wordt afgenomen bij elke verwijzing naar de gespecialiseerde zorg voor EPA-patiënten zoals een FACT-team vanwege de gevonden hoge prevalentie (van ongeveer 40%, hoofdstuk 4). Het afnemen van de SCIL duurt slechts 15 minuten en voor het gebruik van de SCIL is geen specifiek vakdiploma vereist . Wel is training gewenst. Daarnaast is de SCIL het enige screeningsinstrument dat ook screent op ZB. Dit is vrij uniek en relevant voor de klinische praktijk. Verschillende studies hebben aangetoond dat patiënten met ZB, meer nog dan patiënten met LVB, te kampen hebben met ernstige psychische en sociale problemen en stress.

Het stellen van de diagnose LVB/ZB zou niet langer alleen de taak van psychologen moeten zijn, maar ook van psychiaters. Dit vraagt om meer samenwerking (hoofdstuk 2). Bij het gebruik van de SCIL moeten clinici worden opgeleid om de uitkomst op maat te communiceren en de volgende stappen voor behandeling en begeleiding te kennen. Het belang van een ontwikkelingsanamnese wordt besproken onder andere om inzicht te krijgen op mogelijke negatieve ervaringen in de kindertijd en op de emotionele- en sociale ontwikkeling. Daarnaast is het afnemen van een goede hetero-anamnese een essentieel aanvullende bron van informatie. Verder worden aanbevelingen gegeven voor goede diagnostiek van een verstandelijke beperking zoals afname van intelligentie onderzoek, het uitvoeren van emotioneel ontwikkelingsonderzoek, en onderzoek naar adaptieve functies. Dit alles met als doel om tot een integratieve diagnose te komen en de behandeling aan te passen aan het niveau en de mogelijkheden van de patiënt. Niet passende en niet effectieve behandeling en daarmee het risico op onnodig langdurige zorg en/of chroniciteit kunnen daarmee voorkomen worden.

In dit hoofdstuk wordt ook stilgestaan bij de literatuur die ingaat op de preventie van agressie incidenten vanwege onze bevindingen dat patiënten met een LVB/ZB vaker bij agressie incidenten betrokken zijn. Aandacht voor interacties tussen patiënten en personeelsleden maar ook met medepatiënten, kan een essentieel aangrijpingspunt zijn voor interventies in de klinische praktijk. Gestructureerde klinische beoordeling van agressief gedrag zoals de SOAS-R kan helpen bij het ontwikkelen en beoordelen van de effecten van mogelijke interventies.

De hoge prevalentie van trauma (85%) en veronderstelde PTSS (47,8%) die gevonden werd bij EPA-patiënten die positief screenden op LVB/ZB (Hoofdstuk 6) vraagt om nader onderzoek naar het belang en de effecten van screening op trauma en PTSS. Dit zou bijvoorbeeld kunnen worden gedaan met de TSQ bij elke doorverwezen patiënt naar de gespecialiseerde geestelijke gezondheidszorg om het aantal potentieel ontbrekende diagnoses met betrekking tot PTSS in relatie met intellectueel functioneren te minimaliseren. Uit onze studie kwam dit duidelijk naar voren. Wanneer het medisch dossier van een patiënt deze relevante informatie nog niet bevat dient informatie over de kindertijd en de ontwikkeling, de schoolcarrière, de gezins- en sociale omstandigheden, veiligheid in relaties en traumatische gebeurtenissen van de patiënt te worden verzameld. Indien de TSQ wijst op mogelijke PTSS, is een op de VB aangepaste verdere diagnostiek wenselijk en aangepaste (psychotherapeutische) behandeling nodig.

Zowel vakliteratuur als dagelijkse praktijk laten zien dat patiënten met een VB met complexe psychiatrische stoornissen zeer goed kunnen profiteren van passende behandelingen. Er kan zowel symptomatisch- als persoonlijk-, en maatschappelijk herstel plaatsvinden. Dit vraagt ook om het afstemmen van de sociale herstelinterventies op de specifieke adaptieve vaardigheden, het emotionele ontwikkelingsniveau en de persoonlijke behoeften van de patiënt. Steun van familie en omgeving is echter aanvankelijk vaak afwezig, evenals andere bronnen van steun. Dit vraagt om een actieve benadering. Sociaal herstel en een gevoel van zingeving kan worden bereikt met bijvoorbeeld aangepast werk of dagbesteding en hobby's. Wonen met (ambulante) ondersteuning waarbij de eisen van het dagelijks leven de patiënt niet overvragen is van groot belang. Ondersteuning bij administratie en financiën is essentieel om de daarmee vaak gepaard gaande stress te verminderen.

Wat betreft toekomstig onderzoek lijkt het de moeite waard om te beginnen met onderzoek naar de prevalentie van LVB/VB in de setting van de huisarts bij de Praktijk Ondersteuning Huisartsen (POH) en de Basis GGZ. Dit is nog braak liggend terrein. Ten tweede zal het nodig zijn onze studies in Nederland en internationaal te repliceren om meer te weten te komen over de prevalentie van LVB/ZB bij EPA-patiënten en factoren die daarmee geassocieerd zijn. Verder is herhaald onderzoek naar de validiteit van de SCIL in termen van de invloed van psychiatrische symptomen op de SCIL-scores, gewenst. Eveneens zijn er prospectieve studies nodig onder andere om de effecten van LVB/VB bij EPA-patiënten op het langetermijnresultaat van de behandeling in beeld te brengen.

Ook zouden verschillende screenings- en diagnostische instrumenten die gebruikt worden in de geestelijke gezondheidszorg bij patiënten met (veelal niet herkende) VB specifiek voor deze groep gevalideerd moeten worden. Ten slotte zijn er meer prospectieve onderzoeken naar trauma behandeling voor deze doelgroep nodig om het scala aan interventies uit te breiden en de effecten van deze en al bestaande interventies voor deze patiëntengroep te onderzoeken.

Onderzoeken wijzen op een aanzienlijk kans op onder-behandeling van psychiatrische problemen bij deze omvangrijke patiëntengroep. De vermijdbare ziektelast en maatschappelijke kosten zijn naar verwachting evenmin gering. De erkenning en herkenning daarvan in de geestelijke gezondheidszorg vereist mijns (of ons) inziens een "deltaplan" van actie waarin naast de patiënten-, cliënten- en familieraden en organisaties, ook de zorgverzekeraars (e.a financiers), de politiek, de Nederlandse GGZ, de Nederlandse Vereniging voor Psychiatrie (en andere beroepsorganisatie) maar ook de Vereniging Gehandicaptenzorg Nederland zullen moeten participeren. In de diverse

opleidingen en trainingen van beroepsbeoefenaren werkend in de GGZ, moet meer aandacht aan dit onderwerp worden besteed. Dit is nodig om de behandeluitkomsten, het welbevinden en maatschappelijke deelname op maat van deze patiënten in de toekomst te verbeteren en de onnodige ziektelast en maatschappelijke kosten terug te dringen. In dit hoofdstuk wordt tevens stilgestaan bij het grote belang van het vormen van actieve netwerken op lokaal niveau tussen Verstandelijk Gehandicapten instellingen, de GGZ, de Gemeenten, maatschappelijke voorzieningen etc. Daarnaast is het van belang om daar waar nodig en mogelijk, op bestuurlijk en politiek niveau schotten weg te nemen en om meer te profiteren van elkaars kennis, expertise en infrastructuur. Met als doel om de systeemfout sinds de 60-stiger jaren van een veel te absolute scheiding tussen VG en GGZ in de praktijk rondom deze patiënten te herstellen.

Tenslotte staan we stil bij het belang van gespecialiseerde centra voor geestelijke gezondheidszorg en LVB/ZB-zorg, zoals VGGNet. Deze zijn niet alleen nodig om de meest complexe patiënten te behandelen, maar ook om samen te werken en bestaande richtlijnen en behandelprogramma's en screenings-en diagnostiek instrumenten te ontwikkelen of aan te passen. Bovendien kunnen gespecialiseerde LVB/ZB-centra in de geestelijke gezondheidszorg een rol spelen in opleidings- en onderwijsprogramma's voor studenten van alle in de GGZ werkende beroepsgroepen. Dit heeft als doel om aangepaste communicatie, specifieke diagnostiek en psychotherapie op maat succesvol toe te leren passen. Een stage in zo'n gespecialiseerd centrum of in de Verstandelijk Gehandicaptenzorg is een aanbeveling gezien de hoge prevalentie van de LVB/ZB patiëntengroep in de GGZ. Zodoende raken professionals meer vertrouwd met de problematiek van deze groep patiënten, maar ook met elkaars werkwijze, taal, context en positie in het netwerk van de patiënt.

Samenwerking en het delen van kennis door kenniscentra zoals het Landelijk Kennis Centrum LVB en Phrenos (kenniscentrum voor mensen met psychotische of andere ernstige en langdurige aandoeningen) speelt tevens een belangrijke rol bij het bouwen van bruggen tussen beide gebieden.

Ten slotte zijn de vroegtijdige preventie van negatieve jeugdervaringen en trauma en vroeg- herkenning van LVB/ZB van groot belang bij het voorkomen van langdurige ernstige geestelijke en lichamelijke gezondheidsproblemen en om de intergenerationele cirkel van sociale, maatschappelijke en psychiatrische problemen te doorbreken. Dit betekent dat scholen, consultatie bureaus, huisartsen, jeugdhulpverlening in de breedste zin, kinder- en jeugdpsychiatrie etc. zich meer bewust zouden moeten zijn van de grote en diverse groep, vaak onopgemerkte, mensen met LVB/ZB in de samenleving. Er valt wat dat betreft nog een wereld te winnen!

## Other Journal publications

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| Date | Type | Title | ID nr | CME points |
|---|---|---|---|---|
| | Nascholing psychiatrie | GGZ-congres \| Behandeling van suïcidaal gedrag | (ID nr: 431785) | 5 CME points |
| 11-10-2021 | Nascholing psychiatrie | Update over psychofarmacologie | (ID nr: 442834) | 3 CME points |
| 24-06-2021 | Nascholing psychiatrie | Wyggz | (ID nr: 430454) | 3 CME points |
| 08-09-2020 | Nascholing psychiatrie | Hoezo intelligentie | (ID nr: 400529) | 4 CME points |
| | Nascholing psychiatrie | Eindrefereerbijeenkomst 25 juni 2020 | (ID nr: 399590) | 2 CME points |
| 18-05-2020 | Nascholing psychiatrie | Landelijke Training Tutoren 2020 | (ID nr: 390197) | 4 CME points |
| 13-02-2020 | Nascholing psychiatrie | Aan de slag met 'De Psychiater'. | | |
| | | Introductieworkshop nieuw landelijk opleidingsplan | (ID nr: 388823) | 3 CME points |
| 29-01-2020 | | 1e auteur van publicatie in een tijdschrift | | |
| | | A blind spot PLOS ONE 2017 | | 10 CME points |
| 29-01-2020 | | 1e auteur van publicatie in een tijdschrift | | |
| | | Not Recognised enough European Journal | | 10 CME points |
| 29-01-2020 | | 1e auteur van publicatie in een tijdschrift | | |
| | | Herkenning en diagnostiek van laagbegaafdheid in de geestelijke gezondheidszorg NTvP | | 10 CME points |
| 29-01-2020 | | 4e auteur en verder van publicatie in een tijdschrift | | |
| | | Screening for intellectual disabilities and borderline intelligence in Dutch outpatients with severe mental illness, JARID | | |
| 09-12-2019 | Nascholing psychiatrie | Nascholingsmiddag | (ID nr: 380355) | 2 CME points |
| 07-09-2019 | Nascholing psychiatrie | 5th European Conference on Integrated Care and Assertive Outreach. Shaping the future of community mental health care | | 3 CME points |
| 06-09-2019 | Nascholing psychiatrie | 5th European Conference on Integrated Care and Assertive Outreach. Shaping the future of community mental health care | (ID nr: 365628) | 6 CME points |
| 05-09-2019 | Nascholing psychiatrie | 5th European Conference on Integrated Care and Assertive Outreach. Shaping the future of community mental health care | (ID nr: 365628) | 6 CME points |
| 04-04-2019 | Nascholing psychiatrie | 47e NVvP Voorjaarscongres: Psychiatrie van de Toekomst | (ID nr: 354585) | 6 CME points |
| 03-04-2019 | Nascholing psychiatrie | 47e NVvP Voorjaarscongres: Psychiatrie van de Toekomst | (ID nr: 354585) | 6 CME points |
| 14-02-2019 | Nascholing psychiatrie | How about Intelligence? Denkwerk in de GGz. | (ID nr: 347953) | 3 CME points |
| 19-10-2018 | Nascholing psychiatrie | International Conference on Crisis, Coercion and Intensive Treatment in Psychiatry (CCITP). Theme of the conference: 'Zero-Strategies: From Dream to Reality' | | |
| 18-10-2018 | Nascholing psychiatrie | International Conference on Crisis, Coercion and Intensive Treatment in Psychiatry (CCITP). Theme of the conference: 'Zero-Strategies: From Dream to Reality' | (ID nr: 326073) | 5 CME points |
| | Nascholing psychiatrie | Congres Psychiatrie en LVB: werken aan samenspel | (ID nr: 326073) | 6 CME points |
| 17-05-2018 | Nascholing psychiatrie | | (ID nr: 317652) | 5 CME points |

| Date | Category | Description | ID | CME points |
|---|---|---|---|---|
| 13-04-2018 | Nascholing psychiatrie | 46e NVvP Voorjaarscongres: Translationele uitdagingen in de psychiatrie | (ID nr: 318036) | 6 CME points |
| 12-04-2018 | Nascholing psychiatrie | 46e NVvP Voorjaarscongres: Translationele uitdagingen in de psychiatrie | (ID nr: 318036) | 6 CME points |
| 11-04-2018 | Nascholing psychiatrie | 46e NVvP Voorjaarscongres: Translationele uitdagingen in de psychiatrie | (ID nr: 318036) | 6 CME points |
| 15-11-2017 | Nascholing psychiatrie | LVB & Psychiatrie | (ID nr: 295782) | 4 CME points |
| 15-09-2017 | Nascholing psychiatrie | 4th European Conference on Integrated Care & Assertive Outreach in Mental Disorders | (ID nr: 290202) | 13 CME points |
| 23-05-2017 | Nascholing psychiatrie | LVB en psychiatrie; van blinde vlek naar herkenning en maatwerk | (ID nr: 288687) | 4 CME points |
| 06-04-2017 | Nascholing psychiatrie | 45e NVvP Voorjaarscongres: Veerkracht | (ID nr: 280355) | 6 CME points |
| 05-04-2017 | Nascholing psychiatrie | 45e NVvP Voorjaarscongres: Veerkracht | (ID nr: 280355) | 6 CME points |
| 20-06-2016 | Nascholing psychiatrie | Refereermiddag 2016 | (ID nr: 254195) | 3 CME points |
| 09-06-2016 | Nascholing psychiatrie | Prikkelgevoeligheid bij ontwikkelingsstoornissen: nieuwe wegen in diagnostiek en behandeling (Jaarcyclus KJP 2015-2016) | (ID nr: 253932) | 4 CME points |
| 01-04-2016 | Nascholing psychiatrie | 44e NVvP Voorjaarscongres: Samen Beter, Beter Samen | (ID nr: 241498) | 6 CME points |
| 31-03-2016 | Nascholing psychiatrie | 44e NVvP Voorjaarscongres: Samen Beter, Beter Samen | (ID nr: 241498) | 6 CME points |
| 30-03-2016 | Nascholing psychiatrie | 44e NVvP Voorjaarscongres: Samen Beter, Beter Samen | (ID nr: 241498) | 6 CME points |
| 01-03-2016 | Nascholing psychiatrie | Zwakbegaafdheid in de GGZ | (ID nr: 240918) | 3 CME points |
| 06-10-2015 | Nascholing psychiatrie | De relatie tussen depressie en cognitieve functies | (ID nr: 225601) | 4 CME points |
| 11-09-2015 | Nascholing psychiatrie | Niet door NVVP vooraf geaccrediteerde nascholing (buitenland) !0th European Congress of Mental Health in Intellectual Disability | | |
| 08-11-2018 | Algemene scholing | Principes van epidemiologische data-analyse (V20) cluster 1, 2 en 3 | (ID nr: 99440) | 5 CME points |
| 07-11-2018 | Algemene scholing | Principes van epidemiologische data-analyse (V20) cluster 1, 2 en 3 | (ID nr: 99440) | 5 CME points |
| 02-11-2018 | Algemene scholing | Principes van epidemiologische data-analyse (V20) cluster 1, 2 en 3 | (ID nr: 99440) | 5 CME points |
| 01-11-2018 | Algemene scholing | Principes van epidemiologische data-analyse (V20) cluster 1, 2 en 3 | (ID nr: 99440) | 5 CME points |
| 31-10-2018 | Algemene scholing | Principes van epidemiologische data-analyse (V20) cluster 1, 2 en 3 | (ID nr: 99440) | 5 CME points |
| 23-09-2016 | Algemene scholing | Epidemiologisch onderzoek: opzet en interpretatie (V10) cluster 1, 2 en 3 | (ID nr: 99439) | 6 CME points |
| 22-09-2016 | Algemene scholing | Epidemiologisch onderzoek: opzet en interpretatie (V10) cluster 1, 2 en 3 | (ID nr: 99439) | 6 CME points |
| 21-09-2016 | Algemene scholing | Epidemiologisch onderzoek: opzet en interpretatie (V10) cluster 1, 2 en 3 | (ID nr: 99439) | 6 CME points |
| 20-09-2016 | Algemene scholing | Epidemiologisch onderzoek: opzet en interpretatie (V10) | (ID nr: 99439) | 6 CME points |

| Datum | | Omschrijving | ID nr. | Punten |
|---|---|---|---|---|
| 19-09-2016 | Algemene scholing | cluster 1, 2 en 3<br>Epidemiologisch onderzoek: opzet en interpretatie (V10) | (ID nr: 99439) | 13 CME points |
| 08-11-2018 | Algemene scholing | cluster 1, 2 en 3<br>Principes van epidemiologische data-analyse (V20) | (ID nr: 99440) | 5 CME points |
| 07-11-2018 | Algemene scholing | cluster 1, 2 en 3<br>Principes van epidemiologische data-analyse (V20) | (ID nr: 99440) | 5 CME points |
| 02-11-2018 | Algemene scholing | cluster 1, 2 en 3<br>Principes van epidemiologische data-analyse (V20) | (ID nr: 99440) | 5 CME points |
| 01-11-2018 | Algemene scholing | cluster 1, 2 en 3<br>Principes van epidemiologische data-analyse (V20) | (ID nr: 99440) | 5 CME points |
| 31-10-2018 | Algemene scholing | cluster 1, 2 en 3<br>Principes van epidemiologische data-analyse (V20) | (ID nr: 99440) | 5 CME points |
| 23-09-2016 | Algemene scholing | cluster 1, 2 en 3<br>Epidemiologisch onderzoek: opzet en interpretatie (V10) | (ID nr: 99439) | 6 CME points |
| 22-09-2016 | Algemene scholing | cluster 1, 2 en 3<br>Epidemiologisch onderzoek: opzet en interpretatie (V10) | (ID nr: 99439) | 6 CME points |
| 21-09-2016 | Algemene scholing | cluster 1, 2 en 3<br>Epidemiologisch onderzoek: opzet en interpretatie (V10) | (ID nr: 99439) | 6 CME points |
| 20-09-2016 | Algemene scholing | cluster 1, 2 en 3<br>Epidemiologisch onderzoek: opzet en interpretatie (V10) | (ID nr: 99439) | 6 CME points |
| 19-09-2016 | Algemene scholing | cluster 1, 2 en 3<br>Epidemiologisch onderzoek: opzet en interpretatie (V10) | (ID nr: 99439) | 6 CME points |

Een man kan een belangrijk ingrediënt zijn voor een team, maar een man kan nooit een heel team maken

Kareem Abdul-Jabbar

# Dankwoord
Acknowledgements

# Dankwoord

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Na de gesprekken met collega Mike Veereschild (destijds psychiater van de opname afdeling in Winterswijk) en de uitnodiging van Esther van Gaalen (destijds manager van de GGZ opname afdelingen in Doetinchem en Winterswijk) om daar aan de slag te gaan, kon de eerste pilot gestart worden. Maar ja, hoe doe je dat precies? Daarvoor benaderde ik in eerste instantie Niels Mulder.

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en dwangbehandeling, weten of er meer Dwang en Drang werd toegepast bij deze doelgroep. Dat werd ons eerste artikel. Ik heb enorm veel van je geleerd, teveel om hier op te noemen. Ik kon altijd bij je terecht ook als er op het laatste moment nog zaken af moesten en ik dit vanwege het drukke werk op de poli of de kliniek het echt niet meer allemaal voor elkaar kreeg. Of als op mijn verzoek er toch nog een andere analyse door jouw gemaakt moest worden omdat ik een nieuw idee gekregen had. Dank voor de aanmoediging om mee te gaan naar Split waar ik voor het eerst mijn eerste bevindingen en ideeën over vervolg onderzoek kon presenteren bij de EVIPRIG-onderzoeksgroep. Vanuit de EVIPRIG zijn er mooie contacten ontstaan met andere collega's in Europa die zich bezig houden met "Violence" in de brede zin van het woord en het voorkomen daarvan willen terugdringen in de GGZ. En natuurlijk dank voor het verbinden van mijn/ons "onderzoeksclubje" met de onderzoekers binnen FACT van GGZ Oost-Brabant, als Berry Penterman, Birgit Seelen en Hedwig Smits. Samen sta je sterker is een uitdrukking die zeker van toepassing is geweest. We hebben samen mooi onderzoek kunnen doen zoals het valideren van de SCIL binnen FACT teams en onderzoek naar het al dan niet herstellen van patiënten met LVB en trauma. Belangrijk voor de dagelijkse klinische praktijk.

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Dit niet in het laats ook dankzij Eddy Adolfsen (destijds directeur Specifieke Zorg)) en Chantal Koopmans (destijds manager VGGNet) die het onderzoek in aanmerking lieten komen voor zorginnovatie onderzoeksgelden van het ONG fonds (Oude Nieuwe gasthuizen). Daarmee kon de eerste start gemaakt worden. Ik ben hen en het hele SCIL Projectteam enorm erkentelijk voor hun bevlogenheid, inzet en geduld.

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One of the
proving grounds for
our freedom is in
how we relate to
our loved ones

Edith Eva Eger

About the author

Curriculum Vitae

## CV Jeanet Nieuwenhuis

Jeanet (Janna Grietje) Nieuwenhuis werd geboren op 7 maart 1961 te Doorwerth. Zij groeide op in Oosterbeek en bezocht het Stedelijk Gymnasium in Arnhem. Daar haalde zij het diploma gymnasium bèta in 1979. Na uitgeloot te zijn voor de Geneeskunde studie, studeerde zij met veel plezier een jaar Biologie aan de RU te Utrecht. Een jaar later startte zij alsnog met haar Geneeskundeopleiding. Zij studeerde af in 1988. Na een jaar als wisselassistent gewerkt te hebben in het Streekziekenhuis te Sliedrecht werkte zij een jaar als assistent niet in opleiding bij de afdeling kinderpsychiatrie van de Riagg Oost-Veluwe te Apeldoorn. Daarna werd zij toegelaten tot de huisartsen opleiding te Utrecht. Na deze opleiding te hebben afgerond, keerde zij terug naar de kinderpsychiatrie. Na drie jaar werkzaam te zijn geweest als assistent niet in opleiding bij Riagg Zwolle werd zij aangenomen voor de opleiding tot psychiater aan de Radboud te Nijmegen. Hier kreeg zij les van Prof Dr. Anton Došen in psychiatrie bij mensen met een licht verstandelijke beperking. Een zaadje was gepland. Na de keuze stage kinder- en jeugdpsychiatrie binnen de opleiding tot psychiater, volgde zij aansluitend haar specialisatie tot kinder- en jeugdpsychiater bij het KJPON (thans Karakter) te Zetten.

Na afronding van deze opleiding in 2000 ging zij als kinder- en jeugdpsychiater werken bij Spatie, het huidige GGNet Apeldoorn. In 2002 verhuisde het gezin naar Zeeland en werkte zij daar op diverse kind- jeugd poliklinieken van Emergis en later op jeugdkliniek Ithaka (thans Kliniek Kinder en Jeugd) te Goes.

In 2006 keerde het gezin terug naar Gelderland en trad zij, met ontwikkelingsstoornissen als expertise, in dienst bij Dimence. Aanvankelijk locatie Almelo, later Deventer en Twello. In 2010 maakte zij als (beleids)psychiater de overstap naar de polikliniek en deeltijd van VGGNet, een specialisme binnen GGNet voor mensen met een licht verstandelijke beperking en complexe psychiatrie. Aanvankelijk locatie Doetinchem en later was zij betrokken bij de start van polikliniek VGGNet in Apeldoorn waar zij van 2004 tot 2019 werkzaam was. Na een eerste vooronderzoek met veel belovende resultaten te hebben gedaan naar de prevalentie van LVB binnen GGNet, startte zij als buitenpromovendus haar promotie in 2015. Na de doorontwikkeling van VGGNet naar een hoog specialistische voorziening en daarmee centralisatie van alle locaties van VGGNet op het terrein in Warnsveld, ging zij werken op de kliniek. Sinds 2021 is zij werkzaam op de polikliniek en neemt zij structureel waar voor de kliniek.

Daarnaast is zij betrokken bij diverse beleidsmatige projecten en werkgroepen binnen GGNet, is zij werkbegeleider/supervisor van assistenten psychiatrie tijdens hun keuze stage bij VGGNet en geeft zij met regelmaat les aan de assistenten binnen de opleiding tot psychiater. Zij is lid van de EVIPRIG onderzoeksgroep, lid van de raad van advies van het Landelijk Kenniscentrum LVB, boegbeeld van de kennisgroep LVB en mede samensteller van de website Informatiebronnen LVB en GGZ van het Kenniscentrum Phrenos. Zij gaf afgelopen jaren diverse lezingen, presentaties en workshops in binnen en buitenland. Onder andere bij congressen van de EAMHID in Florence en Luxemburg, bij Europese FACT congressen in Hamburg, Verona en Rotterdam en bij de CCITP in Dublin. Zij verzorgde workshops en trainingen over diverse onderwerpen binnen de LVB psychiatrie zoals over psychose en preventie van suïcidaliteit. Ook werkte zij mee aan webinars onder andere over MCDD bij stichting Het onbegrijpelijke brein en over trauma en LVB bij PAO psychologie en CELEVT. Tot slot is zij met haar expertise betrokken bij de ontwikkelingen van richtlijnen, onder andere de richtlijn Psychose Spectrum Stoornissen voor volwassenen en voor jongeren.



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**Stellingen**
behorende bij het proefschrift

# A blind spot?

Screening for mild intellectual disabilities and borderline intellectual functioning in psychiatric patients in specialized mental health care in the Netherlands: prevalence and associations

1. LVB is een blinde vlek voor behandelaren in de psychiatrie (dit proefschrift).

2. Trauma en PTSS komen significant meer voor bij patiënten met LVB dan normaalbegaafde patiënten en wordt onvoldoende herkend (dit proefschrift).

3. Niet onderkende LVB bij EPA patiënten leidt makkelijk tot een "a highway to chronicity" (dit proefschrift).

4. In de interactie met behandelaren komen patiënten met niet herkende LVB vaker in conflictsituaties terecht (dit proefschrift).

5. Het toestandsbeeld van de patiënt heeft een bescheiden invloed op de uitslag van de SCIL (dit proefschrift).

6. Topsport is mogelijk met diabetes (Nederlands Tijdschrift voor diabetologie 11, pages 43-45 (2013) Leo Heere).

7. MRI breinonderzoek suggereert dat regelmatige beoefening van Zen meditatie neuro protectieve effecten kan hebben en de cognitieve vermindering zoals geassocieerd met normale veroudering kan verminderen. J of Neurobiology of aging, Volume 28, 2007 Pagnoni G and Cekic M.

8. Degelijk uitgevoerd Deense cohortstudie toont aan dat er geen verband is tussen een mazelen-bof-rubella-vaccinatie en de ontwikkeling van autismespectrumstoornis (Minerva-Bondige besprekingen 2019• www.minerva-ebm.be).

9. Onder invloed van muziektraining ontstaan plastische veranderingen in alle betrokken neurale systemen (Muziek en brein (2) Ben van Cranenburgh, Neuropraxis (2007) 11:139–145

10. De belangrijkste genetische risicofactor voor ernstige COVID-19 wordt overgeërfd van de Neanderthaler. (The major genetic risk factor for severe COVID-19 is inherited from Neanderthals Hugo Zebreg en Svante Pääbo PNAS).

11. Als mijn ouders het advies van de lagere school hadden gevolgd, dan had ik nooit aan een promotieonderzoek kunnen beginnen.