JYU DISSERTATIONS 570

Minna Peltopuro

Borderline Intellectual Functioning – Exploring the Invisible

UNIVERSITY OF JYVÄSKYLÄ
FACULTY OF EDUCATION AND PSYCHOLOGY

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Esitetään Jyväskylän yliopiston kasvatustieteiden ja psykologian tiedekunnan suostumuksella
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ABSTRACT

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Borderline intellectual functioning (BIF) is poorly recognised phenomenon characterised by lower-than-average cognitive functioning (intelligence quotient [IQ] of 70–85) and challenges in adaptive behaviour. This thesis explored the individual, neurocognitive and societal aspects of BIF through a systematic literature review and two population-based studies. The findings were compared with parallel aspects of the general population (GP): people with average intelligence and learning problems (LPs), and people with mild intellectual disabilities (MIDs). In the systematic literature review, which applied pre-specified eligibility criteria, 1,726 abstracts and 203 full texts were evaluated; 49 studies were closely analysed. In the population-based studies, the highly unique Finland-in-Miniature sample, originally planned to evaluate people with intellectual disabilities, was used. The sample was gathered in 1962 from 57 municipalities (N = 416,973) and followed until 1998. For the purpose of this research, three groups were formed: BIF (IQ = 70–85; n = 416/156), MID (IQ < 70; n = 312/170) and LP (IQ > 85; n = 284/91). Results of the study show that people with BIF struggled more than their peers of average intelligence in cognitive and academic performance, social relations, education, work and mental health. Moreover, a 3.4-fold risk for severe mental health problems and a 2.7-fold risk for disability to work were found. An increased risk for social exclusion was also evident because of a combination of a high prevalence of mental health problems, non-secure work and low educational level. In general, BIF was in between the continuum from LP to MID, but had unique features of more mental health problems and insecure employment. It was concluded that people with BIF have evident, manifold risks for well-being throughout their lifespan; yet, they are not recognised in research or practice. To enable support, BIF needs to be acknowledged at every stage of the lifespan. Societal and political discussions and guidelines are needed. The volume of research concerning BIF should be increased; in particular, population-based studies are necessary, as are studies focusing on more individual perspectives, such as recognition and support.

Keywords: borderline intellectual functioning, cognitive difficulties, lifespan, mental health, social exclusion

TIIVISTELMÄ (ABSTRACT IN FINNISH)

Peltopuro, Minna
Laaja-alaiset oppimisvaikeudet – näkymätöntä tarkastelemassa
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Laaja-alaiset oppimisvaikeudet (LOV) ovat riittämättömästi huomioitu ilmiö, jota kuvaavat keskimääräistä alhaisempi kognitiivinen kykytaso (älykkyysosamäärä, ÄO, 70–85), sekä toimintakyvyn haasteet. Väitöskirjassa tarkasteltiin laaja-alaisten oppimisvaikeuksien yksilöllisiä, neurokognitiivisia ja yhteiskunnallisia näkökulmia systemaattisen kirjallisuuskatsauksen sekä kahden väestöpohjaisen tutkimuksen avulla. Saatuja tuloksia verrattiin vastaaviin tuloksiin väestössä, sekä oppimisvaikeuksia (OV; ÄO > 85) ja lievää kehitysvammaisuutta (KV; ÄO < 70) omaaviin henkilöihin. Systemaattisessa kirjallisuuskatsauksessa arvioitiin 1726 abstraktia sekä 203 artikkelia, ja lopulliseen katsaukseen päätyi 49 tutkimusta. Väestöpohjaisissa tutkimuksissa käytettiin ainutkertaista Mini-Suomi-aineistoa, joka oli alun perin kerätty kartoittamaan kehitysvammaisuuden esiintymistä Suomessa. Vuonna 1962 yhteensä 57 kunnasta (N = 416,973) kerättiin aineisto, jota seurattiin vuoteen 1998. Väitöskirjan tutkimuksia varten aineistosta erotettiin kolme ryhmää: LOV (n = 416/156), KV (312/170) ja OV (284/91). Väitöskirjan tulokset osoittivat, että henkilöillä, joilla oli LOV, oli keskimääräistä enemmän vaikeuksia kognitiivisessa ja akateemisessa suoriutumisessa, sosiaalisissa suhteissa, koulutuksessa, työelämässä, sekä mielenterveydessä. Verrattuna samanikäiseen väestöön riski vakaville mielenterveyden ongelmille oli 3.4 kertainen ja työkyvyttömyyteen 2.7 kertainen. Myös syrjäytymisriski osoittautui ilmeiseksi matalan koulutustason, epävarman työelämän sekä suuren mielenterveyden ongelmien esiintyvyyden vuoksi. LOV näytti olevan keskellä jatkumoa oppimisvaikeuksien ja lievän kehitysvammaisuuden välissä, poikkeuksenaan enemmän mielenterveysongelmia sekä työelämän epävarmuutta. Tutkimuksen perusteella todettiin, että henkilöillä, joilla on LOV, on selviä, monimuotoisia, riskejä hyvinvoinnille läpi elämänkaaren. Tästä huolimatta LOV on näkymätön tutkimusmaailmassa sekä käytännön tasolla. Tuen mahdollistumiseksi LOV tulee tunnistaa joka elämän vaiheessa, tarvitaan yhteiskunnallisia ja poliittisia keskusteluita sekä suuntaviivoja. Tieteellisten tutkimusten määrää tulee kasvattaa, etenkin väestöpohjaista tutkimusta tarvitaan, mutta myös keskittymistä yksilöllisempään näkökulmaan, kuten tuen suunnitteluun.

Avainsanat: laaja-alaiset oppimisvaikeudet, kognitiiviset vaikeudet, elämänkaari, mielenterveys, syrjäytyminen

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Life is not a series of gig lamps symmetrically arranged;
life is a luminous halo;
a semi-transparent envelope surrounding us
from the beginning of consciousness to the end.

Virginia Woolf

Riihimäellä 26.9.2022
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LIST OF ORIGINAL PUBLICATIONS

I Peltopuro, M., Ahonen, T., Kaartinen, J., Seppälä, H., & Närhi, V. (2014). Borderline intellectual functioning: A systematic literature review. *Intellectual and Developmental Disabilities*, *52*, 419–443.

II Peltopuro, M., Vesala, H. T., Ahonen, T., & Närhi, V. M. (2020) Borderline intellectual functioning: An increased risk of severe psychiatric problems and inability to work. *Journal of Intellectual Disability Research*, *64*, 923–933. https://doi.org/10.1111/jir.12783

III Peltopuro, M., Vesala, H. T., Ahonen, T., & Närhi, V. M. (2022). Borderline intellectual functioning and vulnerability in education, employment and family. Manuscript submitted for publication.

Taking into account the instructions given, comments made and collaboration with the co-authors, the author of the thesis collected the data, conducted the main analysis and wrote the report of Study I. In Studies II and III, she had an active role in planning the initial research settings. She applied the previously collected data, planned the analysis, conducted parts of the analysis and wrote the reports of the publications.

FIGURES

TABLES

CONTENTS

1 INTRODUCTION

Borderline intellectual functioning (BIF) is a phenomenon that is invisible when scientific knowledge, official diagnoses and practical guidelines are considered, yet the issue concerns a vast number of people. Through my work as a clinical neuropsychologist, I have been in the fortunate position to be able to help people with various cognitive challenges. For several disabilities, such as attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD) and reading disability, there are clear guidelines facilitating diagnosis, rehabilitation and societal support, which have greatly benefitted many people, their family members and the surrounding society. For BIF, the situation has been less fortunate, as recognition has been insufficient, consequently, targeted support has remained uncertain. Only recently, over the last two decades, have there been any systematic characterisations of BIF in the academic literature underlying clinical work. Despite this gradual recognition, research-based understanding has remained shattered, clear guidelines are missing and societal support mechanisms remain inadequate.

This dissertation is motivated by the discrepancy between the obvious vulnerabilities of life caused by BIF and the minimal scientific, clinical and societal recognition of this phenomenon. As the name of this dissertation suggests, *Borderline Intellectual Functioning - Exploring the Invisible*, an obvious starting point for a better understanding is naming and defining the phenomenon. For BIF, however, there is currently only one diagnostic manual, the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM–5) that mentions it as an extra V-code in a section entitled 'Other Conditions That May Be a Focus of Clinical Attention' (American Psychiatric Association, 2013, p. 715). As the location and conditional title indicate, BIF is not in the mainstream but invisible at the margins of the clinical work and, thus, in research.

To make a difference in recognition, definitions are only part of the game. Without a better understanding of this phenomenon, it is highly unlikely that future manuals will provide any more concrete titles and guidelines. What is missing is a basic understanding of this phenomenon, and this can only be attained through systematic research. To engage in such a mission, I have

devoted this dissertation to the exploration of BIF through three separate research articles that approach this phenomenon from multiple perspectives using multiple research methods. Article I was the first ever published literature review of BIF that aimed to synthesise current academic knowledge on the subject. Articles II and III contributed to a better empirical understanding of this phenomenon by investigating the Finland-in-Miniature data that was originally gathered in 1962 and updated through 1998. Using this research as the starting point, in this dissertation, I provide an overview of the key findings and discuss their relevance in terms of the individual-level, neurocognitive-level and societal-level implications.

1.1 Definition of borderline intellectual functioning

BIF is not an officially recognised diagnosis in diagnostic manuals. The definition adopted in this dissertation is largely based on a consensus statement created by a group of researchers working with BIF, the Girona Declaration on borderline intellectual functioning (Martinez-Leal et al. on behalf of BIF consensus group, 2020) and generally accepted descriptions used by several researchers (e.g. Hassiotis et al., 2019; Salvador-Carulla et al., 2013; Wieland and ten Doesschate 2018). The definition of BIF includes both lower-than-average cognitive functioning and adaptive challenges (see Figure 1). Also, a differentiation needs to be done to intellectual disability (ID) and to normal intellectual functioning, particularly in terms of specific learning disabilities (SLDs; e.g. difficulties in reading, writing and math). There are several neurodevelopmental disorders, such as SLD, ADHD and ASD, that need to be acknowledged as they might produce similar types of adaptive challenges or they might co-occur with BIF.

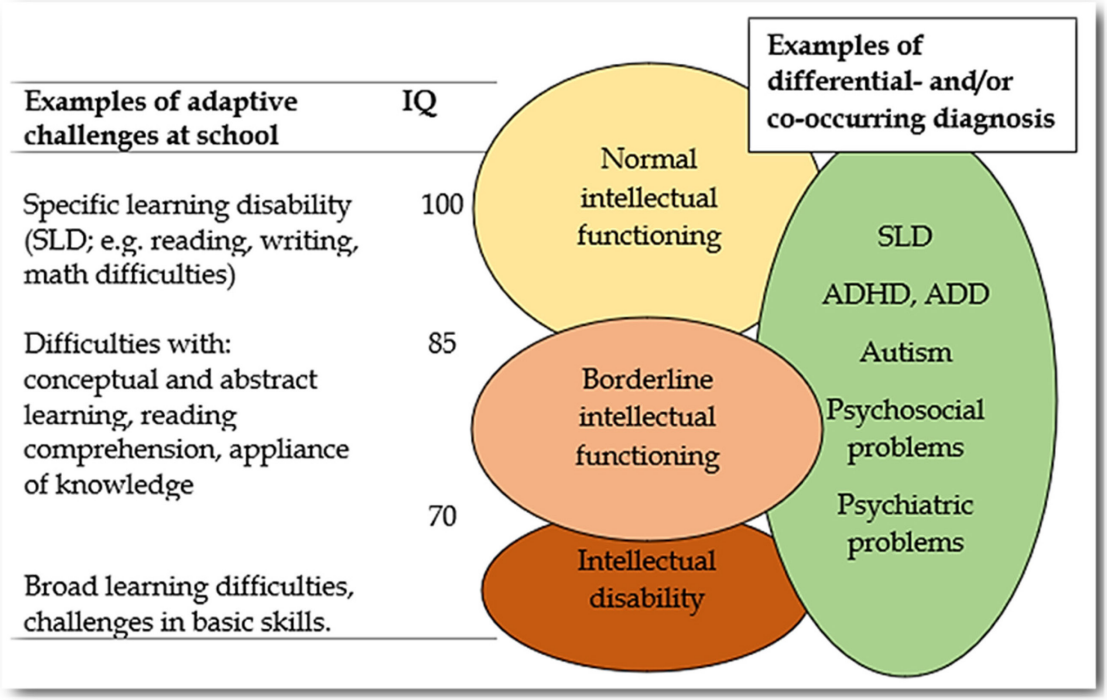

FIGURE 1 Definition of borderline intellectual functioning (BIF). Definition includes both lower than average cognitive functioning, *and* adaptive challenges. Differentiation to normal intellectual functioning and intellectual disability should be considered. Other neuropsychiatric disorders need to be acknowledged as a possible differential- and/or co-occurring diagnoses.

1.1.1 Cognitive functioning

Lower-than-average cognitive functioning is related to BIF. Typically, this is determined by one to two standard deviations (*SD*s) below average on a standardised intelligence test; thus, the intelligent quotient (IQ) is approximately 70 to 85. When the normal distribution of intelligence is examined, 13.6% of people belong to this group (see Figure 2). However, not all people having an IQ in this range are considered to have BIF, but rather the population that falls in this IQ range can be seen as persons who have a risk for BIF. Many people manage well despite lower-than-average cognitive skills, and because of a lack of adaptive challenges, they are not considered to have BIF. Thus, the incidence, which takes into account both IQ and the adaptive challenges of BIF in the population, remains unknown because of the absence of international consensus on the classification and related studies concerning its prevalence.

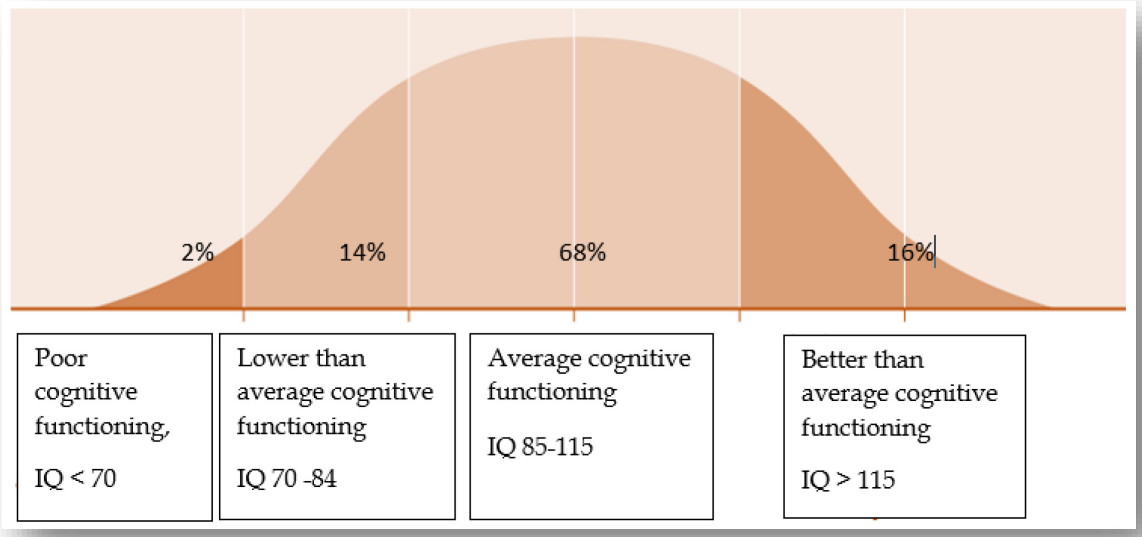

FIGURE 2 Normal distribution of IQ in population, proportions of people in different IQ intervals, and description of the level of cognitive functioning.

1.1.2 Adaptive challenges

In addition to lower-than-average cognitive functioning, people with BIF have adaptive challenges when compared with peers with normal cognitive functioning. The challenges may manifest as learning problems at school, difficulties in social relations, challenges in finding and maintaining a job and vulnerabilities with physical and mental health.

1.1.3 Differentiation of other disorders

BIF can be seen as a continuum, being in between normal intellectual functioning and intellectual disabilities. Differentiation in both directions is challenging, as there are no clear cut-off division where one condition starts and another ends. Historically, an IQ < 70 was used as a diagnostic cut-off point for ID, but practice has shown it to be a poor indicator for solely predicting individual functioning. The latest diagnostic manuals, the International Classification of Diseases 11th Revision (ICD-11; World Health Organisation, 2019) and the DSM-5, emphasise the role of adaptive functioning, and IQ is used less strictly. Even though there are no diagnostic criteria for BIF in the manuals, based on ID diagnostic criteria, it is possible to determine the 'lower end' of BIF. Intellectual disability is described in the DSM-5 as follows:

> Intellectual disability [(intellectual developmental disorder)] is a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains.

The description in ICD-11 is equivalent, although the manuals use different diagnostic terms:

> Disorders of intellectual development are a group of etiologically diverse conditions originating during the developmental period characterised by significantly below average intellectual functioning and adaptive behaviour that are approximately two or more standard deviations below the mean (approximately less than the 2.3rd percentile), based on appropriately normed, individually administered standardized tests.

Thus, according to these descriptions, people with ID have wider and more extensive difficulties than people with BIF.

In terms of the 'upper end' of BIF, the diagnostic manuals do not provide any help. As with ID, a clear cut-off point towards normal intellectual functioning is missing, and differentiation of SLDs may be particularly difficult. Specific learning disorder (in DSM-5) or developmental learning disorder (in ICD-11) is characterised by difficulties in learning academic skills, such as reading, writing or arithmetic. Performance in these skills is markedly below what would be expected for an individual's general level of intellectual functioning (ICD-11). People with BIF may have similar difficulties in academic skills. However, these difficulties may not differ markedly from their general level of intellectual functioning; thus, difficulties may be expected when taking into account lower-than-average intelligence. Also, academic difficulties in people with BIF may be more extensive than those with SLD, as they concern multiple areas of conceptual and abstract learning.

Other neurodevelopmental disorders, such as ASDs and ADHD, need to be considered as a differentiation, but also as possible co-occurring disorders. Lower-than-average test scores on intelligence tests can be due, for example, to situational attention problems or problems related to social interaction instead of real cognitive capacity. Also, challenges related to psychosocial environment and mental health need to be considered as possible reasons for temporarily lower-than-average IQ test scores.

1.2 Different perspectives on BIF

BIF as a phenomenon can be viewed from various levels, each of which gives a distinct perspective on the issue. In this thesis, individual, neurocognitive and societal perspectives are explored. At the *neurocognitive level*, learning difficulties, cognitive capacity, intellectual functioning and possible differences in brain structure and/or activity are the focus of interest. At the *societal level,* people with BIF can be considered as an officially invisible group which is affected by global changes in work markets, rapidly accelerating society and computerisation, and which is in danger of marginalisation and social exclusion, unemployment and mental health problems. At the *individual level*, BIF has an impact on the entire lifespan, from early childhood to the senior years. These three levels –

neurocognitive, societal and individual—are described next in more detail in light of the current literature.

1.2.1 Neurocognitive perspective

From a neurocognitive perspective, learning difficulties, cognitive capacity, intellectual functioning and differences in brain activity and/or structure are relevant issues concerning BIF. Also, differences and similarities related to other disabilities, such as SLDs and mild intellectual disabilities (MIDs), need to be considered in order to form a complete picture of BIF.

1.2.1.1 Intelligence, IQ and cognitive capacity

Intelligence is a controversial concept without an explicit definition. Comprehensive definition describes intelligence as the ability to reason, understand complex thoughts and ideas, adapt to situational demands, learn effectively from experience and solve problems (Neisser et al., 1996). However, when we measure intelligence, we use IQ, which is an agreed upon collection of cognitive skills, which are measured, normed and calculated into one number representing general intelligence. Thus, IQ does not represent the broad concept of intelligence; rather, it is an approximation of cognitive skills. IQ is used as a diagnostic tool, for example, when defining intellectual functioning and developmental disorders, thus, also BIF. Usually, IQ is measured with well-normed psychometric tests, such as the Wechsler Intelligence Scales, which are normed for different age groups. In these tests, usually at least verbal, visual and working memory skills are measured with several subtests. The subtests are designed to measure different components of the skills, for example, in the Wechsler Intelligence Scale for Children (Wechsler, 2010), Verbal Comprehension IQ is measured with subtests on similarities, vocabulary and general comprehension and FSIQ, that is full-scale-IQ, containing verbal, perceptual, working memory and processing speed skills, includes altogether 10 subtests. The results of each subtest are converted into age-normed standard points (from 1 to 19), which are calculated together and transferred into IQ value that represents general intelligence. Besides an IQ value, psychometric tests produce an individual cognitive profile, which is an informative cross-section that reflects a person's strengths and weaknesses, and can be used for diagnosing and support planning. Often in neuropsychology, the term intelligence is replaced with cognitive capacity when intelligence tests are referred to.

In relation to BIF, intelligence needs to be addressed with a few words, as it is a necessary part of defining BIF. Measured IQ levels from approximately 70 to 85 usually are associated with BIF. However, using IQ as the sole diagnostic tool for BIF is not adequate because one value representing general intelligence does not reveal anything about the individual strengths and weaknesses of a person or their needs for support. The same IQ value can be achieved through very different cognitive profiles, and it is likely that even when IQ profiles at the group level with people with BIF are flat, individual heterogeneity is great (see Figure

3). Närhi and Kuikka (2010) viewed the WISC-III profiles of adolescents with an IQ of 70–84 (n = 64), and reported that heterogeneity was evident. They stated that within single profiles: a) differences between verbal and non-verbal skills were common, b) there were great variations among different part-tests and c) there was at least one part-test result for all participants, which reached average performance. At the group level, however, the IQ profile of all participants was flat (see Figure 4). A different outcome was reported by Pulina et al. (2019). When they compared profiles of the WISC-IV of children with BIF (n = 204) and typically developed (TD) peers, they found a low working memory peak for BIF at the group level. They concluded that children with BIF have a characteristic profile with specific weaknesses (working memory). That is, in children with BIF, performance was weaker than with TD children, but working memory skills seemed to be damaged more than other skills. Clearly, more studies on the relationship between IQ and BIF are needed. In practise, IQ is a useful tool from which to start an evaluation of cognitive and adaptive skills. However, to obtain an understanding of personal skills, support needs and the possibility of existing BIF, a more detailed examination of single cognitive areas and whole cognitive profile is needed.

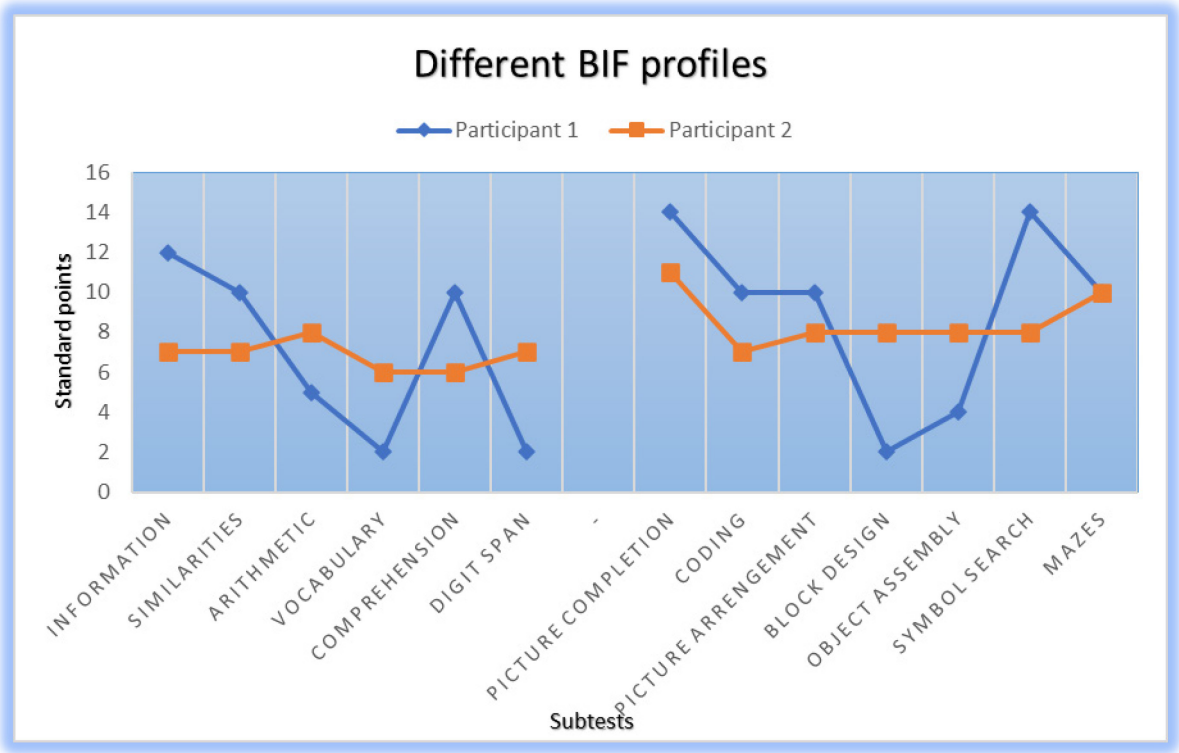

FIGURE 3 Example of individual heterogeneity of BIF in Finnish version of Weschler Intelligence Scale for children III (WISC-III; Original idea of the picture by V. Närhi, taken from data of the two adolescents with BIF participating in Jyväskylä BIF studies, see also Närhi & Kuikka, 2010).

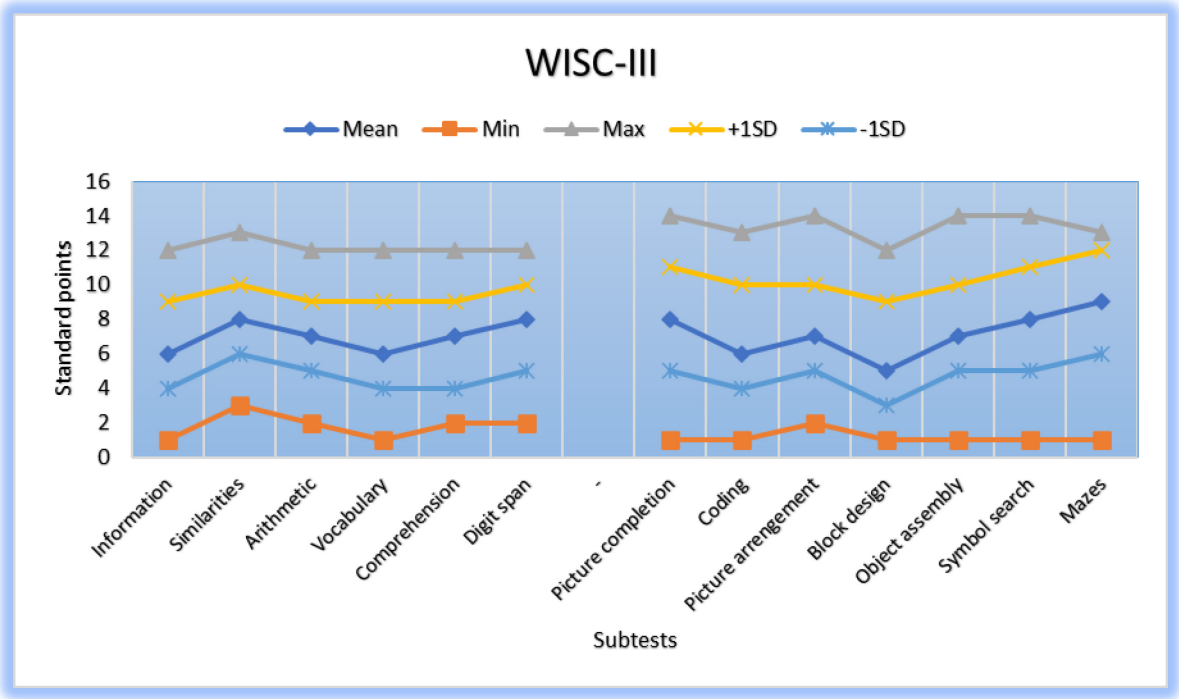

FIGURE 4 BIF profile at a group level, involving 64 adolescents with IQ 70-84 (Närhi & Kuikka, 2010, unpublished figure).

1.2.1.2 BIF and the double sorites paradox

The sorites paradox is a puzzle that is often described as a heap of sand. One grain of sand is not a heap. Two grains of sand are not a heap, either. When do the grains become a heap? The exact point, citing a particular added grain, is impossible to show. Yet, it is an undeniable fact that the heap of grains exists. This paradox does not follow classical logic, which would mean that there must exist a sharp boundary between heap and non-heap.

Measured IQ in a population is set to follow a normal distribution, and there are historically agreed upon boundaries of what is considered normal or lower than normal intelligence (see also Figure 2). BIF can be viewed as being in between normal intelligence (IQ = 85–115) and intellectual disabilities (IQ < 70). Despite these acknowledged boundaries, a real-life differentiation in both directions is challenging as it is difficult to know exactly when one condition ends and another begins.

Garrels (2022) described intellectual disability as a philosophical sorites paradox. She suggests that diagnosing intellectual disability is such a paradox, as each step (referring IQ and adaptive behaviour [AB] scores) is indistinguishable from its neighbour. That is, according to Garrels, we could not observe any difference in cognitive or adaptive functioning between a person with IQ and AB scores of 70 and a person with IQ and AB scores of 69. Yet, a clear boundary at the 70 cut-off point is used to define intellectual disability. The sorites paradox perfectly expresses the difficulties of evaluating the boundaries and differentiation of BIF and normal functioning, or BIF and ID. Thus, when

defining BIF, there is a double sorites paradox at both ends of the evaluation: one where BIF ends and intellectual disability begins, and another where 'normal' ends and BIF starts. Despite the real-life vagueness of these boundaries, IQ is set to be 1 to 2 *SD*s below mean, which is from 70 to 84. As Garrels also stated, measured IQ, however, is an approximation of cognitive skills, including imprecisions, such as standard errors (*SE*s) of the measurements. Thus, other things (e.g. whole cognitive profile, adaptive functioning, contextual demands) than IQ value alone should be taken into account when diagnosing BIF and differentiating it from normal intellectual functioning and ID. Particularly difficult is this differentiation with people with average intelligence and SLD, as academic achievement may seem similar for these two groups. From this perspective, it is important to compare BIF with both its ends, MID and SLD, in order to form a picture of what is similar and what is different. An interesting question is also whether better cognitive capacity automatically means a better outcome in life.

1.2.1.3 Cognitive skills and academic learning difficulties

Based on the current literature, it seems evident that at the group level, children with BIF perform poorly in both academic and cognitive tasks when compared with same-aged peers with average intelligence. In particular, working memory and mathematical skills have been systematically reported to be clearly poorer, although children with BIF are outperformed by peers in all areas. Study I, a review article published in 2014, reported several studies concerning cognitive skills and academic learning difficulties in children with BIF as compared with peers with average intellectual functioning. A brief summary of those findings and the results of the more recent studies on the topic follow.

With *memory skills* (verbal, visual, visuospatial, auditory, phonological, central executive and complex memory), children with BIF showed poorer task performance than their peers. This was shown in eight studies in which, out of 51 tasks, in only six tasks was the performance at the same level as peers (Alloway, 2010; Birch, 2003; Bonifacci & Snowling, 2008; Henry, 2001; Kortteinen et al., 2009; Maehler & Schuchardt, 2009; Schuchardt et al., 2010; Swanson, 1994). *Executive functioning* (from five studies: planning, shifting attention, inhibition, problem-solving, processing speed, sustained attention, impulse control) was systematically shown to be at a poorer level than in peers of average intelligence (Alloway, 2010; Bonifacci & Snowing, 2008; Hartman et al., 2010; Napora-Nulton, 2003). Only one study reported impulse control being at the same level as peers (van der Meer & van der Meere, 2004). *Motor skills* (from three studies: run, gallop, hop, leap, jump, slide, strike, bounce, catch, kick, throw, roll, manual dexterity, ball skills, statistic and dynamic balance) were reported as being either clearly poorer than that of peers, or that when compared with test norms, about 60% of children with BIF had motor problems (Hartman et al. 2010; Vuijk et al. 2010; Westendorp et al. 2011). *Academic learning difficulties* seemed evident based on eight studies. With reading, spelling and related skills (phonological processing, rapid naming, reading comprehension, syntactic skills), in general, the task

performance was poorer than with peers (Atkinson 1984; Birch, 2003; Bonifacci & Snowling, 2008; Claypool et al., 2008; Kortteinen et al. 2009; MacMillan et al., 1998). Exceptions were reported in two studies where participants with BIF were divided into groups with BIF and reading disabilities (RDs) and BIF without RD. Those without RD showed similar performance to that of their peers in reading, spelling and rapid naming (Birch et al., 2003; Kortteinen et al. 2009). With math (calculation, arithmetic), children with BIF were observed to perform consistently poorer than their peers (Claypool et al., 2008; Kortteinen et al., 2009; MacMillan et al., 1998).

More recent studies (published after 2014), support the above findings. In their longitudinal study, Träff and Östergren (2021) found that children with BIF were outperformed by peers without BIF in all measured cognitive and academic tasks. They studied processing speed, executive function, shifting, semantic fluency, phonological fluency, visual-spatial working memory, calculation, arithmetic fluency, arithmetic problem solving, word reading and reading comprehension. They concluded that the results showed a cognitive developmental lag of less than one year, but an academic developmental lag of two years in relation to arithmetic and reading skills when compared with the chronological age-matched comparison group. Stefanelli and Alloway (2020) also reported findings concerning mathematical abilities and working memory. They found that children with BIF had impairment of mathematical skills and working memory when compared with their peers. Água Dias et al. (2019) studied verbal short-term memory, rapid naming, phonemic verbal fluency, visual short-term memory and long-term visual memory and found deficits in all measured skills except for long-term visual memory. Smirni et al. (2019) studied skills related to attentive, memory, executive functions and speed of processing in adolescents with BIF and found worse performance in all measurements when compared with peers.

1.2.1.4 Brain characteristics

There is growing evidence showing that many neuropsychiatric disorders and learning disabilities are associated with deviations from normal brain development (Baglio et al., 2014). With this knowledge, it is reasonable to assume that the brain development of people with BIF is affected as well. There are few studies investigating BIF and brain characteristics, but the few that do exist, even with a small number of subjects, show that this is a relevant and important relationship that has yet to be fully explored.

Vaney and others (2015) used event-related potentials (ERPs) to study children with BIF (n = 19; IQ = 70–85) and controls with average intelligence. Two auditory stimuli (target 20% and nontarget 80%) were presented through headphones. Responses were given by pressing a button. The results showed a significant prolongation of the latency of 3 channels (P200, N200, P300), but no differences in the amplitudes. The authors concluded that brain systems that are important for stimulus discrimination and for using cognitive representation to

guide cognition and behaviour are impaired with BIF. They also stated that the results were partly similar to those reported for poor readers.

Baglio and others (2014) compared children with BIF (n = 13) and TD peers (n = 14) using magnetic resonance imaging (MRI), and found abnormal gray matter (GM) development in children with BIF. Regional GM volume was increased in bilateral sensomotor and right posterior temporal cortices and decreased in the right parahippocampal gyrus. The authors concluded that brain development is affected, and motor and visuomotor cortices in particular are abnormally developed in children with BIF.

1.2.2 Societal perspective

1.2.2.1 How BIF is viewed by society

If you ask a psychologist, neurologist, teacher, administrator in an employment office or psychiatric nurse about persons with BIF, they would all recognise the issues involved with this condition immediately. However, BIF does not officially exist in society, as a diagnosis, explicit criteria for assessing BIF and targeted support are missing, and the terminology around the issue is unclear. Only one of the current diagnostic manuals, the DSM-5, acknowledges BIF, but only in a V-code section referring to a condition that may have clinical significance (American Psychiatric Association, 2013a). The category, V62.89, is recommended to be used if BIF is the focus of clinical attention or if it has an impact on treatment or prognosis. Differentiating between BIF and MID is stated in the guidelines as requiring careful assessment taking into account intellectual and adaptive functions and their discrepancies, but no specific instructions on how to do this are given. It is unknown how often this V-code is used in real-life situations by physicians. In some countries, the choice of terminology may even result in the disappearance of the whole issue from the manual. In the English version of the DSM-5, the term Borderline Intellectual Functioning is used. In the Finnish version, for example, the term is *Älyllisen selviytymisen vaikeus*, which means something like difficulty in intellectual coping. However, in Finland, BIF is called *laaja-alainen oppimisvaikeus*, meaning a broad learning disability. Thus, Finnish physicians cannot find BIF in the Finnish version of the DSM-5 (American Psychiatric Association 2013b).

Unclear and undefined terminology concerning BIF causes problems in both the fields of research and practise. During the 2010s in the research literature in English, the term borderline intellectual function became an established usage. However, historically, there has been a great variety names referring to BIF. When previous literature is scanned, an important and probably, at origin, an ideological division between terms related to intelligence (e.g. borderline intelligence, borderline mental retardation, sub-average IQ) and learning (e.g. slow learners, marginal learners, general learning disability) is obvious. Traditionally, intelligence-related terms have been used in medical studies and learning-related terms have been used in educational studies and pedagogy. This division can also be seen in different societies, as in some countries learning-

related terms are used (e.g. Finland, Sweden), while other countries use intelligence-related terms (e.g. English speaking countries, Spain). Learning-related terms might be less stigmatising than intelligence-related terms, but there is a danger of the issue becoming invisible after school years if difficulties in learning are understood only in reference to school learning and not related to one's entire life. Thus, the learning diagnosis does not follow a person after leaving school, so targeted support is not available.

Historically, the situation of people with BIF has previously been perhaps more preferable than the current one, in terms of recognition and targeted support. Before 1973, people with BIF were eligible for classification as mentally retarded (former term for intellectual disability), and thus they were entitled to support systems available to this group. In the early 1970s, the classification system for mental retardation was modified, and people with BIF were removed from the diagnoses. The reason for this removal was the concern that there were numerous children who seemed to manage reasonably well outside of the academic setting, but still were labelled as mentally retarded (President's Committee on Mental Retardation, 1969). In the late 1990s, the situation was re-examined, and it was found that adults with BIF face challenges in every aspect of life, and that they are more vulnerable because of the demands of the increasingly complex society (President's Committee on Mental Retardation, 1999; see a more detailed summary of the history in the Introduction of Study I). BIF was removed from a diagnostic classification approximately 50 years ago. Society today is very different from that of the 1970s, and today's children, adolescents and adults with BIF have difficulties to manage also outside of school settings, it seems.

1.2.2.2 Societal changes

For the last 30 years, changes in Western societies have been extremely rapid because of globalisation, automatisation and digitalisation. For people with BIF, all of these changes have not necessarily been good. Previously, it was normal that many people graduated only from elementary school and then entered the job market. Now, in many Western societies, it is the norm that studies continue at least into the secondary school stage, and academic degrees have also increased notably. Some qualification is required for most of the jobs, and where it is not required, the job often goes to the applicant who has it (Soininvaara, 2020). People with BIF struggle with their studies, and secondary school qualifications may be unattainable for many. Without qualifications, they are vulnerable in the work market.

Soininvaara (2020) pointed out in his book on social politics in 2020 that work markets have lately changed dramatically because of globalisation, automatisation and digitalisation. In particular, jobs that include routine and operating work and are unacademic have vanished. Automatisation has replaced human labour, and globalisation has shifted jobs to countries that offer cheap labour. Thus, many occupations that people with BIF could manage are no longer available. In addition, this loss of occupations affects people with qualifications

from secondary schools as well. Because of their higher status of schooling, they are still in a better position as job applicants than many people with BIF when the remaining jobs are available. Soininvaara also emphasised that the nature of available work has changed. Previously, there were jobs that one could perform well if one's personal industry and work ethic were in order, regardless of personal qualities. Today, personal qualities and skills, such as creativity, reasoning and independent initiative, are highly valued. It could be said that with some people, the demand for their labour input is decreasing, and for some, it is increasing. Unfortunately, people with BIF belong to the former group.

Digitalisation also presents a serious challenge to people with BIF. Digi-skills are required not only at work, but also in many basic functions of modern society, such as paying bills, filling out applications, getting information etc. For many people with BIF, these skills may be difficult to learn, and even if basic skills are learned, finding the right information through digital sources might be impossible.

1.2.2.3 Social impacts of insufficient support

Current literature has documented the major difficulties encountered in the areas of education, employment and mental health when people with BIF are compared with peers in the general population (GP). All these areas also have, besides an individual meaning related to personal well-being, a societal dimension in the form of societal productivity and societal costs. Difficulties in these areas also have negative effects on societal productivity.

Education was studied by Hassiotis et al. (2008) with a cross-sectional survey of 8,450 adults in the UK. They found that people with BIF had significantly fewer educational qualifications than those with average intelligence (52% and 77%, respectively). Two recent studies have reported that full-time employment was less common, and part-time employment and unemployment were more common with people with BIF than with peers. Emerson et al. (2018a) examined a nationally representative UK cohort (over 17,000 children born during one week in 1970) and reported markedly lower employment rates for people with BIF, from 55% to 76%, as compared with peers with average intelligence, from 70% to 83%, in different ages of adulthood. In another study with the same birth cohort data, Emerson et al. (2018b) showed that people with BIF were at risk of being exposed to non-standard employment conditions, such as temporary employment, part-time or on-call work, and disguised employment. These conditions, in turn, were shown to be associated with poorer physical and mental health in people with BIF (Emerson et al. 2018a).

The high incidence of mental health problems, both in terms of diagnoses and symptoms, related to BIF have been well established by several recent studies (Chen et al., 2006; Dekker & Koot, 2003; Emerson et al., 2010; Gigi et al., 2014; Hassiotis et al., 2008; Hassiotis et al., 2017; King et al., 2019). Prevalence rates have been varied among the studies, but at least twice as many mental health problems have been reported by all studies for people with BIF as compared with control groups with normal intelligence or with the GP group.

Moreover, a high incidence of mental health problems has been reported for children (Dekker & Koot, 2003; Emerson et al., 2010), adolescents (Gigi, 2014; King, 2019) and adults (Chen et al., 2006; Hassiotis et al., 2008; Hassiotis et al., 2017) with BIF.

At the moment, BIF is an unrecognised issue in society, and support systems that would be targeted to BIF are lacking. People with BIF can get support as any other person in society, but the challenge is that often lower-than-average cognitive capacity is not detected, and when it is, there is not enough expertise to effectively address it. This can lead to inefficient support for people with BIF. Insufficient support may lead to failures in education and work and to health and mental health problems. Purely from a cost to the society point of view, insufficient and inefficient support is really expensive if it leads to unemployment, disablement to work, mental health problems etc., and society supports persons with benefits and health service costs. And yet, society also loses incomes, due the loss of taxes.

1.2.3 Individual perspective

From an individual perspective, BIF is a condition that lasts for the entire lifespan and can complicate life at different stages. From this perspective, it is important to consider what difficulties and/or risks may be involved at different stages of life. These risks in each stage of the lifespan are dealt with in more detail next.

1.2.3.1 Childhood

Several studies have reported an increased risk for BIF in children with low birth weight (Chaudhari et al., 2004; Chen et al., 2006; Ramey et al., 1992). Low birth weight, besides causing many developmental problems, may also have a negative effect on the first relationships a baby has, particularly if the first months are spent in an incubator. Hassiotis et al. (2019) found that children with BIF were significantly more likely than their peers to have experienced childhood adversities related to social and/or material deprivation, (e.g. living in a poor area or overcrowded housing, low social class, low income, living with a single parent, potential maternal psychiatric morbidity). Children with BIF had an average of six experienced adversities, whereas peers had three. Hassiotis et al. also found that adverse childhood experiences faced by children with BIF were significantly related to adult psychiatric morbidity.

Fenning et al. reported that children with BIF were at risk for poor parenting. In their first study (2007), mothers of children with BIF exhibited less positive and less sensitive parenting and displayed lower positive engagement with their children as compared with mothers of TD children or mothers of children with developmental delays (IQ < 70). In their second study (2014), fathers were also included, and families were followed for a period of one year (from five to six years of age). Both parents showed more negative controlling behaviour than did parents of TD children.

There is evidence that children with BIF struggle more with peer relationships than their TD counterparts. Two studies have reported that children with BIF have different play behaviour than peers: less peer- or group-play and more solitary play were found (Guralnick & Groom, 1987; Roberts et al., 1991). Children with BIF also seem to have difficulties with interpretation and responding to social situations. Two studies examined children's responses to demanding social situations (e.g. evaluating social situations, generating spontaneous responses to problems and choosing from different ways to behave). Children with BIF showed more passive and more aggressive and less assertive responses in various social situations than their peers (Embregts & van Niuwenhuijzen, 2009; van Niuwenhuijzen et al., 2011).

1.2.3.2 Adolescence

Baglio et al. (2016) studied social competence in children with BIF by investigating the development of theory of mind (ToM). They described ToM as an ability to attribute mental states, such as intentions, desires, emotions and beliefs, to ourselves and others and to predict our own and others' behaviour. Also, ToM has been said to be involved in self-awareness, in the encoding of others' behaviour, in self-regulation, in mastering novel situations and in building satisfying relationships. Baglio et al. found that children with BIF showed a significantly lower performance across all the levels of ToM development compared with the TD control group. They also stated that a possible explanation of the results may be due to poor executive functions, which lead to an overload of information when the complexity of the situation increases. They concluded that early intervention during childhood is essential. In adolescents with BIF, the delayed development of ToM creates a risk of drifting apart from social relations, as understanding subtle social signals of peers may be compromised. In addition, delayed development of ToM likely means delayed development of identity as well.

Only a few studies have reported on the relationship between education and adolescents with BIF. However, significantly fewer qualifications of adolescents with BIF were reported when compared with peers with normal intelligence (Hassiotis et al., 2008; see also Section 1.2.3.2). Also, in the Australian Longitudinal Study of Children (Kavanagh et al., 2018), adolescents with BIF were shown to be likelier to have experienced bullying victimisation at school than their peers.

1.2.3.3 Early adulthood

Hassiotis et al. (2008) found a significant difference in rates of living as couples between people with BIF and their peers (56% and 70%, respectively). With respect to employment, recent studies show that part-time jobs, unemployment and overall non-secure working conditions are more common with people with BIF than with peers (Emerson et al., 2018a; Emerson et al., 2018b; see more detailed description in Section 1.2.3.2). Emerson et al. (2018a) reported that at age 26, notably more people with BIF were unemployed or economically inactive,

and they also had fewer full-time jobs than people with average intelligence. There is also some evidence that, particularly in young adulthood, people with BIF have difficulties maintaining jobs. Zetlin and Murtaugh (1990) reported that around the time of high school graduation, young adults with BIF did get jobs, as approximately 80% had held at least one job during a three-year period. However, they had difficulties maintaining jobs and many ended up changing jobs after a short time. All of these were unskilled or semi-skilled jobs.

1.2.3.4 Adulthood

Studies concerning BIF and old age are unavailable in the current literature, as, to the best of my knowledge, none of the existing studies have focused on the ageing of people with BIF. Instead, there are studies reporting on middle adulthood. Emerson et al. (2018a) reported that at age 42, people with BIF were notably more often unemployed or economically inactive than their peers, and also had fewer full-time jobs compared with their peers. Moreover, there is growing evidence that people with BIF, at all ages, have at least two times more mental health problems than people in the GP (see Section 1.2.3.2.). At an older age, it is possible that mental health problems are caused by cumulative adverse life experiences, to which people with BIF are exposed (Hassiotis et al., 2019).

Thus, in light of the current literature, risks to normal psychosocial development and well-being in people with BIF are evident in many stages of life over the entire lifespan. In childhood, low birth weight, poor parenting and childhood adversities, as well as difficulties with learning, social relations and motor performance, are possible threats to normal development. At adolescence, difficulties in finishing school and delayed development of social competence can be considered potential risks. In adulthood, difficulties with forming partnerships, problems in having a job and mental health problems are potential threats to having a satisfying life.

1.3 Aims of the research

Considering the above discussion and understanding how significant BIF is as a psychological and social phenomenon and how little scientific knowledge supports its diagnosis, social recognition and support, the overall aim of this dissertation was *to increase systematic knowledge of BIF in respect to three levels of activity: individual, neurocognitive and societal.* The overall objective was further divided into the following sub-aims:

Sub-aim 1: *Better understanding of BIF as an individual-level phenomenon.*
BIF is a condition that lasts for an entire lifespan which is why it is important to study it at different phases of life. The main issues include social behaviour and relations, learning, education, work, partnerships, mental health and life satisfaction. To detect possible threats to individual well-being of people with BIF, the way they are affected by these issues needs to be compared with how

either peers with average intelligence or peers with in general population are affected by them.

Sub-aim 2: *More solid understanding of BIF at the level of neurocognitive functioning*.

Neurocognitive issues to be explored in this dissertation include possible risks and preventive factors and cognitive and academic difficulties concerning BIF. BIF is a neurodevelopmental phenomenon that can be better understood, especially by comparing it with other related but more thoroughly examined neurodevelopmental states. Differences among BIF, MID and SLD will be addressed in the following areas: use of services, family, work, education and life satisfaction. Besides determining what is similar and different among these groups, two particularly interesting questions are whether better IQ means better outcomes in life and where exactly BIF falls on the continuum from normal IQ to ID, rather than considering it only from a pure IQ point of view.

Sub-aim 3: *Increased understanding of the societal aspects of BIF*.

BIF is a common phenomenon in society, and so are issues that it raises for society and its welfare systems. Although it is not the aim of this dissertation to systematically cover these issues, a better understanding is endeavoured by examining the following areas: education, employment, unemployment and the use of services, from the point of view of possible social exclusion, recognition and societal support.

The primary motivation for this dissertation was scientific: to increase systematic, research-based knowledge of this neglected topic in scientific literature. However, as a clinician with first-hand experience on this phenomenon and a deep sense of its invisibility in our society and diagnostic manuals, I also had more pragmatic and instrumental motivations in mind. Along with gaining a better scientific understanding of this phenomenon, we can also support its recognition in society, welfare systems and practices. Therefore, the true motivation of this dissertation was the better scientific understanding to promote better societal awareness and support for the better life of people with BIF.

2 METHODS

2.1 Systematic literature review (Study I)

In Study I, empirical group evidence that fit pre-specified eligibility criteria was systematically collated in order to answer research questions. An explicit, systematic method selected with a view to minimising bias was used. Table 1 shows eligibility criteria, relevant topics, details of database searches and methods for handling data, which were used in the study selection process. The table also shows four journals, which were those commonly found in the reference lists of already included studies, and which were manually searched in order to find additional studies. Through database searches, 1,726 abstracts were found, 203 full texts were evaluated, and 49 studies were included in the review. During the study selection process, two reliability checks were conducted.

The methodological quality of the included studies was analysed using the criteria list for nonrandomised studies created by Dalemans et al. (2008). The list consisted of 15 items. Two of the authors (MP and VN) independently evaluated the quality of all the studies. Initial agreement on the evaluations was 91% (Cohen's kappa = 0.78), and final consensus was reached by discussing the differences.

TABLE 1 Study selection methods in Study I. Information about eligibility criteria, relevant issues, search strategies and methods for handling data of the included studies in systematic review.

Eligibility criteria	- IQ around 70-85 - all age groups - group studies - reporting topic relevant to our study questions
Relevant topics	- neuropsychological - social - mental health - independence

	- risk - preventive
Database searches	Databases: - ERIC (Educational Resources Information Center, 1960 to 2012) - ISI (Web of Science, 1945 to 2012) - MEDLINE (1950 to 2012) - PsycINFO (1887 to 2012) Language: English Search Terms: - borderline developmental disability - borderline intellectual functioning - borderline intellectual disability - borderline IQ - borderline learning disability - borderline mental retardation - minor intellectual disability - general learning disability - general learning disorder - grey-area children - marginal learners - slow learners - garden variety slow learners - non-specific learning disabilities
Journals of additional searches (2000-2012)	- American Journal on Intellectual and Developmental Disabilities - Intellectual and Developmental Disabilities - Journal of Applied Research in Intellectual Disabilities - Journal of Intellectual Disability Research
Methods for handling data	RefWorks: - Reference management program Extraction sheet: - Details of excluded studies: author, publication year, population characteristics, aim, results and conclusions, reasons for exclusion Inclusion sheet: - Details of included studies: author, year, country, journal, number of participants, gender, age, term used, data collection year, how data was collected, IQ score and how it was measured, aims, hypotheses, main outcomes, main conclusions

2.2 Participants (Studies II & III)

In Studies II and III, a sample from a population-based, multidisciplinary (medicine, psychology, social sciences) Finland-in-Miniature study was used. The data were originally collected in 1962 from 57 municipalities chosen to represent Finland in terms of economic, social and occupational issues as well as in its two official languages, Finnish and Swedish. The aim of the original study was to investigate the number of and need for care for persons with ID in Finland. Officials, such as teachers, doctors and nurses, of the municipalities were instructed to refer to the study all cases of persons from two to 64 years of age who were suspected of having ID, or had been diagnosed with ID.

Altogether, 9.4% (416,973 persons) of the Finnish population at the time were inhabitants of the participating municipalities. As Figure 5 shows, 4,013 persons were referred for examination, of which 2,372 persons with an IQ < 70 were assigned the diagnosis of ID. For the purpose of Studies II and III, the remaining 1,376 persons were divided into two groups based on their levels of intelligence. The group of participants with BIF (n = 760), with an IQ from 70 to 85, was identified. A comparison group was also identified with participants with average intelligence, IQ > 85 (n = 527). This group was designated as people with LPs because they also had been sent for original examination with the assumption that they had ID and thus must have had visible adaptive problems. Participants in Studies II and III ranged from five to 17 years of age, so it was likely that most of their problems involved some kind of learning and/or behavioural difficulties at school. Of those with an ID diagnosis, an MID group (n = 1,101) with IQs from 50 to 69 were included in the study as well to serve as a comparison group. To reduce the age heterogeneity among the study groups, only participants aged 5–17 years in 1962 were included in the final sample, resulting in 537, 377 and 368 participants in the BIF, MID and LP groups, respectively.

In 1998, in the BIF, MID and LP groups, 121 (22.5%), 65 (17.2%) and 84 (22.8%) persons, respectively, were lost due to deaths as well as failures in identifying social security codes (which connected their data to the national registers) that were usually caused by incorrect names or missing date of birth information in the 1962 data. Loss analysis of the original data showed no systematic selection based on age or gender. The final data of Study II included 416, 312 and 284 participants in the BIF, MID and LP groups, respectively. The final data of Study III was composed of those who returned the Living Conditions Questionnaire: 156 (response rate 37.5%), 179 (response rate 57.4%) and 91 (response rate 32.0%) participants in the BIF, MID and LP groups, respectively (see Figure 5).

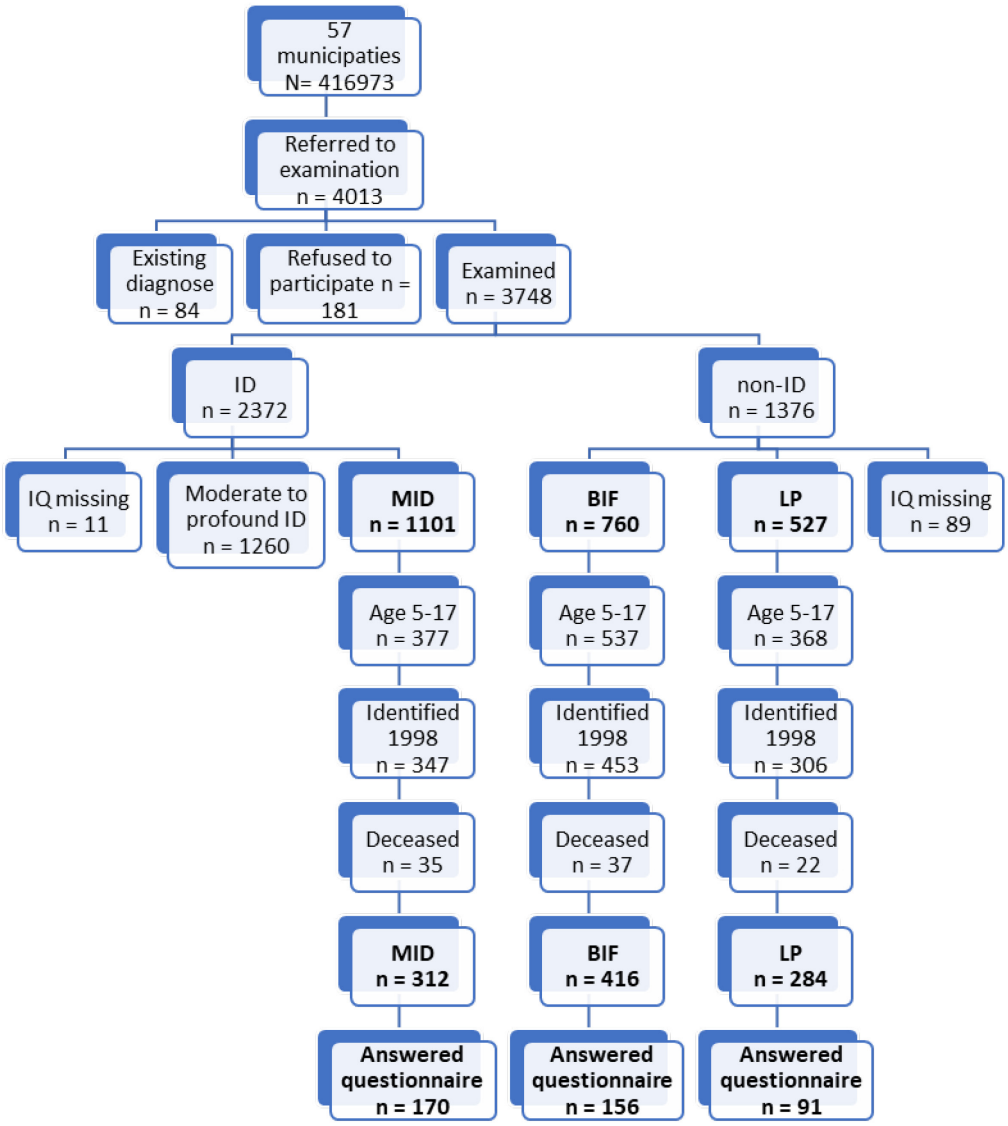

FIGURE 5 Participants in the Finland-in-Miniature study.

2.3 Measures and design (Studies II & III)

2.3.1 IQ assessment in 1962 (Studies II & III)

In 1962, psychologists conducted a screening test for participants to examine their level of intelligence. If the test indicated an IQ of one *SD* below average, additional tests were conducted to obtain a more specific estimate of the level of intelligence. Table 2 shows a list of the screening tests and additional tests. Some of the participants (42 and 141 in the BIF and LP groups, respectively) were evaluated using only background information about school performance, work

or other skills needed in life. Detailed descriptions and reliabilities of the tests can be found in original publications from Ruoppila (1966), and from a more recent publication by Ruoppila and Iivanainen (2011).

TABLE 2 Tests used to measure IQ in 1962.

Test types	Test	Reference
Screening tests	Kohs block test/KTK C5	Elonen et al. 1961 a
	Kohs-Häkkinen Square Test/ KTK A 3	Elonen et al. 1961 b
	Häkkinen's Square Test	Häkkinen 1958
Additional tests	KTK Performance Scale	Elonen et al. 1961 b
	Vocabulary Test	Siloma 1960
	Picture Vocabulary Test	Ruoppila 1963
	Ravens Coloured Progressive Matrices	Raven 1956 a, b
	Form Board Test	Kääriäinen 1962
	Tests for reading, writing, and mathematics	

2.3.2 National registers (Studies II & III)

To obtain information about utilisation of services and comparison information about the GP, different national registers were used. An overview of the registers is provided in Table 3.

TABLE 3 Overview of the national registers used in Studies II and III. Different national registers were used in order to obtain information about utilisation of services in study groups (BIF, MID, LP), as well as matching information from GP regarding utilization of services, family, work, and satisfaction.

Topic	Study II	Study III	Statistic obtained from
Psychiatric inpatient care	X		Study groups: STAKES [a] GP: THL [b]
Disability pension	X		Study groups: SII [c] GP: Statistical Yearbook of pensioners in Finland 1998 (SII)
Inpatient health care	X		Study groups: STAKES GP: Sotkanet [d]
ID services	X		Study groups: STAKES
Partnership		X	GP: Statistical Yearbook of Finland 1999 (table 29)
Education		X	GP: Statistical Yearbook of Finland 1999 (table 468)

Work		X	GP: Statistical Yearbook of Finland 1999 (table 333)
No of children		X	GP: Official Statistics of Finland 2016
Satisfaction with job		X	GP: Sotkanet
Satisfaction with life		X	GP: EVA [e]
Satisfaction with subsistence		X	GP: EVA

Note: [a] The National Research and Developmental Centre for Welfare and Health, [b] Finnish Institute for Health and Welfare, [c] The Social Insurance Institution, [d] Indicator Bank maintained by THL, [e] Finnish Business and Policy Forum

2.3.3 Living Conditions Questionnaire (Study III)

A postal questionnaire was sent to all participants who were alive in 1998 and whose postal address was known. The questionnaire had 35 main questions and included several sub-questions. Questions concerning family, education, work and satisfaction, altogether 13, were included in Study III. Table 4 shows these questions in detail and the method that was used to answer the questions. Most of the questions were answered by marking a cross in a box, but there were also open-ended questions in which participants were allowed to answer in writing. The questionnaire in general and the details about the content and execution of the questionnaire are described by Vesala and Matikka (2000).

2.3.4 Statistical analysis (Studies II & III)

Statistical analyses were conducted using SPSS software. In group comparisons (MID, BIF and LP) of Study II, chi-square tests and risk ratios were used. In Study III, differences among the groups were tested by chi-square and one-way analysis of variance (ANOVA).

TABLE 4 Questions on the Living Conditions Questionnaire.

Question	Sub-questions	Answering method
1. Are you	Single, Married, Cohabited, Divorced, Widow	Mark the relevant box
2. Do you have living children?	No, Yes; Number of children:	Mark the relevant box / open answer
19. At the moment, are you	Working full-time; Working part-time; Unemployed or laid-off; Pensioner; Elsewhere, where:	Mark the relevant box (no; yes) / open answer

20. What is your current or was your former occupation?		Open answer
21. What schools you have attended?	Elementary school; Vocational school or vocational courses; Upper secondary school; University; Other:	Mark the relevant box (not at all; partly; whole) /open answer
22. How many years of schooling you have?	_____ years	Open answer
23. How satisfied you are with following in your life?	Health; Subsistence; Living conditions; Partnership; Relation with children; Relation with friends; Relation with neighbour; Hobbies; Services; Job; Education; Life in general	Mark the relevant box (Likert-scale 4: not at all satisfied; to some extent satisfied; fairly satisfied; very satisfied)
25. Have you ever felt different or excluded?	No; Yes	Mark the relevant box
26. If yes, in which situations?	At childhood home; School; Work; With friends; Hobbies; With neighbours; Elsewhere, where:	Mark the relevant box (no; yes) /open answer
27. In which things have you succeeded the most in your life?		Open answer
28. In which things have you failed in your life?		Open answer
29. What things are difficult in your life?		Open answer
35. What things bring joy and satisfaction in your life?		Open answer

2.4 Ethical issues

Concerning Studies II and III, several research permits were requested in 1998 by the researchers involved in the Finland-in-Miniature project. The study design was thoroughly examined by various offices, such as the Data Protection Ombudsman, Ministry of Social Affairs and Health, Ministry of Education, STAKES, National Archives Service of Finland, Population Register Centre of Finland, Statistics Finland, and Social Insurance Institution, which all granted the necessary research permits. In 2010, a research permit for collecting data, from

the original 1962 data, concerning BIF was granted by the National Archives Service of Finland.

3 OVERVIEW OF THE ORIGINAL STUDIES

3.1 Study I: Borderline intellectual functioning: A systematic literature review

This study was the first literature review to be published concerning BIF. The aims of the study were to increase knowledge about current literature, problems, risk factors and preventive factors around BIF and to bring the topic up for societal and scientific discussion.

The literature related to people with BIF was systematically reviewed to summarise current knowledge. A total of 1,726 citations were found through database searches, of which only 49 studies fulfilled the eligibility criteria. Studies were eligible when IQ was around 70 to 85, and the topic was related to neuropsychological, social, mental health, work, marriage, risks or preventive factors.

The results concerning details of the included literature showed that, in general, the information on BIF was fragmentary, and there were few studies available for each topic. Most of the studies, 76%, were published after 2000, and most often in the United States and the Netherlands (39% and 18%, respectively). The majority of the studies focused on children and adolescents (81%). Only 8% of studies were conducted with GP samples. The most often used term was 'borderline intellectual functioning', which was used in 31% of the studies. The methodological quality among the studies varied greatly (see Table 2 in Study II). Six studies dealing with mental health scored high on quality evaluation (mean = 12.8 of a total of 15). These studies also had large sample sizes, with many being population-based samples.

Results of the neurocognitive functioning (e.g. reading, writing, math, memory, executive functioning and motor skills) showed that in most of the measurements, children with BIF performed more poorly than peers with average intelligence. Of the total 52 reported skills, the performance was at the same level in only seven skills (visual-spatial memory, complex memory, spelling, rapid naming, text reading, visual memory, response inhibition).

However, all of these skills were also reported as being poorer for children with BIF in another study of the review.

Social behaviour was found to be different between people with BIF and the general population. Differences were seen in play behaviour, recognition of emotions, social information processing, social participation and antisocial behaviour. Children were reported to be at risk for poor parenting because of the lack of explanation for the child's difficulties. In addition, people with BIF were overrepresented in criminal samples.

Mental health problems were found to be more prevalent among subjects with BIF than in the GP, whether comparing existing diagnoses or symptoms. Adults with BIF were found to receive less treatment than the GP group and to be more likely treated with medication and less likely with counselling.

People with BIF held lower-skilled jobs, earned lower wages, and had longer careers in the same job than their peers in the GP.

Potential risk factors for BIF were identified as low birth weight, poor family environment, low level of maternal education, exposure to toxic metals, maternal drug use during pregnancy, and familial history of ID. Preventive factors, that is, things that seemed to have a positive effect on the lives of the people with BIF, were identified: education (good school records, education beyond high school, more years of education), social contacts (supportive parents, role models for achievements, warm relationships) and some personal qualities (flexibility to change, childhood competence). Risk and preventive factors were not specific to BIF but were rather general.

It was concluded that, despite the obvious everyday problems people with BIF face, the issue was almost invisible in the field of research. The need for longitudinal and population-based studies focusing on people with BIF was highlighted. Also, the need for societal discussions and flexible support systems was emphasised.

3.2 Study II: Borderline intellectual functioning: An increased risk of severe psychiatric problems and inability to work

The aim of this study was to retrospectively examine the utilisation of services (disability pension, psychiatric inpatient care, inpatient health care, and services for people with ID) by people with BIF using national registers of Finland. The utilisation of services was compared with that of GP, as well as with the sample's two other study groups: people with MID and those facing learning problems at school and with average intelligence (LP).

A population-based sample, Finland-in-Miniature, was gathered in 1962 and followed until 1998. Participants were collected from 57 municipalities chosen to represent Finland in terms of economic, social and occupational characteristics as well as language (N = 416,973). For the purpose of this study,

three groups were formed: BIF (n = 416), MID (n = 312) and LP (n = 284). In 1998, the participants were from 41 to 53 years of age.

The results showed that participants with BIF were granted disability pensions 2.7 times more often than GPs of the same age. Also, they had been inpatients in a psychiatric hospital 3.4 times more often than their GP peers. Contrary to expectations, the rates of inpatient health care were similar between participants with BIF and the GPs, although people with BIF had spent longer periods in care. More than 11% had used ID services, which indicates that these participants had been diagnosed with ID at some point in their lives.

A comparison among the three study groups systematically showed that the most services were used by participants with MID, with fewer used by those with BIF and the least by those with LP. However, when psychiatric inpatient care was examined in detail from 1987 onward, participants with BIF were more often inpatients as compared with the two other groups. From the 1970s onward, there was a trend in Finland towards reducing placements in psychiatric hospitals, and from the 1980s onward, there was a trend of deinstitutionalisation of people with ID from psychiatric hospitals (where they had been systematically placed previously). This trend of reducing inpatients and developing outpatient care was seen in the dropping rates of inpatients of the MID and LP groups by the end of the 1990s. However, this lowering trend was not seen in people with BIF, which suggested more severe mental health problems than in the other two groups.

It was concluded that people with BIF have an increased risk of inability to work and severe mental health problems. Moreover, mental health problems seemed more severe in people with BIF than in those with MID or LP. Cumulative adverse life experiences were seen as a possible cause of high rates of psychiatric problems and disability pensions. It was highlighted that psychiatric treatment and diagnosis with people with BIF should take into account the lower-than-average cognitive capacity. Finally, the crucial need for an increase in knowledge about BIF in society was emphasised.

3.3 Study III: Borderline intellectual functioning and vulnerability in education, employment and family

The aim of this study was to retrospectively examine the lives (family, education, work, satisfaction in life) of people with BIF using a questionnaire, which was sent to the participants in 1998. To the best of our knowledge, this was the first study to examine the satisfaction in life of people with BIF. Results were compared with those of GP, as well as with the two other study groups: MID and LP. Matching information about GP was searched through national registers and/or surveys.

As in Study II, the population-based representative sample, Finland-in-Miniature, was used in this study. The three study groups were based on the

same grouping as in Study II, but the final data were composed of those who had returned the Living Conditions Questionnaire: BIF (n = 156), MID (n = 179) and LP (n = 91).

Results showed that 64% of the people with BIF had had a partnership, whereas the rate was 83% with peers in the GP. There were no differences in the average number of children. More than 90% had completed elementary school, of which 37% had completed secondary school. In the GP, 66% had completed secondary school. In the BIF group, only 44% were employed, 23% were unemployed and 31% had been granted disability pensions. Matching rates in the GP were 88%, 8.9% and 5.3%, respectively. The two most common occupational categories were 'industrial production' and 'services', in which 75% of the occupations belonged. The three most common categories in the GP were technical, natural and social science, humanistic and artistic work (29.8%), industrial production (20.7%) and administrative, managerial and clerical work (16.5%). Jobs that people with BIF held were not commonly valued by the general public, as only six of the occupations (police, businessman, nurse, engineer, lecturer, care-giver) were among the 100 most valued occupations in Finland.

Almost 50% had experienced feelings of exclusion, the most often at school (24%) but often at their childhood home as well (17%). Overall, people with BIF were fairly satisfied with their lives. Relation to children, living conditions and life in general brought the most satisfaction. More than 80% rated these as at least fairly satisfying. Job, economy, and education brought the least satisfaction, proportions for at least satisfied were 67 %; 56 %; 54 %, respectively. Differences in the GP were seen with satisfaction with job and economy, where proportions were 84% and 67%, respectively.

Regarding family, education and work, people with MID had lower rates, and people with LP had higher rates than their counterparts with BIF. However, there were no major differences regarding life satisfaction and feelings of exclusion. The only exception was that people with MID were more satisfied with their economy than the two other groups.

It was concluded that people with BIF were more vulnerable than their peers in the GP group regarding partnership, family, education, work and life satisfaction. Based on findings among the MID, BIF and LP groups, it seemed that cognitive and adaptive functioning had an impact on family, education and work, but not necessarily on life satisfaction and feelings of exclusion. Regarding work, it was concluded that despite people with BIF often having, by general opinion, unvalued and low-skilled jobs, many felt at least fairly satisfied, and had feelings of success with their work. It was highlighted how important it is that society finds means to help secure and maintain jobs for people with BIF.

4 DISCUSSION

The aim of this dissertation was to increase systematic knowledge of BIF at the individual, neurocognitive and societal levels. The results of the studies discussed here show that people with BIF have difficulties coping within all of these three perspectives. The results indicated threats to individual well-being throughout the lifespan, evident neurocognitive difficulties, and the need for societal recognition and discussions.

4.1 Vulnerability in lifespan

Results of this thesis indicate that people with BIF have vulnerabilities in many stages of their lifespan, both as a child and as an adult. In general, it could be said that in relation to all the aspects that were studied, people with BIF seemed to struggle more than their peers with average intelligence. In Section 1.2.3., the current literature was reviewed and challenges faced by people with BIF in different stages of life were examined. It was found that people with BIF had evident risks for well-being throughout their lifespan. The results described in this dissertation confirm this conclusion. Figure 6 shows the threats to individual well-being in each stage of the lifespan, as determined by Studies I, II and III. There is no information about possible threats in old age because of the lack of research concerning old age and BIF. It is evident, however, that except for old age, in every other stage, people with BIF have manifold risks to their well-being.

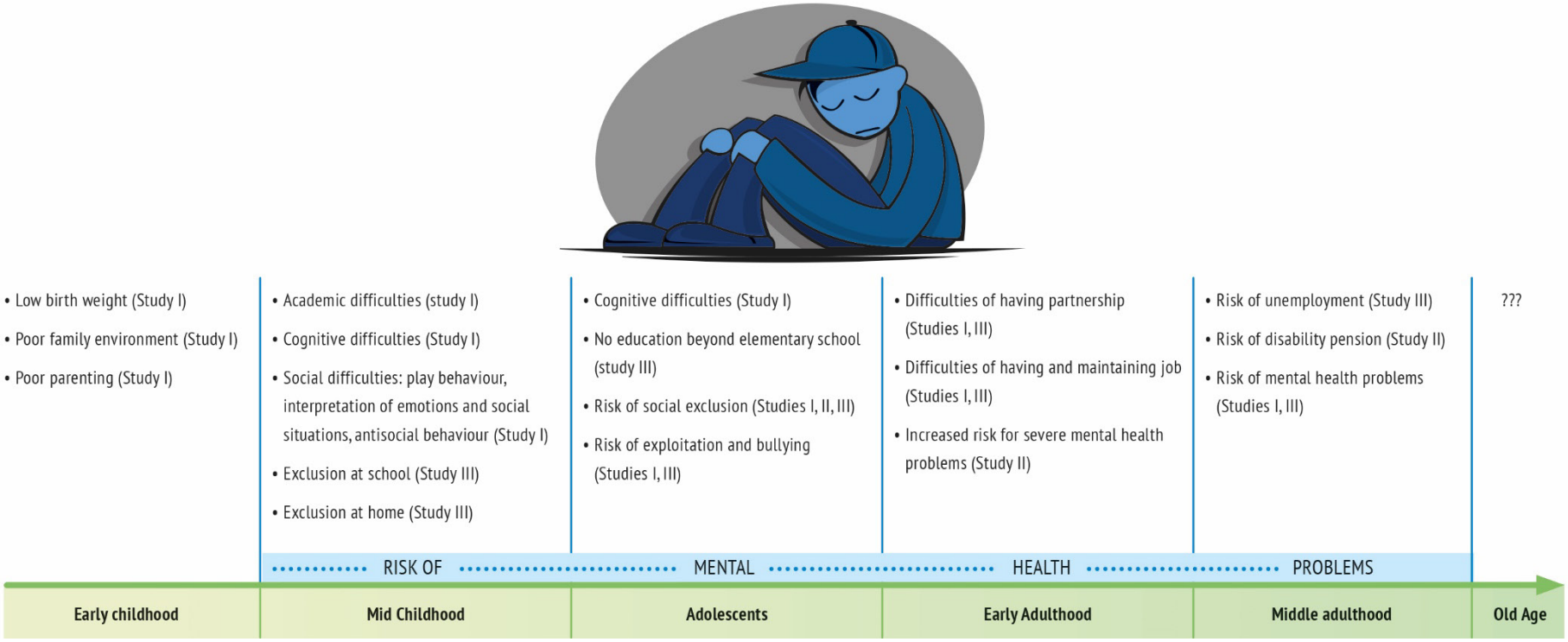

FIGURE 6 Threats to individual well-being at each stage of life.

As shown in Figure 6, low birth weight, poor family environment and risk for poor parenting create threats to early childhood well-being. During school age, academic difficulties (discussed in Section 4.2), differences in social behaviour compared with peers, mental health problems and risk for exclusion were evident. Literature concerning social behaviour showed that there were differences in play behaviour, recognition of emotions, social information processing, social participation and antisocial behaviour between children with BIF and their peers with average intelligence. Study III showed that almost half of the adults with BIF experienced exclusion, most often at school or at their childhood home. The results concerning social difficulties and exclusion indicate that in childhood, BIF is not just a problem of slower learning or academic failure, but it can have a major effect on social relations and friendships. If the interpretation of emotions, social clues or subtle messages of peers is difficult, one may end up being bullied or excluded from the group.

As an adolescent, mental health problems, difficulties in learning and low prevalence of education beyond elementary school create a risk for social exclusion (discussed in detail in Section 4.3). Due to difficulties in social behaviour, adolescents also have a risk of being bullied. In addition, they have a greater risk for different forms of exploitation than their peers because of difficulties in the interpretation of social situations or difficulties in social reasoning. For example, Baglio et al. (2016) showed that a 'social map', or Theory of mind, was poorly developed with children with BIF. As adults, people with BIF had fewer partnerships, less education and less employment. They also had a significantly higher number of disability pensions than their peers. As a young adult, maintaining a job can be difficult. An interesting finding was reported about young adults in Study II, as they had 4.5 times more increased risk for severe mental health problems than their peers in the GP group. This could be explained by the fact that as a young adult between the ages of 20 and 30, there is a lot to deal with: education, work, starting a family, having your own home etc. These are the years when independent life is built, and this may be a particularly challenging task for young adults with BIF. Overall, a risk of increased mental health problems in all age groups was shown in Studies I and II. The comorbidity of mental health problems and BIF are dealt with in more detail in the next section, due to their high incidence and disabling nature.

4.1.1 BIF and mental health

In Study I, the reviewed literature showed that mental health diagnoses and symptoms were more prevalent with children, adolescents and adults with BIF than with peers. In Study II, people with BIF were in a psychiatric hospital 3.4 times more often than peers in the GP. For young adults, the risk was even higher, 4.5 times more than peers. These results are in line with growing evidence that people with BIF have more mental health problems than what is seen in the GP (see Section 1.2.2.3). Reasons behind more prevalent mental

health symptoms may be adverse life experiences, especially in childhood, which cumulate and cause mental health issues, as was proposed by Hassiotis et al. (2019). It is easy to see, as shown in Figure 6, how negative life experiences can cumulate and eventually lead to mental health problems. There are not many studies concerning the possible reasons behind BIF and mental health problems, but it seems that lower-than-average cognitive functioning does not solely explain the issue. In Study II, people with BIF seemed to have more psychiatric problems than did people with MID. As the measured IQ in the MID group was lower than that of the BIF group, it is safe to say that things other than mere intelligence are reasons for their mental health problems. Wieland and ten Doesschate (2018) also pointed out that people with BIF have been reported to have poorer mental health and to have more severe personal problems than people with MID. What could then explain this high prevalence of mental health problems, particularly with BIF? Future research should at least cover the next potential area. It seems that many people with BIF struggle with the demand to fit in or perform at a 'normal' level, and they are required to perform at their highest cognitive level at all times. This would be very stressing for anybody and might lead to exhaustion. Also, feelings of not being able, or being worthless, might be present when one constantly fails to live up to expectations and does not understand why. This demand of 'performing as normal' and the reality of not being able to do so might explain why so many people with BIF end up having mental health issues. With people with ID, the situation is often different as they and their surroundings have, due to their official diagnoses, a better understanding of their skills.

As some researchers have strongly addressed, in mental health care, lower-than-average intelligence should be taken into account (Hassiotis et al., 2008; Wieneland & ten Doesschate, 2018), as neglecting it can lead to adverse treatment effects. In the Netherlands, a recent study found that in units of mental health services, the personnel had a clear awareness of the high prevalence of patients with BIF; the estimation was around 30%. However, most of the services did not routinely estimate an IQ, and more than half of the places indicated not having expertise and knowledge on mental health problems and BIF (Wieneland & ten Doesschate, 2018).

There are few studies concerning BIF and efficient treatment for mental health problems. Another study from the Netherlands (Neijmeijer et al., 2020) reported on Flexible Assertive Community Treatment (FACT), a treatment designed for people with BIF or MID and mental health problems. FACT has become the standard for organising care for people with severe mental illness in the Netherlands, and it has also further developed to serve groups with special needs, such as BIF/MID and mental health problems or challenging behaviour. FACT teams include several health service providers from a range of disciplines, such as psychiatrists, behavioural therapists, social workers, psychiatric nurses and addiction specialists. They provide treatment and support with daily activities, housing, finances and administration, work and

day structure. The purpose is to support people in their direct needs and in their own environment, and to improve the client's functioning and participation in society. Care is long-term, and teams stay in touch in case of admission to a psychiatric hospital or detention. In practice, staff members visit clients at their home, and clients can reach team staff if they need help by phone, text message or email. A longitudinal study of the FACT and people with BIF/MID showed in general that improvement was measured in psychological and social functioning, admission rates to psychiatric hospitals and the level of social disturbance (Neijmeijer et al., 2019). A study focusing on the experiences of FACT service users showed that most users highly appreciated contact with the staff and the emotional and practical help. Most clients experienced improvement over time. The authors concluded that from the perspective of service users, FACT appears to have an added value (Neijmeijer et al., 2020).

4.1.2 Means of support for individual well-being

Clearly, there is enough evidence to conclude that people with BIF have manifold threats to their well-being throughout their lifespan, apart from old age, due to the lack of research. These threats should be recognised and means of support should be enabled. It may be that many forms of support that would benefit people with BIF already exist, but are not routinely available to them. At this point, we can only speculate concerning the means of support, as the research on the topic is seriously lacking. There are only a few studies reporting support, interventions or training. In Figure 7, possible means of support, suggested by some studies concerning BIF, are listed in every age stage to counter the threats. These means are discussed in more detail below.

In childhood, early detection of BIF and possible differences in cognitive development would be important in order to start early support. Fenning et al. (2007, 2014) showed that children with BIF were in danger of poor parenting and that many parents seemed to lack understanding of the cognitive deficits of their child, which increased negative parenting. They found that awareness of the deficits increased positive parenting, and pointed out the importance of a family as a target of prevention and intervention. Thus, based on these studies by Fenning et al., it could be concluded that educating parents about the cognitive skills of their child might support them to be more understanding parents, and early family intervention might support parents in engaging in positive parenting methods. Family intervention was shown to be efficient by Schuiringa et al. (2016), as they studied children with BIF and behaviour problems and their parents, who participated in group intervention (with separate groups for children and parents). As a result, problem behaviour decreased, positive parenting increased and the parent–child relationship improved.

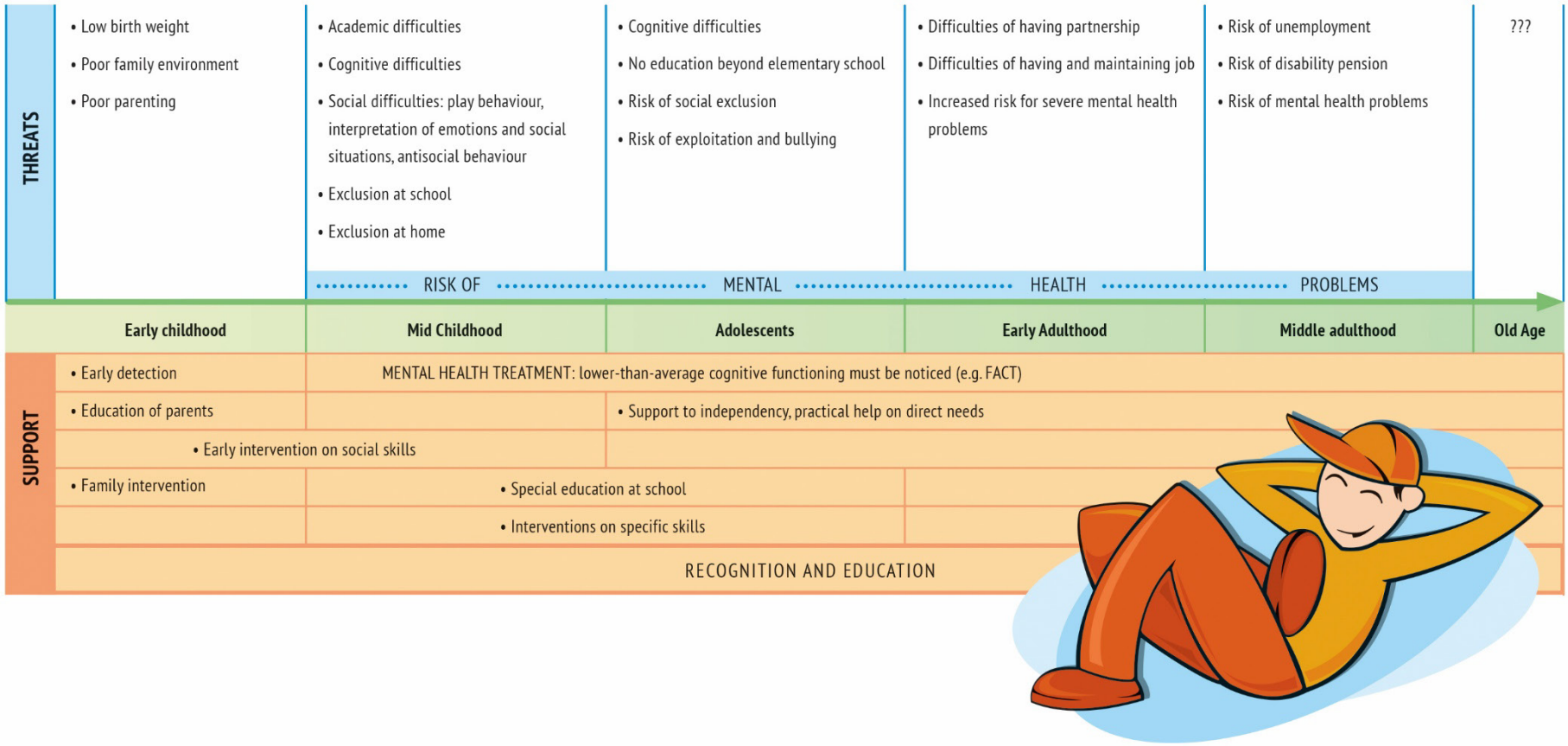

FIGURE 7 Threats and possible means of support at each stage of life.

Children with BIF seem to have many social difficulties compared with their peers. Baglio et al. (2016) studied skills related to Theory of Mind, and found that children with BIF had deficits in ToM, which was connected to deficits in executive function and meta-representation competences. The authors stated that an early intervention is essential to support mentalisation development. Furthermore, they concluded that in children with BIF, the timing of intervention is crucial, as the most advantageous window of opportunity is open in childhood. Thus, early intervention in social skills during childhood might benefit people with BIF in their everyday social life. It seems, however, that adolescents with BIF might also benefit from social competence training. Nestler and Goldbeck (2011) studied adolescents from vocational education with BIF (n = 40) with a group intervention of social competence training. After three months of training, some parts of social competence were improved, and the authors concluded that the method seemed promising, although more research has to focus on the long-term effects of this type of training.

As for school-aged children and adolescents, special education at school should be routinely given support for dealing with learning difficulties. Special education teachers should be involved to at least coordinate the studies when it seems that learning difficulties in several subjects are present. There are only a few studies concerning BIF and intervention on specific skills. Van der Molen et al. (2010) studied working memory and computer-based interventions with adolescents with BIF and mild ID (n = 95). They found that computer-based training had positive effects on verbal short-term memory, visual short-term memory, arithmetic skills and memorising a story. The author concluded that computerised working memory training can be effective with adolescents with BIF. Jansen et al. (2012) also used a computer-based method to study the effectiveness of math training with adolescents with BIF and mild ID (; n = 58). After five weeks of training, their math skills had significantly improved. The authors concluded that sufficient math training can improve math abilities in adolescents with BIF. Thus, even though there have not been many intervention studies on the topic, it seems that intervention for specific skills benefits people with BIF.

FACT is a model that is designed to treat mental health problems with people with BIF, as was discussed in the section dealing with BIF and mental health (4.1.1). The benefit of FACT is that it is designed for treating lower-than-average cognitive functioning. Something similar, a lighter version maybe, could be utilised in order to support adults with BIF without mental health issues, as well. In the FACT model, clients can get practical help whenever they need it by text messaging or emailing a contact person. That is, if they need help for technical support or support for running errands, filling applications etc., they can get it, and there is always someone who can answer their questions. Many people with BIF would benefit from this kind of service, focusing on direct needs, which would help them independently manage their lives.

Overall, recognition and education are forms of support that at least need to be executed in every stage of the lifespan. People with BIF need to be noticed and education on the nature of BIF needs to be provided to the person in question and to surrounding people (parents, teachers, spouse etc.).

4.2 Neurocognitive difficulties are evident

According to the findings of Study I, it is evident that children with BIF have difficulties in academic and cognitive skills. They performed more poorly than their peers both in academic tasks and cognitive tasks: out of 52 different measured cognitive skills, their performance was poorer in 45 of them. Results of Study I and other recent studies (see Section 1.2.2.1) show that working memory and mathematical skills in particular have been reported to be clearly poorer, although children with BIF were outperformed by peers in all areas, such as reading, writing and related skills, memory, executive functioning and motor skills. The results of poorer than average cognitive skills are expected because of the lower-than-average IQ of people with BIF, which is calculated by measuring these cognitive skills. In addition, their difficulties in academic skills as compared with peers can be expected as well, because academic learning is based on cognitive skills. Lower-than-average cognitive function should also be addressed in real-life settings, such as schools, for example, by lowering expectations in difficult academic subjects, supporting students academically, and providing alternative and realistic routes to education. However, this should be done by taking into account the heterogenic nature of BIF: even though their cognitive performance at the group level seems to be poorer than that of peers, at the individual level, there might be great variation in their skills.

One neurocognitive aim was to study the possible risk and preventive factors concerning BIF. Study I found that reported findings of these factors were not specific to BIF but rather common to many neuropsychiatric and neurodevelopmental disorders. Low birth weight, poor family environment, low level of maternal education, exposure to toxic metals, maternal drug use during pregnancy and familiar history of ID were detected as possible risk factors for BIF. Education, social contacts, and some personal qualities were detected as possible preventive factors.

4.2.1 BIF, MID and SLD

BIF can be viewed as being in between of continuum ranging from average intelligence to intellectual disabilities, although it is difficult to know exactly when one condition ends and another begins, as was described earlier with the example of sorites paradox (see Section 1.2.1.2). Particularly difficult is this differentiation between BIF and people with average intelligence and SLD, as academic achievement may seem similar for these two groups. From this perspective, an important aim of the dissertation was to compare BIF to both ends

of the continuum, with MID and SLD, in order to form a picture of what is similar and what is different and to determine where BIF falls on the continuum ranging from average intelligence to ID in terms of issues other than pure IQ. An interesting question was also whether or not better cognitive capacity automatically means better outcomes in life.

Table 5 lists the results from all three studies discussed in this dissertation, and it shows a comparison of BIF and MID and BIF and SLD. For the sake of clarifying the terms used in the studies, I wish to point out that in the original Studies II and III, instead of the term specific learning disability (SLD), the term learning problem (LP) was used. The term LP was chosen because it was not clear what exact difficulties these people had. However, they had problems that were significant enough that they were sent to investigation for ID. Thus, they had an average IQ and problems in learning, possibly in reading, spelling, math or, for example, problems in executive functioning. Here, they are referred to as people with SLD.

As Table 5 shows, in general, people with MID had less favourable outcomes in many areas of life when compared with people with BIF: poorer academic and cognitive skills, fewer partnerships, less education and employment and more disability pensions. However, there were some exceptions, as they had less psychiatric inpatient care, less unemployment and more satisfaction with subsistence. An unexpected finding that people with BIF were more often inpatients in psychiatric hospitals than peers with MID indicates that people with BIF might have had more severe mental health problems, which could not be treated with outpatient care. Another explanation might be that people with MID were treated elsewhere, for example, within services targeted to people with ID. There are some similar findings showing that people with BIF have more mental health problems than people with MID (Wieland & ten Doesschate, 2018). The reasons behind this difference with mental health problems as seen in our study might be related to the fact that in Finland, people with MID have access to services and support targeted to them. They are, for example, entitled to support targeting independent living and different benefits, such as disability pensions. This support is not available for people with BIF, even though they might have similar challenges in life, and without 'light' support for everyday problems, they may end up having severe mental health problems with the need for 'heavy' support. Another unexpected finding was that people with MID were more satisfied with their subsistence than their peers with BIF. This might be explained by the fact that although people with MID had less employment than their peers with BIF, they also had less unemployment because of high rates of disablement pensions. Thus, even though they had low income, their subsistence was secured, where many of those with BIF were unemployed, or their income might have been insecure because of non-standard working conditions.

TABLE 5 Comparison to MID and SLD.

Issues reported by studies I, II, III	*MID compared to BIF*	*SLD compared to BIF*
Cognitive skills (study I)	poorer / same [a]	better / same [b]
Academic skills (study I)	poorer / same [c]	better / same [d]
ID services (study II)	more	less
Health care (study II)	same	same
Disability pension (study II)	more	less
Psychiatric care (study II)	less	less
Partnership (study III)	less	more
Education after elementary school (study III)	less	more
Employment (study III)	less	more
Unemployment (study III)	less	less
Satisfaction (overall) (study III)	same	same
Satisfaction to subsistence (study III)	more	same
Feelings of exclusion (study III)	same	same

Note.
[a] Poorer: locomotor skills, motor performance, working memory, visual-spatial memory, complex memory; Same: object control/motor skills, executive functioning, phonological memory
[b] Better: phonological processing, rapid naming, auditory processing, memory, speed of processing, sustained attention, learning strategies, verbal memory, visual-spatial memory; Same: working memory, verbal short-term memory, rapid naming
[c] Poorer: reading; Same: arithmetic, spelling
[d] Better: Reading comprehension, arithmetic; Same: reading, spelling.

Table 5 shows that most often people with SLD had more favourable outcomes in different areas of life than people with BIF. They used fewer social services and had more partnerships, education and employment. The review article showed that in most of the cognitive and academic skills, children with BIF were outperformed by their peers with SLD. However, some studies (Bonifacci & Snowling, 2008; Kortteinen et al., 2009; Maehler & Schuchardt, 2009) reported performance of the same level when a particular skill was central to the SLD in question. That is, the same level of performance was reported for children with BIF and peers with SLD who had reading disabilities regarding reading, spelling, rapid naming, verbal short-term memory and working memory. This indicates that children with BIF performed at the same level as those who had specific learning disabilities in terms of particular skills, either measuring the academic skill (e.g. reading, spelling) or measuring the cognitive background skills related to this academic skill (e.g. rapid naming, verbal short-term memory). Nevertheless, more research is needed on the differences and similarities of skills related to SLD (reading, writing, math) and performance of children with BIF and peers with SLD. Studies concerning effective support are also needed, for example, to determine if children with BIF would benefit from the same, already

existing support systems as children with SLD or if support should be different in order to be more efficient.

Overall, the studies discussed in this dissertation support the idea that BIF is in between of the continuum from normal intellectual functioning to intellectual disabilities. In general, people with BIF performed more poorly than those with average intelligence and SLD and better than those with MID. However, the results also indicate that some features are unique to BIF, which puts people with BIF in a more vulnerable position compared with the two other groups. One is severe mental health problems, which seemed to be more prevalent among people with BIF than among other groups. Another is unsecure employment status in the BIF group, as people with SLD were more often employed, and people with MID were more often pensioners. Thus, in both groups, income was more secure than within the BIF group.

So, does a higher IQ automatically mean a better outcome in life? Based on our findings, it seems that in many life areas, higher cognitive capacity means a better outcome, but this is not the whole story. On the one hand, in academic performance, education beyond high school, employment and partnerships, better IQ helps to achieve better outcomes. On the other hand, with life satisfaction or feelings of exclusion, IQ does not seem to have the same central role, but instead other things generate these feelings. Also, despite a higher IQ, people with BIF were found to have more severe psychiatric problems than their peers with MID. It can be concluded that the answer to this question is not black or white, but rather includes some shades of gray.

4.3 Societal acknowledgement and discussions are needed

The results of this thesis indicate that people with BIF have an increased risk for social exclusion from society. Studies II and III showed that education beyond elementary school was uncommon, rates of unemployment and disablement pensions were high, and severe mental health problems were evidently more common than with peers in general population. Low education levels, long-term unemployment, problems with personal economy and mental health problems are reported to be significant risk factors behind social exclusion (THL, 2022). These results are in line with previously reported findings about people with BIF having low proportions of educational qualifications (Hassiotis et al., 2008), high incidence of mental health problems (Chen et al., 2006; Dekker & Koot, 2003; Emerson et al., 2010; Gigi et al., 2014; Hassiotis et al., 2017; Hassiotis et al., 2008; King et al., 2019) and non-secure working conditions (Emerson et al., 2018b). The National Audit Office of Finland reported an estimated price for social exclusion in Finland in 2007. They calculated how much it would cost society if one adolescent would not be able to work for the rest of their life, noting that the cost would be partly from the production losses (wages, taxes) and partly from increasing costs (benefits, health care costs etc.). The result was more than one million euros (Valtiontalouden tarkastusvirasto, 2007). Thus, it is extremely

important, of course, from both an individual but also an economical point of view that people with BIF are supported enough to be active participants in society.

What could this support then consist of? First, BIF needs to be added to societal discussions in order to be acknowledged and supported. Second, the studies discussed here showed that there are vulnerabilities in different transitions, such as continuing education after elementary school into secondary school, getting a job, and starting a partnership. Problems with these transitions should be noticed and examined carefully in order to plan targeted support for people with BIF. Study III showed that only about one-third of people with BIF had education beyond elementary school, whereas peers in the GP had twice as many qualifications. Work markets today are brutal in the sense that some education after elementary school is usually required in all fields, regardless of the content of the education or its benefit to the job in question. A qualification is like a business card, showing that a person has the persistence to complete something (Soininvaara, 2020). Also, as was already discussed in an earlier section (1.2.3.2), the loss of operating work occupations in Western countries puts persons without any qualification in a poor position as job applicants because they fight for the same jobs as those who have finished secondary school. Therefore, to be noteworthy job applicants, people with BIF need to be supported to continue and finish at least a secondary school education. In Finland, a recent law concerning compulsory education was expanded to include all children from seven to 18 years of age (Oppivelvollisuuslaki, 2020). Elementary school is usually finished at age 15 or 16, so adolescents have at least two years of compulsory education remaining. From the BIF viewpoint, this is an advancement, as they are now required to participate in education after elementary school, and as a result, if they struggle to cope in their studies, new methods of support will probably need to be developed in the schools to respond to their challenges. This law is a new one, yet it is not known how many adolescents struggle with their studies, what kind of problems teachers face and what kind of support might be needed. However, it is likely that people with BIF need some support to finish their secondary school education.

People with BIF might benefit from some kind of 'citizen's wage' in order to enter the work markets. Soininvaara (2020) described a basic income that would be given monthly as a basic right. The nature of available work has changed over the past decades, and now creativity, reasoning and independent initiative are highly valued qualities in work markets; however, for many people, this means that the demand for their labour input is decreasing. A basic guaranteed income might balance this development. This kind of solution would also help people with BIF to have and maintain a job. At the moment in Finland, benefits granted to people without jobs often prevent them from entering the work markets because low-income jobs are not enough to financially support them, but because of the job benefits stop running, and an employee might end up with less money than without a job. With a basic income, lower-paid jobs would be more desirable as the wage would add to the total income and not take

any benefit away. Studies of this thesis showed that the occupations that people with BIF held were low-paid, unskilled and not valued in the opinion of the general public; however, for the employees themselves the job brought feelings of satisfaction. Overall, because work is important for self-esteem and self-worth, it is essential to support people with BIF to be active in work markets.

People with BIF need support to find and maintain suitable jobs. There is a potential competence to master many occupations when enough support is given. Such support can be, for example, to make sure that the complexity of the work equals the level of functioning of the person, or that the introduction period should be longer and more supportive, to give more time to assimilate content of the work, or that there would be a support person to help manage the job. Garrels (2022) pointed out that context and content, that is, environment and the nature of demands, have a great role when borderline cases of intellectual disability and their functioning are evaluated. She argued that a young person with BIF would function poorly in a context where the focus is on academic achievement, but in a work environment where work tasks would be matched with cognitive functioning and interest, they could function in way that would most likely be similar to that of everyone else.

As already mentioned above, there is a major need for societal discussion about BIF because in order to develop adequate support, the existence of BIF first needs to be acknowledged. BIF is not an officially recognised diagnosis. In many societies, however, support is based on official diagnoses, and that is why people with BIF are often left out. Decades ago, BIF was listed as a part of an intellectual disability, until it was removed from the manuals in the early 1970s. This removal was done mainly because there were concerns that many children were labelled as mentally retarded, the term formerly used for intellectual disabilities, despite their ability to manage reasonably well outside the school setting. The world now, with automatisation, digitalisation and globalisation, is a very different place than it was 50 years ago when this removal from the manuals was done, and it is clear that people with BIF do not manage reasonably well today. Studies of this thesis show conclusively that people with BIF struggle with every aspect of life, whether at school or outside the school setting. It is very likely, however, that the lack of an official diagnosis prevents them from being routinely recognised and supported. Many researchers have pointed out the importance of the specified criteria or official diagnoses for BIF. In Girona's declaration (Martínez-Leal et al., 2020), the BIF consensus group stated that BIF is a complex health meta-condition rather than a descriptive V-code solely characterised by IQ. Furthermore, they stated that the absence of an official definition of BIF poses the question as to how differential diagnosis between mild ID and BIF could be made, especially because the former IQ ranges stated in the manuals have been eliminated as an outmoded definition. Greenspan (2017) proposed that BIF should be eliminated from V-code diagnoses in the DSM-5 and that the IQ range should be increased for the ID category (to above 75, even to 85), because people with BIF have deficits in adaptive functioning that meet DSM-5 criteria. Greenspan stated that diagnoses should be made only if the person shows significant signs of adaptive

impairment, not be merely based on IQ. Whether BIF has its own specified criteria or is considered the part of the ID category, for the sake of recognition and support, BIF should be listed in some diagnostic category.

4.4 Practical implications

There are three important things that professionals should be able to completely facilitate concerning BIF: recognition, individual support and raising awareness. First of all, psychologists, teachers and physicians should routinely recognise BIF. It is important that facts concerning the definition of BIF are known by workers in human-related fields from early childhood to late adulthood, so that BIF is not misinterpreted as SLDs, motivational problems, psychiatric problems or some other condition. It is reasonable to expect that BIF occurs at the latest after the early elementary school years when learning material in school becomes more difficult and more reasoning is needed. Teachers and special education teachers at schools are at the most important link for the recognition of BIF with school-aged children. Based on the difficulties in learning, they can direct a child to an evaluation made by a psychologist. If BIF is evident, even though it is not an official diagnosis, it should always be clearly stated in the report by psychologists and physicians. Moreover, by using the correct terminology in official statements, knowledge of BIF will not then disappear during other transition periods.

Second, support for people with BIF should be individually planned, as their abilities, problems and cognitive profiles are heterogeneous. Planning the support should be based on a carefully made evaluation of the strengths and difficulties of a person. An important form of support is psychoeducation about BIF, for the persons themselves and for the surrounding people. Psychoeducation helps to increase an understanding of one's challenges and skills and to form a realistic picture of future possibilities. Many people with BIF seem to struggle with demands to keep up with others, which can lead to exhaustion. One form of support could be to decrease overall load, so that exhaustion passes, and a person can use their full capacity.

Third, raising the awareness of BIF in human-related fields is much needed. Because BIF is a rarely studied topic in scientific research, experts or specialists possessing deep information about the topic are also lacking. It would be extremely important that all professionals who work with the issue and understand the core traits of BIF share this information with other professionals in the field. This information sharing could be in the form of education, conversations or writing an article for a journal. BIF needs to be understood as a condition that lasts for a lifespan, and that is why it is necessary that those who work with children in kindergarten and those who work with adults in psychiatric hospitals have equal opportunities to gain knowledge about BIF and to use that knowledge in their work.

In short, BIF needs to be routinely recognised by professionals and clearly identified in reports so that recognition does not vanish during the person's

lifespan. Individually planned support for the people with BIF needs to be based on a carefully made evaluation of the strengths and weaknesses of the person. Psychoeducation and lowering the overall load are important forms of support for people with BIF. All professionals who have a core understanding of BIF should educate others in order to increase knowledge in all the fields of human work and study.

4.5 Implications for future research

Study I, a systematic literature review, was the first ever made review of BIF, and showed that there has been remarkably little scientific research focusing on BIF, although lately studies have been increasing. Scientific information on BIF was fragmentary, and few studies were available for each topic. Studies were few (N = 49), and only 8% of them were population-based. The most often used term was 'borderline intellectual functioning', which was thus used in the name of the review. Use of this term and the overall volume of the research has continued to increase after the publication of Study I, but it is fair to say that studies concerning BIF are still few and fragmentary. There are some areas that are starting to be reasonably well studied, but in these areas as well, the manifold perspectives are missing. For example, we now know that children, adolescents and adults with BIF have more mental health problems than their peers, but we do not know enough about the reasons, treatments and individual differences for this. In the future, it would be extremely important for the volume of research concerning BIF, in any area, to increase. In the near future, the research could focus at least on two different paths: one, expanded population studies in order to increase overall understanding of BIF, and two, studies with a more individual perspective focusing on recognition and support.

To gather overall information, all kinds of larger settings with wide data would be welcome, such as longitudinal or cross-sectional, prospective or retrospective, population-based or birth-cohort studies, in order to increase knowledge about challenges in various stages of life and the paths leading to better or worse outcomes in life. Studies concerning BIF and old age are needed, as they are currently missing. The results of these studies would provide directions for how BIF should be viewed and treated at the societal level. Retrospective utilisation of already existing databases, like in our Studies II and III, would be an efficient way to quickly collect information about BIF. Many databases, which were originally collected, for example, to study ID, also contain data concerning people with BIF, which might originally either have been removed from the study or used to serve as a comparison group.

A more individual and practical path of research, focusing on recognition and support, is also needed. Urgent questions that research could help to answer could be the following: What kind of support is needed and when? Could it be similar to or different from already existing support designed for other groups, for example, those having SLDs or ID? What would be needed in order to better

recognise people with BIF: is education of professionals enough or do we need some tools designed for ensuring recognition of BIF?

4.6 Limitations

One of the limitations of this dissertation is the age of the data used in Studies II and III, which were first collected in 1962 and then in 1998. While the data of the second phase of the Finland-in-Miniature studies were collected in 1998, the results of our studies are highly relevant today. In fact, as discussed earlier, the current era is more complex and fast-paced than those in the past, and it seems that the situation is now even worse for people with BIF than it was 20 years ago. Jobs have become more complicated and are often replaced by machinery, which leaves people with BIF fewer choices in work markets. Personal flexibility, resilience and independent reasoning are needed to navigate through everyday tasks in society, yet the targeted support is lacking. Thus, it can be argued, at least, that even though the results describe the situation prior to the first decades of this century, the current situation for people with BIF is not any better, but rather may be worse. Also, the aim of this study was, besides gathering information on BIF, to compare results on similar aspects with those in the GP and people with SLD and MID. In these comparisons, the age of the data is not relevant, but rather the differences between BIF and other groups at the time the data were gathered.

Another limitation concerning the data used in Studies II and III is the possibility that the BIF sample may be biased towards more serious adaptive problems. That is because the original study in 1962 concentrated on ID, and all people who were sent for the examination were suspected, based on observed problems in adaptive functioning, to have ID. Thus, people with 'milder' BIF were not necessarily even identified. Also, in Study III, almost 70% of those who had been granted a disability pension answered the Living Condition Questionnaire, even though the response rate in total was 38% in the BIF group. This indicates that people with BIF and a disability pension were overrepresented in Study III, and the generalisation of the results to the entire population with BIF should be done with caution. However, at the same time, we can be sure that the population with BIF in our Studies II and III fulfil both criteria of the definition of BIF: lower-than-average cognitive functioning *and* adaptive challenges.

4.7 Conclusions

People with BIF face evident, manifold risks to their well-being throughout their lifespan, and this makes them more vulnerable than their peers with average intellectual functioning. These risks include a risk of poor parenting, learning difficulties, social difficulties, problems with education, employment and

inability to work and difficulties of having partnership. Particularly disabling is an increased risk for mental health problems. A higher incidence of psychiatric problems is evident in all ages. Lower-than average intelligence should be taken into account in treatment in order to avoid adverse treatment effects. Due to difficulties in education, employment and mental health, there is also an increased risk for social exclusion.

To enable support for people with BIF, BIF needs to be acknowledged at every stage of the lifespan. In order to do this, teachers, officials, physicians and practitioners need to be educated to recognise the phenomenon. Also, societal and political discussion is needed in order to transfer invisible BIF into visible BIF in a society. There should be official policy concerning BIF, starting with terms or diagnoses used and guidelines on how to evaluate and support people with BIF. In addition, employment should be supported with political decisions.

When cognitive skills and coping in life are examined, BIF seems to fall in between of the continuum from normal intellectual functioning to intellectual disabilities, but with unique features of more difficulties with mental health and more unsecure employment than others.

It would be extremely important that a that volume of research concerning BIF, in any area, should be increased. In the near future, the research could focus at least on two different paths: one, expanded population studies in order to increase overall understanding of BIF, and two, studies with a more individual perspective focusing on recognition and support.

YHTEENVETO (SUMMARY)

Laaja-alaiset oppimisvaikeudet – näkymätöntä tarkastelemassa

Väitöskirjassani tarkastelen laaja-alaisia oppimisvaikeuksia (LOV), jotka vain harvoin ovat olleet tieteellisen tutkimuksen keskiössä. Ilmiön voi sanoa olevan näkymätön, sillä tieteellisten julkaisuiden vähyyden lisäksi virallinen diagnoosi, määritelmä, sekä käytännön suuntaviivat tunnistamiseen ja tukeen puuttuvat. Tästä huolimatta laaja-alaiset oppimisvaikeudet ilmiönä tunnetaan laajasti käytännön työn parissa, esimerkiksi kouluissa, terveydenhuollossa ja työvoimatoimistoissa. Virallisten suuntaviivojen ja diagnoosin puuttumisen vuoksi henkilöt, joilla on laaja-alaisia oppimisvaikeuksia, jäävät kuitenkin usein tunnistamatta ja tukematta. Laaja-alaisten oppimisvaikeuksien määritelmään liittyy keskimääräistä alhaisempi kognitiivinen kykykapasiteetti, yleinen älykkyys noin 70 – 85, sekä toimintakyvyn haasteita, kuten vaikeuksia kouluaineissa, opiskelussa, sosiaalisissa suhteissa ja työelämässä. Laaja-alaisia oppimisvaikeuksia määriteltäessä rajanvetoa tulee tehdä lievään kehitysvammaisuuteen sekä erityisiin oppimisvaikeuksiin. Lievässä kehitysvammassa yleisen älykkyyden katsotaan olevan alempana kuin laaja-alaisissa oppimisvaikeuksissa, noin 2 keskihajonnan verran keskiarvon alapuolella, sekä toimintakyvyn heikkouksien olevan selvästi rajoittavampia. Erityisissä oppimisvaikeuksissa, kuten lukemisen, kirjoittamisen tai matematiikan vaikeuksissa, taidot liittyen kyseisiin alueisiin ovat merkittävästi heikommat kuin henkilön yleinen älykkyys. Oppiminen saattaa näyttäytyä samankaltaisena myös laaja-alaisissa oppimisvaikeuksissa, mutta taidot ovat kauttaaltaan keskimääräistä heikommalla tasolla, eivät vain liittyen erityisesti tiettyyn oppiaineeseen. Tämän tutkimuksen tarkoitus oli tarkastella laaja-alaisia oppimisvaikeuksia yksilöllisestä, neurokognitiivisesta sekä yhteiskunnallisesta näkökulmasta keräten mahdollisimman paljon tietoa laaja-alaisista oppimisvaikeuksista ilmiönä. Saatuja tuloksia verrattiin vastaaviin tuloksiin väestössä, sekä henkilöihin, joilla oli oppimisvaikeuksia, ja henkilöihin, joilla oli lievä kehitysvamma.

Väitöskirjan ensimmäinen osatutkimus oli systemaattinen kirjallisuuskatsaus, joka oli myös maailmanlaajuisesti ensimmäinen laaja-alaisista oppimisvaikeuksista tehty katsaus. Katsauksen tavoitteena oli tarkastella aihepiiristä julkaistua tutkimusta, kartoittaa vaikeuksia, riski- ja suojaavia tekijöitä, sekä tuoda aihepiiriä esille yhteiskunnallisia ja tieteellisiä keskusteluita varten. Kirjallisuuskatsaus toteutettiin noudattaen systemaattisen katsauksen periaatteita. Kirjallisuushaku tuotti yhteensä 1726 läpikäytävää tiivistelmää, joista 236 arvioitiin, ja 49 päätyi mukaan katsaukseen. Katsaukseen hyväksytyt tutkimukset sisälsivät laaja-alaisen oppimisvaikeuden määritelmänä ÄO:n noin 70-85, ja liittyivät aihepiiriin, joka käsitteli neuropsykologisia, sosiaalisia, mielenterveyteen, työhön, parisuhteeseen, riskeihin tai suojaaviin tekijöihin liittyviä asioita. Tulokset osoittivat, että aihepiirin tutkimus on vähäistä, hajanaista ja metodologiselta laadultaan vaihtelevaa. Vain 8 % tutkimuksista oli tehty väestöpohjaisilla aineistoilla ja suurin osa tutkimuksen kohteista oli lapsia tai nuoria. Tulokset liittyen neuro-

kognitiivisiin taitoihin (lukeminen, kirjoittaminen, matematiikka, muisti, toiminnanohjaus, motoriset taidot) osoittivat, että lapset ja nuoret, joilla oli laaja-alaisia oppimisvaikeuksia, suoriutuivat säännönmukaisesti heikommin kuin ikäisensä kanssatoverit. Eroja ikätovereiden eduksi näkyi myös sosiaalisessa käyttäytymisessä, mm. leikkimisessä, tunteiden tunnistamisessa, sosiaalisen tiedon prosessoinnissa, sosiaalisessa osallistumisessa ja epäsosiaalisessa käyttäytymisessä. Mielenterveysongelmien esiintyvyys näyttäytyi kaikissa ikäryhmissä selvästi suurempana kuin väestössä keskimäärin. Työelämää hallitsivat työt, jotka eivät vaatineet koulutusta ja olivat pienipalkkaisia. Mahdollisia riski- ja suojaavia tekijöitä löytyi, mutta ne eivät olleet erityisiä juuri laaja-alaisten oppimisvaikeuksien kannalta, vaan yleisiä myös muihin kehityksellisiin vaikeuksiin liittyviä (esimerkiksi pienipainoisuus, epäedullinen perhetilanne, altistuminen myrkyllisille aineille). Tutkimuksen perusteella todettiin, että selvistä jokapäiväisistä vaikeuksista huolimatta laaja-alainen oppimisvaikeus on lähes näkymätön kirjallisuudessa, ja tarve pitkäkestoisille väestöpohjaisille tutkimuksille on ilmeinen. Yhteiskunnallisten keskusteluiden ja joustavien tukimuotojen tarve nostettiin esille.

Laaja-alaisista oppimisvaikeuksista on maailmanlaajuisesti tehty vain vähän väestöpohjaista tutkimusta. Tästä syystä väitöskirjan toisessa ja kolmannessa osatutkimuksessa hyödynnettiin laajaa ja edustavaa Suomen väestöstä kerättyä, Mini-Suomi -aineistoa, jonka alkuperäinen tarkoitus oli tutkia kehitysvammaisuuden esiintymistä Suomessa. Ainutkertainen tutkimusaineisto kerättiin moniammatillisena yhteistyönä vuonna 1962, yhteensä 57 kunnan alueelta (N = 416 973). Kuntien työntekijät lähettivät tutkimuksiin kaikki henkilöt, joilla he tiesivät, tai epäilivät olevan kehitysvamma. Vuonna 1998 tutkimuksessa mukana oleville henkilöille lähetettiin elämänkulkua kartoittava kyselylomake, sekä yhteiskunnallisten palveluiden käytön selvittämiseksi heidät yhdistettiin erilaisiin Suomessa ylläpidettäviin rekistereihin henkilötietojen perusteella. Tässä aineistossa oli mukana myös suuri määrä henkilöitä, jotka jäivät kehitysvammaisuuden rajan ulkopuolelle, mutta joista ei aiemmin ole tehty tutkimusta. Väitöskirjan tutkimuksia varten tämä osa jaettiin henkilöihin, joilla oli laaja-alaisia oppimisvaikeuksia, ja kontrolliryhmään, joilla oli oppimisen vaikeuksia, mutta keskimääräinen yleinen älykkyys. Lisäksi toiseksi kontrolliryhmäksi otettiin aineistosta mukaan lievästi kehitysvammaisten ryhmä.

Väitöskirjan toisen osatutkimuksen tarkoituksena oli tutkia yhteiskunnallisten palveluiden käyttöä henkilöillä, joilla oli laaja-alaisia oppimisvaikeuksia. Näitä palveluita olivat työkyvyttömyyseläke, psykiatrinen sairaalahoito, sairaalahoito ja kehitysvammapalvelut. Palveluiden käyttöä verrattiin sekä muuhun väestöön, että kahteen muuhun tutkimuksen kontrolliryhmään, eli henkilöihin, joilla oli lievä kehitysvamma tai oppimisvaikeuksia. Tulokset osoittivat, että verrattuna Suomen väestöön, henkilöillä, joilla oli laaja-alainen oppimisvaikeus, oli 2.7 -kertainen riski työkyvyttömyyteen, sekä 3.4 -kertainen riski vakaviin mielenterveysongelmiin. Vertailu kontrolliryhmiin osoitti systemaattisesti, että lievästi kehitysvammaiset henkilöt olivat käyttäneet eniten palveluita, ja henkilöt, joilla oli oppimisvaikeuksia, vähiten. Psykiatrisen sairaalahoidon tarkempi tarkastelu kuitenkin osoitti, että vuoden 1987 jälkeen henkilöillä, joilla oli laaja-

alaisia oppimisvaikeuksia, oli nähtävissä enemmän psykiatrista sairaalahoitoa kuin kahdella muulla ryhmällä. Vielä 1970-luvulla oli yleistä, että kehitysvammaisiksi luokiteltuja henkilöitä sijoitettiin psykiatrisiin sairaaloihin, mutta 1980-luvulle tultaessa laitosasumista pyrittiin vähentämään. Lisäksi yleisesti psykiatrisia sairauksia pyrittiin hoitamaan enemmän avohoidossa. Nämä trendit, laitoshoidon väheneminen ja avohoidon lisääminen, näkyivät tutkimuksessa sekä lievästi kehitysvammaisten ryhmässä, että oppimisvaikeusryhmässä, mutta ei laaja-alaisten oppimisvaikeuksien ryhmässä, joiden psykiatrinen sairaalahoito ei vähentynyt. Tämä viittasi siihen, että heillä oli ollut vakavampia mielenterveyden ongelmia, jotka eivät hoituneet avohoidossa. Tutkimuksen perusteella todettiinkin, että laaja-alainen oppimisvaikeus lisää riskiä mielenterveysongelmille ja työkyvyttömyydelle. Lisäksi henkilöiden, joilla on laaja-alaisia oppimisvaikeuksia, mielenterveyden ongelmat näyttäytyivät vakavampana kuin kontrolliryhmien.

Kolmas osatutkimus tarkasteli yleisesti elämää (perhettä, koulutusta, työtä, tyytyväisyyttä) henkilöillä, joilla oli laaja-alaisia oppimisvaikeuksia, vuonna 1998 lähetetyn kyselylomakkeen avulla. Osallistujat olivat tuolloin 41-53 vuotiaita. Tuloksia verrattiin väestöön ja kontrolliryhmiin. Tulokset osoittivat, että verrattuna väestöön parisuhteen luominen, peruskoulun jälkeinen koulutus, työssäkäynti, ja tyytyväisyys olivat selvästi vähäisempää. Lähes puolet olivat kokeneet syrjintää elämässään, yleisimmin koulussa, mutta usein myös lapsuuden kodissa. Työ tuotti monelle tyytyväisyyttä, mutta vain 44 % oli työssä. Yleisimmät ammattikategoriat olivat tehdastyö ja palvelutyö. Ammatit, joissa työskenneltiin, eivät olleet yleisen mielipiteen mukaan arvostettuja. Verrattuna kontrolliryhmiin pääsääntöisesti lievästi kehitysvammaisilla henkilöillä oli vähemmän, ja oppimisvaikeuksia omaavilla henkilöillä enemmän koulutusta, parisuhteita, ja työtä. Eroja ei ollut nähtävissä elämän tyytyväisyyden ja syrjinnän kokemuksen suhteen. Tutkimuksen perusteella todettiin, että verrattuna väestöön, henkilöt, joilla on laaja-alaisia oppimisvaikeuksia ovat selvästi haavoittuvaisemmassa asemassa perheen perustamisen, koulutuksen ja työn suhteen. Lisäksi todettiin, että yleisellä älykkyydellä näyttää olevan vaikutusta parisuhteen muodostamiseen, koulutukseen ja työhön, mutta ei niinkään välttämättä elämäntyytyväisyyteen tai syrjintään. Työn merkitystä, sekä yhteiskunnan tukea työn saamiseksi painotettiin.

Kolme osatutkimusta osoittivat, että oli näkökulma sitten yksilöllinen, neurokognitiivinen tai yhteiskunnallinen, laaja-alaisiin oppimisvaikeuksiin liittyy ilmeisiä ja monimuotoisia riskejä hyvinvoinnille läpi elämänkaaren. Verrattaessa väestöön tai ikätovereihin, yleisesti ottaen selvät vaikeudet näkyivät kaikilla tutkituilla osa-alueilla. Erityisesti mielenterveysongelmien yleisyys kaikissa ikäryhmissä oli selvästi nähtävillä. Tulokset antoivat vahvoja viitteitä syrjäytymisen uhasta, sillä syrjäytymisen merkittävinä riskitekijöinä on raportoitu olevan matala koulutustaso, pitkäaikaistyöttömyys sekä mielenterveyden ongelmat (THL, 2022). Verrattaessa laaja-alaisia oppimisvaikeuksia lievästi kehitysvammaisuuteen ja oppimisvaikeuteen, väitöskirjan tulokset yleisesti ottaen tukivat ajatusta, että laaja-alaiset oppimisvaikeudet ovat keskellä jatkumoa näiden

kahden ilmiön välissä. Kuitenkin, tulokset myös viittasivat siihen, että oli muutamia poikkeuksia, kuten vaikeat mielenterveysongelmat sekä epävarma työllisyys, jotka näyttäytyivät yleisempänä laaja-alaisten oppimisvaikeuksien ryhmässä.

Väitöskirjan tulosten perusteella voi todeta, että laaja-alaisiin oppimisvaikeuksiin liittyy moninaisia ja selviä riskejä hyvinvoinnille läpi elämänkaaren. Näitä riskejä ovat vanhempien heikot kasvatusmenetelmät, oppimisvaikeudet, sosiaaliset vaikeudet, haasteet kouluttautumisessa ja työssä, työkyvyttömyys, haaste muodostaa parisuhdetta sekä syrjäytyminen. Erityisen lamauttava on riski vaikeille mielenterveysongelmille. Mielenterveysongelmien hoidossa tulisi huomioida laaja-alaiseen oppimisvaikeuteen liittyvä keskimääräistä alempi kykytaso. Jotta kohdennetun tuen suunnittelu olisi mahdollista, laaja-alaiset oppimisvaikeudet tulisi tunnistaa jokaisessa elämän vaiheessa. Yhteiskunnallisia ja poliittisia keskusteluja tarvitaan, sillä laaja-alaisilla oppimisvaikeuksilla tulisi olla virallisesti sovitut toimintaperiaatteet käytetyn termin, diagnostiikan ja käytännön suuntaviivojen suhteen. Lisäksi tämän ryhmän työllisyyttä tulisi tukea poliittisen päätöksenteon keinoin. Tieteellisen tutkimuksen määrää liittyen laaja-alaisiin oppimisvaikeuksiin tulisi lisätä kaikin keinoin. Tutkimusta tarvitaan sekä laajoista väestöpohjaisista otoksista, että yksilötason näkökulmasta.

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ORIGINAL PAPERS

I

BORDERLINE INTELLECTUAL FUNCTIONING: A SYSTEMATIC LITERATURE REVIEW

by

Minna Peltopuro, Timo Ahonen, Jukka Kaartinen, Heikki Seppälä & Vesa Närhi, 2014

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II

BORDERLINE INTELLECTUAL FUNCTIONING: AN INCREASED RISK FOR SEVERE PSYCHIATRIC PROBLEMS AND INABILITY TO WORK

by

Minna Peltopuro, Hannu T. Vesala, Timo Ahonen & Vesa Närhi, 2020

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Abstract

Background The use of facilities such as disability pension, psychiatric care, health care, and services for people with intellectual disabilities (ID) and borderline intellectual functioning (BIF) were compared to the general population and two other study groups comprising people with mild intellectual disabilities: (MID) and learning problems (LP). *Methods* The population-based sample (N = 416,973), "Finland-in-Miniature", was gathered in 1962 and followed until 1998. For the purpose of the present study, three groups were formed: BIF (n = 416), MID (n = 312), and LP (n = 284). The use of services was examined with the help of national registers. *Results* As compared to the general population, people with BIF had been granted disability pension 2.7 times more often and had been patients in psychiatric care 3.4 times more often. They had also systematically used more services than people with LP. *Conclusions* People with BIF are at risk of inability to work and facing severe mental health problems. They also seem to have more severe psychiatric problems than people with MID and LP. There is, therefore, a crucial need for increasing the awareness in society of BIF. Although, this study's follow-up data were collected about 20 years ago; it is still relevant because people with BIF are a neglected group and still face growing demands in school and work life with no marked changes in services.

Keywords: Borderline intellectual functioning, psychiatric inpatient care, disability pension, inpatient health care, ID services, population-based

Background

People with borderline intellectual functioning (BIF) are considered to have an intelligence quotient (IQ) between 1 and 2 standard deviations (SD) below the average; but not as low as those having mild intellectual disability (MID). If only the normal distribution of intelligence is examined, then 13.6% of the population fit into the BIF category. However, in addition to below average intelligence, people with BIF also have difficulties in adaptive functioning, which limits their academic, social, and work performance (see also Salvador-Carulla et al. 2013).

BIF is a rarely studied topic; and information on it is fragmentary. Previous studies showed major difficulties across the course of life (see review by Peltopuro et al. 2014). Academic and neurocognitive problems were evident when children with BIF were compared to their peers with average intelligence (MacMillan et al. 1998; Bonifacci & Snowling 2008; Kortteinen et al. 2009; Alloway 2010; Hartman et al. 2010; Dekker et al. 2016). Moreover, difficulties in social competence and antisocial behaviour were also established (Guralnick & Groom 1987; Crocker et al. 2007; Douma et al. 2007; Baglio et al. 2016). Higher rates of mental health problems (both symptoms and diagnoses) were systematically reported in people with BIF, when compared to their peers (Dekker & Koot 2003; Chen et al. 2006; Hassiotis et al. 2008; Emerson et al. 2010; Hassiotis et al. 2017). Adults with BIF usually held lower-skilled jobs and earned lower income than the general population (GP) (Seltzer et al. 2005). They were also at risk of being exposed to non-standard employment conditions (e.g. temporary employment; part-time or on-call work; and disguised employment (Emerson et al. 2018).

From the available literature, we can conclude people with BIF face difficulties in many areas of life. However, due to limited recognition (Nieuwenhuis et al. 2019) people with BIF lacks adequate treatment and support. To bring about a change, BIF needs to be acknowledged not only from the individual perspective but also at the societal level. There is a need for population-based studies that show the magnitude of the problems from the society's point of view.

The aim of the present study was to prospectively examine the utilisation of services by people with BIF using the national registers of Finland. The population-based sample, "Finland-in-Miniature", was gathered in 1962 and followed until 1998. This study concentrated on intellectual disability (ID); (see Ruoppila 1966; Ruoppila & Iivanainen 2011), but results on BIF have not been previously reported. In the present study, we compared the utilisation of services by people with BIF with that of the GP in Finland, as well as with the sample's two other study groups: people with MID and those with average intelligence but facing learning problems at school (LP). The services that are examined include disability pension, psychiatric inpatient care, inpatient health care and services for people with ID.

The first study question was whether people with BIF differ from the general population in the use of services. From previous studies, we can conclude that people with BIF show a higher prevalence of mental health problems than their peers. This gives us reason to expect that in the present study, the use of psychiatric inpatient care was higher in the BIF group than in the GP. We can also expect the disability pension and inpatient health care rates to be higher, as it is evident that people with BIF face a variety of hardships in life (Peltopuro et al. 2014). Besides mental health problems, they seem to be at risk of alienation, dropping out of school, or unemployment – all of which can compromise health, and finally lead to a disability pension.

The second study question was whether there were differences in service use between the three study groups: BIF, MID, and LP. It can be assumed that people with MID will need more support in their lives than the other two groups; and overall, will use more services. Among people with BIF and LP, it is more difficult to set expectations. In the original 1962 study, officials in municipalities sent people for examination only if they suspected them of having an ID. This means that even people, who were within the normal range of intelligence had some qualities in their behaviour that were estimated to be abnormal, for example learning problems at school. An interesting question is whether the use of services among people with BIF and LP are similar; or whether higher cognitive capacity predicts a better outcome later in life.

METHODS

Participants

A population-based "Finland-in-Miniature" sample was collected from 57 municipalities, chosen to represent Finland in economic, social, and occupational issues as well as in two official languages (Finnish and Swedish). Officials of the municipalities (e.g. nurses and teachers) were instructed to refer to the study all cases of persons between 2 and 64 years, who had been diagnosed with ID, or were suspected to have ID because of, for example, delayed speaking or walking, learning difficulties, social problems, difficulties in self-care as adults, or inability to work. In 1998, the social security codes, introduced after the original data collection, of the subjects were traced to connect their data to the national registers.

Measures

In 1962, psychologists conducted a screening test (see below) for most of the participants to examine their level of intelligence. If the test indicated intelligence of 1 SD below average; additional tests were conducted to obtain a more specific estimate of the level of intelligence. Some of the participants (42 and 141 in the BIF and LP groups, respectively) were evaluated using only background information about school performance, work, or other skills needed in life. While the screening tests were Kohs block test/KTK C5 (Elonen et al. 1961 a) and Kohs-Häkkinen Square Test/KTK A 3 (Elonen et al. 1961 b) or Häkkinen's Square

Test (Häkkinen 1958); additional tests included measures of both verbal and non-verbal intelligence: KTK Performance Scale (Elonen et al. 1961b), Vocabulary Test (Siloma 1960), Picture Vocabulary Test (Ruoppila 1963), Ravens Coloured Progressive Matrices (Raven 1956a, b), Kääriäinen's Form Board Test (1962, 1970, 1987); and tests for reading, writing, and mathematics. The reliabilities of the KTK Performance Scale, Picture Vocabulary, and Vocabulary tests varied across the different age groups from 0.86 to 0.97. The various tests used and their reliabilities have been described in detail elsewhere (Ruoppila 1966; Ruoppila & Iivanainen 2011).

Services and registers

Psychiatric inpatient care

Psychiatric inpatient care for severe mental health problems was provided either in a psychiatric hospital or in the psychiatric unit of a hospital. In 1998, the National Research and Development Centre for Welfare and Health (STAKES) provided information about the psychiatric inpatient care of our participants, which included the total use of psychiatric inpatient care and the number of days in care per year from 1970–1998. For the purpose of the present study, the Finnish Institute for Health and Welfare (THL) provided comparable information from the general population for the corresponding period (1970–1998) of same-aged participants.

Since the 1970s, there has been a trend to decrease psychiatric hospital and inpatient care; and to increase outpatient mental health services for patients with less severe mental health problems. In the 1960s and the 1970s, psychiatric hospitals were commonly used for placement of the elderly and those with ID (Pirkola & Sohlman 2005).

Disability pension

Disability pension was granted to Finnish citizens aged 16 to 64 years, to provide them with a reasonable income when illness, injury, or defects prevented them from working. In 1998, information about the disability pensions of our participants was provided by the Social Insurance Institution (SII). Matching information about the GP was available from the Statistical Yearbook of Pensioners in Finland 1998, maintained by SII.

Inpatient health care

Inpatient health care is defined as medical treatment administered in hospitals, both in the public sector (municipalities, joint municipal boards, and the state) and in the private sector. In 1998, STAKES provided information about our participants, which included the total use of inpatient health care and number of days in care per year from 1970 to 1998. Statistical information for the years 1994 to 1998, on the GP aged

16 to 64 years (which was a larger age range than in our sample) was available from the SOTKAnet Indicator Bank, maintained by THL.

ID services

Finland grants special care services to people diagnosed with ID. While these services mainly comprised institutional care in the 1960s, 1970s, and 1980s; from the 1990s onward, they included housing services (housing with 24-hour and part-time assistance; supported housing; and family care), sheltered work, and day activity centres (Vesala 2003). Our participants' information was available from 1978 to 1986 and from 1994 to 1998 on two different registers maintained by STAKES. Besides the total use of services by the ID, it also included details on the usage of institutional care, housing services, sheltered work, day activities, and the number of days per year, in each of the services.

Statistical analysis

Statistical analyses were conducted using SPSS software. In group comparisons, chi-square tests and risk ratios were used.

Ethical questions

In 1998, the study design was thoroughly examined by various offices such as the Data Protection Ombudsman, Ministry of Social Affairs and Health, Ministry of Education, STAKES, National Archives Service of Finland, Population Register Centre of Finland, Statistics Finland, and Social Insurance Institution, which granted the research permits.

RESULTS

Altogether, 416,973 persons (9.4% of the Finnish population) were inhabitants of the participating municipalities. As Figure 1 shows, of the 4013 persons referred, 181 (4.5%) chose not to participate, and 84 had already been diagnosed with ID. Based on the assessment, 2372 persons with an IQ < 70 were assigned the diagnosis of ID. For the purpose of the present study, the remaining 1376 persons were divided into two groups based on their levels of intelligence. The BIF and the LP groups each comprised 760 and 527 persons; with IQs between 70 and 85 and > 85, respectively. Data of 89 persons (6.5%), whose IQ information was missing, were removed. Of those with an ID diagnosis, a MID group (n = 1101) with IQs between 50 and 69 were included in the study. In 1962, for the BIF, MID, and LP groups; the mean ages were 17.2 (SD 13.4), 29.8 (SD 17.6) and 16.4 (SD 13.3) years, respectively. To reduce the age heterogeneity, only school-aged participants aged 5–17 years were included in the final sample, resulting in 537, 377, and 368 participants in the BIF, the MID, and the LP groups, respectively.

In 1998, the social security codes were identified for 84.4%, 92.0%, and 83.2% of the BIF, MID, and LP groups, respectively. However, in the BIF, MID, and LP groups; 121 (22.5%), 65 (17.2%), and 84 (22.8%) persons respectively, were lost on account of deaths as well as failures in identifying social security codes that were usually because of incorrect names or missing date of birth information, in the 1962 data. Loss analysis of the original data showed no systematic selection based on age or gender. Figure 1 shows the final data, which includes 416, 312, and 284 participants in the BIF, MID, and LP groups, respectively, whose social security numbers were found and who were alive in 1998 (see Table 1).

Table 2 lists results relating to the GP as well as the BIF, MID, and LP study groups' utilisation of services, disability pension, psychiatric inpatient care, inpatient health care, and ID services. Almost half of the people with BIF had availed of some of the services. Service use was more than 70% in the MID group and approximately 30% in the LP group. In the BIF and LP groups; overall, women had used more services than men, which was due to differences in the use of inpatient health care.

Psychiatric inpatient care

Table 2 shows that 18.8% of those with BIF had been in psychiatric inpatient care between 1969 and 1998. Percentages were higher in the MID group and lower in the LP group. There were no gender differences. Table 3 presents psychiatric inpatient care per year. On an average, 3% of the people with BIF had been in psychiatric inpatient care each year. Proportions in the MID and LP groups; and the GP were 3.3, 2.1, and 0.9, respectively. Table 3 also shows that the BIF group had 3.4 times more psychiatric inpatients per year than the GP. Risk ratios relative to the GP were 3.8 and 2.4 for the MID and the LP groups, respectively.

Figure 2 presents the results of psychiatric inpatient care between 1970 and 1998. Around 3% of people with BIF had been in psychiatric inpatient care between 1979 and 1998. From 1974 to 1978, when participants were 17 to 33 years of age, there was a peak rising to 4%, which was 4.4 times higher than in the GP. Participants with MID showed a decreasing trend in psychiatric inpatient care over time. Apart from the early 1970s, the rates constantly diminished from about 5% to 2%. From 1987 onwards, the rates of the MID group were systematically lower than the BIF group. In participants with LP, until around 1980, the rates increased from 2% to 3%, but thereafter began decreasing again, settling to 1.5%. For the GP, the rates varied between 0.6% and 1%.

A yearly comparison of the average number of days per person in psychiatric care from 1994 to 1998 showed that participants with BIF and LP spent longer periods in care than the GP (mean: 101, 119, and 68 days, respectively). For people with MID, the periods were shorter (mean: 33 days).

Disability pension

Table 2 shows the disability pension rates for the three study groups and the GP of the same age. Disability pensions were granted more frequently to the BIF group than to the LP group, but were clearly less frequent than the MID group. As compared to the GP, disability pension rates were higher in all the three study groups. Risk rates were 2.7, 6.9, and 1.9 in the BIF, MID and the LP groups, respectively, when compared to the GP. None of the groups showed gender differences.

Inpatient health care

Almost 80% of the participants within all study groups had been in inpatient health care between 1969 and 1998. Thus, the differences between these study groups were not significant - BIF 79.8%; MID 75.6%; LP 77.8%. Table 2 shows the proportion of subjects who were in inpatient care for more than 30 days. In all groups, women had used inpatient health care more than men. Table 3 presents yearly inpatient health care. The proportion of subjects who had used inpatient health care per year were similar in all groups, ranging from 10.5% to 12.1%. Table 3 also shows a yearly comparison of the average number of days in hospital per year from 1994 to 1998.

ID services

There were significant differences between the groups regarding the use of ID services (see Table 2). Participants in the MID group, had clearly used ID services more than the BIF and LD groups. In addition, those in the BIF group had used ID services more than the LP group. There were no gender differences. The most used service in all groups were day activities, whose average percentages per year were 6.7, 28.3, and 1.3, for the BIF, MID, and LD groups, respectively. On an average, the per year usage percentages for institutional care and housing services were 1.9% and 0.9%, respectively, in the BIF group. In the MID group, the per year percentages were 8.0 for institutional care and 3.7 for housing services; whereas in the LP group, the percentages were 0.3, for both.

DISCUSSION

There were several differences between how the Finnish population and participants with BIF utilised the various services. Participants with BIF were granted disability pensions almost 3 times more often than the GP of the same age. They had also been inpatients in a psychiatric hospital 3.4 times more often and spent more days than their peers in the GP. Contrary to expectations, the rates of inpatient care for physical problems were similar between participants with BIF and the GP; although, it appeared that the BIF group participants had spent longer periods in care. This might imply more serious and/or more chronic conditions.

More than 11% of the participants in the BIF group had used ID services. In Finland, these services are granted only if a person has an ID diagnosis. In 1962, none of the participants in the BIF group had been diagnosed with ID, but evidently, at least 11% of them were diagnosed later in life. Day activities in work or activity centres, were the most used service. The use of housing services and institutional care were minimal. This indicates that help has been more to do with basic support, for example, daily activities, than with intensive support, for example, supported living.

In the original 1962 study, the participants were referred to the study assuming that each of them might have an ID. This indicates that all the participants had problems in adaptive functioning. In our sample, children and adolescents aged 5 to 17 years were most likely to have had some kind of problems in learning or at school, which led teachers to refer them to the study. The results indicate that people with average intellectual functioning, who also had adaptive functioning difficulties in youth, had better outcomes later in life than those with BIF, when severe mental health problems, inability to work, and ID services were examined. However, they also clearly had more problems as compared to the GP.

A comparison between the three study groups systematically showed that overall, the most services were used by participants with MID, then those with BIF, and the least services by those with LP. However, when psychiatric inpatient care was examined in greater detail, from 1987 onward; those with BIF were more often in psychiatric inpatient care as compared to the two other groups. While the psychiatric inpatient rates of those with MID were high in the 1970s, they began to systematically diminish. This reveals the practice in the 1960s and 1970s, when people with ID were commonly placed in psychiatric hospitals in Finland. From the 1970s onward, there was a trend towards reducing placements in psychiatric hospitals as well as psychiatric inpatients (Pirkola & Sohlman 2005), and from the 1980s onward, a trend of the deinstitutialisation of people with ID (Tøssebro et al. 2012). The admissions of people with ID from the 1970s to the late 1980s may thus indicate more societal changes than milder mental health problems. The trend of reducing inpatients and developing outpatient care for psychiatric patients can also be seen in the LP group. From the early 1980s to the late 1990s, their psychiatric inpatient rates dropped by half, suggesting that milder mental health problems were treated with outpatient care. Interestingly, this lowering trend was not seen in people with BIF. Instead, their psychiatric hospital usage seemed to linger around 3% over time. This suggest that as compared to the other two groups, the BIF group had more severe mental health problems, which could not be supported with outpatient care.

Our result of high rates in psychiatric hospital use are in line with the frequently reported high rates of mental health problems among people with BIF (Hassiotis et al. 2008; Gigi et al. 2014; Hassiotis et al. 2017). Our study indicates that participants with BIF have a more than threefold risk of severe mental health problems than their peers in the GP. Over time, the risk ratio was about 3, except for a peak of almost 4.5

in young adulthood. This peak could be explained by the challenges that young adults with BIF encounter in their lives. At this stage in life, young adults have to solve numerous challenges such as gaining independence from parents, partnerships, studies, getting a job, and starting a family. Previous studies have shown that people with BIF struggle with these challenges more than their peers (see Peltopuro et al. 2014).

Disability pension was 2.7 times more common among people with BIF than among the GP. In 1998, the two most common reasons for disability pension being granted in Finland were musculoskeletal diseases and psychiatric disorders (about one-third of each) (Gould & Nyman 2004). As usage of inpatient health care of people with BIF was similar to that of the GP; while their inpatient psychiatric care was clearly more than that of the GP; it can be assumed that the heightened disability pension rates of people with BIF were due to psychiatric problems rather than other medical conditions. Gould and Nyman (2004) reported that among Finnish disability pensioners with mental disorders, there seemed to be two different groups. One group was described as having fairly good jobs with higher-than-average wages, until suddenly shifting to disability pensions; whereas the other group had a history of by shattered working and long periods of unemployment. Since previous studies have shown that people with BIF had low-skilled jobs and earned less than average money (Peltopuro et al. 2014); it is possible that many people with BIF belong to the latter group. In addition, two recent studies have shown that they were more often exposed to part-time, non-secure working conditions, which in turn were associated with poorer physical and mental health (Emerson et al. 2018a, 2018b). Thus, for people with BIF, besides mental health problems, a shattered working history leading to poorer health may explain the higher disability pension rates, found in our study.

The reasons behind the high rates of ID service use, psychiatric problems, and disability pension among people with BIF might be the cumulative sum of adverse life experiences that led to failures at crucial milestones. Support systems targeting people with BIF were lacking, which may have led to their drifting into serious problems before they got support. It is possible that some of the adverse life experiences could be supported by already existing services, but the lack of information on BIF is perhaps preventing people with BIF accessing these services. Awareness of BIF, therefore, needs to be built up in all sectors of society.

Limitations

Participants with normal intelligence were not in the focus of the original Finland in Miniature study. This can be seen in the IQ measures, particularly in the LP group, since many of them were evaluated using only background information instead of tests. However, it seems that our study groups, which were formed on the basis of 1962 assessments, differed from one another.

While we were able to use relevant national registers in our research; some information was not available. The register data were originally collected for administrative and not for research purposes, and there were some years for which the data was not available in electronic form. Also, concerning the GP exact information on the age range was not available for inpatient health care. As such, the data restricted the specificity of the results obtained. Unfortunately, the data on psychiatric inpatient care usage did not include the reasons for the care. While it is possible that because of the severity of psychiatric problems, admissions for the BIF group did not decrease like it did in the other two study groups; the fact of admissions not decreasing could also be attributed to other reasons such as unidentified BIF and consequently inadequate treatment.

Commented [MP1]: Response 1.

Although the original data were collected prior to the millennium, we believe that the results of our study are highly relevant, even today. In fact, it can be argued that the current era is even worse for people with BIF. Society today is fast, complex, and informative. Self-regulation, flexibility, and independent reasoning are needed to navigate through everyday tasks in society. Jobs have become more complicated, or they are replaced by computers and machinery, which leaves people with BIF even fewer choices in work markets. Unfortunately, individuals with BIF still lack support systems that target them.

The original study concentrated on ID, and as expected, more participants had ID than BIF, although in the normal population, the prevalence of BIF is clearly higher than that of ID. This means that many people with BIF were not included in the original data. We expect our BIF sample to be biased towards more serious adaptive (and academic) problems, and the generalization of the results to the whole population with BIF should be done with caution. However, since the starting point of the recruitment of the sample was the observed problems in adaptive functioning and the below average IQ were confirmed later; we believe that our study's BIF group comprised 'true' cases with BIF.

Conclusions

People with BIF have an increased risk of inability to work and severe mental health problems. It also seems that people with BIF have more severe mental health problems than people with MID or LP. Cumulative adverse life experiences may be the cause of high rates of psychiatric problems and disability pensions. Treatment and diagnoses for mental health problems of people with BIF should take into account the lower than average cognitive capacity. Ability to communicate, for example to tell about one's emotions or experiences, may be impaired. Because these language and communicative skills are essential in therapeutic and diagnostic settings, professionals should ensure sufficient support for them. Also, possible adaptational needs which may hamper the daily life must be noticed in treatment, by supporting daily skills. There is a crucial need for an increase in knowledge about BIF in society.

Commented [MP2]: Response 2.

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Table 1 Descriptive statistics of the three study groups: borderline intelligence functioning (BIF), mild intellectual disability (MID), and learning difficulties (LP).

	MID	**BIF**	**LP**
n	312	416	284
male	56.4%	57.9%	69.0%
mean age	48.2 (SD 3.2)	47.0 (SD 2.9)	46.3 (SD 2.7)

Table 2 The use of services by the general population (GP) and the three study groups: borderline intellectual functioning (BIF), mild intellectual disability (MID), and learning problems (LP).

	All	χ^2	Men / Women	χ^2
Use of services [a]				
MID	74.0% (237)		71.0% / 77.9%	1.910
BIF	48.6% (202)	98.929***	44.0% / 54.9%	4.799*
LP	34.2% (97)		28.6% / 46.6%	8.769**
Disability pension				
MID	42.6% (133)		42.0% / 43.4%	0.293
BIF	16.6% (69)	96.047***	17.4% / 15.4%	0.056
LP	12.0% (34)		12.2% / 11.4%	0.045
GP	6.2% (64 486)		6.7% / 5.6%	
Psychiatric inpatient care				
MID	22.1% (69)		21.6% / 22.8%	0.064
BIF	18.8% (78)	11.648**	18.7% / 18.9%	0.002
LP	11.6% (33)		11.2% / 12.5%	0.096
Inpatient health care [b]				
MID	31.1% (97)		24.4% / 39.7%	8.354**
BIF	31.7% (132)	5.596	24.1% / 42.3%	15.535***
LP	23.9% (68)		16.8% / 39.4%	17.544***
ID services				
MID	44.2% (138)		41.5% / 47.8%	1.241
BIF	11.4% (48)	185.499***	12.4% / 10.3%	0.464
LP	3.5% (10)		3.6% / 3.4%	0.005

Note. [a] Disability pension and/or psychiatric inpatient care and/or ID services and/or > 30 days in inpatient health care. [b] > 30 days. *p < 0.05 ** p < 0.01 ***p < 0.001

Table 3 Average percentages of psychiatric inpatient care and inpatient heath care per year, calculated risk ratios to general population, and average number of days in care. Percentages of psychiatric inpatient care are presented over time in Figure 2.

	% in psychiatric inpatient care / year				Risk ratio to general population			Days in psychiatric inpatient care / year			
	MID	**BIF**	**LP**	**GP**	**MID**	**BIF**	**LP**	**MID**	**BIF**	**LP**	**GP**
Mean all years	3.3	3.0	2.1	0.9	3.8	3.4	2.4	33	101	119	68
min	0.3	0.9	0.3	0.6	0.4	1.2	0.4	17	80	83	65
max	5.6	5.2	4.3	1.0	7.4	6.2	4.6	72	127	130	85
Mean 1998 – 1994	2.1	3.2	1.5	0.9	2.3	3.6	1.7	33	101	119	68
Mean 1993 – 1989	1.8	3.1	1.5	0.8	2.2	3.7	1.8				
Mean 1988 – 1984	3.6	3.4	2.2	0.9	4.0	3.7	2.4				
Mean 1983 – 1979	3.9	2.7	3.2	1.0	4.0	2.9	3.4				
Mean 1978 – 1974	4.6	4.0	2.5	0.9	5.1	4.4	2.7				
Mean 1973 – 1970	4.0	1.6	1.6	0.7	5.3	2.2	2.2				

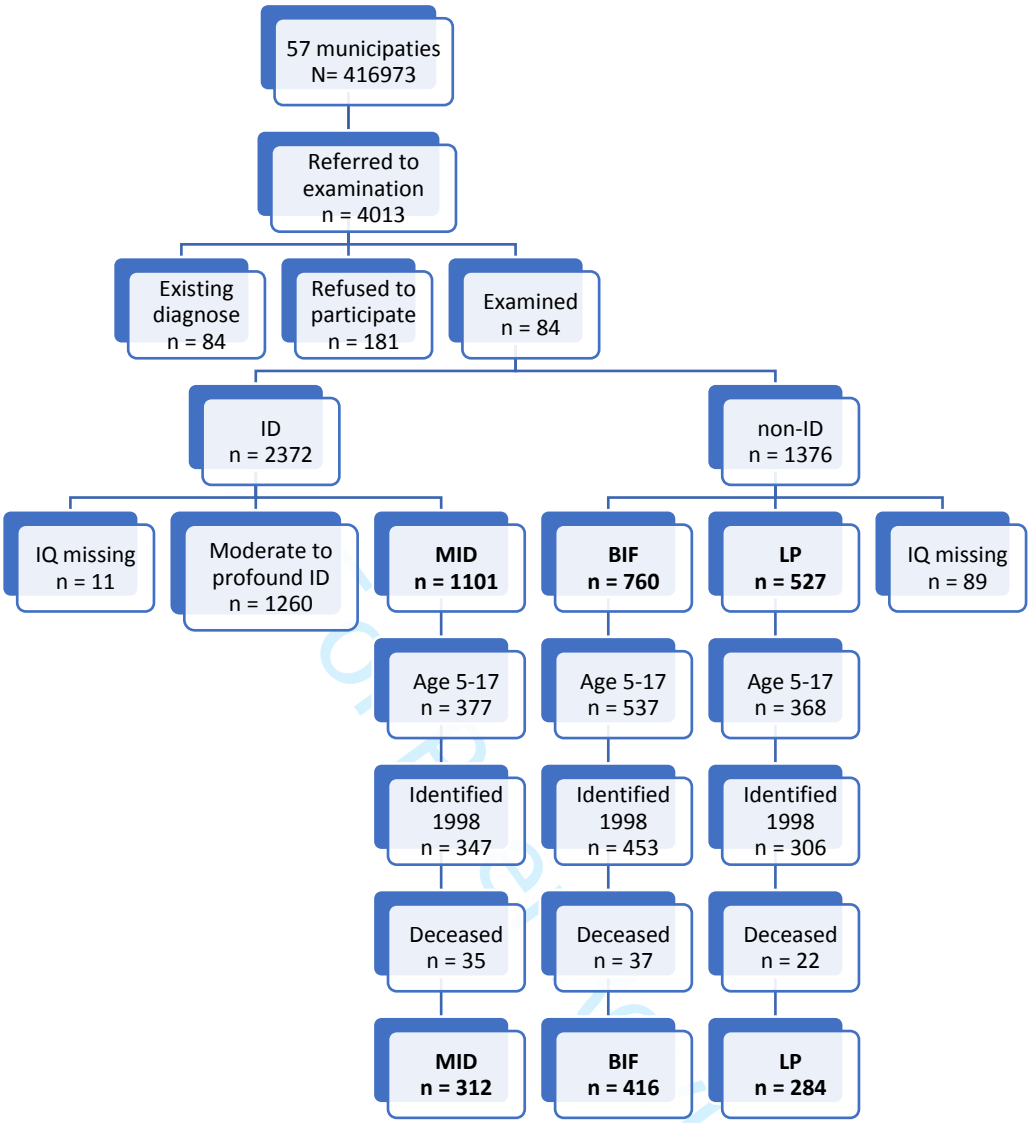
	% in inpatient heath care / year				Risk ratio to general population			Days in inpatient health care / year			
	MID	**BIF**	**LP**	**GP** [a]	**MID**	**BIF**	**LP**	**MID**	**BIF**	**LP**	**GP** [a]
Mean all years	11.6	11.6	10.5	12.1				14	11	6	6
min	2.9	0.9	0.6	11.8				10	7	5	5
max	19.6	14.6	14.3	12.3				18	14	7	6
Mean 1998 – 1994	15.2	13.3	12.5	12.1	1.3	1.1	1.0	14	11	6	6
Mean 1993 – 1989	12.5	12.9	11.3								
Mean 1988 – 1984	11.2	11.5	10.2								
Mean 1983 – 1979	9.9	11.5	10.9								
Mean 1978 – 1974	11.9	12.7	9.9								
Mean 1973 – 1970	8.3	7.0	7.5								

[a] From 18 to 64 years

Figure legends:

Figure 1 Attrition and grouping of persons in different phases of the study.

Figure 2 Mean percentages and range of all study groups and the general population in psychiatric inpatient care between 1970 and 1998.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N= 416973
Referred to examination
n = 4013
Existing diagnose
n = 84
Refused to participate
n = 181
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n = 84
ID
n = 2372
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n = 1376
IQ missing
n = 11
Moderate to profound ID
n = 1260
MID
n = 1101
BIF
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LP
n = 527
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n = 368
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n = 35
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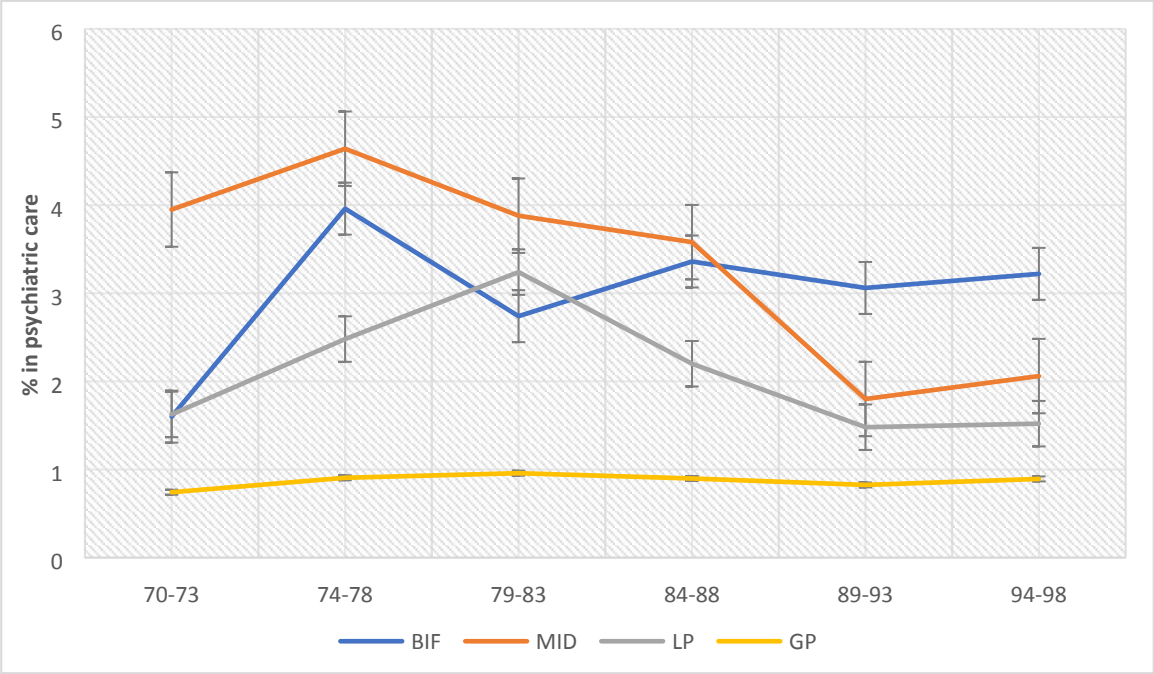
n = 37
Deceased
n = 22
MID
n = 312
BIF
n = 416
LP
n = 284


% in psychiatric care
0
1
2
3
4
5
6
70-73
74-78
79-83
84-88
89-93
94-98
BIF
MID
LP
GP

III

BORDERLINE INTELLECTUAL FUNCTIONING AND VULNERABILITY IN EDUCATION, EMPLOYMENT AND FAMILY

by

Minna Peltopuro, Hannu T. Vesala, Timo Ahonen & Vesa Närhi, 2022

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