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## **Older people with intellectual disability and affective and anxiety disorders: Comorbidities, healthcare utilisation, pharmacotherapy and frailty factors requiring support and social services**

El Mrayyan, Nadia

2020

*Document Version:*

Publisher's PDF, also known as Version of record

[Link to publication](#)

*Citation for published version (APA):*

El Mrayyan, N. (2020). *Older people with intellectual disability and affective and anxiety disorders: Comorbidities, healthcare utilisation, pharmacotherapy and frailty factors requiring support and social services*. [Doctoral Thesis (compilation), Department of Health Sciences]. Lund University: Faculty of Medicine.

*Total number of authors:*

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# Older people with intellectual disability and affective and anxiety disorders:

Comorbidities, healthcare utilisation, pharmacotherapy and frailty factors requiring support and social services

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DEPARTMENT OF HEALTH SCIENCES | LUND UNIVERSITY





# Older people with intellectual disability and affective and anxiety disorders:

Comorbidities, healthcare utilisation, pharmacotherapy and frailty  
factors requiring support and social services

Nadia El Mrayyan



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DOCTORAL DISSERTATION

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To be defended at Health Science Centre, Lund, on 11 December 2020 at 13:00.

*Faculty opponent*  
Professor Ruth Northway  
University of South Wales, Cardiff

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	<b>Date of issue</b> 11 <sup>th</sup> December, 2020	
<b>Title and subtitle</b> Older people with intellectual disability and affective and anxiety disorders: comorbidities, healthcare utilisation, pharmacotherapy and frailty factors requiring support and social services		
<b>Abstract</b> <p><b>Background:</b> Affective and anxiety disorders have a higher occurrence in older people with intellectual disability (ID) than in the general population. However, there is a lack of research into this ageing group from the point of view of their health panorama, use of medicines, healthcare utilisation and social welfare support. This thesis is part of a Swedish national population project on health, mortality, healthcare and social welfare utilisation among older people with ID.</p> <p><b>Aim:</b> The main aim of the thesis was to investigate comorbidities, healthcare utilisation and pharmacotherapy in older people with ID, compared to older people from the general population, diagnosed with affective and/or anxiety disorders. A further aim was to investigate, within the ID group, the association between frailty factors and use of support and social services provided through Swedish disability regulations.</p> <p><b>Methods:</b> All of the studies have a longitudinal design, based on Swedish national registries during an 11-year period. The ID cohort was a sample from the national study population, aged at least 55 years and alive at the end of 2012 (n=7,936), and a control group of the same size was matched by birth year and sex from the general population. Studies I–III investigated those in both cohorts with at least one affective disorder (n=918) and/or anxiety disorder (n=825) who visited specialist healthcare, examining diagnoses, healthcare utilisation and pharmacotherapy in these subgroups. Study IV focused on the ID group only (n=871), examining their frailty factors and use of support and social services.</p> <p><b>Results:</b> Older people with ID were more likely to have other comorbidities, to visit inpatient healthcare and to be prescribed drugs such as anxiolytics, compared to older people in the general population with affective and/or anxiety disorders (Studies I–III). The most common psychiatric comorbidities in the ID group were unspecified or other mental disorders. Concerning somatic comorbidities, they were more likely to have neurological problems, injuries and falls (Study I). The ID group was more likely to have inpatient and unplanned healthcare visits to both psychiatric and somatic healthcare (Study II). Those with affective and/or anxiety disorders in the ID group were more likely to be prescribed anxiolytics and GABA agonists (Study III). Those having more than 12 visits to healthcare and having multimorbidity were less likely to live in residential arrangements, the opposite was found for polypharmacy and moderate or severe levels of ID compare to those without (Study IV).</p> <p><b>Conclusion:</b> The results verify that older people with ID and with affective and/or anxiety disorders have comprehensive and complex needs for healthcare, treatment and social services, which puts exceptionally high demands on promoting healthy ageing for this target group. From the results of these studies, as well as from the increasing number of ageing people with ID in all developed countries in the world, there is an urgent need to develop specific medical guidelines for health surveillance and structured care programmes for this frail group of older people. Preventive interventions for affective and anxiety disorders need to focus on communication strategies and tools to foster healthy ageing and person-centred healthcare. Implementation of Peplau's model of the nurse client relationship and EU policy of healthy ageing may improve the quality of care.</p>		
<b>Key words:</b> Ageing, intellectual disability, affective disorders, anxiety disorders, healthcare, social services, drugs, frailty factors		
Classification system and/or index terms (if any)		
Supplementary bibliographical information	<b>Language:</b> English	
ISSN and key title: 1652-8220 Lund, Faculty of Medicine Doctoral Dissertation Series 2020:135.	<b>ISBN:</b> 978-91-8021-002-7	
Recipient's notes	<b>Number of pages</b> 78	Price
	Security classification	

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Lund University, Faculty of Medicine  
Department of Health Sciences  
Doctoral Dissertation Series 2020:135

ISBN 978-91-8021-002-7  
ISSN 1652-8220

Printed in Sweden by Media-Tryck, Lund University  
Lund 2020



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# Abstract

**Background:** Affective and anxiety disorders have a higher occurrence in older people with intellectual disability (ID) than in the general population. However, there is a lack of research into this ageing group from the point of view of their health panorama, use of medicines, healthcare utilisation and social welfare support. This thesis is part of a Swedish national population project on health, mortality, healthcare and social welfare utilisation among older people with ID.

**Aim:** The main aim of the thesis was to investigate comorbidities, healthcare utilisation and pharmacotherapy in older people with ID, compared to older people from the general population, diagnosed with affective and/or anxiety disorders. A further aim was to investigate, within the ID group, the association between frailty factors and use of support and social services provided through Swedish disability regulations.

**Methods:** All of the studies have a longitudinal design, based on Swedish national registries during an 11-year period. The ID cohort was a sample from the national study population, aged at least 55 years and alive at the end of 2012 (n=7,936), and a control group of the same size was matched by birth year and sex from the general population. Studies I–III investigated those in both cohorts with at least one affective disorder (n=918) and/or anxiety disorder (n=825) who visited specialist healthcare, examining diagnoses, healthcare utilisation and pharmacotherapy in these subgroups. Study IV focused on the ID group only (n=871), examining their frailty factors and use of support and social services.

**Results:** Older people with ID were more likely to have other comorbidities, to visit inpatient healthcare and to be prescribed drugs such as anxiolytics, compared to older people in the general population with affective and/or anxiety disorders (Studies I–III). The most common psychiatric comorbidities in the ID group were unspecified or other mental disorders. Concerning somatic comorbidities, they were more likely to have neurological problems, injuries and falls (Study I). The ID group was more likely to have inpatient and unplanned healthcare visits to both psychiatric and somatic healthcare (Study II). Those with affective and/or anxiety disorders in the ID group were more likely to be prescribed anxiolytics and GABA agonists (Study III). Those having more than 12 visits to healthcare and having multimorbidity were less likely to live in residential arrangements, the opposite was found for polypharmacy and moderate or severe levels of ID compare to those without (Study IV).

**Conclusion:** The results verify that older people with ID and with affective and/or anxiety disorders have comprehensive and complex needs for healthcare, treatment and social services, which puts exceptionally high demands on promoting healthy ageing

for this target group. From the results of these studies, as well as from the increasing number of ageing people with ID in all developed countries in the world, there is an urgent need to develop specific medical guidelines for health surveillance and structured care programmes for this frail group of older people. Preventive interventions for affective and anxiety disorders need to focus on communication strategies and tools to foster healthy ageing and person-centred healthcare. Implementation of Peplau's model of the nurse client relationship and EU policy of healthy ageing may improve the quality of care.

## Abbreviations

ACT	Anatomical Therapeutic Chemical classification system
CI	Confidence interval
GLM	Generalised linear model
gRef	General reference group from the general population
HSL	Hälso och sjukvårdslagen (the Health and Medical Services Act)
ID	Intellectual disability
ICD-10	International Classification of Diseases, 10 <sup>th</sup> edition
IQ	Intelligence quotient
LSS	Lagen om stöd och service till vissa funktionshindrade (the Act Concerning Support and Service for People with Certain Functional Impairments)
NPR	National Patient Register
OR	Odds ratio
RR	Relative risk
SoL	Socialtjänstlagen (The Social Services Act)
TPR	Total Population Register
UN	United Nations
WHO	World Health Organization

## List of papers

This thesis is based on the following papers referred to in the text by their Roman numerals I-IV:

- I. El Mrayyan, N., Eberhard, J., & Ahlström, G. (2019). The occurrence of comorbidities with affective and anxiety disorders among older people with intellectual disability compared with the general population: a register study. *BMC Psychiatry*, 19(1):166.
- II. El Mrayyan, N., Bökberg, C., Eberhard, J., & Ahlström, G. Healthcare utilisation patterns among older people with intellectual disability and with affective and anxiety diagnoses in comparison with the general population. *Ageing & Mental Health*, 1-10.
- III. Axmon, A., El Mrayyan, N., Eberhard, J., & Ahlström, G. (2019). Pharmacotherapy for mood and anxiety disorders in older people with intellectual disability in comparison with the general population. *BMC Psychiatry*, 19(1):238.
- IV. El Mrayyan, N., Bökberg, C., Eberhard, J., & Ahlström, G. Frailty associated with support and social services in older people with intellectual disability and affective and anxiety diagnoses: A Swedish national population-based register study. Submitted (2020).

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# Introduction

My interest in this thesis topic started many years before starting my PhD studies. After I finished my bachelor's degree in nursing, I was fortunate to be involved in a project with the World Health Organization (WHO) in Jordan. The project focused on mental health policy to provide biopsychosocial interventions through developing community-based mental health services (WHO, 2013). As a part of a multidisciplinary team, my role in this project was as a community mental health nurse trying to help people in need of mental health care. I provided family support for families of individuals with intellectual disability (ID). At this point, many questions started invading my mind, such as what these people understand and experience, and how we can help and support them. I have wanted to find answers to such questions for a long time, and I reflected on whether I had the right knowledge and skills to promote their health and well-being. I have decided to learn more, do more and make my ultimate goal not only to understand these people in need but also to help them. My interest has grown gradually for this topic since I completed my master's degree but also from my practical experiences as a community mental health nurse. After several years in this position, I came to know that people with ID have complex needs, especially when they have communication problems or other disabilities. I realised there is a need for more knowledge about the challenges they may face throughout their lives. Not only was I convinced that I need to investigate this specific area, but I also wanted to make some impact and try to help in providing a better care service to these people.

Moving to Sweden and starting to learn about the Swedish health and welfare system, I immediately noticed that the health and social services are much better, with much higher capabilities than in other countries. However, reading through the mental health literature I have noticed that, even in Sweden, people with ID are facing problems, and that this area is still not well studied. Moreover, most of the available literature concerns studies with a small sample size, and a study at the population level is therefore of great importance. The invitation to be a part of a large project marked the starting point of my PhD journey; the topic was partly identified conventionally by spotting a gap in the literature, but arose mainly from an awareness of the shortcomings that many communities across the world are experiencing.

# Background

## The history of Swedish disability policy

Until 1980, people with ID in Sweden lived in large institutions (Tøssebro et al., 2012). On an international level, the Universal Declaration of Human Rights on the Rights of Persons with Disabilities, enshrines the principle that people with disabilities are citizens with the same rights and obligation as other citizens (United Nations, 1948). The shift from the biomedical perspective to normalisation and full integration as a citizen were introduced in Sweden during the second half of the 1970s and strengthened during the following decades (Tøssebro, et al., 2012). The dismantling of institutions for people with ID, which was ongoing from 1980 to the first years after 2000, aimed to promote equality and participation in society for people with ID (Tøssebro, et al., 2012). In 2000, the Swedish government established a national action plan for disability policy, “*From Patient to Citizen*”, which concentrated on three main areas: (1) to ensure that the disability perspective permeates all sectors of the society, (2) to create an accessible society and (3) to improve the encounter with people with disability (Ministry of Social Affairs, 1999/2000:79). Thus, the view of people with ID changed from a medical perspective to a citizen perspective focusing on social roles (Ministry of Social Affairs, 1999/2000:79; Umb Carlsson, 2020). This implies equal worth and rights as human beings and the possibility to live like everyone else in the society (Ministry of Social Affairs, 1999/2000:79).

This change in the disability policy reformed the care and services for people with ID. The previous focus was on the person’s disability, but this focus shifted to the possibilities the individual has, the opportunity for social interaction with others and the ability to perform different activities (Tøssebro, 2016; Tøssebro, et al., 2012). The goal of the national action plan “*From Patient to Citizen*” (Ministry of Social Affairs, 1999/2000:79) has the social model as its basis. This means that society must be designed to meet the needs of people with ID of all ages and enable them to become fully involved in society with equal living conditions. To achieve this goal, the focus needs to be on identifying differences and barriers to full participation of this group in society. The government, municipalities and county councils are responsible for ensuring that people with disabilities are guaranteed good health and economic and



social stability, also enabling them to lead an independent life (The National Board of Health and Welfare, 2020a).

Today, the Swedish disability policy is strongly based on the UN Convention on the Rights of Persons with Disabilities (United Nations, 2006). This has contributed to the closure of the old institutions from the 1980s and increased the opportunities to live in group homes and participate in everyday life (Tøssebro, et al., 2012). The disability was no longer attributed to the individual's deficits; instead, the focus shifted to deficiencies and obstacles in the environment and the society (Eriksson, 2002, Umb Carlsson, 2008). The transfer from institutions to community-based residential care was reported as having a positive impact on the person's quality of life and increased social interaction (Chowdhury and Benson, 2011; Tøssebro, 2016). However, several studies identified negative aspects of residential care, such as the risk of social isolation, limited social inclusion in community life and inadequate healthcare (Chowdhury and Benson, 2011; Ericsson, 2002; Sheerin, Griffiths, de Vries, & Keenan, 2015). Moreover, the services and support provided were focused on the political and financial situation in the municipality and optimised to meet common needs considered to be shared by all people with ID rather than individual needs and preferences (Umb Carlsson, 2008, 2020). A follow-up study after 16 years concerning living conditions after deinstitutionalisation in Sweden found that people with ID lived in more restricted social environments, had less leisure time and had a more limited social life compared to the general population (Umb Carlsson, 2020).

## Intellectual disability (ID)

ID is defined as a significant limitation in intellectual functioning and adaptive behaviour which covers many daily social and practical skills. Such disability has its onset before the age of 18 years (American Association on Intellectual and Developmental Disability, 2020). WHO defines ID as significantly impaired intelligence reducing the ability to understand complex or new information and to learn new skills, resulting in impairment of social functioning, starting before adulthood (WHO, 2020). In the International Classification of Diseases (ICD-10), the outdated term *mental retardation* is used in the category name (encompassing codes F70–F79) (WHO, 2016). This is defined as “*a condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, skills which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities*”(WHO, 2016). However, *intellectual disability* is now the internationally established term used in disability research and policy and by

health professionals, and it has replaced the term mental retardation in the ICD-11 (Salvador-Carulla et al., 2011). This thesis used the term “ID” which is used in disability research and policy, health professionals and people with ID in Sweden and internationally.

The intelligence quotient (IQ) test is a major tool in measuring intellectual function, where people with IQ below 70 are considered to have ID. In ICD-10, ID is divided into four severity levels: F70 mild (approximate IQ 50–69), F71 moderate (IQ 35–49), F72 severe (IQ 24–34), and F73 profound (IQ under 20) (WHO, 2016). A mild level of ID is likely to result in some learning difficulties in school but, in adulthood, people with mild ID will be able to work and maintain social relationships and contribute to society. A moderate level of ID is associated with developmental delays in childhood and, although those at this level can develop some degree of independence in self-care, as adults they need support to live and work in the community. Those at the severe level have a continuous need of support throughout life. Finally, the profound level results in severe limitations in self-care, continence, communication and mobility. To summarise, people with a mild level of ID can live independently, and those with more severe levels are unable to communicate verbally, walk or feed themselves independently and will always need some support and care. This implies that the quality of the interpersonal relationship between the nurse and the client might potentially be affected, leading to a poor quality of care. For example, when visiting a health clinic for a health problem, the person with ID might have difficulties explaining their signs and symptoms correctly because they have problems expressing feelings in abstract terms, reasoning and problem-solving. In turn, the staff may have difficulties understanding the person’s needs and providing the necessary care. This means that people with ID are a vulnerable group in society, which is reinforced by their premature ageing compared with the general population (Coppus, 2013).

## Ageing and people with ID

Ageing is a natural process of life, involving progressive biological, psychological and social changes. Globally, the ageing population is growing rapidly, and this includes people with ID (Fisher and Kettl, 2005; WHO, 2017). Increased age implies a higher risk of developing chronic disease and multimorbidity; the consequent increased prescription of drugs might result in a decreased quality of life (McCarron et al., 2013; Scheifes et al., 2016; WHO, 2000). Compared to older people in the general population, those with ID have a higher rate of chronic conditions such as epilepsy

(Cooper et al., 2015; Espie et al., 2003; McCarron, et al., 2013), dementia (McCarron, McCallion, Reilly, & Mulryan, 2014), cardiovascular diseases (de Winter, van den Berge, Schoufour, Oppewal, & Evenhuis, 2016), and osteoporosis (Burke et al., 2019), and they have a different pattern of co-occurring conditions, such as mental health problems (McCarron, et al., 2013), and unhealthy lifestyle (McCarron, et al., 2013). This means a higher level of medication use (O'Dwyer, Peklar, McCallion, McCarron, & Henman, 2016) compared to older people in the general population.

WHO emphasises the importance of healthy ageing of developing and maintaining the physical, social and mental ability that promotes wellbeing in older age (WHO, 2000). This has been also acknowledged by the health policy initiative Healthy ageing in Sweden and EU (Folkhälsomyndigheten/ The Public Health Agency of Sweden, 2018; The European Innovation Partnership on Active and Healthy Ageing (EIP-AHA), 2011). At the same time WHO has drawn attention to the fact that older people with ID are a neglected group and at risk of being treated unfairly when it comes to the provision of care and welfare (WHO, 2000). Strydom, Hassiotis, & Livingston (2005), found that older people with ID have a higher risk of undiscovered and underestimated problems with their physical and mental health, and more research is needed in the field. Several studies have confirmed that older people with ID have a higher risk of both psychiatric and somatic diagnoses than the general population (Axmon, Bjorne, Nylander, & Ahlström, 2018; Cooper, et al., 2015; Hermans and Evenhuis, 2014; McCarron, et al., 2013; Sandberg, Ahlström, & Kristensson, 2017). Furthermore, several studies reported that psychiatric diagnoses, such as affective and anxiety disorders, are very common in older people with ID (Axmon, Bjorne, et al., 2018; Cooper, et al., 2015; Cooper, Smiley, Morrison, Williamson, & Allan, 2007; McCarron, et al., 2013). The ageing process adds more complexity and demands competence among the care staff to recognise these needs and to provide good and adequate health and social care (Brown, MacArthur, McKechnie, Hayes, & Fletcher, 2010; Kåhlin, Kjellberg, & Hagberg, 2016). Clearly, older people with ID present a range of multiple psychiatric disorders, including affective and anxiety disorders, and it is essential to understand their particular expressions of mental health problems.

## Affective(mood) and anxiety disorders in older people with ID

Mental health problems such as depression and anxiety are the most common public health problems in older ages; they which can impact physical health, just as declining

physical health can give rise to mental health problems, which causes great suffering and leads to impaired functioning in daily life (WHO, 2017). The ICD-10 defines **affective disorder** as. “*disorders in which the fundamental disturbance is a change in affect or mood to depression (with or without associated anxiety) or to elation*” (WHO, 2016). The affective disorders are categorised into depression, bipolar affective disorder, manic episode, recurrent depression and persistent mood disorders. **Anxiety disorders** are considered to be stress-related disturbances causing significant maladaptation in social, occupational or personal function; they are classified in ICD-10 as phobic anxiety disorders, other anxiety disorders, obsessive- compulsive disorder, reaction to severe stress, adjustment disorders, and dissociative and somatoform disorders (WHO, 2016). Many studies have reported that older people with ID have a higher risk of psychiatric diagnoses such as affective (mood) and anxiety disorders than the general population (Axmon, Bjorne, et al., 2018; Cooper, et al., 2007; McCarron, et al., 2013). Moreover, depression and anxiety are considered to be two common disorders in individuals with ID, and they commonly occur together (Cooper, et al., 2007; Hermans, Beekman, & Evenhuis, 2013).

The identification of psychiatric symptoms relies on the person’s verbal expression, which is limited in people with ID, reducing their ability to describe their symptoms appropriately. Previous research has identified depression and anxiety symptoms in people with ID as a challenge for healthcare providers, due to (1) lower cognitive ability, (2) little or no communication skills and (3) the fact that behavioural impairment usually masks symptoms of psychiatric diagnoses (Hurley, 2008; Wu, Desarkar, Palucka, Lunskey, & Liu, 2013). Hermans, Beekman, & Evenhuis (2014) stressed the importance of differentiating between anxiety symptoms and a diagnosis of anxiety disorder. In their study, they compared anxiety symptoms reported by older people with and without ID. They found that those with mild and moderate ID showed more symptoms of anxiety than those without ID (Hermans, et al., 2014). Even though it is established that older people with ID have a higher occurrence of mental health problems than the general population, there is a lack of mental health professionals such as nurses specialised in ID in the nursing education system (Adshead, Collier, & Kennedy, 2015; Evans et al., 2012). Therefore, research into comorbidities with affective and anxiety disorders is critical for our understanding of the needs of people with ID.

### **Comorbidity associated with affective and anxiety disorders**

Affective and anxiety disorders may be associated with a higher risk of other diseases (Cooper, et al., 2007). A Swedish study investigated the occurrence of psychiatric

diagnoses in a specialist healthcare setting among older people with ID and found that they were almost twice as likely to have affective and anxiety disorders compared to the general population (Axmon, Bjorne, et al., 2018). In the general population, affective and anxiety disorders have been associated with chronic conditions and a higher risk of healthcare utilisation and cost among individuals with diabetes (Huang et al., 2015; Kyung Lee and Hee Lee, 2014), cancer (Mausbach and Irwin, 2017), spinal cord injury (Ullrich, Smith, Blow, Valenstein, & Weaver, 2014) and chronic obstructive pulmonary disease (Albrecht et al., 2017). These conditions may cause an increased burden for people with ID, as they are highly vulnerable due to their communication difficulties (McCarron, et al., 2013; Perkins and Moran, 2010; Tuffrey-Wijne and McEnhill, 2008).

The deficit in communications limits the ability of people with ID to describe and report their symptoms to health care providers. This results in unsatisfactory clinical consultations and poor treatment choices (Esbensen, Rojahn, Aman, & Ruedrich, 2003; Glynn et al., 2011; Lennox, Diggins, & Ugoni, 1997). These problems may increase with the severity level of the ID, limiting the clinician's ability to diagnose affective and anxiety disorders (Hermans, et al., 2013; Marston, Perry, & Roy, 1997; Reid, Smiley, & Cooper, 2011). Additionally, affective and anxiety disorders may be associated with a higher risk of other psychiatric conditions and somatic diseases (Cooper, et al., 2007). Because older people with ID and a diagnosed affective or anxiety disorder manifest a different symptom expression for the same diagnoses and comorbidities, it is essential to understand these differences in order to develop appropriate policy strategies and reduce disparities in access to healthcare (Hermans, et al., 2014).

## **Healthcare utilisation among older people with ID**

As people age, the number of complex disease problems increases, which leads to adverse health outcomes such as longer hospitalisation, higher health cost, increased risk of hospitalisation and decreased quality of life (Emerson and Baines, 2011; Lunskey and Balogh, 2010; Wu, et al., 2013). Several studies comparing older people with ID to the general population have reported longer hospitalisation with psychiatric diagnoses, diabetes, cancer and vision problems but also inadequate access to healthcare (Ahlström, Axmon, Sandberg, & Hultqvist, 2020; Axmon, Björne, Nylander, & Ahlström, 2016; Lunskey and Balogh, 2010; McCarron, Cleary, & McCallion, 2017; Perkins and Moran, 2010).

Previous studies of older people with ID compared to the general population have shown that, of the older people with ID, the youngest ones were found to utilise more

inpatient and outpatient healthcare (Axmon, et al., 2016; Sandberg, Ahlström, Axmon, & Kristensson, 2016). Furthermore, these studies showed longer stays in psychiatric inpatient facilities and a higher risk of somatic healthcare utilisation in younger than older age groups in people with ID; this pattern was not observed in the general population. Although affective and anxiety disorders are commonly diagnosed in older people with ID, a deeper understanding of the healthcare utilisation patterns of people with ID who have affective and anxiety disorders is needed, as it might be expected that this group is more vulnerable than others with ID. The presence of comorbidities and higher healthcare utilisation increase the risk of prescribing medication, resulting in a decreased quality of life (Chitty et al., 2016; Emerson and Baines, 2011; Sheehan, Strydom, Morant, Pappa, & Hassiotis, 2017).

### **Pharmacotherapy among older people with ID**

Older people with ID are at higher risk of being prescribed significantly more psychotropic drugs due to the high prevalence of psychiatric comorbidities (Bowring, Totsika, Hastings, Toogood, & McMahon, 2017; Cooper, et al., 2007; Deb, Unwin, & Deb, 2015; Sheehan et al., 2015; Singh and Matson, 2009; Tsiouris, Kim, Brown, Pettinger, & Cohen, 2013). Antidepressants, anxiolytics, sedatives and hypnotics are between 10% and 23% more likely to be prescribed than other psychotropic drugs to older people with ID (Chitty, et al., 2016; Tsiouris, et al., 2013). In addition, in people with ID, with or without a psychiatric diagnosis, these drugs are commonly prescribed to manage severe behavioural impairment or challenging (problem) behaviours and the symptoms of the ID itself (McGillivray and McCabe, 2004; Tsiouris, 2010). At present, there is no evidence of the effectiveness of using psychotropic drugs on challenging behaviours, which should be taken into consideration by the physicians and health care providers when prescribing psychotropic drugs (Emerson and Baines, 2011; Tsiouris, 2010). All staff need to understand that challenging behaviour is often a response to a situation where the individual's living situation breaks down because of an unsuitable social environment and may be a response to specific events (Emerson et al., 2001; Lundqvist, Hultqvist, Granvik, Minton, & Ahlström, 2020).

The prescription of inappropriate drugs is more commonly found in older people with ID than in the general population (Axmon, Sandberg, Ahlström, & Midlöv, 2017). Anxiolytics such as benzodiazepine, are associated with a wide range of side effects (Schulte and Hser, 2013) and, despite the risk of addiction, these drugs are more likely to be prescribed to older people with ID (Axmon, Kristensson, Ahlström, & Midlov, 2017). Moreover, the use of benzodiazepines and sedatives increases the risk of several adverse effects, such as falls and injuries in older people (Ham et al., 2014; Schulte and

Hser, 2013). This increase in inappropriate prescription of psychotropic drugs, especially in older people with ID, may exacerbate mental and physical problems and decrease their quality of life (Scheifes, Walraven, et al., 2016). Accordingly, health care providers should pay closer attention to understanding the problems associated with ageing in people with ID, in order to provide a better quality of care (Hermans, et al., 2014; Hermans, et al., 2013; Hermans and Evenhuis, 2013). Given that people with ID experience more health discrepancies, the rate of polypharmacy is higher than in the general population. The more health problems they have, the more frail they are compared to the general population (Schoufour, Mitnitski, Rockwood, Evenhuis, & Echteld, 2013; Schoufour et al., 2014).

### **Frailty in older people with ID**

The term *frailty* is a recognised concept for a prevalent problem in the ageing population (O'Caoimh et al., 2018). Frailty is a state in which individuals are more prone to adverse health outcomes compared to others of the same age (Clegg, Young, Iliffe, Rikkert, & Rockwood, 2013; Schoufour, Echteld, Bastiaanse, & Evenhuis, 2015). Currently, there is no general definition for frailty, and various definitions are reported in the literature (Rockwood, 2005; Sezgin, O'Donovan, Cornally, Liew, & O'Caoimh, 2019). Each is based on a particular context and setting, which may influence how it was defined and used. Generally, these studies focus on methods to identify frailty rather than clarifying the terminology (Rockwood, 2005; Sezgin, et al., 2019). However, the majority describe frailty as a clinical syndrome in which several interacting factors related to decreasing physiological reserves lead to increasing susceptibility to acute illness, disability and mortality (Evenhuis, Hermans, Hilgenkamp, Bastiaanse, & Echteld, 2012; Gordon, Masud, & Gladman, 2013; Junius-Walker et al., 2018; Sezgin, et al., 2019).

In this thesis, the focus of frailty is in a broader perspective because older people with ID have, apart from their long-standing disability, a higher risk of multimorbidity (McCarron, et al., 2013), medication use (M. O'Dwyer, et al., 2016), negative health outcomes and higher mortality than people in the general population of the same age (Ng, Flygare Wallén, & Ahlström, 2017); they have lived with negative psychological and environmental factors (Bond et al., 2020) throughout their lives, which all contributes to increased frailty in older age. These frailty factors develop earlier in people with ID, which may lead to discrepancies in the use of healthcare compared to the general population (Evenhuis, et al., 2012; Gale, Cooper, & Sayer, 2015; Ouellette-Kuntz et al., 2019; Schoufour, et al., 2015; Schoufour, et al., 2013). Other factors such as nutritional deficit (malnutrition and weight loss or obesity)

(Sezgin, et al., 2019) and a more limited social network and environment, increase further the existing frailty (Sezgin, et al., 2019). The impact of frailty in older people with ID is evident in their physical and psychological health and quality of life (Sezgin, et al., 2019). Frailty increases the risk of depression and anxiety, and the co-occurrence of depression and other mental illness is high among older people with ID (Schoufour, et al., 2014). Frailty implies a risk of adverse health outcomes, and therefore these individuals need support from caregivers within several healthcare sectors and social care systems. The importance of understanding the factors that affect the health and social care system is essential in the planning of interventions for older people with ID aimed at increasing their quality of life.

## The Swedish healthcare and welfare system

In Sweden, the health and welfare system is distributed across 21 county councils, responsible for healthcare, and 290 municipalities for social services and home care (Anell, Glengard, & Merkur, 2012). It is also nationally-funded through taxes to ensure that everyone has equal access to health and social care (Swedish Institute 2020). The municipalities are responsible for the care of people with multiple disabilities and older people, and the provision of support and services for people in home and residential arrangement care (Anell, et al., 2012; Swedish Institute 2020). The Swedish government states that every county council and municipality is responsible for providing good quality of health and social care for the whole population (Anell, et al., 2012). The National Board of Health and Welfare (*Socialstyrelsen*), an authority controlled by the Swedish government, ensures that the whole population has equal access to good health and social care (The National Board of Health and Welfare, 2019). This authority also plays an important role in producing and developing statistics through registries, but also disseminating information, regulations and guidelines for health and social care (The National Board of Health and Welfare, 2019).

The Health and Medical Services Act from 1982, abbreviated HSL, regulates the Swedish healthcare system and ensures that everyone living in Sweden has equal access to healthcare within the county councils and municipalities (SFS 1982:763, 1982). The Social Services Act from 2001, abbreviated SoL, specifies that people have the right to receive public services and social support at all stages of life (SFS 2001:453, 2001). People with ID are also entitled under the Act Concerning Support and Service for Persons with Certain Functional Impairments (SFS 1993:387, 1993), abbreviated LSS, to receive support, care and services to ensure equal living conditions to the general



population. LSS is a law that sets out the rights of individuals with significant and permanent functional impairment to special support and services with the purpose of providing living conditions that equal those of people without these disabilities. LSS encompasses three groups: Person group 1 is people with ID, autism or autism spectrum disorders since early childhood or before the age of 18 years. Person group 2 is people with ID as a result of permanent brain damage in adulthood due to external force or physical illness from adult ages. Person group 3; is people with other major and permanent physical or mental impairment that is clearly not due to normal aging. The LSS act is based on the UN Universal Declaration of Human Rights and the Convention on the Rights of Persons with Disabilities, in that it is designed to offer equalisation of opportunities between people with disabilities and other citizens (United Nations, 1948, 2006). The fact that discrepancies still exist between people with ID and the general population is an important issue that needs to be examined further. This concerns older people with ID especially, because the literature is sparse regarding changes as they age. Therefore, staff encountering people with ID in general healthcare and in targeted ID services should understand the differences and barriers in order to meet the needs of people with ID and provide the most appropriate treatment and services.

### **Staff encountering people with ID and mental health problems**

The complex needs of people with ID require the involvement of care providers in different parts of the Swedish welfare system. Torr et al. (2008) studied the changes in psychiatric care staff training, and treatment of people with ID over a 10-year period, and found an improvement in the ability of the staff to manage mental health problems. However, they reported that mental health services did not meet the needs of adults with severe ID (Torr et al., 2008). A study in Norway (Fredheim, Haavet, Danbolt, Kjongsberg, & Lien, 2013) investigated the experience of general physicians providing care for people with ID and mental health or behavioural problems. This study revealed the issues with the physicians' limited knowledge about communication and patient management for these people. Moreover, the study reported *diagnostic overshadowing*, the tendency of health professionals to overlook symptoms of mental health problems in this patient group and attribute the symptoms to having an ID (Mason and Scior, 2004). Furthermore, other studies revealed that the staff used the diagnostic criteria of general symptoms of mental health problems such as depression presented in the general population (Hermans, et al., 2014; Hermans and Evenhuis, 2014; Quigley, Murray, McKenzie, & Elliot, 2001).

The physician has the responsibility to diagnose mental health problems; however, other professionals, including nurses and social service staff, play an essential role in detecting and recognising mental health problems such as mood changes or problem behaviours (Kilanska and Priest, 2014). Nurses working with people with ID should be educationally prepared and trained to support this group and to be able to address their needs with the relevant competencies and skills within different settings.

As a result of normalisation, people with ID are not perceived by health and social care staff as a distinct and vulnerable group with healthcare needs beyond what is normal for the general population (While and Clark, 2010). One challenge might be that the nurses and other staff working in different care settings are not prepared to support people with ID with their health needs. The staff might not be able to understand the issues related to ID or other comorbid disorders and therefore not adapt their care accordingly. Hence the health and social care staff encountering people with ID should have the right knowledge and skills to support this group; nurses play an important role in addressing their needs in different settings. The relationship between the nurse and client is the cornerstone to understanding people with ID and their needs. Nurses need to constantly use their ability to communicate verbally and nonverbally when interacting with this group (Jim Donovan, 2002; Ndengeyingoma and Ruel, 2016). Nurses have reported that they experienced nonverbal communication as a complex skill, which they needed to use consistently when interacting with people with ID (Jim Donovan, 2002; Martin, Connor-Fenelon, & Lyons, 2012).

Moreover, as previously described, people with ID have different patterns of illness leading to increased frailty and exposure to a greater burden of illness than the general population. Staff working in the community and residential care settings have reported difficulties encountering people with ID, especially when the disability is severe and includes communication difficulties and behavioural problems (Kåhlin, Kjellberg, & Hagberg, 2015; Kåhlin, et al., 2016; Kilanska and M. Priest, 2014; Quigley, et al., 2001). Therefore, the interaction between the health and social care staff encountering people with ID is of great importance to provide holistic care and meet their needs (Appelgren, Bahtsevani, Persson, & Borglin, 2018).

# Theoretical nursing perspective

## Interpersonal relations theory

Hildegard Peplau's interpersonal relations theory provides a perspective that may deepen our understanding of the caring issues embedded in this thesis (Peplau, 1952/1991). Her work has strongly influenced the psychiatric nursing community, and it remains relevant and useful, not only in psychiatric settings but in other areas of nursing practice as well (Alligood and Marriner-Tomey, 1998; Peplau, 1952/1991). Her interpersonal theory has influenced largely psychiatric nursing for several decades, and her middle-range nursing theory illustrates what applied person-centred psychiatric care is, even if she lived (died in 1999) before the concept person-centred care is found in the literature (Deane and Fain, 2015; Peplau, 1997). Peplau used the nurse-client relationship to help the client towards self-empowering and health-promoting behaviours (Peplau, 1952/1991). She used knowledge borrowed from psychological and physiological models to develop her theory (Alligood and Marriner-Tomey, 1998; Peplau, 1952/1991). The framework refers to the nurse-client relationship as the foundation of nursing practice. Peplau describes three phases of the nurse-client relationship, which interlock and overlap over time: (1) *orientation*, (2) *working* and (3) *termination*. These phases describe the interpersonal relationship and also guide nurses towards developing intervention and care plans adapted to clients with specific needs (such as people with ID) in health and social care.

The *orientation* phase starts when the client has a need and seeks assistance from professionals. During this phase, the nurse begins to understand the client's history through therapeutic communication (Alligood and Marriner-Tomey, 1998; Deane and Fain, 2015). By gaining the trust of the client and eliciting the necessary information, the nurse is able to communicate with the client using personal resources such as knowledge and experience (Deane and Fain, 2015; Reynolds, 1997). During this phase, the nurse helps the client to recognise and understand the problem and determine the need for help (Alligood and Marriner-Tomey, 1998). However, this might be a challenge for nurses working with people with ID, because communication difficulties might create a barrier to understanding and limit the therapeutic interaction. The

nurse's role in this phase is to skilfully detect anxiety-related behaviours, elicit information and make an initial assessment of the person with ID.

The *working* phase consists of the majority of the nurse's time with the client. This phase is the implementation of the nursing plan, taking actions towards meeting the goals set in the orientation phase (Alligood and Marriner-Tomey, 1998). The nurse permits the exploration of feelings to foster reorientation and to strengthen the positive forces in the client's personality (Alligood and Marriner-Tomey, 1998). This provides the satisfaction of client needs. Through the nurse's ability to initiate meaningful communication with people with ID, this goal can be achieved. It is here that nurses use their professional knowledge and skills to help clients who cannot pinpoint the problem immediately (Deane and Fain, 2015; Reynolds, 1997). This stage is important, in that the focus is on the client's reaction to the problem and the ability of the nurse to understand the problem and eventually help the client to understand and learn more (Alligood and Marriner-Tomey, 1998). Examples of questions the nurse must explore are: 1) What is the client current status?; 2) What does the client need to know or acknowledge about this health status and how does this relate to what he or she is feeling? and 3) How can the nurse facilitate the client's acknowledgement of the condition, such as an affective or anxiety disorder and related behaviour problems?. In this way, the nurse encourages the client's self-expression and progression towards increased well-being.

Finally, the *termination* phase is the process of summarising and providing closure to the work accomplished by the nurse and the client (Alligood and Marriner-Tomey, 1998). It is very important to establish and maintain the connection and communication between the client and the nurse through the whole process adapted from Peplau theory, Figure 1.

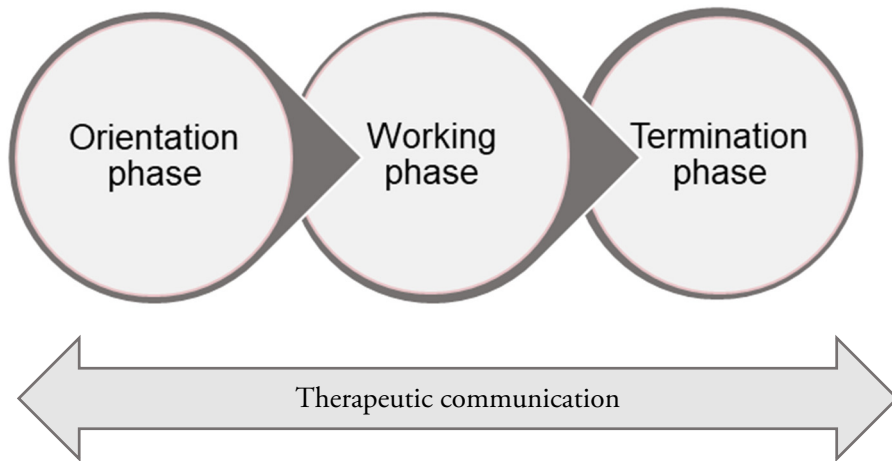


Figure 1. Phases of the nurse-client relationship in Hildegard Peplau's interpersonal relations theory (1997).

Peplau's theory was used in a study examining depression and anxiety in people with coronary heart disease (Zarea, Maghsoudi, Dashtbozorgi, Hghighizadeh, & Javadi, 2014). The results of this study revealed that a positive therapeutic communication reduced anxiety and depression. A study by Manzari, Meamarian, & Vanaki (2014) found that the severity of pain in burn patients was reduced by applying Peplau's interpersonal relations theory into their therapeutic communication, which indicates the importance of communication between the nurse and client. Peplau's theory was also incorporated into the training of nursing students to apply holistic communication to understanding the needs of older people (Deane and Fain, 2015; Devine, 2008). Peplau's phases of the nurse-client relationship can be applied by nurses in a variety of settings, and it would even be applicable to working with people with ID with affective and anxiety disorders. Nurses could use the three phases to educate and train other staff to communicate holistically with older people with ID. The nurses could thus be better equipped to communicate with this population group and to understand their clients' individual needs using holistic knowledge and communication skills (Devine, 2008).

Moreover, nurses in different health care settings can play an important role to improve their outcomes by building a therapeutic relationship (Alligood and Marriner-Tomey, 1998; Deane and Fain, 2015) formed over several interactions with older people with ID and affective and anxiety disorders. Communication is one of the vital methods to establish a connection with people (Deane and Fain, 2015). The nurse who works with

people with ID needs to have the appropriate knowledge and skills (Richard Gäddman and Ulla Hellström, 2018), using various methods to facilitate communication with people with ID . The key objective is creating an environment where people with ID feel safe to express themselves and feel supported (Alligood and Marriner-Tomey, 1998; Richard Gäddman and Ulla Hellström, 2018). Therefore, nurses' therapeutic communication skills should exist through all phases of the interpersonal relationship. Effective therapeutic communication skills should be expanded through training for this particular target group to help nurses and other professionals to engage in a productive interpersonal relationship.

# Rationale

Affective and anxiety disorders are more common among older people with ID than among the general population of the same age. However, little is known about these disorders in older people with ID, for example, whether there is any difference in the comorbidities, healthcare utilisation or pharmacotherapy compared to those without ID. Moreover, frailty factors are known to have an impact on social care and services, although the impact of affective and anxiety disorders in these older people with ID is unknown. Earlier research has shown differences in the prevalence of diseases such as dementia, epilepsy, psychiatric diagnoses and somatic diagnoses such as osteoporosis in older people with ID. However, there are no studies that investigate the differences in older people with ID and a diagnosed affective and/or anxiety disorder compared with older people in the general population.

The health outcomes for those with diagnosed affective and anxiety disorders in older age are known to be poor, potentially leading to an increased mortality rate. People with ID are more vulnerable than their peers as a result of difficulties in communication and abstract thinking, which means limitations in understanding what will happen in a specific situation as well as a lower problem-solving ability and less successful self-care. The staff need to have more knowledge about the presence of affective and anxiety disorders to help this vulnerable group. It is thus of great importance to extend current knowledge about the consequences of affective and anxiety disorders in order to help the staff who encounter people with ID. One way to generate evidence-based knowledge is to move from small-scale studies and to use data from national registers, which can guide nursing and healthcare practice in general.

# Aims

The main aim of the thesis was to investigate comorbidities, healthcare utilisation and pharmacotherapy in older people with ID, diagnosed with affective and/or anxiety disorders, compared to older people from the general population with the same disorders. A further aim was to investigate, within the ID group, the association between frailty factors and use of support and social services provided through Swedish disability regulations. The overall aim is approached through four specific aims:

- I. To investigate the co-occurrence and risk of psychiatric and somatic comorbidities with affective and/or anxiety disorders in older people with ID compared to people of the same age and sex in the general population.
- II. To investigate the specialist psychiatric and somatic healthcare utilisation in older people with ID having affective and/or anxiety diagnoses in comparison with the general population. Moreover, within the ID cohort to investigate healthcare utilisation regarding different levels of ID, behavioural impairment and type of living situation.
- III. To investigate, given a diagnosis of mood disorders or anxiety, if there are any differences between older people with ID and their age peers in the general population with respect to prescription of antidepressants, anxiolytics, hypnotics and sedatives, or (Gamma-Aminobutyric Acid) GABA-agonists. Moreover, to study potential effects of behavioural impairment, severity of ID, sex, and year of birth on prescription of these drugs among older people with ID and diagnosis of mood disorders or anxiety
- IV. To describe support and social service and to investigate the association between support and social service, and frailty factors in terms of level of ID, behavioural impairment, specialist healthcare utilisation (inpatient and outpatient), multimorbidity, and polypharmacy in older people with ID and affective and/or anxiety diagnoses.

This thesis generates a comprehensive awareness about a group of people which has been largely neglected in previous research. A broad knowledge base gives policy makers and the health care professions the opportunity to initiate preventive intervention programmes for healthy ageing and improved services.



# Method

## Design of the studies in the thesis

This thesis is based on four quantitative epidemiological registry studies concerning comorbidities, healthcare utilisation, pharmacotherapy, frailty and use of social services. An overview of each study design, sample, data collection and analysis are presented in Table 1. The national registry data was collected from the LSS register of people with significant and permanent functional disabilities who are entitled to special support and service according to LSS, the Total Population Register (TPR), the National Patient Register (NPR), the Prescribed Drug Register, and the Social Service Register (SOL). The reference group from the general population was taken from the Swedish TPR.

## Research setting

This thesis is a part of a large project entitled “*Health and mortality among ageing persons with intellectual disability and health care utilization and social welfare: a Swedish national population study*”. The aim of the project was to investigate on a national level the disease panorama, healthcare and social services utilisation, medication and cause of death for older people with ID compared to the general population for the period 2002-2012. The project is an epidemiological, observational, cohort study design, and one of the samples used for this thesis included 7,936 living people with ID, aged 55 years and older who had at least one registered support service in the LSS register at the end of 2012. These older people were then matched one to one, by year of birth and sex, with the general population from the TPR) by Statistics Sweden, which means that the study cohorts included a total of 15,872 people. The lower age limit of 55 years was based on previous research reporting that the ageing process starts earlier for people with ID (Coppus, 2013).

Table 1. Overview of design, sample, data collection and analysis for studies I-IV

Study	Design	Sample	Data collection	Analysis
I	Population based register study	Older people with ID with at least one affective (n=918) or anxiety (n=825) diagnosis during 2002-2012.	Data from three national registries; the LSS register, the NPR, and the TPR.	Descriptive analysis, bivariate logistic regression
II	Population based register study	Older people with ID with at least one affective (n=918) or anxiety (n=825) diagnosis and a reference group from the general population during 2002-2012.	Data from three national registries; the LSS register, the NPR, and the TPR.	Descriptive analysis, bivariate logistic regression and Mann-Whitney <i>U</i> -test
III	Population based register study	Older people with ID with at least one mood or anxiety diagnosis during 2006-2012 (n=587) and a reference group from the general population (n=434).	Data from four national registries; the LSS register, the NPR, the Prescribed Drug register, and the TPR.	Relative risks (RR) with 95% confidence intervals (CI) were estimated using generalized linear model (GLMs).
IV	Population based register study	Older people with ID with at least one affective and/or anxiety diagnosis (n=871) and a reference group from the general population during (2002-2012).	Data from three national registries; the LSS register, the SoL register, the NPR and the Prescribed Drug Register.	Descriptive analysis, and multivariate logistic regression

Besides this thesis, the project also included another sample of people with ID, including those who died during the period 2002-2015, selected yearly from the LSS and NPR registers. The inclusion criteria of age and the matching procedure were the same as above, except that each person with ID (n=15,289) was matched to five controls (n=76,445) (Ng, et al., 2017; Segerlantz, Axmon, & Ahlström, 2020).

## Data source: Swedish national registers

### The LSS Register

This thesis included Person group 1, which applies to individuals with intellectual disability, autism or autism spectrum disorders in Studies I-IV. LSS entitles persons to eleven measures of special support and service provided by the municipality to enable normalised living conditions. The following measures are available for adults: counselling and other personal support, personal assistance, companion service, personal contact, relief service in the home, short stay away from home, residential arrangements with special services for adults, other specially adapted residential arrangements and daily activities. Eight of the nine support services for adults are documented in the LSS register, as well as two additional services for children (not included in this sample). The first service for adults, counselling and other personal support, is not included in the LSS register, because the information is provided by the county council (region) not the municipalities. Each municipality is mandated to submit information about people receiving LSS services to the National Board of Health and Welfare. The ID study group in Studies I-IV was selected from the LSS register (Person group 1), and the data on which support services older people with ID used is presented in Study IV.

### The National Patient Register (NPR)

The NPR includes all inpatient and outpatient specialist healthcare in Sweden, public as well as private. The register does not contain information about primary healthcare. The NPR provides information about diagnoses and healthcare utilisation in the population in order to improve the prevention and treatment of diseases and to monitor the healthcare system (Ludvigsson et al., 2016). The information in the NPR is divided into four parts: personal data (e.g., age, gender, personal identity number), geographical data (e.g., county, hospital, clinic), administrative inpatient and outpatient data (e.g. date of admission and discharge, inpatient or outpatient, whether the visit was planned

or unplanned), and medical data about the diagnosis (e.g. primary or main cause of the visit and up to 21 secondary diagnoses or contributory causes). The diagnosis is based on the ICD-10 classification codes, registered at discharge from hospital and at outpatient visits. The information about *diagnoses* in Studies I-IV, *healthcare utilisation* in Study II and the *frailty factors* in Study IV were collected from the NPR for the period 2002-2012.

### **The Prescribed Drug Register**

This register contains all drugs prescribed by a physician in Swedish primary and specialist healthcare, public as well as private, and dispensed by the pharmacy to the patient (The National Board of Health and Welfare, 2020b). The drugs are coded according to the Anatomical Therapeutic Chemical (ATC) classification system, which groups the active substances on five levels that specify the organ or system they act upon and their therapeutic, pharmacological and chemical properties. The register started in July 2005, and 2006 was the first year with complete data. The data about *anxiolytics*, *hypnotics*, *sedatives and antidepressants* in Study III and *polypharmacy* in Study IV were therefore available from 2006-2012.

### **The Total Population Register (TPR)**

The TPR contains information on all citizens in Sweden, such as age, sex, civil status, address and personal identity number. The TPR is administered by the Swedish Tax Agency and maintained by Statistics Sweden, which is the authorised source of population statistics in Sweden (Ludvigsson, et al., 2016). The reference group (gRef) from the general population in Studies I-III was extracted from the TPR through one to one matching with the people with ID.

### **Social Service Register (SOL)**

The SoL register includes information about social services provided according to the 2001 Social services Act, (SFS 2001:453, 2001). These services are available to all citizens, but children, older people and people with disabilities who have difficulties in everyday life are prioritised. People with ID are entitled to social services according to their needs or as a complement to their entitlement to support services under the LSS act. The assessment of needs is made by a social worker, which always starts with eligibility for LSS support. The available SoL register data used in Study IV covered the period 2007-2012.

# Sampling

## The national population of people with ID

The national population consisted of older people in Person group 1, aged 55 years and older with at least one LSS support service and alive at the end of 2012 (n=7,936). The general population cohort was selected from TPR, matched one to one to the ID cohort by sex and year of birth. The older people with ID who received support and services from LSS in 2012 were excluded the general population cohort. For the studies in this thesis, a study group was extracted from the national population in the main project described above (see Research setting).

## The study groups in this thesis

In all studies in the thesis, an inclusion criterion for both the ID study group and the gRef group was having at least one diagnosed affective and/or anxiety disorder coded in the NPR according to the block codes in ICD-10 chapter V, *Mental and behavioural disorders*. (see Table 2). The procedure of sampling to identify the study groups presented in Figure 2.

Table 2. ICD-10 classification of affective and anxiety disorders used in this thesis

Paper		ICD-code and diagnosis
I, II, III, IV	At least one affective (F3) disorder	F30 Manic episode* F31 Bipolar affective disorder* F32 Depressive episode F33 Recurrent depressive disorder F38 Persistent mood [affective] disorders F39 Other mood [affective] disorders
	At least one anxiety (F4) disorder	F40 Phobic anxiety disorders F41 Other anxiety disorders F42 Obsessive-compulsive disorder F43 Reaction to severe stress, adjustment disorders F44 Dissociative [conversion] disorders F45 Somatoform disorders F48 Other neurotic disorders

\*Excluded in study III.

In Studies I, II and IV, people were included if they had at least one affective (F3) and/or anxiety (F4) disorder, during 2002-2012. In Studies I and II, a total of 1,047 in the ID cohort (F3, n=576 and F4, n=471) and 696 in the gRef cohort (F3, n=342 and F4, n=354) had at least one diagnosis during 2002-2012. In Study III, a total of 587 in the ID group and 434 in the gRef group were identified with at least one mood and/or anxiety disorder during 2006-2012, based on data available from the Prescribed Drug Register. In Study IV, there were n=871 older people with ID and at least one affective and/or anxiety disorder. The gRef group was not included in Study IV, see Figure 2.

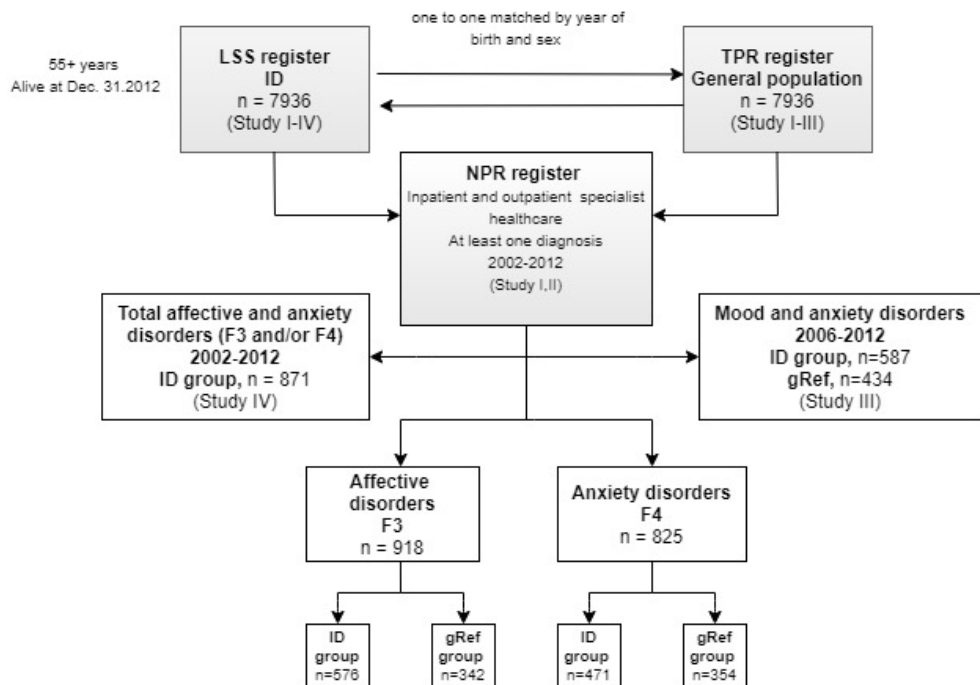


Figure 2. Flow chart of the sampling procedure for Studies I-IV.

## Outcome measures

### Comorbidity

Study I examined data on psychiatric and somatic comorbidity diagnoses from the NPR during 2002–2012. The *psychiatric comorbidities* consisted of all diagnoses in ICD-10 chapter V, excluding the diagnoses that define both study groups, namely, affective disorders (F3) and anxiety disorders (F4), and those that define the ID group: intellectual disability (F7), disorders of psychological development (F8), behavioural and emotional disorders with onset usually occurring in childhood and adolescence (F9), and Down syndrome (Q90). The included psychiatric comorbidities were based on the ICD-10 block subdivisions with 3 digits (such as F20 Schizophrenia, F60 Specific personality disorders) because affective and anxiety disorders are included in the same chapter. The *somatic comorbidities* were presented as all other diagnoses than the mental and behavioural ones, based on ICD-10 chapter levels (such as chapter II Neoplasms, chapter VI Diseases of the nervous system). Chapter XXI, Factors influencing health status and contact with health services, was excluded, as that chapter contains information about health care services and not diagnoses.

### Healthcare utilisation

For Study II, the healthcare utilisation data were collected from the inpatient and outpatient specialist healthcare visits registered in the NPR. The inpatient data used were primary diagnosis (main cause) and secondary diagnosis (contributory causes), psychiatric or somatic healthcare visits, planned and unplanned healthcare visits and length of stay in inpatient healthcare. The same data were collected for outpatient healthcare, except for length of stay, which only applies to inpatient healthcare. In this study, all people having at least one inpatient or outpatient visit with an F3 and/or F4 diagnosis as a reason for the visit were included, regardless of the number of visits registered.

To investigate the healthcare utilisation more closely in the ID group, level of ID was classified for people with at least one F7 diagnosis, using the following three digits ICD-10 codes: mild (F70), moderate (F71), or severe and profound (F72 and F73). Also, individuals with a diagnosis of behavioural impairment (problem behaviour or challenging behaviour) were identified based on ICD-10 four digits codes such as F70.1 (Mild intellectual disability with significant impairment of behaviour requiring attention or treatment).

## Prescription of drugs

Study III examined data on the prescription of anxiolytics, hypnotics, sedatives, antidepressants and GABA agonists (drugs with a strong anxiolytic effect via the GABA system). These were identified through the Prescribed Drug Register. for the study group of people with at least one diagnoses of mood and/or anxiety disorder. The ACT codes for the drugs were aggregated from five to four levels of organ or system that they have an effect on. GABA agonists included benzodiazepine derivatives, benzodiazepine-related drugs, aldehydes and derivatives, and clomethiazole.

Through the NPR, the level of ID was identified among those in the ID group with at least one diagnosis of ID (F7). The level of ID was dichotomised to two groups based on three digits in ICD-10, one mild and the other moderate/severe and profound (MSP). Other or unspecified levels of ID were excluded. Behavioural impairment was identified and recorded as in Study II.

## Frailty with the use of support and social services

Study IV examined the ID group's use of special support and social services, identified through the LSS register for the period 2004-2012 and through the SoL register for the period 2007-2012, according to the availability of the data. The following frailty factors were collected from the NPR (healthcare visits, multimorbidity, level of ID and behavioural impairment). Polypharmacy was collected from the "*Prescribed Drug Register*". Healthcare visits were calculated as the total sum of inpatient and outpatient specialist healthcare visits for each person during 2002-2012. Then the variable was dichotomised based on the median into low utilisation (<12 visits) and high utilisation ( $\geq 12$  visits). Multimorbidity was defined as two or more diagnoses (<2 and  $\geq 2$ ), based on two digits in the ICD-10 codes. The diagnoses of F3 and/or F4, ID, autism spectrum disorder and Down syndrome were excluded because these are among the inclusion criteria for ID the study group.

Regarding polypharmacy, the number of prescriptions each year for each person were counted and then aggregated to the total number of persons with at least one year with polypharmacy during 2006 to 2012. Polypharmacy was defined based on the cut-off score of five or more drugs (<5 and  $\geq 5$ ) of importance for older people with ID. The following are the selected drugs from the Prescribed Drug Register: Alimentary tract and metabolism, Blood and blood forming organs, Cardiovascular system, Genitourinary system and sex hormones, Systematic hormonal preparation excluding sex hormones, Insulin, Musculoskeletal system, Nervous system including pain drugs



and antipsychotics, Respiratory system and Sensory organs. The identification of levels of ID and the presence of behavioural impairment was the same as in Study II.

## Statistical analysis

### *Characteristics and comparisons between the ID and gRef groups*

Studies I-IV include descriptive data with frequencies and percentages within the study groups. In Study I-II, information about sex and age, were represented in numbers and proportion (n and %) and for categorical variables in the ID group and gRef. In Study II, Chi-square analysis was used to test the differences of categorical outcome variables between the two study groups. For the continuous variables age and length of stay, median and quartiles are presented due to the skewed distribution of the data and Mann-Whitney U-tests were therefore used to measure differences between the study groups. The age in Study III was dichotomised at the median date of birth.

### *Regression analysis*

Logistic regression analysis was used to investigate binary outcomes in these studies. In Study I, the occurrence rates, odds ratio (OR) and 95% confidence intervals (CI) were estimated, for having psychiatric and somatic comorbidities with affective and anxiety disorders in the ID group compared to the gRef group.

In Study II, multivariate logistic regression analysis was used to compare the healthcare utilisation patterns in the study groups, estimating OR and 95% CI. Age was treated as a continuous variable and the regression analysis was adjusted for differences in age at the end of the study period 2012 and for sex.

In Study III, a generalised linear model (GLM) was used to estimate relative risk (RR) and 95% CI to compare the ID group and gRef. GLM was also used to analyse the potential effect of level of ID, presence of behavioural impairment, sex and age group within the ID group. The age variable in Study III was dichotomised as above or below the median date of birth.

In Study IV, multivariate logistic regression analysis was used to investigate the association between the frailty variables and use of support and social services. Age was treated as a continuous variable and the regression analysis was adjusted for differences in age at the end of the study period and for sex. *P*-values less than 0.05 were considered statistically significant in all the studies. Statistical analysis was performed using IBM SPSS Statistics version 24 and 25.

## Ethical considerations

Approval was obtained from the Regional Ethical Review Board in Lund (a Swedish government agency), (approval reference 2013/15). The government authorities responsible for the national registers used in this study do not disclose personal identification numbers to researchers for research purposes. Thus, it was not possible to obtain informed written consent from the participants in this study. Instead, the Ethical Review Board mandated that the planned study be announced publicly in national media, including information on how to withdraw from the study so that the participants would have an opportunity to actively decline access to their register data. In accordance with this requirement, the study was announced in two major newspapers in Sweden. One of these is a major national public newspaper (Dagens Nyheter) and the other a national newspaper called Unik, distributed by the Swedish National Association for Persons with Intellectual Disability (FUB) and supporting organisations.

Following that, permission was required to access the data from the two register holders. The National Board of Health and Welfare, and Statistics Sweden each implemented separate secrecy reviews in 2014 before providing access to the data. All analyses were performed using anonymised datasets. The studies in this thesis were performed in accordance with the revised version of the Declaration of Helsinki from 2013 (World Medical Association, 2013).

Another ethical principle is that research findings on a general level should be disseminated openly. In this thesis, we investigated an underprivileged group and it was deemed important for the wider society to know more about this population. This study contains information about vulnerable individuals, but their data and all analyses were anonymised without any information allowing personal identification. Besides the Regional Ethical Review Board review for securing the anonymity of the participants in the research project before approval, also the National Board of Health and Welfare and the Statistics Sweden did reviews independently before providing the data to the researchers. This to avoid accidentally revealing the identity of any individuals in the registers used in this thesis. The results are presenting on an aggregated level, preventing any individual from being identified. Disseminating the study findings through this thesis offers increased knowledge about the needs of people with ID and affective and/or anxiety disorders, comorbidities, their healthcare and social service utilisation patterns and pharmacotherapy compared to the general population. Further, this thesis will increase understanding of the association between frailty factors and the provision of healthcare and social services for people with ID and affective and/or anxiety disorders.

# Results

This section presents the overall results from the four studies included in this thesis. The findings are structured under the headings by each study focus.

## Study I: Comorbidities

### **Psychiatric comorbidities**

The results in Study I revealed that the most common psychiatric comorbidities in the ID group with at least one affective or anxiety disorder were: other mental disorders due to brain damage and dysfunction and to somatic disease, unspecified nonorganic psychosis and specific personality disorders. Among those in the ID group with at least one anxiety disorder, specific personality disorder was the most frequent comorbidity.

Those with affective disorders in the ID group were more likely than the general population to have a diagnosis of other mental disorders due to brain damage (OR=3.45, 95% CI 1.61–7.43) and acute and transient psychotic disorders (OR=3.06, CI 1.16–8.07). Those with anxiety disorders in the ID group had statistically significant higher odds of having a diagnosis of other mental disorders due to brain damage (OR=3.01, CI 1.30–7.00), acute and transient psychotic disorders (OR=2.93, CI 1.09–7.94) and specific personality disorders (OR=1.95, CI 1.03–3.68) than those in the general population.

### **Somatic comorbidities**

The following were the most common somatic comorbidities among those with at least one affective or anxiety disorder in the ID group: injury, poisoning and certain other consequences of external causes, followed by symptoms, signs and abnormal clinical and laboratory findings not elsewhere classified, and diseases of the digestive system.

Those with at least one affective disorder in the ID group were more likely than the general population to have disease of the nervous system (OR=1.66, 95% CI 1.20–

2.28), disease of the genitourinary system (OR=1.41, CI 1.01–1.96) and injury, poisoning and certain other consequences of external causes, (OR=1.37, CI 1.04–1.76). Those with at least one anxiety disorder in the ID group were more likely than the general population to have a diagnosis of disease of the nervous system (OR=2.03, 95% CI 1.44–2.86), disease of the genitourinary system (OR=1.84, CI 1.30–2.61) or injury, poisoning and certain other consequences of external causes, (OR=1.46, CI 1.10–1.93).

## Study II: Healthcare utilisation

### Psychiatric and somatic healthcare

People in the ID group were more likely to visit psychiatric healthcare (affective disorders: OR=1.60, 95% CI 1.50–1.70; anxiety disorders: OR=1.53, CI 1.43–1.64) compared to the general population. In addition, those who visited psychiatric health care were one time more likely to have inpatient and unplanned visits than the general population. On the other hand, they were less likely to visit somatic healthcare (affective disorders: OR=0.63, 95% CI 0.58–0.66; anxiety disorders: OR=0.65, CI 0.60–0.69) compared to the general population.

### Length of stay

People in the ID group with affective disorders, their total average length of stay in inpatient healthcare was significantly higher ( $p<0.05$ ) than those in the general population. On the other hand, those with anxiety disorders in the general population had significantly higher ( $p<0.05$ ) average of length of stay in inpatient somatic healthcare than the ID group.

When the length of stay assessed on individual level, those with affective disorders, the median length of stay (number of days) for inpatient psychiatric healthcare visits was 9 in the ID group and 4 in the general population ( $p<0.05$ ). For those with anxiety disorders, the total inpatient healthcare visits in ID group had a median of 5 days ( $p<0.05$ ), while the general population had a median of 3 days.

## **Level of ID, behavioural impairment and special housing**

Within the ID group, a consistently significant pattern was found of more use of inpatient healthcare in those with a moderate/severe level of ID (affective disorders: OR=1.26, 95% CI 1.11–1.44; anxiety disorders: OR=1.57, CI 1.36–1.80), those with behavioural impairment (affective disorders: OR=1.37, 95% CI 1.20–1.56; anxiety disorders: OR=1.34, CI 1.16–1.54) and those living in special housing (affective disorders: OR=1.12, 95% CI 1.02–1.23; anxiety disorders: OR=1.26, CI 1.15–1.38). Furthermore, those living in special housing who had at least one anxiety disorder were more likely to have unplanned visits than planned visits (OR=0.79, 95% CI 0.73–0.86). The length of stay in inpatient healthcare was significantly longer ( $p<0.05$ ) among those with at least one anxiety disorder in combination with a moderate/severe level of ID, behavioural impairment or living in special housing.

## **Study III: Pharmacotherapy for affective (mood) and anxiety disorders**

### **Anxiety disorders with or without affective disorders**

The people in the ID group with anxiety disorders, regardless of whether the diagnosis of affective disorders was present, were more likely to be prescribed with anxiolytics (RR=1.32, 95% CI 1.19–1.46) and GABA agonists (RR=1.19, 95% CI 1.08–1.31) than the reference subgroup. However, those with anxiety disorders only were more likely to be prescribed antidepressants (RR=1.20, 95% CI 1.03–1.39) than the general population.

### **Level of ID and behavioural impairment**

Within the ID group, those with moderate/severe/profound ID were more likely to have a greater prescription of anxiolytics if they had at least one affective disorder (RR=1.26, 95% CI 1.04–1.52), and a greater prescription of anxiolytics (RR=1.23, 95% CI 1.10–1.38) and GABA agonists (RR=1.23, 95% CI 1.10–1.38) if they had at least one anxiety disorder. Furthermore, within the ID group, those with anxiety disorders and behaviour impairment were more likely than those with anxiety but without behaviour impairment to be prescribed anxiolytics (RR=1.15, 95% CI 1.03–1.30).

## Study IV: Frailty factors and use of support and social services

### Commonly-used services

According to the LSS register data, the most commonly used services and social support by the people with ID and affective and/or anxiety disorders in this study were residential arrangement (75%), daily activities (76%) and a personal contact (66%). The most common complementary services recorded in the SoL register were home help services 56%, safety 32%, residential service in daily living, and special housing 33%.

### Frailty factors

Between 80% and 90% of the people with ID and with multimorbidity or polypharmacy received companion services, a personal contact person, residential arrangement and daily activities under the LSS provision. The regression analysis showed that people with more than 12 visits to specialist healthcare were less likely to live in residential arrangement (OR=0.63, 95% CI 0.46–0.88) compared to those with less than 12 visits. Those with multimorbidity were less likely to live in residential arrangement (OR=0.48, CI 0.24–0.94) compared to those without multimorbidity. Those with polypharmacy were more likely to have a personal contact person (OR=1.63, 95% CI 1.07–2.50) and more likely to live in residential arrangement (OR=3.21, CI 2.06–5.01) than those without polypharmacy. Within the ID group people with a moderate/severe/profound level of ID were more likely to live in residential arrangement (OR=3.19, 95% CI 1.75–5.80) and have daily activities (OR=1.66, CI 1.03–2.68) than those with a mild level of ID.

# Discussion

This thesis is the first identified publication based on a sample of people with ID and with affective and anxiety disorders selected from a national population. Studying multidimensional aspects in one larger sample is one way to detect whether people with ID and with affective and anxiety disorders have equality in health and how the welfare state meets their needs. The results of Studies I-III show the pattern and differences regarding disease burden, healthcare utilisation and drug prescription in older people with ID and with affective and anxiety disorders compared to the general population with these psychiatric disorders. The main findings were that older people with ID and affective and anxiety diagnoses have a larger percentage (between 80% and 90%) of psychiatric comorbidities compared to 40% to 50% in the general population (Study I). The most common significant psychiatric comorbidities in the ID group were unspecified or not elsewhere classified, and external causes or other mental disorders due to brain damage or physical diseases. The most common somatic comorbidities were nervous system disease, injuries and poisoning or consequences of external causes. In addition, the ID group was twice as likely to have inpatient and unplanned visits to psychiatric and somatic healthcare compared to the general population (Study II). Regarding pharmacotherapy, the ID group was found to be more likely to receive excessive prescription of anxiolytics but not of antidepressants compared to the general population (Study III). The findings in Study IV with respect to social support and services within the ID group showed that frailty factors such as more than twelve visits to healthcare, and multimorbidity were associated with fewer days in residential arrangement with staff support. However, those with polypharmacy and a moderate or severe level of ID were more likely to live in residential arrangement.

The results of this thesis highlight that the presence of affective and anxiety disorders among people with ID constitutes a double vulnerability in addition to their disabilities since early childhood. The presence of this vulnerability further increases the risk of having an unidentified diagnosis and poor treatment for the complex problem of psychiatric comorbidities when people have more severe or profound ID (Baxter et al., 2006). Challenging behaviour (also named problem behaviour or behavioural impairment) may also exist as psychiatric problems or might be atypical symptoms of an underlying mental and somatic health problem (Devine, 2008). In addition,

healthcare providers often attribute the symptoms of challenging behaviour to ID, i.e. diagnostic overshadowing, when in fact the problems are related to a separate psychiatric diagnosis (Mason and Scior, 2004). When healthcare providers lack knowledge and sufficient training in the assessment of challenging behaviour, it leads to poor or absent treatment for people with ID and unsatisfactory fulfilment of people's needs (Ndengeyingoma and Ruel, 2016; Olsson and Gustafsson, 2020; Werner and Stawski, 2012). Furthermore, the presentation of psychiatric and somatic health problems might be influenced by the person's level of ID and communication ability to describe their symptoms. Given enough time, people with a mild level of ID and good communication skills can describe and present their symptoms in a manner familiar to most healthcare providers (Tomlinson and Hewitt, 2018). Those with a more severe level of ID and communication difficulties may present symptoms in a more atypical manner, with mental disorders mainly presenting as behaviour impairment (Ali et al., 2013; Devine, 2008). Therefore, healthcare providers meeting people with ID have to make careful assessments and consider a range of alternative contributing factors, and subsequently provide appropriate intervention adapted to the individual's specific needs for quality of life improvement (Ouellette-Kuntz, et al., 2019).

Regarding somatic comorbidities of diseases in the nervous system, injury and poisoning were found to be more common in the ID group compared to the general population. The results are in line with previous studies confirming that neurological diseases such as epilepsy increase the risk of depression and anxiety (McCarron, et al., 2013). A previous study reported that comorbid epilepsy, constipation and dyspepsia occurred more frequently in individuals with ID (Cooper, et al., 2015). However, in Study I, digestive problems occurred more frequently in the general population than in older people with ID. A possible explanation might be that health care providers fail to identify digestive system symptoms and problems. They might perceive them as less severe somatic problems for these frail people with complex needs. The results about injuries and poisoning indicate that older people with ID and affective and/or anxiety disorders are more vulnerable and prone to injuries than the general population. (Cox, Clemson, Stancliffe, Durvasula, & Sherrington, 2010) and others, identified several risk factors for injuries and falls in people with ID, such as polypharmacy and the use of psychotropic medication (Axmon, Sandberg, Ahlström, & Midlöv, 2018; Schoufour, et al., 2015). Previous research shows that they are more likely to be prescribed multiple medications, such as antipsychotics, anxiolytics and benzodiazepine, which are associated with a wide range of side effects that increase the risk of falls and injuries (Axmon, Kristensson, et al., 2017; Cox, et al., 2010; Ham, et al., 2014; Schulte and Hser, 2013; Sorock and Shimkin, 1988). In addition,



high rates of prescribing anxiolytics, in particular benzodiazepines, were found in older people with ID with comorbid dementia and pain management, compared to the general population (Axmon, Ahlström, & Westergren, 2018; Axmon, Kristensson, et al., 2017; Axmon, Sandberg, et al., 2017, 2018; Cox, et al., 2010; Sorock and Shimkin, 1988). This is in line with the results in Study III regarding the excess prescription of anxiolytics and GABA agonists in older people with ID and affective and anxiety disorders compared to the general population. The result indicates that older people with ID are more vulnerable to the use of potentially inappropriate medication compared to the general population.

Study III investigated the prescription of anxiolytics and GABA agonists among those with the diagnosis of anxiety from inpatient and outpatient care. Nonetheless, older people with ID who visit inpatient and outpatient care tend to have severe levels of anxiety, which could explain the high prescription of medication. As previously mentioned, the presence of behavioural impairment and a severe level of ID is associated with increased prescription of psychotropic medication, which could explain the discrepancy compared to the general population. This indicates that the underlying reason for prescription of these medications might be related to behavioural impairment rather than the presence of the diagnoses. Additionally, the lack of available adapted resources, facilities and treatment modalities other than medication may lead to excessive prescriptions (Lunsky, Garcin, Morin, Cobigo, & Bradley, 2007). This would indicate that adapted services do not exist to meet the demands and needs of people with ID and affective and anxiety disorders.

The results in Study II show that the ID group was more likely than the general population to have inpatient and unplanned healthcare visits. This has been related to a high prevalence of psychiatric diagnoses, the presence of behavioural impairment and a severe level of ID (Bowring, et al., 2017; O'Dwyer et al., 2016; O'Dwyer, McCallion, McCarron, & Henman, 2018; Tsiouris, et al., 2013). Furthermore, this thesis found that older people with ID and with anxiety disorders have a longer average length of stay in psychiatric healthcare and excessive prescription of anxiolytics than the general population. The increased length of stay in inpatient healthcare can be expected in cases of severe ID with behavioural impairment. This indicates that anxiety combined with more severe levels of ID and behavioural impairment is associated with increased duration of inpatient healthcare. People with ID with more comorbid and complex problems have difficulties in communicating their symptoms properly, which may lead to diagnostic overshadowing and increased healthcare utilisation (Mason and Scior, 2004; Myrbakk and von Tetzchner, 2008). Unfamiliar environments and staff, combined with difficulties in expressing their thoughts and needs, causes fear and anxiety, which further limits their ability to communicate effectively with care providers

and leads to increased use of healthcare services (Raymaker et al., 2017; Williamson, Contreras, Rodriguez, Smith, & Perkins, 2017). This should alert our attention to identifying effective strategies to address their needs appropriately.

The ID group consisted of older people, which means that they, like all other citizens in the European Union are covered by the health policy initiative Healthy ageing (The European Innovation Partnership on Active and Healthy Ageing (EIP-AHA), 2011) which defined as a process of developing and maintain long healthy life to support wellbeing in older age (WHO, 2000) Frailty factors such as multimorbidity, polypharmacy and frequent visits to healthcare are expected to be highly prevalent in people with ID and to negatively affect their quality of life (Cooper, et al., 2015; Fisher and Kettl, 2005; Scheifes, Egberts, Stolker, Nijman, & Heerdink, 2016; Scheifes, Walraven, et al., 2016). Study IV revealed that, among people with ID and affective and anxiety disorders, frailty factors such as polypharmacy are more likely among those who live in residential arrangement (supportive housing) compared to those without polypharmacy. This could probably be explained by the fact that the residential arrangement staff are responsible for picking up the prescribed medication from the pharmacy and administering it to the residents. Study IV also showed that those in the ID group who had polypharmacy were less likely to get daily activities compared to those without polypharmacy. This could be a consequence of the high prescription of psychotropic medication, giving several side effects, such as decreased interest, lethargy and reduced mobility, leading to more isolation (Scheifes, Egberts, et al., 2016; Scheifes, Walraven, et al., 2016). Thus, because of these side effects, older people with ID might be less engaged in daily activities, and their needs will not be met by the residential care staff. This indicates that their needs might not be adequately addressed, which will negatively affect their wellbeing.

Study IV showed that those with multimorbidity were less likely to live in residential arrangement compared to those without multimorbidity. The communication difficulties that people with ID have might reduce their ability to describe their symptoms. This may lead to a more severe stage of disease progression, which is expected to be associated with more visits to specialist healthcare due to unfulfilled needs (Bond et al., 2019; Bond, et al., 2020). This indicates that the 24-hour support from residential arrangement staff is not enough for the fulfilment of the needs of older people with ID. These staff members play a crucial role in maintaining the wellbeing of older people with ID (Kählin, et al., 2016; Tøssebro, et al., 2012; Webber, Bowers, & Bigby, 2014; Webber, Bowers, & Bigby, 2016). For example, if a person with ID has communication problems and cannot show feelings and desires through body language, or by facial expression, the person needs a lot of assistance from staff members who know him or her well. The regular staff know the residents well and are

experienced at reading the person's facial and body signs for communication. However, they are not equally accustomed to identifying symptoms of emerging health problems (Kåhlin, et al., 2015). In Sweden, as in other countries, there are no specific requirements of specialised education for residential care staff who work with people with complex needs, such as people with ID (Emilsson, 2009; Martin, Ouellette-Kuntz, & McKenzie, 2018; Northway, Jenkins, & Holland-Hart, 2016). Hence, the general education for the social care workers concerning people with ID will not provide staff with the specific knowledge and skills they need to handle the complex health needs in people with ID (Olsson and Gustafsson, 2020). This could be incompatible with the important role the staff members play in monitoring the health status of people with ID and in identifying early symptoms or problems to improve the quality of life for this frail population. Necessary training would consist of knowledge about ageing and healthy ageing in the encounter with older people, including people with ID. Furthermore, from the best, I couldn't identify any publication in the literature on education about ageing and healthy ageing with ID and there is a lack of specific guidelines for the municipalities to implement in Sweden.(Ahlström, et al., 2020 unpublished). Therefore, due to the increased number and higher life expectancy of older people with ID, the staff working in health and social services need to understand ageing and be able to implement healthy ageing perspectives.

Several studies reported challenges such as lack of knowledge, lack of skills, misunderstanding and miscommunication which lead to lack of confidence in care delivery among people with ID in residential arrangements (Costello, Bouras, & Davis, 2007; Innes, McCabe, & Watchman, 2012; Kåhlin, et al., 2016; Kilanska and M. Priest, 2014; Quigley, et al., 2001). This highlights the importance of training and educating the residential arrangement staff about the frailty and health issues of people with ID (Northway, et al., 2016). Increased knowledge and skills could reduce the health inequalities for people with ID, as well as fostering the development of strategies with meaningful care planning according to their needs, to improve their wellbeing and quality of life (Emerson and Baines, 2011; Emerson and Hatton, 2008). Besides necessary knowledge and skills for social support and services in residential arrangements, the staff need knowledge of existing resources in the healthcare system and about ageing issues (Alftberg, Johansson, & Ahlström, 2019; Holst, Johansson, & Ahlström, 2018)). This type of expertise promotes greater integration and collaboration with other professionals and being a part of the team that delivers the best quality of care to meet the needs of older people with ID and with a complex, comorbid and challenging presentation (Alftberg, et al., 2019; Holst, et al., 2018).

## Care for people with ID in line with Hildegard Peplau's interpersonal relations theory

The results of this thesis assert that older people with ID and affective and/or anxiety disorders have complex needs for healthcare, treatment and social services (Studies I-IV). This indicates that healthcare providers face challenges and difficulties to identify these needs. The staff working with people with ID and affective and anxiety disorders might have communication barriers to overcome before they can understand and meet those people's needs. The health and social care staff use the interpersonal relationship to facilitate the provision of adapted care (Alligood and Marriner-Tomey, 1998; Reynolds, 1997) suited to this population's needs. The difficulties are related to the cognitive impairment that strongly limits the person's ability to communicate and describe their subjective feeling and experience to others (Devine, 2008). In addition, the presence of challenging behaviour such as aggression and self-injury may lead to diagnostic overshadowing making it difficult to recognise the presence of the psychiatric problem (Devine, 2008). The lack of knowledge about ID and communication skills among health and social care providers increases their difficulties to recognise and properly address the psychological problems in this population (Devine, 2008).

Given the challenges previously mentioned in recognising psychiatric symptoms, the interpersonal relationship between the nurse and client is a vital tool for understanding the mental health problems of this population and meeting their actual needs. The nurses are often on the front line in different health and social care settings and therefore need to have the appropriate knowledge and skills (specialised knowledge) when interacting with older people with ID and affective and anxiety disorders. The nurse and other care providers must be able to identify and report typical and atypical symptoms, as well as any changes in the usual patterns of behaviour for this population (Devine, 2008). Therapeutic effective communication requires considerable knowledge, skills, time, attention to the person and their needs, and adaptations by the staff in their communication (Trollor and Ching, 2014).

In applied person-centred care, the patients feel that they are treated as a person not as a passive patient. They experience respect and dignity, and that their needs, wants and preferences are considered (McCormack, 2003, 2004; Nolte, Merkur, & Anell, 2020). Person-centred care is widely used in European health policies to better address health system challenges (Nolte, et al., 2020), it is therefore of great value to explore how it can be implemented for older people with affective and anxiety disorders.

### *The orientation phase*

In accordance with the theory of interpersonal relations (Peplau, 1997; Reynolds, 1997), comprehensive therapeutic assessment with appropriate knowledge and skills in the orientation phase is central for understanding the needs of people with ID and affective and anxiety diagnoses. A recent literature review reported that the long-term bond based on the therapeutic relationship is experienced as a prerequisite to help nurses to read and understand the needs of people with ID (Appelgren, et al., 2018). The long period of this relationship helps to develop the in-depth communication between the nurse and the person with ID to recognise changes in temperament or behaviour that occur because of psychological distress (Donovan, 2002). A close, caring relationship provides reflections and understanding from experiences (Holst, et al., 2018). However, in some cases, this could be a challenge for nurses working with people with complex problems in different healthcare settings (Lee and Kiemle, 2015). The nurse can create a relationship with relevant others, such as staff working in social services, to be able to create a long relationship with the person with ID. At the same time, the residential care staff need a relationship with psychiatric nurses to help them adapt their supportive residential care (Holst et al. 2018). Other researchers have confirmed the essential importance of building a trust relationship in the orientation phase (Belcher and Jones, 2009). This will help to develop a secure and stable relationship and ensure that the person with ID and affective and anxiety disorders can cooperate with different care activities, tests, or medical examinations.

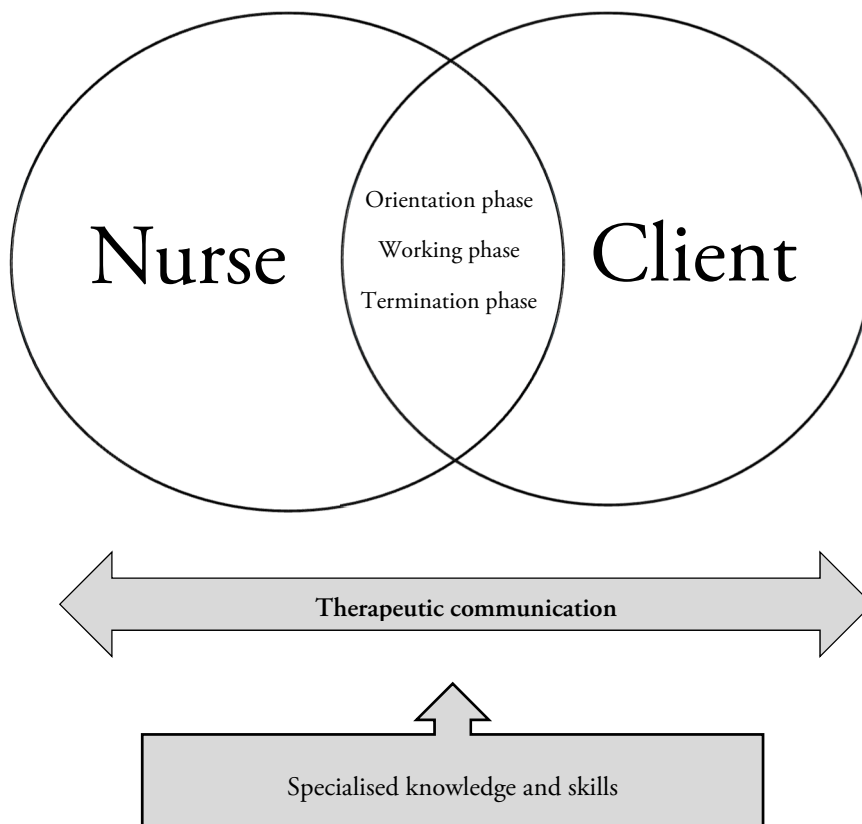
### *The working phase*

During the working phase, the nurse may use skills such as a reflective approach, feedback for continuously monitoring and adapting the style of communication. For example, it might be appropriate to adjust the rate of speech, complexity of language and concepts, and to use nonverbal communication when interacting with people with ID. The need to communicate verbally and nonverbally in parallel could help the nurse to understand the complex needs of people with ID and could greatly improve quality of care (Fitzgerald and Sweeney 2013). The nurse should ask and be aware of how the person would prefer to communicate and whether there is any method, trusted person or communication aid that can be used (such as gestures, key word signing, IT platforms, pictures) or using a specific device or interpreter (Trollor and Ching, 2014). The psychiatric nurse should be educated about ID and have the skills to use appropriate nonverbal communication adequately adapted to the cognitive ability and health problems of the person with ID to fully achieve the goals of communication (Appelgren, et al., 2018; Hemsley and Balandin, 2004; Hemsley et al., 2001). Otherwise, the nurses and other care professionals will not be able to understand the

person's usual methods of communication, and their mannerisms and behaviour can be misunderstood and seen as non-compliant or problematic (Appelgren, et al., 2018).

### *The termination phase*

At the termination phase, it is important to establish whether the person with ID has understood what has been said. With the appropriate (specialised) knowledge and skills about ageing and ID, on how to care for this population, the nurse will feel prepared to deliver appropriate care and support to meet their needs, Figure 3. The challenge is at both the individual and the organisational level. If nurses experience difficulties when interacting with people with ID, this will lead to an increase in the demand on the healthcare system.



**Figure 3.** Peplau's interpersonal relationship between the nurse and client

## Clinical implications

The results of this thesis revealed that older people with ID and affective and/or anxiety disorders have complex needs for healthcare, treatment and social services. Their needs have to be adequately addressed because they are entitled to the same rights as others and they have equal worth. The healthcare and social services for people with ID should be maintained within a human rights and healthy ageing framework, promoting equal health care access and wellbeing throughout the life span. Consequently, older people with ID should be given access to all available services, including those that aim for health promotion and prevention of disease, such as affective and anxiety disorders. To improve the quality of life for this group of people, health and care providers need to develop the ability to adapt care strategies to meet their special needs. Adopting a person-centred approach with a special focus on the individual as a person may help health and care providers to communicate, and integrate health policy with services. A person-centred partner role encourages the health and care providers to focus on the person's abilities from the healthy ageing perspective instead of being shadowed by the disability itself or the unilateral perspective of diagnoses. Through this approach of communicating and building a trusting relationship, health and care providers learn to understand the needs of people with ID, discover what is important to each person, and how to promote their wellbeing. To be able to assume this approach, the health and care providers need knowledge and skills through training in therapeutic communication, allowing effective intervention to meet the needs of the older person with ID and affective and/or anxiety disorders.

The availability of specialised education about healthy ageing and ID is important. Specialist psychiatric nurses can educate caregivers and staff in social services about care intervention for ageing people with ID, which is expected to reduce health discrepancies in this group compared with the general population. Nurses and other professionals play an important role in the identification of changes and unmet needs in people with ID and affective and/or anxiety disorders. The observation and reporting of symptoms of people who cannot communicate verbally may prevent deterioration in older persons who exhibit decline or changes in behaviour. In addition, the availability of specialised services can help performing comprehensive assessments to identify needs promptly and initiate prevention measures. Furthermore, expert knowledge can support physicians and other care providers when reviewing psychotropic medication and preventing inappropriate medication being prescribed.

Health and social services should be centred around individual needs and grounded in partnership between different care providers and professions to optimise the outcomes (Emilsson, 2009; Nolte, et al., 2020; WHO, 2000). Collaboration between

professionals and coordination of healthcare and social services are important tools for fulfilment of the needs of older people with ID and psychiatric health problems. The psychiatric nurse, as a part of the team, can transfer vital information and knowledge about people with ID, which will improve the support provided, and facilitate the development and planning of appropriate interventions for this population. The inclusion of professionals from different backgrounds might help to provide holistic and collaborative care for older people with ID. Furthermore, a multidisciplinary approach with collaboration between professionals enables the sharing of expertise and tailoring of resources, especially for people with complex needs, and improves their quality of care (WHO, 2000). There is also a need for referral protocols between primary healthcare, specialized healthcare and social services within the care systems, to coordinate care for people with ID.

Education and support in clinical practice for primary healthcare is necessary to increase knowledge, establish preventive programmes and develop clinical expertise regarding the special needs of older people with ID and affective and anxiety disorders. It is important that healthcare providers acknowledge that many people with intellectual disabilities have special needs which may require adaptation of standard care practices and service models (WHO, 2000). Services that specifically provide healthcare to older people with ID do not exist in Sweden. The necessary infrastructures need to be developed, such as specialised resource centres where clinicians, older people with ID, families and carers can seek information, referral and training.

Finally, all efforts to improve preventive interventions, practice guidelines and policy, as well as all evaluation of the quality of care, should be informed by evidence-based research on the needs of this frail group. National preventive health strategies should focus on promoting mental health, minimising negative outcomes of mental health problems (such as affective and anxiety) and thus improving the quality of life in older people with ID. Health and social care professionals should continuously seek to enhance their knowledge and skills based on the latest research findings. Health and social care providers working with people with ID are advised to receive specialised training concerning ID and ageing. Such training must highlight the differentiation between the burden of ID itself and the presence of mental illnesses.

## Methods considerations

Given the national population-based design of the studies in this thesis, the findings may further our understanding of possible differences and patterns of healthcare in people with ID compared to the general ageing population. The inclusion criteria for



our study group were people aged 55 years or older with ID and with at least one affective and/or anxiety disorder. Using the same study group through Studies I–IV, can be viewed as a strength because it is the first sample with these characteristics based on the national population in Sweden and it is also unique internationally. Moreover, using the same sample to answer different research questions by examining different variables and outcomes is invaluable for obtaining focused and comprehensive knowledge of a subject that has been sparsely studied in the literature. Using the same study design and analytical approach consistently for all the studies in this thesis increases the potential to understand the findings better and develop a more focused knowledge about the subject under investigation.

The selection of study groups from a national population increases the generalisability of the results. The unique personal identification system in Sweden allows the opportunity to link with other registries and minimise selection bias, often preventing the misclassification of exposures and outcomes (Thygesen and Ersbøll, 2014). The outcomes in the study group have until now never been reported at a national population level or for such a long follow-up period (11 years). It is mandatory for physicians to register the diagnoses according to the ICD-10 at each specialist inpatient or outpatient visit involving a medical examination. Therefore, the diagnoses available in the NPR are the best proxy for clinical diagnosis available on a national level. Also, the medical diagnoses registered in the NPR have been validated in several studies and have demonstrated high validity and sensitivity (Ludvigsson et al., 2011; Rück et al., 2015; Sellgren, Landén, Lichtenstein, Hultman, & Långström, 2011). Consequently, the data registration in the NPR used in the present thesis has high validity and includes all older people with ID alive and visited inpatient and outpatient specialist healthcare during the study period.

One of the limitations of register data is that variables are defined by administrators for statistical purposes and not by the researcher aiming for completeness for research purposes (Thygesen & Ersbøll, 2014). Therefore, the available data in this thesis was limited to the variables included in the registers. The lack of information reported to the registry, such as the first time the disorder was diagnosed and its subsequent progress, should be borne in mind. For example, as the NPR does not include any data from primary healthcare, this could limit the information that reaches specialist healthcare about the progress of affective and anxiety disorders. Data files about primary healthcare in Sweden are collected on the county level and were often started in the last decade by the 21 county councils. The current absence of national primary health care data needs to be reconsidered, given that affective and anxiety disorders are usually treated in the primary healthcare setting. One recent study based on data from the Primary Care Register in nine counties included 72% of the Swedish adult

population and reported that 80% of depression and anxiety disorders were diagnosed only by the primary healthcare provider (Sundquist, Ohlsson, Sundquist, & Kendler, 2017). However, that study focused on the general population, and it is unknown whether the pattern is the same for people with ID. Since older people with ID are a frail group with more complex needs, we can expect them to have more visits to specialist healthcare than the primary healthcare.

The results from this thesis should be interpreted taking into consideration some limitations in the studies. In Study I, comorbidities were investigated without controlling for the level of ID in our ID group. The risk of multimorbidity has previously been reported to increase with the severity of ID (Bratek, Krysta, & Kucia, 2017; Hermans and Evenhuis, 2014). ID severity complicates the assessment of clinical manifestations and of other psychiatric disorders and can increase the length of stay in a healthcare facility (Lunsky and Balogh, 2010) and increases the risk of diagnostic overshadowing (Mason and Scior, 2004).

In addition, we chose to analyse different levels of diagnostic specificity for psychiatric comorbidities than for somatic comorbidities, due to our focus on psychiatric diagnoses in this study, which means that we have less information on somatic diagnoses.

The LSS register provide information from all municipalities mandated to register the social support and services provided according to the LSS act (Socialstyrelsen, 2018). People in the ID group, (Person group 1), constitute almost 90% of those who receive LSS support and services (Socialstyrelsen, 2019). In Studies I–IV, the LSS register was used both to identify the people with ID and to investigate use of support and social services as an outcome variable. The LSS register does not contain information about the ID diagnosis but it is considered to be the best proxy today for identifying older people with ID on the national level in Sweden. This is the only way to identify a national cohort of people with ID who have had their disability since early childhood or before the age of 18 years. The information about the specific ID diagnosis was collected from the NPR, but it is only registered if the healthcare visits were caused of this condition or if the ID were a contributing cause of the visits (means secondary reason to the visit).

This thesis investigated people with at least one diagnosis of affective and/or anxiety disorder based on the chapter and block level in ICD-10; more specific diagnoses might be more feasible to investigate in practice. This weakness needs to be in consideration when interpreting the results. Another limitation concerns the lack of information in the Prescribed Drug Register in Study III. We don't know whether the diagnoses came before the prescription or vice versa. Thus, all analyses of prescriptions

were performed on an aggregated level with at least one affective or anxiety disorder in the study period.

In Study IV, the provision of personal assistance for more than 20 hours a week is not included in the LSS register, since the data is only available in other registers by the social security agency. However, a lower degree of personal assistance is expected because most older people with ID live in residential arrangement (75%) and have staff available 24 hours. Polypharmacy was defined by specific drugs that are of importance for older people and those with ID, but it could be that other drugs might be prescribed in healthcare. Finally, other potential confounders (such as lifestyle, education level or income) that might have had an effect on the findings of Studies I–IV should be considered.

# Conclusion

The findings of this thesis show that older people with ID and affective and/or anxiety disorders are more likely to have unspecified comorbidity, inpatient and unplanned healthcare utilisation and more prescription of anxiolytics, compared to people in the general population with affective and/or anxiety disorders. Older people with ID and polypharmacy were more likely to live in residential arrangement with social support and services around the clock with the presence of affective and/or anxiety disorders. On the other hand, those with multimorbidity and made more than twelve healthcare visits were less likely to live in residential arrangement with social support and services.

The results from this thesis confirm that older people with ID have complex needs for healthcare, treatment and social support and services. This might suggest that the health and social services do not meet the even more complex needs of people with ID and affective and/or anxiety disorders, which puts exceptionally high demands on promoting healthy ageing for this target group.

This thesis, consists of on four population-based studies about older people with ID and with affective and anxiety disorders in Sweden, argues that although this population receives tremendous attention and care, still there are fundamental problems in care provision. Therefore, it is crucial to give this group special attention to understand their needs and to develop targeted interventions with appropriate evidence based practice guidelines.

# Summary in Swedish

Äldre personer med intellektuell funktionsnedsättning och samtidig depressions- och/eller ångestsjukdom: Samsjuklighet, vårdutnyttjande, läkemedelsbehandling samt skörhetsfaktorer som kräver sociala stödinsatser.

## *Bakgrund*

Globalt ökar den åldrande befolkningen, liksom antalet äldre personer med intellektuell funktionsnedsättning (internationellt benämnt Intellectual Disability, ID), (Fisher och Kettl, 2005, Världshälsoorganisationen, WHO, 2017). Ökad ålder innebär en högre risk för att utveckla kronisk sjukdom, multisjuklighet och därmed ett ökat behov av många olika läkemedel (polyfarmaci). Hos äldre personer med ID ses en ökad frekvens av epilepsi (McCarron et al., 2013, Espie et al., 2003, Cooper et al., 2015), demens (McCarron et al., 2014), hjärt-kärlsjukdomar (de Winter et al., 2016), osteoporos (Burke et al., 2019), psykiska problem och ohälsosam livsstil (McCarron et al., 2013). Dessa faktorer kan sammantagna, och var för sig, leda till sänkt livskvalitet och ökat vårdbehov (McCarron et al., 2013, Scheifes et al., 2016, WHO, 2000).

WHO har uppmärksammat att äldre personer med ID är en försummad grupp som riskerar att bli orättvist behandlad när det gäller tillgång till vård och välfärdsservice (WHO, 2000). Strydom et al. (2005) fann att äldre personer med ID har ökad risk för att deras problem relaterade till den fysiska och psykiska hälsan, inte upptäcks eller underskattas. I litteraturen efterfrågas mer forskning inom området.

Depressions- och ångesttillstånd är vanliga i den allmänna befolkningen och hos äldre personer med ID (Cooper et al., 2007, Perkins och Moran, 2010, McCarron et al., 2013, Tuffrey-Wijne och McEnhill, 2008). Diagnostisering av dessa sjukdomar bygger på patientens förmåga att redogöra för sina upplevda problem. Detta innebär en särskild utmaning för vården, då personer med ID inte sällan uttrycker sitt psykiska lidande på ett atypiskt sätt, ofta genom beteendeproblem på grund av intellektuella och kommunikativa svårigheter. Det saknas forskning och därmed kunskaper om denna patientgrupps problem jämfört med den allmänna befolkningens. Denna avhandling, som är en del av en svensk nationell befolkningsstudie om hälsa, dödlighet, sjukvård

och social välfärd bland äldre personer med ID, har som mål att minska detta kunskapsgap i syfte att förstå hur stödinsatser kan förbättras för denna patientgrupp.

### *Syfte*

Det övergripande syftet med avhandlingen var att undersöka samsjuklighet, vårdutnyttjande och läkemedelsbehandling hos äldre personer med ID, vilka diagnostiserats med depression och/eller ångest. Detta undersöktes i jämförelse med äldre personer utan ID, men med samma psykiatriska diagnoser. Ett ytterligare syfte var att inom gruppen med ID undersöka sambandet mellan skörhetsfaktorer och användning av stöd och social service. Dessa tillhandahålls genom svensk lagstiftning omfattande personer med långvariga och omfattande funktionshinder (SFS1993:387, Lag om stöd och service till vissa funktionshindrade, s.k. LSS-lagen) samt socialtjänst (SFS 2019:909).

### *Metod*

Samtliga fyra studier har en longitudinell design, baserad på svenska nationella register under en 11-årsperiod. ID-kohorten är ett urval från den större nationella populationsstudien (n=7 936) som inkluderade äldre i åldern 55 år eller äldre med minst en beslutad stödinsats enligt LSS-lagen i december 2012. En kontrollgrupp från den allmänna populationen i Sverige matchades 1:1 efter födelseår och kön.

I studierna I-III inkluderades dels personer med ID med minst en depressiv sjukdom (n=918) och/eller ångestsjukdom (n=825) samt en referensgrupp ur den allmänna befolkningen med motsvarande sjukdomar. De båda grupperna jämfördes avseende samsjuklighet (psykiatriska och somatiska diagnoser), vårdutnyttjande och läkemedelsbehandling. Studie IV fokuserade endast på ID-gruppen (n=871). I denna studie undersöktes skörhetsfaktorer kopplat till stöd och social service.

Registeruppgifterna samlades in från LSS-registret, Nationella patientregistret, Befolkningsregistret, Läkemedelsregistret och Socialtjänstregistret.

Analyserna har utförts med beskrivande och jämförande statistik mellan studiegruppen och referensgruppen ur den allmänna befolkningen. Dessutom har logistisk regressionsanalys använts i samtliga studier.

### *Etikprövning*

Godkännande att genomföra studien erhöles från Regionala Etikprövningsnämnden i Lund (diarie nr. 2013/15). Socialstyrelsen och Statistiska Centralbyrån, som ansvarar för de nationella register som användes i denna studie, lämnar endast ut avidentifierade personuppgifter till forskningsstudier. Detta innebär att det inte var möjligt att få

informerat skriftligt samtycke från deltagarna i denna studie. Istället tillämpades ett aktivt avslagsförfarande genom annonsering om den planerade studien i den nationella tidningen Dagens Nyheter och i en lättläst version i medlemstidningen "Unik" som distribueras av Svensk nationell föreningen för personer med intellektuell funktionsnedsättning (FUB). I annonsen informerades om den planerade studien och hur personen skulle avböja deltagande i studien. Därefter utförde Socialstyrelsen och SCB separata sekretessgranskningar innan utlämnandet av anonymiserade data.

### *Forskningens huvudsakliga resultat*

Resultatet visade att äldre personer med ID hade ökad samsjuklighet, behövde oftare slutenvård och använde oplanerad vård (utan tidsbokning före) samt fick fler receptbelagda ångstdämpande läkemedel utskrivna, jämfört med den äldre befolkningen i jämförelsegruppen (Studie I-III). Den vanligaste psykiatriska samsjukligheten i ID-gruppen var ospecificerad sjukdom, vilket återspeglar svårigheterna att diagnosticera psykiska problem. Den somatiska samsjukligheten var lägre och det framkom en ökad sannolikhet för neurologiska sjukdomar, skador och fall (Studie I).

Resultatet visade att det var mer sannolikt att ID-gruppen hade fler besök inom slutenvården och mer oplanerad vård både inom psykiatrisk och somatisk vård, jämfört med referensgruppen. Inom ID-gruppen, med depression och/eller ångestsjukdom fanns en ökad sannolikhet för att de med beteendeproblem, måttlig/svår ID och boende i bostäder med särskild service enligt LSS (ex. gruppboende, satellitlägenhet) blev inlagda på sjukhus. Det genomsnittliga antalet vård dagar på sjukhus var signifikant högre för kvinnor, och för dem med beteendeproblem (Studie II).

De med ångestsjukdom i ID-gruppen hade ökad sannolikhet för receptbelagda potentiellt beroendeframkallande ångstdämpande läkemedel än personerna i jämförelsegruppen. Bland dem med ångest men utan depressiv sjukdom, var emellertid ID förknippat med ökad förskrivning av recept på antidepressiva läkemedel. Beteendeproblem och ID av måttlig till svår grad var kopplat till ökad receptförskrivning av ångstdämpande läkemedel hos dem med både depression och ångestsjukdom (Studie III).

Det vanligaste stödet som beslutades enligt LSS för dem med depressions- och/eller ångestsjukdomar var bostad med särskild service (75 %), dagliga aktiviteter (76 %) och personlig kontakt (66 %). Vanligaste stöd som tillhandahålls enligt Socialtjänstlagen (SoL) var hemtjänst (56 %), trygghetsinsatser såsom exempelvis larm (32 %) och särskilt boende (33 %). De med multisjuklighet hade mindre sannolikhet att bo i bostad med särskild service. Det motsatta, ökad sannolikhet för bostad med särskild service framkom för polyfarmaci och de med måttlig eller svår ID (Studie IV).

### *Slutsatser och implikationer*

Resultaten verifierar att äldre personer med ID och med depression och/eller ångestsjukdomar har omfattande och komplexa behov av vård, behandling och sociala stödinsatser. Även om uppmärksamhet och omsorg om personer med ID tillhandahålls från samhället, främst via LSS-lagstiftningen indikerar denna avhandling att det fortfarande finns brister med att tillhandahålla vård med hög kvalitet.

Det är därför viktigt att ge denna grupp ytterligare uppmärksamhet och fördjupa förståelsen för deras unika behov i syfte att utveckla lämpliga evidensbaserade riktlinjer och interventioner. Utifrån ett ökat antal äldre med ID i världen och resultatet av studierna i denna avhandling, visas ett behov av att skyndsamt utveckla specifika medicinska riktlinjer för hälsoövervakning och strukturerade vårdprogram för denna sköra grupp äldre med psykisk ohälsa. Förebyggande insatser för depression och/eller ångestsjukdomar behöver fokusera på kommunikationsstrategier och verktyg för att främja hälsosamt åldrande och personcentrerad vård. Stöd för förbättrad vårdkvalité kan hämtas från Peplaus omvårdnadsmodell och EU:s politik för hälsosamt åldrande. Ett resurscenter med särskild kompetens inom vård av äldre med ID och samtidig psykisk sjuklighet behöver därför tillskapas för att stödja andra verksamheter inom LSS omsorgen, sjukvården, och personerna med ID samt deras anhöriga.



# Acknowledgement

My thesis studies were carried out at the Department of Health Sciences, Faculty of Medicine, Lund University, Sweden. I would like to express my deepest and sincere gratitude to everyone who had a part in this thesis. In particular I would like to thank the following people:

I am extremely grateful to my supervisor *Gerd Ahlström*, for believing in me, giving me the opportunity to do research and providing invaluable guidance throughout this rewarding journey. Thank you for introducing me to the research field of intellectual disability. I appreciate everything you have taught me about how to carry out and present scientific research. I learned a lot from you and I couldn't do this without your dedication and support. Your knowledge, dynamism, vision, sincerity and motivation have deeply inspired and helped me, and they will shape my future research life. It was a great privilege and honour to work and study under your guidance.

To my supervisor during the last year of my education and co-supervisor *Jonas Eberhard*, for your knowledge, support, motivation and collaboration at the end of my studies. Thank you for helping me to complete this thesis successfully.

To my co-supervisor *Christina Bökberg*, thank you for joining the supervision team halfway through my thesis studies. Your valuable comments and feedback on my manuscripts and your continuous support and motivation have been much appreciated.

To co-author *Anna Axmon*, for expertise and collaboration in Study III.

*Helene Jacobsson*, thank you for your great collaboration and statistical advice in Study IV.

My special thanks go especially to the *Health promoting Complex Interventions research group* for their wonderful feedback, constructive criticism and support. This has been a long voyage of discovery, and without the knowledge gained from the many courses at *Lund University* and the *European Academy of Nursing Science (EANS)* summer school, I wouldn't be able to reach this point, so thank you all.

*Anna Blomgren*, thank you for helping with layout and formatting of this thesis before printing.

*Catriona M Chaplin*, thank you for careful language editing.

My family, thank you for your unconditional support, encouragement and love. I dedicate this thesis to my wonderful parents *Hisham and Gabriella*; without the inspiration, drive and support you gave me I might not be person I am today. I am extremely grateful to you for giving me all the best things you could, that have opened many doors for me to grow and succeed. Thank you for believing in me throughout this journey. I hope I make you as proud as you make me. Multumesc Mama si Tata!

Completing this work would have been almost impossible were it not for the support provided by my husband. My warmest thanks to my dear *Imad*, for your love and understanding during all the stressful moments and late-night work. Thank you for preparing delicious meals; now you will have the time to teach me some of your recipes.

My sweethearts, *Adam and Elina*, you are my greatest achievement and I am proud of having loving children like you. Being your mother is a blessing and worth every sleepless night. No words can describe the happiness and love I feel for you every day. You know that each of you is “the apple of my eye”.

My beautiful sisters, *Nina, Nida, Shereen and Lara*, I am so blessed to have you in my life. Thank you for believing in me and supporting me, for being my best friends and being there every time I needed you. *Nina and Nida*, you each have a wonderful family and this thesis is for your children to remember that there is nothing impossible in life if they believe in themselves. To my wonderful grandmother Ileana, Te imbratisez cu multa dragoste!

Finally, I have travelled far, and my sincere thanks go to all the people and friends around the world who have enabled me to complete this thesis.

This thesis was supported by the Jordanian South Society for Special Education, the Swedish Research Council for Health, Working Life and Welfare (FORTE) and the Faculty of Medicine at Lund University.

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Department of Health Sciences

Lund University, Faculty of Medicine  
Doctoral Dissertation Series 2020:135  
ISBN 978-91-8021-002-7  
ISSN 1652-8220

