Chapter 2
Prevalence of Mental, Behavioural, and Neurobehavioural Disorders

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Introduction

Since the start of the twentieth Century, a combination of enhanced health-care provision, the development and implementation of new life-saving technologies, and a greater appreciation for the rights for people with individuals with intellectual and developmental disabilities (IDD) has seen the life expectancy of this cohort increase dramatically [1–3]. Improved knowledge and the timely provision of health services across the lifespan has resulted in many individuals with complex care needs surviving childhood [4] and now living into adulthood and beyond, even with severe physical and mental health co-morbidities [5]. It is recognised that, in developed countries all around the world, people with intellectual disabilities are now living longer than at any time in recorded history [6–9].

The improvements in early medical diagnosis and treatment, when combined with appropriate ongoing care management, has seen progress that now means that a person with a mild IDD in the United States has a life expectancy that exceeds 70 years [10]. If people who have a specific genetic disability, such as Down, Angelman or Prader–Willi syndrome, as well as those individuals with complex and severe associated health co-morbidities, are removed from the total figures, the life expectancy of an Australian individual with IDD now approximates that of the mainstream [11]. Similarly, a United States study estimated the difference in lifespan between the standard population and a person with a mild IDD to be only 2% [12].

The present cohort of people with IDD is the first that has lived into chronological old age in large numbers, and can also reasonably expect to outlive their parents

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[8]. While it may seem obvious that older people with IDD will face additional problems when compared to the mainstream ageing community, it should not be automatically assumed that every individual will experience significantly worse health or social problems [13]. Nonetheless, the mere extension of life does not necessarily equate to a high quality of life if health issues are not appropriately treated [14], and there is limited data and information regarding the mental health of people with an IDD as they grow older. This lack of knowledge in turn limits the capacity of support services to effectively meet emerging and changing mental health needs.

It is important to recognise that many older people with IDD may be just as 'healthy' as other older persons without long-standing disabilities. However, service providers and government bureaucracy will often argue whether the lifelong IDD or a newly emerging ageing-related problem is the predominant issue that requires support [15], and this approach can lead to a focus upon areas of weakness, rather than the continuing strengths of the individual. It can result in a distorted view that older people with IDD are more dependent and require a greater level of care than is actually needed. The concentration upon the care needs of the individual, rather than upon the maintenance of existing skills and abilities, can lead to a situation in which people with IDD are prematurely viewed as being non-productive and unnecessarily reliant upon external assistance as they grow older [16]. With this in mind, there do remain a number of both internal and external issues that impact upon the capacity of people with IDD to be successfully supported as they grow older. One of these factors is the co-morbidity of mental and behavioural disorders in this cohort, and this issue is the focus of this chapter.

Moving Away from the Biomedical Model: An Acknowledgement of Change in Approach

There are a variety of different theoretical perspectives for considering the concept of health in general and, more specifically, the issue of disability. Historically, there has been a strong focus upon medical models and individual rehabilitation in mainstream society; however, concurrently with the emergence of ageing as a significant support issue, the past three decades have seen the proposal of an increasing number of social models of disability [17]. Disability can be defined within a variety of potentially disparate contexts including public health, economics, politics, history and feminism. The various social models of disability facilitate a greater examination of environmental, community and cultural aspects to disability than the previous medically orientated frameworks.

The past 100 years have seen a major shift in thinking with respect to the perception of disability. It has been previously argued that the presence of IDD denies the individual 'personhood' as a result of a perceived inability for self-awareness. This premise was the basis of many now condemned practices, such as widespread compulsory sterilisation and even euthanasia [18]. Through much of the past century, the dominant conceptualisation of disability saw it related to a diagnostic medical model that was premised around deficit. This approach has been more recently challenged by the alternate view that disability is instead a reflection of human diversity [19] and is impacted by a variety of other factors.

The World Health Organisation (WHO) had initially defined health in 1948 as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" ([20], online). This definition effectively categorized the presence of a disability as inferring the point when health ceased. The diagnostic medical approach to disability was based upon the premise of an underpinning medical problem within the individual. It had an internal focus, with the belief that the person with a disability was in some way defective when compared to wider societal norms. This deficit or problem could then be addressed through medical diagnosis and subsequent intervention [19]. This framework is predominantly derived from the work of Parsons in the 1960s, who argued that an illness provided the individual with an opportunity to ignore or discard the normal socially enforced beliefs of the society. However, with this reduced expectation was an associated insistence upon compliance with curative medical interventions [21]. People with IDD would appear to present a significant problem to this paradigm, as the likelihood of medicine providing a cure for their lifelong problems was minimal. It was argued that the diagnostic medical framework was applicable to individuals suffering from a temporary or acute episode of illness, but not necessarily appropriate to people who were older or who had a permanent disability [22].

Over time, WHO and others started to re-conceptualize the understanding of health to incorporate both medical and social aspects [23] that better accommodated the rights of people with disability. These changes in perception were associated with the possible application of a number of different theoretical models and frameworks, ranging from diagnostic medical perspectives through to a social constructionist perspective [24]. A movement away from a purely medical model can be seen through changes to the research focus of the IDD sector. For example, in the 1970s, 42% of papers in the *Journal of Intellectual and Developmental Disability* had a medical focus. In the following decades, this figure dropped to just 7% of articles being framed within the medical model [25].

This was a welcome shift in approach. It facilitated a greater emphasis on the individual and their specific needs, rather than just being seen simplistically in terms of a medical diagnosis. However, the older diagnostic medical model is not necessarily redundant, and an understanding of population health is still important if we are to better support individuals with their health-care needs. It is acknowledged that social models are more commonplace in IDD research today, but the focus of this chapter is on the epidemiology of mental and behavioural disorders of older people with IDD. In its simplest state, epidemiology can be considered to be study of the disease patterns in either entire populations, or more commonly, in specifically defined sub-groups of an entire population. In practice, this means examining factors such as incidence (number of new cases of the disease), prevalence (number of people currently with the disease), the distribution of the disease, any possible controls for the disease, and consideration of any other health determinants that may contribute towards these factors. Epidemiology can assist us to understand the distribution of certain disease, what factors may contribute towards increases or decreases in the number of people with the disease, and identify possible methods to assist with reducing the impact of the disease.

This chapter will be primarily on the prevalence of mental, behavioural and neurobehavioural disorders (the disease) among older people with IDD (the population). However, as it is known that some disorders may present for the first time in older persons, in particular many neurobehavioural disorders, there will also be consideration of the factors that may affect incidence in this population. Solely for the purposes of this chapter, both autism and dementia are not considered as either mental or behavioural disorders, as there is separate and more detailed focus (in Chaps. 8 and 12 respectively) within this book on these important issues.

Prevalence of Mental, Behavioural and Neurobehavioural Disorders

What Is Prevalence?

Prevalence, as noted earlier, is the number of people who can be definitively identified as having a specific condition (e.g. disease, disorder, symptom). However, prevalence can be measured in a number of different ways. A ‘snapshot’ approach can be used, whereby the number of people with a disease at a specific point in time, such as 31 July, is determined, and this is called *point prevalence*. In contrast, *period prevalence* will measure the number of people who have the disease during a longer period of time, such as a month or a year. A third type of measurement, *lifetime prevalence*, examines the number of people who have experienced that disease at any time previously in their life. However, while lifetime prevalence has been commonly used within psychiatric epidemiology, concerns have been raised about its validity and recommendations have been made to cease using it [26]. With respect to prevalence, the focus in this chapter will be predominantly on point or period prevalence, as it is felt that these measures better establish current health issues facing older people with IDD.

What Is an Intellectual Disability and What Is ‘Older’?

It is worth noting in advance that there are two pivotal concepts that may differ for readers around the world. These relate to the definitions used to determine whether a person has an IDD and also in relation to the commencement point for someone being considered ‘older’.

There is no single accepted definition of precisely what factors allow for the diagnosis of an IDD [27]. There are a number of different clinical classification systems used in research and service delivery areas to define IDD, and these include the World Health Organisation's (WHO) International Classification of Diseases (ICD) [28] and International Classification of Functioning, Disability and Health (ICF) [29], the American Psychiatric Association (APA) Diagnostic and Statistical Manual (DSM) [30], and a definition by the American Association on Intellectual and Developmental Disabilities [31]. While these classification systems are in many ways conceptually quite consistent, the variance in usage between the models has resulted in data inconsistency with respect to accurately establishing the prevalence of IDD [32]. The clinical diagnosis of IDD has traditionally been based upon a measured Intelligence Quotient (IQ) for the individual, however recent years has seen a greater emphasis on also considering any limitations in adaptive behaviours in areas including socialisation, daily living skills and conceptualisation. A diagnosis of IDD for a person is then commonly sub-categorized in relation to its measured severity, including labels such as mild, moderate, severe and profound intellectual disability.

Similarly, there are numerous different, and sometimes conflicting, definitions pertaining to the ageing process that all people undergo. There is no universally accepted classification of what combination of symptoms comprise ageing or being 'older'. The common themes of most definitions relate to changes that occur progressively or over time that result in some loss of function for the individual. Determining precisely when ageing commences in a defined population, or when a specific individual is considered to be older, is not simple. Ageing is not an event that can be accurately predicted and takes place over an extended period of time and varies between every person [33]. As such, providing a clear definition of 'older' for an entire population sub-group, such as people with IDD, is problematic. While ageing should not be viewed as a singularity, many attempts to categorize or define it are usually framed in terms of a specific chronological age, such as 65 or 70. However, this approach has not resulted in a standard definition of ageing as there are no chronologically definitive and consistent physical, psychological or social phenomena associated with ageing that support the establishment of set ageing criteria in the same way that infancy or puberty can be so defined [34].

Researchers worldwide often use retirement or pension ages as a convenient marker in describing the onset of ageing [35], in spite of the fact there appears limited medical or social reasons for this decision. The United Nations has recognised this problem and nominated the use of chronological age as merely a crude mechanism for the identification of population groups and their respective needs [36]. However, various different classifications of ageing have continued to be proposed, with the United Nations generally using the age of 60 to define older people [37].

In the same way that IDD is sometimes sub-categorized into mild, moderate, severe and profound, there have been attempts to stratify the cohort of older people into smaller sub-sets. As one example, one ageing model defines a person aged 65–75 as 'young old', someone 76–85 as 'old old', and people over the age of 85 as the 'oldest old' [38]. Another methodology defines people between 65 and 80 who are predominantly independent and socially active as ‘third age’ and people who are over 80 years old and requiring more support as ‘fourth age’ [35].

The lack of consistency regarding diagnosis of IDD, in conjunction with no universally accepted definition for ageing, means that there will be differences in the interpretations of research findings due to the variations in criteria used to derive any samples. To allow the reader to determine the relevance of results for their own particular situation, an attempt will be made to note throughout this chapter the specific location of studies (i.e. the city, state, territory or country) and what criteria (i.e. age brackets, severity of disability) were used within the research. This is not always possible, as not all research contains this demographic information.

Problems in Determining Prevalence

Historically, it has been difficult to accurately determine the prevalence of some health issues in older people with IDD. Prior to the 1990s, the majority of research or government reports that noted the prevalence of mental or behavioural disorders tended to be based on *convenience samples*. A convenience sample is one that is used because it is easily accessible and is therefore not necessarily representative of the wider population. For older people with IDD, convenience samples in this context were predominantly of composed of individuals referred through to specialist mental health services for support. This means that these samples are potentially biased, as they may miss individuals who were perceived, correctly or otherwise, to have less serious mental health issues that did not require specialist support, as well as people in areas where there were simply no services available for referral, such as rural locations. These convenience samples were often quite small and attempts to extrapolate their findings across the entire population of older people with IDD is inherently problematic. It is also important to recognise that there may be further data disparities depending upon the methodology used for collection. Personal interviews with an individual with IDD may not result in the same identification of issues as a personal interview with a parent or paid carer, online surveys, a review of medical records and so on.

In order to overcome some of these issues, many researchers have started to use large databases or registries from disability support organisations, health services and government records. Such data can be considered more representative of an entire community and allows for a retrospective analysis of all individuals at a given point in time. It can also include people living independently in the community with minimal support, as well as those referred to specific mental health services. While this approach is preferable to the convenience sampling method, it also has a number of limitations that limit the accurate estimates of prevalence. Registries are often still restricted to certain areas, such as one rural or urban location, and therefore the results may not be generalizable to other areas even within the same country. A solution to this problem would be to combine the findings from numerous different registries, but this approach then raises another issue that impacts on prevalence estimates; how accurate and consistent is the diagnosis of mental or behavioural disorders across regions of one country, and internationally?

Diagnosis of a Mental Disorder in Older Persons with IDD

In order to determine the epidemiology of any disease, an accurate and consistent diagnosis is required. In the general community, mental disorders are primarily first diagnosed usually by a general practitioner, with additional support from a psychiatrist, gerontologist, psychologist or local mental health team. Mental disorders are not usually diagnosed through medical testing, such as a blood test or magnetic resonance imaging (MRI) scan of the brain. Instead, a doctor will usually discuss the presenting symptoms with the patient, and, after ruling out other possible causes of the symptoms, make a diagnosis based off the provided history. This diagnosis will usually be based upon specified criteria in either the *Diagnostic and Statistical Manual of Mental Disorders* (current version: DSM-V), as published by the American Psychiatric Association [30], or the *International Classification of Diseases* (current version: ICD-11) developed by the World Health Organisation [28].

Research since the 1960s has reported that, in general, people with IDD are more likely to be diagnosed with a mental disorder across their lifespan than the mainstream community [39, 40]. For older people with IDD, the process of diagnosis for mental disorders is largely the same as for the mainstream community, but there are a number of differences that are important to recognise and these are discussed in greater detail below. There has also been recognition of a number of specific mental disorders that require proactive monitoring in the population of older people with IDD. In particular, these include delirium, dementia, depression and chronic psychiatric disorders including anxiety and schizophrenia [41]. The symptoms of many psychiatric conditions in this cohort include impaired attention, a decrease in memory or language, or changes in cognition, motor skills and emotional state [41]. Specific mental disorders and their associated symptoms in older people with IDD are explored in greater depth later within this book (e.g. Depression Chap. 5; Autism Spectrum Disorders Chap. 8).

However, there are significant problems in accurately determining the prevalence of mental disorders, as the process of accurate diagnosis is complex. Assessing both the current and previous mental health of people with IDD presents difficulties for families, staff members and general practitioners, as they often do not have the necessary knowledge or information to accurately identify or recognise mental health issues in this cohort [42]. Even if the problem is accurately identified, the lack of available and appropriate mental health services is known [43], and the problem is magnified by the fact that health professionals are unsure of how or who to refer individuals on for further assessment [44]. This problem becomes even more complex, as psychiatrists believe they are generally “untrained and inexperienced” ([45]: p. 191) in supporting people with both IDD and an emerging or chronic mental disorder [15].

Many of the symptoms of a mental disorder can mirror behavioural disorders and it can be difficult for family members or support staff to distinguish between the two, or to determine whether there is a new psychiatric condition associated with ageing or if it is simply the progression of an existing behavioural disorder. It is therefore important that any change in functional skills or behaviour in an older person with IDD is evaluated carefully [46]. The symptoms of some psychiatric conditions can hide the development of other serious diseases and treatment can be unnecessarily delayed until a proper diagnosis takes place [41]. Further discussion of the assessment of behavioural and psychological disorders can be found in Chaps. 3 and 4.

When considering the use of registries and databases to establish prevalence estimates, the issue of accurate and consistent diagnosis becomes evident. If there is variation in how the presence of a disease is determined, this will result in discrepancy in the data. In particular, if the registry data is gathered across a variety of settings and with multiple different assessment criteria for decision making, the final reported data is potentially biased. This problem becomes evident in assessing mental disorders; there are often no universally accepted definitions for specific mental conditions, and practitioners will use different tools and measures, in combination with their own subjective judgement and clinical experiences, in order to make a diagnosis [47].

Diagnosis of a Behavioural or Neurobehavioural Disorder

While mental disorders are relatively well understood conceptually, albeit with the diagnostic difficulties as discussed above, behavioural disorders are less easy to define. Both DSM-V and ICD-11 refer to behavioural disorders, under a variety of different labels, but they are initially conceptualized in relation to the early life stages of infancy, childhood or adolescence. However, within the wider disability sector, issues associate with ‘challenging behaviours’, ‘problem behaviours’, ‘behaviours of concern’ or ‘complex behaviours’ are seen as occurring across the entire lifespan, and can disappear and re-emerge at various time points or in relation to changing life circumstances, stresses and physical health issues. The current frameworks for diagnosing behavioural disorders, and the distinction between an individual having a behavioural disorder as opposed to displaying behaviours that challenge convention, vary greatly between countries, and from an epidemiological perspective, it remains difficult to precisely define what constitutes a behavioural disorder in order to then determine the prevalence within older populations of people with IDD.

Within the adult population, behavioural disorders are generally diagnosed when an individual displays or performs repeated actions that fail to conform to societal expectations of age-appropriate conduct. As examples, such behaviours in adults with IDD may include physical or verbal aggression towards other people, animals or property, self-injury, impulsive or reactive deeds, or sexually deviant actions. In this context, these behaviours may be perceived to be 'irrational' from the perspective of family, friends, carers or the wider community. This is not to say that the behaviour is irrational; instead it is often that the reasoning behind the actions is simply not immediately evident to anyone other than the individual. However, simply displaying such behaviours is not necessarily a sign of a behavioural disorder. For example, physical aggression is well known to be associated with undiagnosed pain, particularly individuals with severe or profound disability and communication impairments [48, 49]. Diagnosis of a behavioural disorder in this situation would be inappropriate, as the behaviour generally disappears once the cause of the pain is removed [50], but differentiation is highly complex and results in significant ambiguity in definitive diagnoses.

In contrast to general behavioural disorders, neurobehavioural disorders are considered more specific in that they occur in individuals who have either experienced a neurological event, such as a stroke or traumatic brain injury including ischemia or hypoxia, or have an emerging disease that affects their neurological function, such as Alzheimer's disease and other dementias, Parkinson's or multiple sclerosis. Behavioural disorders in people with IDD are usually diagnosed in childhood and then may recur across their entire lifespan. However, neurobehavioural disorders are different to behavioural disorders in that they arise following specific health events that are often associated with ageing. The manifestation of behavioural and neurobehavioural disorders may be quite similar, even if the origins may vary. Any older person is susceptible to such diseases, and may therefore experience neurobehavioural disorders as they age. It is known that the process of diagnosing neurobehavioural disorders in the mainstream community is poorly understood, and treatment and support for these disorders is either ignored or only cursorily considered [51]. However, for older individuals with IDD, the diagnosis process can be further complicated by the existence of pre-existing behavioural disorders and co-morbid mental disorders.

Epidemiology of Mental or Behavioural Disorders in Older Persons with Lifelong IDD

While it is acknowledged that there are a large number of limitations in determining the epidemiology of mental or behavioural disorders in older people with IDD, there is a growing research quantum from around the world that estimates the occurrence of these issues. The following section is an attempt to synthesize the general findings of the research base; it is not designed as a systematic review or intended to encapsulate all the research in this area.

Again, it is worth noting that the varying definitions of both 'IDD' and 'older' will see reporting on potentially different samples. It is also important to recognise that, as the cohort of people with IDD has only recently started ageing with significant numbers, many studies will have aggregated data as the sample sizes would be otherwise too small. This means that some research will combine together all levels of disability and all people aged over 60 (for example), while larger studies may have been able to stratify their sample into both different age cohorts (e.g. 60–65, 66–70, 71–75 and so on) and severity of IDD. Readers are encouraged to ensure that they are cognizant of these potential differences and to not attempt to compare findings across disparate samples.

The Pioneering Research

As discussed, both earlier within this chapter and then again in later sections of this book, ageing within the IDD population is a relatively new development associated with a rapidly increasing life expectancy during the twentieth Century [46]. One of the earliest research papers on the issue of ageing and disability was written in United States in the early 1960s by Dybwad, with the report detailing the need for improved planning and additional funding for individuals [52]. Further research over the following decade was spasmodic [53–55] commenting on the changing requirements of older people with a disability.

In the 1970s and 1980s, led by pioneers such as Janicki [56–59] in the United States, research into ageing with IDD was promoted and became more common, but the field was still very much in its infancy. Many of the studies were undertaken in the United States and Europe, and examined a variety of different aspects of ageing in this cohort including occurrence [60], predicted life-span [61], language training opportunities for older people [62], deinstitutionalisation [63], medical problems [64], decision making by ageing carers [65], and social care issues [66] amongst others.

While there was more research looking generally at ageing with IDD, there was minimal focus on mental or behavioural disorders amongst this cohort. Of this research, the majority was based around small clinical populations, with limited attempts to assess the epidemiology of disorders across wider areas. Corbett's 1979 research is recognised as one of the first reports on the prevalence of mental or behavioural disorders among older people with IDD [67]. Drawing on information gathered from carers of 110 individuals aged over 60 living in London, Corbett reported ten diagnoses of mental disorders (including schizophrenia, psychoses and neuroses) and 23 behaviour disorders.

While it was still spasmodic, the 1980s started to see more researchers examining the phenomenon of mental and/or behavioural disorders amongst older people with IDD. In a small comparison sample within a residential aged facility (nursing home) in the United States, Cotton and colleagues [68] noted that the prevalence of behavioural disorders was actually lower among people with lifelong IDD than their ageing peers without lifelong IDD. Day [69] reported on a retrospective analysis of the prevalence of mental and behavioural disorders amongst 357 hospital patients aged over 40 years in England. While there was an overall prevalence of mental disorders of approximately 30%, Day noted a consistent decline in the rate of mental disorders as individuals grew older, with diagnoses of psychiatric illness falling from a high of 48.7% in the 40–49 year old group progressively to 30.3% (50–59 years), 25.2% (60–69 years) and 16.7% (70 years and above). This pattern was replicated for behavioural disorders, with a reduction in diagnoses from 29% in the youngest cohort to 4.2% in the oldest group. In a second English study, Day [70] noted a prevalence rate for psychiatric disorders of approximately 20% in a cohort of long-stay hospital residents aged 65 and over. Other small-scale United States or United Kingdom studies [71–73] noted the prevalence of mental disorders at similar rates for older people with IDD when compared to mainstream community peers. Others noted higher prevalence rates for older people with IDD; Menolascino [74] in the United States noted increasing prevalence of 30% in older people with IDD, while Iverson and Fox [75] reported prevalence rates of 35.9% in a United Sates sample of adults aged over 41 years.

One of the first national-level projects was undertaken by Andersen and colleagues [76] in 1987. They used 1977 nursing home data from across the United States and noted that 7% of residents aged over 54 years with an IDD also had a diagnosis of a co-morbid mental disorder. Jacobson and Harper [77] also used a United States national sampling approach to establish survey data regarding 379 people with IDD aged 55 and above. Their results differed from those reported by Day [69] in that mental disorders did not appear to decline with age. The rate of psychiatric diagnoses was 19.3% in the 55–59 year category, then went up to 22.7% in the 60–74 group, and finally decline slightly to 21.3% in those aged 75 and over. There were very high reports of 'behaviour problems' across all three age cohorts, with examples including *tantrums* (75.9%, 50.9% and 21.3% in the 55–59, 60–74 and 75 and greater groups respectively), *runs/wanders away* (37.3%, 20.8% and 21.3%) and *hyperactive* (27.7%, 53.2% and 21.3%) amongst others. It is also worth noting the report of *suicidal threats/attempts* occurring in 21.7% of 55–59 year olds; even now, the potential risk of suicide for people with IDD is still not widely recognised as being of concern [78].

An Increasing Knowledge Base

The data regarding mental health and behavioural disorders in older people with IDD that was gathered during the 1970s and 1980s was not particularly comprehensive and, as is evident from the previous section, was sometimes contradictory. For example, while there were studies that indicated the prevalence of mental disorders decreased with age [69, 79], some reported that it didn't change [77], and further others noted increases in the diagnosis of mental disorders as individuals got older [58, 80]. Nonetheless, this base provided a framework for future work to build on, and the following decades saw considerable growth in the number of larger-scale projects that focused on this area. However, in spite of this increasing knowledge, accurately determining prevalence of these disorders remained difficult, even within specific countries. As an example of the wide disparity in reporting, Campbell and

Malone [81] noted estimates of prevalence rates for mental disorders in people with IDD varied from a low of 14.3% to a high of 67.3%. Borthwick-Duffy [82] also commented on the vast discrepancy in prevalence rates, with a variation in estimates from below 10% to over 80%. However, much of this research was still focused on people with IDD across all age categories, with minimal consideration or stratification of the data specifically to consider the prevalence among older individuals.

Findings from a small project with 23 people aged over 65 without Down syndrome living in two regions of London was reported [83]. Of this cohort, 17 (74%) had psychiatric symptoms, although only 30% had a current or former diagnosis of a mental disorder. Behavioural disorders were also common, with 27% of the sample having more than 10 ‘maladaptive’ behaviours, such as physical violence, property destruction or self-injurious behaviours. Some researchers have specifically examined whether age was related to the diagnosis of mental disorders, and they reported that there was no difference after adjustment for cognitive capacity and social skills [84]. A further study [85] of 105 individuals aged over 50 years with a range of level of disability reported that 21% of the participants would be diagnosed with a psychiatric condition.

In a study [86] of 124 individuals with IDD aged 60 years and over, prevalence of mood disorders (8.9%) and schizophrenia (6.5%) was reported. This was one of the earlier studies that started to report on specific diagnoses, rather than just a general heading of ‘mental disorder’. A nation-wide study [87] reported on data gathered from 1581 Dutch individuals with IDD, 307 of whom who had Down syndrome, from 83 different group homes and 24 institutions. This study incorporated a wide range of ages, including 715 people aged 50 years and above. It also noted the severity of disability from mild to severe. This study defined ‘psychological problems’ as a category distinct to diagnosed mental disorders. No differences were noted in relation to the prevalence of mental disorders with respect to age, with prevalence rates varying between 23% and 29%. While the data showed a slight decline in psychological problems as individuals aged, this decline was not significant. Behavioural disorders showed a slight increase with age, but again this was not significant.

Cooper [88] undertook an analysis of the prevalence of psychiatric disorders among a cohort of 134 people with IDD aged over 65 years in the UK and compared them to a comparable group of individuals aged 20–64 years. Cooper found an overall higher rate of psychiatric disorder among the older cohort, however it is worth noting that much of this difference can possibly be attributed to not unexpected higher prevalence of dementia in the older cohort. Nonetheless, the prevalence of anxiety (9.0%) and depression (6.0%) were also both higher than the younger group (5.5% and 4.1%), while rates for schizophrenia, delusional disorders and behavioural disorders were similar across both cohorts. The prevalence of any psychiatric disorder, excluding dementia, in a combined sample of 602 people aged over 50 was 38.1%, with behavioural disorders estimated at 11.5%.

Evenhuis [89] undertook a prospective, rather than retrospective, longitudinal study over a period of 10 years between 1983 and 1993. A total of 70 participants aged 60 years and over with IDD in the Netherlands were tracked for a decade for various health conditions. While mental disorders were not specifically reported, other researchers [90] have also followed a similar methodology to Evenhuis [89]. They completed a prospective cohort study over four time periods between 1990 and 1993 in order to determine the prevalence and incidence of a variety of health issues, including mental disorders, in a cohort of 1602 people with IDD in the Netherlands. Prevalence of affective disorders was found to be increasing in people over 50 years when compared to younger age cohorts, but there were no age related change to prevalence for other psychiatric disorders. Prevalence of affective disorders was noted at 6.8%, 8.3% and 5.9% for the age groups of 50–59 years, 60–69 years and >70 years respectively. The prevalence of all other psychiatric disorders was reported as 18.3%, 14.4% and 14.7%.

Findings from 134 people with IDD aged over 65 years in Leicestershire, which represented 93.7% of the known population that could be established through the Leicestershire Learning Disabilities Register, were reported [91]. In total, 63 (47%) of the sample had a psychiatric disorder which was not dementia. This prevalence rate was higher than reported previously [92] of a much larger cross-sectional analysis of 60,752 adults with IDD in the United States. Of this sample, 4878 were aged 60–74 years and 1248 were aged >74 years. Analysis showed 30% of people aged 60–74 had a psychiatric conditions, while this fell to 17% in the greater than 74 years cohort. Behavioural disorders, including emotional lability, aggression and passivity, were noted at high levels across all cohorts and did not vary with age. Emotional lability was noted at 36% and 35% in the 60–74 years and >74 years groups respectively.

Current Knowledge

It is now generally accepted that mental and behavioural disorders are more commonplace in older people with IDD when compared to mainstream peers without a lifelong IDD. While research in the area is still limited, the past decade has seen a focus on providing a more nuanced understanding of the prevalence and incidence of different types of disorders in this cohort, and how factors such as sex, severity of disability, co-morbidities and geographic location may impact on individual experience.

A recently published registry study [93] of people who were aged over 55 years in 2012 in Sweden examined the prevalence of mental and behavioural disorders over the previous decade (2002–2012) specifically in relation to the severity of disability. In general, they found that mental disorders were least common in people with severe/profound disability (54%), but there was minimal difference in prevalence between people with mild (67%) or moderate (66%) disability. However, the opposite was true for behavioural disorders, with the rate in the severe/profound (49%) and moderate groups (49%) being nearly double that of the mild group (25%). It is worth noting that while these prevalence rates appear higher than most other studies, the longer period for assessing prevalence must be considered.

Prevalence rates of 16.8% for depression and 14.1% for anxiety among a cohort of 693 people with IDD in the Netherlands aged over 55 years has been reported [94]. Sheehan and colleagues [95] reported on the incidence of both mental health and behavioural disorders in a cohort of United Kingdom residents with IDD. The incidence of severe mental disorder was reported at 32 per 10,000 person years, which is significantly higher than similar studies conducted on the mainstream population. When considering solely the cohorts of people aged 50–59 years, 60–69 years, 70–79 years and over 80 years, the incidence of behavioural disorders was estimated at 260 per 10,000 person years, 286 per 10,000 person years, 304 per 10,000 person years and 382 per 10,000 person years respectively. The rising incidence as people age is probably indicative of the increasing likelihood of a co-morbid diagnosis of dementia, with little difference evident in the three age brackets between 18 and 49 (incidence rates of 218, 220 and 226 per 10,000 person years).

Scottish Census data [96] was used to examine the entire country's data on mental disorders, and to compare the prevalence of these disorders between individuals with and without IDD. Of this, 2455 people were identified as being over 65 years and having IDD, and 27.2% of this group also had a mental disorder. This was significantly higher than the prevalence of mental disorders in mainstream peers (4.5%). There were slightly more females (51.6%) than males (48.4%) in the cohort over 65 years who also reported a mental disorder, which is similar to some national level data that indicates mental disorders are more commonly diagnosed in females within the mainstream population [97, 98]. It is worth noting that increasing age from birth through to 64 years was associated with higher risks of mental disorder, however this effect was considered to cease from 65 years onwards.

A further study [99] examined the prevalence of problem behaviours in older Irish people with IDD. In a cohort of 683 individuals aged over 40, 53% were noted as displaying problem behaviours, including physical and verbal aggression, destruction and self-injury. Similar to previous reports [93], increases in the prevalence of problem behaviours were associated with the severity of disability, but also with the dual diagnosis of a mental disorder. Also looking at a cohort of Irish individuals with IDD aged over 40 years, other researchers [100] found 47.5% of the participants self-reported that they had been diagnosed at some point with an emotional, nervous or psychiatric condition. Slightly less than 20% of the sample had been diagnosed with depression; the prevalence of depression increased with age and was higher amongst females.

In 2019, Australian data based off a survey of 391 individuals with IDD aged over 60 years from both rural and urban areas was reported [101–103]. It noted prevalence of mental disorders at 35%. Depression or anxiety were the two most common mental disorders, with prevalence for each separately at 22%. Additional stratification by sex indicated that females experienced more mental disorders, and particularly depression and anxiety. Further mental conditions, such as schizophrenia, bipolar and other affective mood disorders, was reported at 3% for the entire sample. However, many of the participants had multiple mental disorders, with over 11% of the sample having two or more diagnosed mental disorders. There was minimal difference between sexes with respect to having multiple mental disorders, with more men than women (13% versus 8%) in the under 65 year group reporting more than one mental disorder, but this trend then reversed for those over 65 years (8% of men and 10% of women). All of the mental disorders were noted to occur at a statistically higher rate when compared on the same survey measures with a control group of 920 people aged over 60 without lifelong IDD. Geographic location (i.e. urban versus rural) wasn't found to be a factor in the prevalence of mental disorders, but the availability of support services decreased dramatically with distance from a capital city. In a related paper, it was reported that Australian doctors had very low levels of pre- and in-service training in how to best support older people with IDD and health co-morbidities, which in turn was reflected in low levels of confidence in providing appropriate medical treatment, advice and assistance [104].

Conclusion

As discussed at the beginning of this chapter, the epidemiology of both mental and behavioural disorders in older people with IDD remains difficult to exactly quantify. The variations in assessment and diagnostic criteria, combined with no clear definition of what constitutes 'older', means that any dataset is open to interpretation, and attempts to combine data is problematic. With that in mind, and while acknowledging that there is still considerable discrepancy in the reported prevalence of mental disorders among older people with IDD, many studies find point prevalence rates that seem to fall roughly into the 20–30% range. There are certainly studies that note prevalence well above the upper figure, although some of these studies report lifetime prevalence rather than point prevalence, and equally there is also research that note lower prevalence. However, at this point, this range of 20–30% would appear to be a reasonable general estimate for point prevalence within the cohort of people with IDD aged over 50 years.

Of course, this figure is only a guide, and readers need to interpret findings with due consideration to their local situation and the specific population demographics. In particular, there appears to be differences based on sex, and also stratified age cohorts over 50 years in relation to both general mental or behavioural disorders, and specific conditions, such as depression. The prevalence of behavioural disorders is even more difficult to determine, as there is wide variation in definitions within the research quantum as to what constitutes a 'behavioural disorder'. Nonetheless, it clear that the prevalence of behavioural disorders is very high among people with intellectual disabilities of all ages, and that this prevalence continues and possibly even increases in older age.

There are a number of emerging trends evident in the more recent research that has started to better discriminate between disorders and various demographic factors, although it is worth noting they all require further investigation before any definitive conclusions can be drawn. Firstly, although people with IDD are more likely to have a co-morbid mental or behavioural disorder across their lifespan than mainstream peers, differences in the prevalence of mental disorders in particular may reduce over the age of 65 years. However, mental and behavioural disorders appear to occur at a higher rate amongst older people with IDD when compared to younger people with IDD, although there is also some contradictory evidence for this premise.

Secondly, the prevalence of mental disorders tends to decrease in relation to the severity of IDD, but the reverse is true for behavioural disorders. Accurate diagnosis of mental disorders in people with severe or profound disability are problematic due to the high likelihood of the individual also having significant impairment to their receptive and expressive communication skills. This limits the capacity of assessors to correctly identify the presence of many mental disorders, such as psychoses, and therefore this data may reflect not actually reflect a decreased prevalence of such disorders but instead highlight flaws in the diagnostic process. Similarly, behavioural disorders are often difficult to distinguish from age-related diseases, such as dementias, and accurately determining the incidence of behavioural disorders in this group tends to be complicated by the subsequent or concurrent diagnosis of Alzheimer's disease or another type of dementia.

Thirdly, some research indicates a greater likelihood of mental disorder amongst the female population of older people with IDD. This finding is largely representative of the general community, where some mental disorders are more common in females, but there is the need for greater examination of this area, and particularly in relation to the varying prevalence of different types of mental disorders. Specifically, anxiety and depression have both been noted by a number of researchers as occurring more commonly in older females than older males, but it is unclear whether this also extends to other specific disorders.

We are gaining a greater understanding of the epidemiology of mental and behavioural disorders among older people with IDD, but the research base is still small, and a lack of standard criteria and diagnostic tools makes comparisons difficult. Further collaborative research is required to enhance our knowledge base, which will allow for earlier diagnosis and better treatment options to be provided for people with intellectual disabilities of all ages. While funding for such studies is difficult to obtain, additional large-scale multi-year prospective studies would allow for better identification of the prevalence and incidence of specific mental and behavioural disorders, and in doing so, facilitate our comprehension of how other key factors, such as ageing, sex and geographic location, may impact on both an individual and the wider community.

One final issue that is starting to emerge, but has not yet been subject to considerable examination, relates to the individuals who went through de-institutionalisation processes from the 1980s and onwards. Many of this cohort, who were successfully moved into more appropriate and supportive community-based accommodation while in their 30s and 40s, are now at an age associated with a high risk of being re-institutionalized; this time into residential aged care facilities. This transition back into congregate care models may be a trigger for the emergence, or re-emergence, of mental disorders arising from previous traumas, and is another appropriate focus of future research.

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