



Epidemiology of Psychiatric Disorders in Persons with Intellectual Disabilities

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Contents

- 9.1 Introduction – 216
- 9.2 Prevalence of Psychiatric Disorders – 217
- 9.3 Prevalence of Psychiatric Disorders Compared with General Population – 218
- 9.4 Prevalence of Psychiatric Disorders in Persons with Co-occurring Intellectual Disabilities and Autism Spectrum Disorder – 220
- 9.5 Aetiology of Psychiatric Disorders – 223
- 9.6 Incidence and Course of Psychiatric Disorders – 224
- 9.7 Conclusion – 224
- References – 225

Learning Objectives

This chapter is devoted to the epidemiology of psychiatric disorders in people with intellectual disabilities (ID). It starts by considering the types of psychiatric disorders that people with ID experience, within the context of diagnostic overshadowing and the multi-morbidity that typically occurs in people with ID, and the implications when conducting assessments. It then considers the reported prevalence of psychiatric disorders across the life-course and compares this with the prevalence in the general population, and also for people with co-occurring ID and autism spectrum disorder. Relevant aspects of aetiology are then considered, followed by information on the course of psychiatric disorders in this population.

1. To understand how commonly psychiatric disorders are experienced by children, young people, and adults with ID
2. To understand variation in the prevalence of psychiatric disorders in people with ID compared with the general population
3. To understand the influence of co-occurring autism spectrum disorder with ID on the prevalence of psychiatric disorders
4. To understand the course of psychiatric disorders in people with ID

9.1 Introduction

People with ID can experience all types of psychiatric disorders that occur in the general population. Some disorders occur more frequently in people with ID than in the general population, and some common disorders, in particular problem behaviours, are not often seen in the general population. Psychiatric disorders are common in people with ID, which is perhaps not surprising, given the complex mix of biological factors, psychological and social disadvantages, and additional developmental factors that people with ID have and are exposed to.

Psychiatric disorders are commonly overlooked in people with ID for a number of rea-

sons including diagnostic overshadowing, complexity and multi-morbidity, reliance on carer reports, and differing presentations (see ► Chap. 5). A previously undiagnosed psychiatric disorder can be found in around 30% of adults, especially in those with more severe ID [1]. The term ‘diagnostic overshadowing’, which is commonly used, describes how the additional problems experienced by a person with ID tend to be misattributed as due to their ID rather than correctly attributed to co-occurring disorders [2]. Failure to identify additional disorders results in failure to offer interventions and care and so is a very important problem.

Psychiatric assessments are complex in people with ID, as psychiatric disorders tend not to occur in isolation. Psychiatric disorders can occur on top of existing long standing neurodevelopmental disorders such as autism spectrum disorder (ASD) or attention-deficit-hyperactivity disorder (ADHD) and co-occur together with physical disorders, impairments, and disabilities. Indeed, multi-morbidity is the norm for people with ID; assessments reveal that almost all adults with ID have multi-morbidity (two or more disorders as well as their ID) [3]. Other studies have found that even when the conditions were restricted to a limited number of physical and psychiatric disorders receiving input from general practitioners (i.e. already identified), the majority with ID had multi-morbidity, and the extent of multi-morbidity in young 20 years old adults with ID was similar to that in the 50- to 54-year-old general population [4, 5]. Additionally, a range of neurodevelopmental conditions tend to co-occur, for which the term ESSENCE has been coined (Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examination) [6]. ESSENCE includes major problems in: motor skills, general development, speech and language, social interaction and communication, behaviour, hyperactivity or impulsivity, hypoactivity, inattention, sleep or feeding difficulties [6]; genetic data also increasingly supports the ESSENCE clustering of neuro-developmental (including epilepsy) and psychiatric disorders [7]. The identification of co-occurring psychiatric disorders in persons with ID or ID

and co-occurring ASD requires specific clinical skills and specific tools, particularly to differentiate between psychopathological symptoms and behavioural changes due to other factors, such as physical pain, response to trauma, or overwhelmed neuro-autonomic, flight, or freeze reactions to environmental stressors (see ► Chap. 5).

Psychiatric disorders, physical disorders, and drug side-effects can mimic each other, so given the high levels of multi-morbidity, psychiatric disorders should not be considered in isolation. Some physical disorders relate to the persons underlying cause of ID, but lifestyle and environmental factors, sub-optimal support, and healthcare are also important contributors [8]. Multi-morbidity also results in polypharmacy and potential problems with disease-disease, disease-drug, and drug-drug interactions. People with ID may not be able to self-report drug side effects and are reliant on others observing these, so pharmacovigilance is essential. Anticholinergic burden can also be an issue due to polypharmacy and the strong anticholinergic effects of many psychotropic drugs. This has potential negative side effects such as further impairments of cognition [9, 10].

As well as multi-morbidity, assessments are complicated further by limitations in reciprocal communication and understanding, and decision-making capacity, visual and hearing impairments, and reliance on carer observations and reports, sometimes several carers/teams of carers. Together, this means that differential diagnosis is not only crucial but also complex, in order to establish the best treatment and care plan for the individual.

► People with ID experience the full range and high rates of psychiatric disorders. These are often overlooked or misattributed to the persons' ID, causing unnecessary suffering. Psychiatric assessments are complex as, in addition to having ID, multi-morbidity is typical. Interventions need to be tailored to each individual's needs, taking account of physical health as well as the psychiatric disorders.

9.2 Prevalence of Psychiatric Disorders

The prevalence of problem behaviours will not be further considered within this chapter, as it is considered in depth in ► Chap. 7.

Studies differ in the prevalence of psychiatric disorders they report, due to the methods they use. In particular, differences in reported rates relate to the disorders included as psychiatric disorders, for example, whether or not problem behaviours and ASD are included along-side other psychiatric disorders, and also how representative the studied population with ID is. Given that the boundary between mild ID and the general population merges, particularly in adulthood, some studies report rates separately for people with mild ID from people with moderate-profound ID. Rates vary also by the age ranges included in the studies. Study results also vary for other reasons, such as the types of assessments completed and diagnostic criteria used, or whether information has been taken from existing records such as general practitioner health records, which are likely to underreport the extent of psychiatric disorders. Studies also vary in the size of the populations studied, therefore limiting conclusions that can be drawn, particularly for less common conditions. Some studies report point prevalence of psychiatric disorders, some report period prevalence, or lifetime prevalence, and some do not provide precise distinction between these, which also impacts on reported rates, contributes to variation in rates, and limits the validity of comparing rates between studies. Some authors have attempted to synthesise information on studies of prevalence of psychiatric disorders in children and young people [11] and in adults [12, 13], but these syntheses have inherent limitations in view of all the reasons given above, as the authors acknowledge. As one would expect, recent meta-analysis found that pooled prevalence is lower in population-based studies than in non-population-based studies, and in low overall risk-of-bias studies as compared to the moderate overall risk-of-bias studies [13].

Reported point prevalence rates of psychiatric disorders in children and young people with ID range from 30% [14, 15] to 50% [16], though it should be noted that these rates include problem behaviours. A study examining robust data from UK private household surveys reported a prevalence of 36% in 641 children and young people (aged 5–16 years) with ID [15]. This study was only of children/youth living in private households, and in view of the general population sampling frame, the individuals with ID had predominantly mild ID. A representative sample of US adolescents found that 65.1% has a lifetime prevalence for a psychiatric disorder [17].

For adults with ID, reported prevalence ranges from 14.5% (excluding problem behaviours, ADHD, ASD, dementia, and personality disorder, people aged 65 and over, and people with severe ID) [16] to 43.8% (adults with moderate to profound ID only) [18], depending on the conditions included and the quality assessment applied [16–21]. The largest adult population-based prevalence study in which each person (aged 16 years and over) was individually assessed included 1023 adults with ID [19]. Using robust methods, it reported a point prevalence of psychiatric disorders of 28.3% (or 40.9% if problem behaviours are also included). It reported rates separately for adults with mild ID at 25.4% and for adults with moderate to profound ID at 30.2% [19].

The effect of severity of ID on prevalence of psychiatric disorders is controversial, with some findings indicating higher rates in persons with severe/profound ID [22–24] and some others indicating the opposite [13, 25]. Some differences are accounted for by whether or not problem behaviours and/or ASD were included within the definition of psychiatric disorders, as they occur more commonly in people with more severe ID.

The effect of sex on prevalence of psychiatric disorders of any type is also currently not clearly understood. Most studies found no differences [13, 17, 26, 27], but some have identified a significantly higher prevalence among males than females [28]. Some of these discrepancies may be explained by whether or

not the definition of psychiatric disorders included problem behaviours and/or ASD.

To date there is a lack of prevalence estimates of co-occurring psychiatric disorders identified using the new Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5) [29] (and proposed International and Statistical Classification of Diseases and Related Health Problems 11th revision: ICD-11) definition of ID/disorders of intellectual development (see new ICD-11 term) [30], and differentiated by severity levels of adaptive functioning and specific (not general IQ) cognitive functioning [31]. Platt and collaborators found low adaptive behaviour to be associated with a higher rate of psychiatric disorders than low IQ, although results of their study have to be interpreted in light of several limitations [17].

➤ Reported point prevalence rates of psychiatric disorders in persons with ID range from 30% to 50% in children and adolescents and from 14.5% to 43.8% in adults. Several factors account for the different rates reported, especially the specific types of conditions included in the definition of psychiatric disorder (e.g. whether ASD and problem behaviours are included), the type of sample, and the assessments used.

9.3 Prevalence of Psychiatric Disorders Compared with General Population

Presentation of psychiatric disorders can differ from that seen in the general population, and so the categories of psychiatric disorders as described in the standard psychiatric diagnostic manuals, the International and Statistical Classification of Diseases and Related Health Problems tenth revision (ICD-10) [32], and the DSM-5 [29] are not always easy for generalists to apply. For this reason, the manuals have been interpreted for use with people with ID, with the publication of DC-LD (Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation) [33], com-

plementary to ICD-10, and The Diagnostic Manual-Intellectual Disability 2 (DM-ID-2) [34], complementary to DSM-5. DC-LD is currently being revised into a second edition, in keeping with the publication of ICD-11. Whilst these differences pose challenges when comparing prevalence of types of psychiatric disorders between the population with ID and the general population (i.e. comparing like with like), work does suggest that similar broad categories of conditions do occur, with the addition of problem behaviours. For example, a study using exploratory and confirmatory factor analyses on two large datasets of psychopathology in adults with mild-profound ID ($n = 457$; $n = 274$) extracted a model of psychopathology with five factors: depressive, anxiety, cognitive decline, psychosis, and affect dysregulation-problem behaviour [35, 36]. The affect dysregulation-problem behaviour factor had good discriminate validity, face validity, and predictive validity over a 5-year follow-up period. This study provides a conceptualisation of problem behaviours within the broad over-arching family of psychiatric disorders, whilst being distinct from the other categories of depression, anxiety, cognitive decline, and psychosis, all of which resonate with the broad categories seen within the general population.

The study of 641 children and young people described above [15] reported a prevalence of psychiatric disorders including problem behaviours/conduct disorder of 36% in 641 children and young people aged 5–16 years with ID, compared with 8% of 17,774 children without ID [15]. Hence in this study, the children and young people with ID accounted for 14% of all children with psychiatric disorders, and their prevalence of psychiatric disorders was higher than for other children and young people for 27 out of 28 ICD-10 categories [15].

A recent study has drawn direct comparison between children/young people with ID and the child/youth general population, using the same methods for both, and appears to be unique in including a whole country sample, so is large, includes people of all ability levels, and is representative [37]. The study used data from Scotland's Census, 2011, which had an

estimated 94% coverage of the whole country, and systematically enquired for everyone whether they had ID (and distinguished this from specific learning disabilities and from autism spectrum disorder) and whether they had a mental health condition. It included 5234 aged 0–15 years with ID and 911,097 without ID. Of the children/young people with ID, 12.8% had mental health conditions compared with only 0.3% of the children/youth without ID. Mental health conditions were significantly more prevalent at all age groups, children, youth, and adults; indeed ID (all ages) had an odds ratio of 7.1 in predicted mental health conditions. The disparity between the people with ID and those without was apparent at all age groups, but more so for the children and young people than for adults. Mental health conditions were also related to poorer general health status [37].

The study using Scotland's Census, 2011 described above, also reported on adults, drawing direct comparison between adults with ID and the adult general population, using the same methods for both [37]. It included 18,660 adults aged 16–64 years with ID compared with 3,470,078 without ID and 2455 adults aged 65 years and over with ID compared with 887,879 without ID. Of the adults with ID, 23.4% of the adults and 27.2% of the older adults had mental health conditions compared with 5.3% and 4.5% of the general population, respectively. Mental health conditions were significantly and substantially more prevalent at all age groups. Mental health conditions were also related to poorer general health status. Contrary to the general population, males rather than females were more likely to have mental health conditions [37].

A Swedish prevalence study specifically concerning older people had a large cohort of people with ID ($n = 7936$), aged 55 years or more and an age, and sex-matched cohort from the general population [25]. Information regarding psychiatric diagnoses was collected from the National Patient Register during 2002–2012. Seventeen per cent of persons with ID had at least one psychiatric diagnosis versus 10% of the general population cohort (OR 1.84). Most common diagnoses in the ID

cohort were ‘other’ psychiatric diagnoses (i.e. not included in any of the diagnostic groups) (10%) and affective disorders (7%), whilst the general population cohort was most often diagnosed with affective disorders (4%) and alcohol/substance-abuse-related disorders (4%). The highest odds for ID were found for psychotic disorder (10.4), ADHD (3.81), dementia (2.71), personality disorder (as a unique group) (2.67), affective disorder (1.74), and anxiety disorder (1.36) [25].

Despite the problems in comparing like for like between the population with ID and the general population, there is considerable evidence to show that most psychiatric disorders are more common in adults with ID than in the general population [23]. This includes schizophrenia [38, 39], bipolar disorder and mania [17, 40, 41], dementia (particularly in adults with Down syndrome [42, 43], but also in people with ID not due to Down syndrome [44, 45]), ASD [15, 46, 47], and ADHD [15].

Unipolar depression and anxiety are common in people with ID. Some research suggests they are more common than in the general population [17], whilst other studies do not [40, 48, 49]. It is perhaps surprising that unipolar depression and anxiety are common, given the high levels of mood stabilising drugs prescribed for people with ID: About 25% of people with ID have epilepsy [3] and so are prescribed anti-epileptic drugs, and whilst mood-stabilisation is not the purpose for their prescription in this situation (epilepsy), most do also have mood-stabilising properties. Epilepsy is much less common in the general population, at about 1% of the population, so the use of these drugs is much less prevalent. Longitudinal studies suggest that depression and anxiety may be more enduring conditions in people with ID than in the general population, although there are small numbers of people with ID within these longitudinal studies, and of those, almost all have mild ID, so are not representative of all people with ID [50–52].

➤ There is considerable evidence to show that some psychiatric disorders are more common in children and adults with ID than in the general population, including

autism spectrum disorder, ADHD, bipolar disorder, dementia, and schizophrenia. Depression and anxiety are also common; it is disputed whether or not they occur more commonly than in the general population, but given the high rate of usage of mood stabilising drugs (for epilepsy), it is notable that they have not been reported to be less common than in the general population.

9.4 Prevalence of Psychiatric Disorders in Persons with Co-occurring Intellectual Disabilities and Autism Spectrum Disorder

Persons with both ID and ASD may present several symptoms and deficits which are not seen in those with ID or ASD alone, and a different frequency of co-occurrent disorders [53], some of which may be accounted for by differing population characteristics such as a higher proportion of males and higher proportion with more severe ID.

As above mentioned, in persons with ID and ASD, one of the main issues in diagnosing co-occurrent psychiatric disorders is represented by the difficulty to distinguish between behavioural changes associated to psychopathological symptoms and those that can be attributed to physical, psychological, or environmental factors. In other words, behavioural responses to pain (including pain associated with sensory hypersensitivities), traumatic life events and life stressors (such as change and loss, both of which are frequent in the lives of people with ID and ASD), overlap with behaviours and symptoms that constitute criteria for psychiatric diagnoses. An essential part of diagnostic practice therefore working with people with ID and ASD is to include assessment of the support environment (e.g. for sensory triggers in ASD, whether expectations are appropriate or overwhelming), as well as examining the lived experience of the individual for past or present trauma circumstances that may be triggering intense emotional responses. In the absence of recog-

nising such life events, other psychiatric disorders (e.g. mood and anxiety disorders) may be diagnosed in error. Epidemiological studies of psychiatric disorders in ID and ASD have not routinely included trauma and adjustment-related diagnoses; the high prevalence of anxiety and mood disorders in this population may relate in part to these diagnostic errors [54].

Investigations on which types of instruments used to support direct clinical assessments are the most valid have been carried out, in particular with regard to screening tools and semi structured interviews (see ► Chap. 8). This point should be considered also whilst reviewing evidence produced so far. Instruments that do not consider the context of the individuals lived experience (e.g. screening instruments considering only behaviours and symptoms in the absence of considering what may have triggered these) will not be able to differentiate between psychopathology associated with unrecognised medical conditions, trauma, and adjustment-related conditions from other major psychiatric disorders.

Research shows an inverse relationship between IQ and severity of ASD, with rate of problem behaviours in ASD being lower at higher IQ [55–58]. Conversely, severity of ASD symptoms – and not that of ID – is directly associated with the rates of stereotypes [59, 60].

Although still limited and controversial, literature on the prevalence of psychiatric disorders in persons with both ID and ASD may indicate a higher rate of the full range of psychiatric disorders in comparison with those with ID or ASD alone [61–63]. Conversely, a study of adults with ASD compared rates with controls with ID matched for age, gender, ability-level, and Down syndrome [64]. They found that although the adults with ASD had a higher point prevalence of problem behaviours compared with the whole adult population with ID, there was no difference in prevalence, or incidence of either problem behaviours or other psychiatric disorders when compared with their matched controls [64]. They concluded that the differences in rates of psychiatric disorders were

accounted for by other factors, including ability level and Down syndrome. The adults with ASD who had problem behaviours were, however, less likely to recover over a 2-year period than were their matched controls [64]. Greater agreement has been identified on higher rates of problem behaviours, stereotypies and rituals, communication difficulties, and social impairment in comparison to ID alone [57, 58, 65–67]. Nevertheless, specific investigation on causes and triggers is lacking and current prevalence might present some overlap issues with behavioural changes of non-psychopathological origin.

Furthermore, the co-occurrence of ASD with ID has been associated with a higher probability to be hospitalised and to receive a psychopharmacological treatment [68–70]. Lunsy and collaborators found that more than half of adults with ID and ASD have a co-occurring psychiatric disorder (26.1% mood disorder, 26.1% psychotic disorder, and 4.3% personality disorder), although they did not include trauma nor adjustment disorder. However, when compared with those with only ID, they did not show statistically significant differences except for the probability of the diagnosis of a psychotic disorder being lower in the co-occurring ID and ASD group [71]. In addition, individuals with problem behaviours and ASD were less likely to receive a diagnosis of schizophrenia, whereas the latter increased if problem behaviours were absent [66]. In all cases, the presence of problem behaviours had a negative impact on overall functioning and quality of life [61, 66, 69, 72–77].

The presence of ID in persons with ASD seems to negatively impact on the possibility of having an adjunctive diagnosis of psychiatric disorder. In a 10-year longitudinal study, Selten and collaborators found that the co-occurrence of ID in persons with ASD reversed the trend of a higher rate of diagnoses of bipolar and psychotic disorders than the general population [78]. Individuals with ASD who have greater cognitive abilities have been reported to have higher rates of depression than those with co-occurrent ID, which has simplistically been explained with a greater awareness of their difficulties [79–82].

Specific diagnostic procedure and tools seem to represent a significant determinant for the reliability of prevalence findings in persons with ID and ASD. These often include too many subjective symptoms which are not easy to identify in this group of patients and should be substituted by behavioural and observable equivalents (see ► Chap. 5). Different studies have found an increasing prevalence of psychiatric disorders as long as the specificity of their assessment tools rose. By using the Psychiatric Assessment Schedules for Adults with Developmental Disabilities (PAS-ADD), Thalen found an overall rate of 69.6% vs 8.6% in persons with ID alone [83], and through the Diagnostic Assessment for the Severely Handicapped-II (DASH-II), Matson and Cervantes found statistically significant differences in 8 out of the 12 subscales of the tools, on anxiety, mania, schizophrenia, stereotypies/tics, self-injurious behaviour, eating disorders, sexual disorders, and impulse control [63]. Nevertheless, the sensitivity for psychopathological features of some tools, such as the DASH, has not definitively been ascertained and high score reports may express mental distress due to other causes, including adaptive response to overwhelming stress.

Among specific psychiatric disorders, mood disorders [62, 83], anxiety disorders [26, 73, 83], somatic symptoms disorder, and impulse control disorders [61, 84–86] have been reported as the most frequent. Nevertheless, most of these study findings could be hampered by issues of multimorbidity and differential diagnosis.

Higher rates of inattention, hyperactivity, and impulsive behaviours have been observed in teens with both ASD and ID in comparison with those without ASD [87]. In addition, people with both conditions resulted to be more vulnerable to sleep problems, organic syndrome, stereotypies, and tics, although the psychopathological nature of this difference has not been confirmed [61].

The co-occurrence of psychiatric disorders has been found to be higher in males, in youth, and in persons with mild-to-moderate ID [66, 69, 71]. Thalen found psychoses and anxiety disorder to trend inversely to the severity of ID more than other disorders [83].

Some high rates of psychiatric disorders in persons with ID and ASD, such as that of bipolar disorder, seem to be related to behavioural dysregulation, as expressed by restlessness, agitation, or distraction, and may reflect the symptom overlap between psychopathological features, autism, and ID rather than a true co-occurrence of psychiatric disorders [26]. A subgroup of persons with ID and ASD, which shows adjunctive symptoms that cross diagnostic boundaries and include psychotic symptoms, excessive anxiety, mood lability, and information-processing deficits, seems to identify a complex neurodevelopmental disorder deserving a new diagnostic category [88]. Multiple complex developmental disorder (MCDD), multiplex developmental disorder (MDD) [89], and multidimensionally impaired disorder [90] are the terms and underlying models proposed for this category.

For psychotic disorders, most prevalence studies did not include adequate methods of assessment that distinguished from autistic features, psychotic-like symptoms, and symptoms of other psychiatric disorders, especially psychotic features of a post-traumatic stress disorder [91]. Psychotic-like behaviour such as talking to one's self, regression, and particular postures can be a common response of person with ID (with or without ASD) to stressful and other negative events [10], whilst bizarre expression or fantastic thinking can represent normal ways of experiencing the world of many persons with ASD. The link between Adverse Childhood Experiences and later psychosis increasingly identified in the general population during the last 20 years [92, 93] is being shown to occur also, or even more, in persons with borderline intellectual functioning, ID, and ASD [94–97].

Compared with the general population, people with co-occurring ID and ASD are markedly more likely to report a mental health condition. A whole population study included 5709 children and adults with co-occurring ID and ASD compared with 5,289,694 other children and adults in the general population [98]. After adjusting for age and sex, the odds ratio for a mental health condition was 25.6 or 130.8 when the interaction between age

co-occurring ID and ASD was also adjusted for [98]. Further study with the same data set reported on the relative independence of ID and ASD in contributing to the high odds ratio for a mental health condition compared with the general population [99]. It reported that 9396 of the 1,548,819 children had ID, 25,063 of the 1,548,819 children had autism, 16,953 of the 3,746,584 adults had ID, and 6649 of the 3,746,584 adults had autism. In the children, both ID (odds ratio of 7.0) and autism (odds ratio of 23.1) independently predicted mental health conditions. Also in adults, ID (odds ratio of 3.5) and autism (odds ratio of 5.3) both independently predicted mental health conditions [99].

- ▶ Although still limited and controversial, the literature on the prevalence of psychiatric disorders in persons with both ID and ASD indicates a higher rate in comparison with those with ID or ASD alone.

9.5 Aetiology of Psychiatric Disorders

The aetiology of psychiatric disorders in people with ID is typically multi-factorial. Some specific causes of ID are associated with specific types of psychiatric disorders ('behavioural phenotypes'), for example, Down syndrome and dementia; other factors can also influence presentations of behavioural phenotypes. Multi-factorial aetiology can be considered on biological, psychological, social, and developmental dimensions and in terms of predisposing, precipitating, and maintaining factors. Aetiology has been represented graphically across the life-course, in detail, by Accessible Cause-Outcome Representation and Notation System (ACORNS) [100]. This shows that some of the multiple, interacting aetiologies are transactional; and linear cause and effect directions cannot usually be inferred. Considering aetiology is helpful in finding ways to prevent or reduce psychiatric disorders, or to aid recovery.

There are both similarities and additional complexity in aetiology of psychiatric disorders in people with ID compared with the

general population. Similarities include that some psychiatric disorders have a degree of heritability so the person may have acquired the disorder even without having ID. Neurological disorders such as epilepsy are considered to increase the risk of psychiatric disorders in the general population, and whilst the ID literature is a bit mixed on this point, epilepsy is about 25 times more common in people with ID compared with the general population [101]. The addition of the developmental dimension adds complexity, including parental bonding and development of attachments at early age, impairments in attentional control, and communication limitations [102–104]. There are transactional effects of the person with ID and carers; psychiatric disorder in the person with ID affecting the carer-person with ID interaction, and carer stress and health, in turn further affecting the mental health of the person with ID; a spiralling vicious circle can be established [105]. Being dependent upon others in daily tasks can be restrictive upon what one can achieve and aspire to, which may also impact upon health.

Further complexity stems from people with ID having greater burden in all of the dimensions, such as the behavioural phenotypes of some causes of ID; additional physical disorders and disabilities; psychological factors associated with ID; and multiple social disadvantages. Abuse, neglect, or exploitation have been shown to predict psychiatric disorders in adults with ID [106]. Life events are more common for people with ID, and when they do occur, they tend to be multiple, for example, the death of a parent-carer leading to multiple changes in the person's life and care, move of home, and dislocation from former environment, family friends, and occupations [15, 19, 48, 107–109]. Lone parent family, poor family functioning, lack of parental educational qualifications, income poverty, and households with no paid employment have been shown to be associated with psychiatric disorders in children and young people with ID [15, 110]. Social disadvantages experienced by people with ID also include lack of paid employment, poverty of environment and recreational opportunities, social exclusion, and

experience of bullying, harassment, stigma, and hate crimes [111–114]. Aetiology of specific psychiatric disorders is considered in greater detail in the relevant chapters.

- The aetiology of psychiatric disorders in people with ID is typically multi-factorial, with biological, psychological, social, and developmental dimensions and in terms of predisposing, precipitating, and maintaining factors. Some specific causes of ID are associated with specific types of psychiatric disorders.

9.6 Incidence and Course of Psychiatric Disorders

There has been less research conducted on the incidence and course of psychiatric disorders in people with ID, compared with prevalence studies. ▶ Chapter 7 considers the course of problem behaviours. The few studies on other psychiatric disorders suggest a more enduring pattern for psychiatric disorders than one might expect from studies with the general population, albeit with episodes of remission along the way. It is not clear if this pattern is due to greater severity of psychiatric disorders in people with ID, or poorer interventions/access to interventions, compared with the general population.

Regarding children and young people, a study followed a cohort of Australian children and young people with ID, aged 4–19.5 years, over 14 years. Hyperactivity was more prominent at younger ages and persisted for longer in the children and young people with more severe ID. Emotional disorders emerged later in childhood [115–117]. Similar findings have been reported from longitudinal studies with children in the Netherlands [118, 119].

Regarding adults, the incidence of mental disorders, excluding problem behaviours, has been reported to be 12.6% over a 2-year period, 8.3% for affective disorders, 1.7% for anxiety disorders, and 1.4% for psy-

chotic disorders [39, 106]. Despite high mood stabiliser use (22.4%), 2-year incident mania has been reported to be 1.1% which is much higher than the general population, with a standardised incident ratio of 41.5 for first episode (or 52.7 excluding Down syndrome) [41]. Full remission of psychosis after 2 years was reported to be only 14.3% [39], poorer than it is for aggression or self-injury [120, 121]. At age 65 years or older, the standardised incidence ratio for dementia is reported to be 4.98 [122], showing it is much higher in adults with ID – it is even higher in adults with Down syndrome. These findings show that incidence is higher than that found in the general population for psychosis, bipolar disorder, and dementia, whilst much of the current high prevalence of common psychiatric disorders is due to enduring disorders, rather than new episodes. The evidence-base is, however, limited in quantity.

- The few available studies on the course of psychiatric disorders in persons with ID suggest a more enduring pattern than in the general population.

9.7 Conclusion

In conclusion, psychiatric disorders are common in people with ID across the whole life-course. Point prevalence (excluding problem behaviours) is about 30% and may be higher in people who have co-occurring ID and ASD. Psychiatric disorders appear to be more enduring than in the general population, but there have been few longitudinal studies investigating the course of psychiatric disorders. Many factors contribute to the high rates. Given the extensive multi-morbidity that people with ID experience, and the added developmental dimension, assessments are complex, but important to get right, so that the most appropriate interventions can be offered to improve the person's quality of life.

Key Points

- Psychiatric disorders are common across the whole life-course, and much more so than in the general population.
- The point prevalence of psychiatric disorders (excluding problem behaviours) is about 30%; having ID increases the odds of psychiatric disorders by about 7 times compared with the general population.
- Schizophrenia, bipolar disorder, dementia, autism, and ADHD all occur more commonly than in the general population.
- The co-occurrence of ID and autism may be associated with a higher rate of the full range of psychiatric disorders in comparison with those with ID or autism alone.
- Aetiology is multi-factorial, due to a range of biological, psychological, social, and developmental factors.
- Psychiatric disorders may be more enduring than in the general population, but there are few studies on the course of psychiatric disorders.
- Psychiatric disorders typically coexist with other physical disorders and impairments, and assessments are therefore complex.

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