Psychological Distress and Physical Vulnerability

Marco O. Bertelli, Robert Fletcher, Germain Weber, Carlo Schuengel, Daniela Scuticchio, Annamaria Bianco, Elisa Rondini, Bhathika Perera, and Ken Courtenay

Contents

M. O. Bertelli et al. (eds.), *Textbook of Psychiatry for Intellectual Disability and Autism Spectrum Disorder*, https://doi.org/10.1007/978-3-319-95720-3_3

3

Learning Objectives

- Psychological distress.
- Causes of psychological distress.
- Manifestation of psychological distress.
- Common physical disorders in people with intellectual disabilities (ID).
- Reasons for increasing prevalence of physical disorders.
- Different stages of life for people with ID.

Tip

People with intellectual disabilities are at a higher risk of developing psychological distress as well as physical disorders.

3.1 Psychological Distress

3.1.1 Introduction

Psychological distress describes the experience of an individual discomforting emotional state in response to a specific stressor, threat or harmful situation [1]. A broad range of events may elicit psychological distress. These events include but are not limited to illness, loss of physical function, victimisation, social conflict and economic insecurity. Irrespective of the severity, psychological distress may contribute to the development of a range of physical and mental health disorders in those who are vulnerable, leading to significant public health concerns [2, 3].

3.1.2 High Risk Among Individuals with Intellectual Disabilities

People with intellectual disabilities (ID) experience psychological distress more often and to a higher extent compared to people without ID. Epidemiological evidence is scant because large-scale assessment of subjective distress states is difficult, especially for people with moderate to severe ID. Results for emotional distress based on proxy reports, clinical interviews and self-reports provide divergent answers [4]. However, epidemiological evidence on the rate of stressors points indirectly to high psychological distress. The rate of traumatic experiences and stressful social situations, for example, is heightened among people with ID [5–8].

3.1.3 Causes of Psychological Distress

Abuse and Violence

Individuals with ID experience high rates of violence and all forms of abuse [9]. Intentional harm experienced by individuals with ID is almost always perpetrated by someone they know, such as a family member, and is commonly exhibited as sexual, physical and verbal/emotional abuse [9]. Individuals with ID are vulnerable to even paid caregivers who may be neglectful or abusive. Compared to the general population, people with ID often experience interpersonal violence. A meta-analysis revealed prevalence figures of 21.2% for violence experiences in children and 6.1% in adults with an ID [10, 11]. An earlier study reported abuse and mistreatment of up to 68% for girls and 30% for boys with an ID [12].

Maladaptive Coping Strategies

People with ID may also experience psychological distress to a higher intensity and chronicity due to maladaptive coping with stressors as these occur to people with and without ID alike. According to Lovallo's [13] model, primary appraisal of stressors as threats or non-threats occurs in cognitive subsystems shaped by experience. If a stressor is labelled on the basis of similar experiences as a threat, it is attended to more closely and appraised in relation to one's self-perceived skills and resources. Outcome of this second-

ary appraisal spurs behavioural, cognitive and physiological responses accompanied by emotions. If people experience their skills and resources as deficient in the face of perceived threat, social engagement with others gives way to noxious cognitive and physiological reactivity as a self-preserving fall-back option [14].

Attachment Styles

People learn to appraise stressors and engage other people in addressing threats in the context of attachment relationships [15]. The low rate of secure attachment relationships among children with ID and the high rate of growing up in residential care with less opportunities for the formation of attachment relationships [16], therefore, increase the vulnerability of people with ID for psychological distress. Psychological interventions addressing attachment needs as well as facilitating the communication of distress have been found to improve stress regulation [17], facilitate the training of adaptive behavioural responses to challenging situations [18] and reduce anxiety [19].

Cognitive Biases

Young people with ID show biases in processing social information. Even innocuous interpersonal events are interpreted more often as hostile [20]. These biases increase the likelihood of escalating aggressive conflict, further exacerbating psychological distress. Attributional style and stressors independently predict depressed mood [21].

Stigma

Stigma increases psychological distress in people with ID. People with ID can be more vulnerable to the psychological distress due to stigma [22]. Some researchers have hypothesised that self-reported stigma is positively associated with psychological distress and negatively associated with quality of life, contact with services, and adherence to treatment in people with ID [23]. There is evidence to suggest that stigma and even the perception of stigma may contribute to poor psychological health in people with ID by increasing psychological distress and reducing quality of life [23].

Communication Impairment

Communication impairment and the challenges to express pain [24] and emotions in a clear and direct way are factors that make recognising psychological distress in individuals with ID difficult, making it necessary to then look at the individual's behaviour. Challenging behaviour may also be a person's attempt to get needs met when they experience lower levels of well-being [25]. The vulnerability of individuals with ID to experience traumatic physical experiences and stressful social situations combined with their inability to engage others in dealing with their emotions creates challenges for caregivers and professionals as well as medical staff.

- Individuals with ID are more likely to experience psychological distress compared to their peers without ID.
- Multiple stressful and traumatic life events, maladaptive coping strategies, attachment styles, socio-environmental factors and communication difficulties have been postulated as some of the reasons for the increased psychological distress.

3.1.4 Manifestation of Psychological Distress

Behavioural Manifestations

Manifestation of symptoms with regard to psychological distress might differ between the general and the ID population. In people with ID, symptoms are more prominently expressed on a behavioural and non-verbal level [26]. People with ID might react in states of strong psychological distress, for example, after sexual abuse, with regression, like bedwetting, or complain of diffuse pain and present symptoms of self-injurious behaviour. Mental health symptoms following trauma exposure might include dissociative behaviour, motor agitation, flight reactions and aggression. This often leads to misidentifying psychological distress or posttraumatic stress

disorder (PTSD) symptoms as symptoms of other mental health or behavioural disorders [27]. In this context, the relevance of an elaborate diagnostic protocol appears evident.

3

- **Mental Disorders**

According to Reeve [28], symptoms of psychological distress fall short of meeting the DSM-5 [29] criteria for a clinical diagnosis of anxiety. However, when left unrecognised and untreated, normal anxiety that can contribute to positive effects such as improved attention and performance can become over-learned, habitual or otherwise dysfunctional. This phenomenon can lead to disruptive behaviour, inefficient brain patterns and avoidance of pleasurable experiences, thereby contributing to psychological distress [28]. For instance, Hartley et al. [30] found that adults with ID who sought reassurance for their distress from caregiving staff to an excessive extent, more often experienced rejection and other negative responses from staff, which in turn was associated with elevated rate of depression. Psychological distress should, therefore, have an important place in diagnostic formulation, caregiver education and care planning.

Besides the higher rate to experience a traumatic event or after being exposed to repetitive traumatising incidents, people with ID show a higher vulnerability to develop PTSD. PTSD is a disorder which a person may develop after being involved in or witnessing traumatic events. PTSD may be described differently in some situations: if a person's symptoms emerge more than 6 months after experiencing trauma, this might be called "delayed-onset PTSD". If a person experienced trauma in an early age or it lasted for a long time, you might describe it as "complex PTSD". Not everyone experiencing trauma will develop PTSD. Best known protective factors are a high intelligence level, as well as reliable memory functions. Thus, a lower developmental level in intelligence, typically going along with lower cognitive competences, will raise the incidence of PTSD in people with ID. In addition, the lower levels in verbal expression often limit people with ID to report such complex experiences [31]. People with ID also suffer from painful conditions more often [32]. Improving and preventing psychologically or physically harmful conditions is therefore bound to reduce psychological distress as well [7].

- Psychological distress increases the risk of mental illness such as depressive and anxiety disorders in people with ID.
- Psychological distress can also manifest as behavioural challenges mainly as aggression.

3.1.5 Assessing Psychological Distress

The Bangor Life Events Schedule for Intellectual Disabilities (BLESID) [33] or the Lifestress Inventory (LI) [34] [5] can be used to assess psychological distress in a systematic way. The BLESID, covering a broad range of 24 life events, can be applied both, as a self- and a third-party report instrument. The Lifestress Inventory, a self-report measure, assesses current stressors with 30 items addressing daily situations or life events, with 13 items on negative interpersonal relations. Traumatic events can be assessed via the Trauma Information Form [35], and PTSD can be assessed by the Lancaster and Northgate Trauma Scale (LANTS) [36] or the Impact of Event Scale–Intellectual Disabilities (IES-IDs) [35].

3.1.6 Life Events and Traumatic Experiences

Regarding the contribution of life events (LE) to this vulnerability, evidence is sparse and methodologically limited. Many authors report that people with ID are more frequently exposed to stressful and traumatic environmental conditions than the general population [5, 31, 37–39], and this may impair their resilience to stressors [40, 41]. In particular, children with ID are resulted to be exposed three/four times more than their counterparts with normal intellectual functioning [42].

It has also been suggested that people with ID generally have more complex living

circumstances and less control over their lives [43, 44]. These conditions include the institutionalised living and dependency on caregivers [45–49], isolation, neglect and/or marginalisation [50–52], reduced and impoverished social networks [53, 54], poor housing and lower income [55], reduced access to adequate forms of affective or practical support [56].

Furthermore, the susceptibility to further adverse LE after trauma [57] may be related to dysfunctional coping strategies [58]. Some authors have identified an association between the impairment of cognitive and emotional skills [59], the inadequate levels of social support [54], and all positive and negative LE. People with ID have specific cognitive profiles [60, 61] and less strategies to cope with environmental stressors. Actually, they encounter a number of difficulties in understanding changes and relationships between events [62] as well as in processing and expressing their distress related to the past experiences [47]. Thus, they might act this out behaviourally, displaying functional problems like challenging behaviours [63, 64].

Starting from the childhood, many families and socioeconomic risk factors are associated with emotional/behavioural problems in people with ID, such as poor physical and mental health, challenging behaviour, and hyperactivity. Family and socioeconomic risk factors which have been more frequently reported are bullying, problems of justice, violence and abuse, cohabitation with a single parent, precarious or inadequate housing, parental unemployment, parents with drug addiction, living in a lower socioeconomic community [65].

As suggested by Herman and Evenhuis [66], the risk of psychiatric problems in older people with ID may be increased due to the exposure to more age-related LE than younger adults [66]. In a sample of 988 adults aged over 50, 97% had been subjected to multiple LE during the past year. The most frequently reported LE were the change of staff in setting/day care (85.05%), holiday (65.3%), new residents (55.1%), mild physical illness (47.2%) and change of main professional caregiver (39.5%). Depressive and anxiety symptoms were significantly heightened in individuals who reported more total and negative LE during the preceding year. This association remained significant also after controlling for a depressive or an anxiety disorder.

Surveys conducted in the last two decades of the twentieth century have reported positive correlations between lifetime exposure to LE and the development of physical, somatoform and psychiatric disorders in adulthood [67–79].

Martorell and colleagues [79] surveyed 177 individuals with mild to moderate ID about the impact of LE and traumatic experiences on their mental health. The retrospective survey was performed by a checklist created ad hoc and the Trauma History Screen (THS) [80]. The psychiatric evaluation was carried out through the administration of the PAS-ADD Checklist (Psychiatric Assessment Schedule for Adults with Developmental Disability) [81]. Results showed the presence of at least one traumatic event in the lifetime of 75% of the participants and at least one traumatic event within the 12 months preceding the study in 50% of cases. The statistical analysis also revealed a significant correlation between exposure to traumatic events and – to a lesser extent – LE, and the likelihood of developing a mental disorder, classified according to the ICD-10 criteria [82].

There is evidence that LE during the previous 6 months are significantly predictive of levels of psychological trauma, behavioural changes (both in frequency and severity) [31, 83] and functioning problems in general [84]. Some studies have found that the high prevalence of challenging behaviour in persons with ID is associated with LE and trauma [85, 86], although it has been confirmed for aggressive behaviour, but not for self-injurious or stereotyped behaviours [87].

Owen and colleagues [87] examined the correlations between LE, problems behaviours and mental health in a residential population of adults with ID. On average, each resident had been subjected to 3.5 negative LE in the past 12 months. Changes of staff and residence, conflicts with care staff and other housemates, family relationships and bereavements, and injuries or illnesses were the events most frequently reported by the participants.

Destructive behaviour and heightened risk for depressive/anxiety disorders were more frequently found in residents who had experienced a higher number of LE.

In 2004, Hastings [73] and collaborators evaluated a large sample of more than 1000 individuals living in various arrangements in Northeast England. The authors found a relationship between the exposure to at least one or two LE in the previous year and the pervasiveness of psychiatric symptoms. The disorders, mainly belonging to the affective spectrum, were detected with the PAS-ADD Checklist [81]. The five LE most frequently reported were changes of residence (15.5%), serious illness of relatives or close friends (9%), serious problems with close relatives or friends (8.8%), serious illness or self-injury (8.5%), and death of family members or close relatives (8.3%) [73].

The LE most frequently associated with mental health problems in people with ID is relocation [73, 77, 87], while among traumatising events abuses, especially sexual abuse, and bereavements are more likely [88–90].

Among traumas, abuse has been the most studied. Reiter and colleagues [90] found that students with ID were more frequently abused – physically, sexually and emotionally – than their peers. In addition to the higher incidence of victimisation in this population, it has also been shown that the abuse often goes unreported or, when reported, it tends to be disregarded. Analysing various life histories, some authors have revealed the presence of sexual abuse as a predictor of self-injury, misuse of alcohol and drugs, PTSD, low self-esteem, anger, depression, guilty relationship problems and behavioural problems [91–93].

Other LE and traumatic experiences observed are unemployed/seeking job, problems with police or authority, alcohol problems and major financial crisis, which have also been frequently associated with personality disorders. On the other hand, serious illnesses or injuries, laid off/sacked from work, and retirement from work have been associated with depression [89].

Different studies have highlighted a positive correlation between the exposure to LE/traumas and the presence of PTSD [83, 91, 94, 95], schizophrenia, personality disorders, depression and adjustment reactions [31, 76, 77]. Findings of a recent longitudinal study [49] have shown that LE were related to depressive, anxiety and psychotic symptoms, as well anger and aggression.

Also, dementia appears to be related to exposure to LE [75, 96]. In particular, the speed of cognitive decline has been found to correlate with the type and the number of LE. Relocations, experiences of loss/separation from significant persons and health problems seem to be the more frequent [75]. Recently, the research has focused on the role of trauma also in the aetiology of obesity [31]. Regarding the role of gender, studies have found no statistically significant differences in the type of LE between men and women [89].

In conclusion, current data confirm that the LE and/or traumas often precede psychological problems, and so they could be considered as risk factors. Evidence is still needed for a better understanding of the possible causal role of LE in the aetiology of mental disorders. The effects of negative events seen in the literature on the general population are not necessarily transferable to people with ID [36].

It is difficult to understand what the threshold is to consider identifying an experience as negative or traumatic for persons with ID. However, it is possible to conclude that an event may have a major impact on the person's ability to adapt and to manage life stressors, especially in case of more severe cognitive impairment [58, 97, 98].

Although the understanding of the role of positive and negative LE in the development of psychopathological vulnerability is becoming more and more important, the literature on traumatic experiences across the lifespan and mental health problems in people with ID is limited and not always consistent [49, 62, 73, 74, 76–78, 84, 87, 99], except for abuse [90, 100, 101], personal victimisation, bereavement [102] and PTSD [74, 75].

These difficulties in the clarification of the relationship between LE, ID and mental disorders are due to different aspects: inaccurate research methodologies, non-representative

samples and LE detection tools, which have not adequately adapted from the ones created for the general population. The instruments used often consist of self-report scales whose administration requires good cognitive, emotional and linguistic skills. Furthermore, the content of their items does not cover a wide timeframe but refers only to recent experiences [4, 5, 54, 80, 103–106].

Once these mechanisms are understood, treatment directions could be identified [49], even if the cognitive behaviour therapy and the eye movement desensitisation and reprocessing are already available and effective [31]. Future studies are needed to contribute to the understanding of the impact of LE and trauma by indicating the specific cognitive profiles of participants and by using prospective methodology [107].

3.2 Physical Vulnerability

Vulnerability is a term that is often used with regard to people with ID and other disabilities and has been defined as "…susceptibility to any kind of harm, whether physical, moral or spiritual, at the hands of an agent or agency" [108]. It is related to dynamics of disempowerment and lack of autonomy. There is, therefore, an important relationship in clinical practice between factors associated with vulnerability, and delivery and accessibility of health care through systems and clinicians. A scoping review of the concept of vulnerability and disparities in health care found evidence to support the authors' hypothesis of a direct correlation between co-existing factors of vulnerability and healthcare disparities [109].

People with ID are prone to experience physical disorders more than in the general population for a variety of reasons associated directly with ID and indirectly because of social challenges in maintaining good health [110]. Maintaining good physical health is particularly important for people with ID because of their vulnerability to developing physical health problems that can have an adverse impact on their quality of life and can be associated with significant inequalities in mortality and morbidity. This paragraph is confined to exploring the prevalence of physical disorders in people with ID and describe specific health problems.

3.2.1 Life Expectancy

Over recent decades, there has been a gradual increase in the life expectancy and a sustained reduction in age-standardised mortality rates in people with ID [111]. Life expectancy has increased from 12 years in 1949 to 60 years in 2004 for people with Down syndrome [112]. Studies have reported that people with mild ID may have similar life expectancy to the non-ID population but for people with more severe ID it is lower [113]. The life expectancy of people without a known organic cause for their ID has also gradually increased [114], but people with ID overall still continue to live shorter lives than people without ID in the United Kingdom [115].

Various studies over the last 20 years have reported on premature death in people with ID. A study in South London showed that people with ID are 58 times more likely to die before the age of 50 than the general population [116]. The MENCAP report in the United Kingdom, "Death by Indifference", on six deaths of people with ID described the role of institutional discrimination against people with ID in not providing adequate intervention and support in hospital and primary care [117]. The subsequent Independent Inquiry by Sir Jonathan Michael recommended the establishment of the Learning Disabilities Public Health Observatory in the United Kingdom [118]. A further confidential inquiry into the deaths of people with learning disabilities [119] was undertaken which investigated the known causes of death of people with ID in South West England and reported that men with ID live 13 years less and women live 20 years less than their counterparts without ID. Some of the reasons for premature deaths included significant difficulties or delays in diagnosis, or delays in further investigation, or specialist referral, and problems with their treatment [120].

3.2.2 Causes of Death

The main causes of death in people with ID are respiratory disorders and cardiovascular conditions secondary to congenital heart disease. In contrast, the leading cause of death in the general population is cancer, followed by ischaemic heart disease and cerebrovascular accidents. Cancer as a cause of death was less common compared to people in the general population [121–123]. Tyrer and McGrother [124] found a relatively high cause-specific mortality for deaths caused by congenital abnormalities and diseases of the nervous system in their study of 503 adults with ID who died during a 14-year follow-up period.

3.2.3 Aetiological Factors for Physical Illnesses and Vulnerability

The aetiological factors for physical illness in people with ID are varied and due to not only the presence of physical disorders but also inherited disorders, communication difficulties, behavioural problems, deficits in support and other social determinants of health. People with ID are at a higher risk of specific diseases compared with the non-ID general population [125]. The presence of certain genetic syndromes further increases the risk of physical illness, for example, the prevalence of hypothyroidism is significantly high in people with Down syndrome. Certain neurological conditions such as epilepsy occur more frequently in people with severe ID with underlying genetic syndromes or organic brain damage [126].

The ability to ask for help and access health care is important for physical health conditions to be diagnosed, treated and prevented. An inability to process information, make informed choices and plan to accept help may reduce a person's access to health care. Communication difficulties in describing symptoms may predispose to a lack of awareness by carers of symptoms or their misattribution to behavioural difficulties instead of identifying accurately a physical health cause. Deficits in adaptive behaviour further reduce the ability to seek assessment and treatment for physical conditions. Inability or lack of motivation to engage in activities increases risk factors such as obesity which in turn may lead to the development of physical illnesses. Lack of appropriately adjusted information and processes of identification and access, as well as lack of awareness in individuals, family and carers, also has an impact on engagement with health screening programmes, for example, breast, bowel and cervical cancers [127].

The occurrence of behavioural difficulties in people with ID can further reduce their access to health care leading to reduced opportunities for assessment, accurate diagnosis and effective treatment. People with ID are prescribed medications more than the general population, particularly in attempts to manage behavioural difficulties [128]. Such medications are associated with metabolic effects that can have significant impacts on a person's physical health, causing weight gain and predisposing them to developing diabetes mellitus.

- Individuals with ID are also more likely to experience physical disorders compared to their peers without ID.
- Studies have highlighted reduced life expectancy of people with ID compared to their peers without ID.
- Reasons for increased physical disorders and premature deaths can be associated with the aetiology of ID, communication difficulties, behavioural problems and lack of social support among many other reasons.
- People with ID can struggle to access health care for various reasons.
- Among physical disorders, epilepsy is one of the commonest conditions seen in people with ID.
- Certain physical health conditions are commonly seen among certain groups of people with ID.
- For example, people with Down syndrome and ID are at a higher risk of hypothyroidism.

3.2.4 Common Physical Health Problems

Morbidity

Physical health morbidities are high in people with ID. A large population-based study in Scotland showed that only 32% of people with ID had no other health condition compared with 51.6% without ID and that adults with ID are more likely to have one to four physical health conditions [125]. Epilepsy (OR-31), constipation (OR-11) and visual impairments (OR-7.8) were significantly more prevalent in the ID population. Interestingly, cardiovascular-related conditions such as coronary heart disease, peripheral vascular disease, hypertension and atrial fibrillation had lower prevalence in this study. Authors also reported hearing loss, eczema, dyspepsia, thyroid disorders and Parkinson's disease to be twice as common in people with ID than non-ID population.

Central Nervous System

The commonest neurological condition in people with ID is epilepsy with a prevalence of 1 in 4 that compares with a prevalence rate of 4 to 10 per 1000 in the general population. Prevalence increases with the severity of ID [129, 130]. Epilepsy is a complex disorder that often has familial and genetic influences, as supported by twin studies [131]. This may further explain the higher prevalence of epilepsy in people with more severe ID and complexities associated with the diagnosis and treatment.

People with genetic disorders are more vulnerable to develop seizure disorders where the prevalence can vary according to the specific condition. Landau–Kleffner syndrome, Dravet syndrome, Doose syndrome and Rett syndrome are some of the genetic conditions associated with both epilepsy and ID. Certain genetic syndromes are associated with different types of seizures. Approximately 60% of people with Angelman syndrome experience multiple seizures with atonic, generalised tonic clonic, absence and complex partial seizures [132]. According to Robertson et al. [130], the pooled estimate of the prevalence of epilepsy in people with Down syndrome was lower than in the total ID population at 10–13%. This contrasts with Uppal and collaborators [133] who found a prevalence rate of epilepsy of 20%.

Epilepsy in people with ID has a poor outcome with about 66% of people with ID experiencing seizures despite using antiepileptic medications [129]. A person with epilepsy can die during or following a seizure for no obvious reason known as Sudden Unexpected Death in Epilepsy (SUDEP). Kiani and colleagues [134] report that SUDEP was the second commonest cause of death with a standardised mortality ratio of 37.6 for men and 52 for women in people with ID. Poorly controlled epilepsy is a risk factor for SUDEP, and people with ID who have epilepsy have a high mortality rate [135].

Metabolic Disorders

Inborn errors of metabolisms are a group of rare genetic conditions that can be associated with and/ or lead to ID. Van Karnebeek and Stockler [136], in a systematic literature review, identified a total of 81 treatable forms of inborn errors of metabolisms in which ID was a major feature. Early recognition, identification and treatment can allow initiation of treatments to prevent or minimise brain damage and improve health outcomes, for example, phenylketonuria. More common are the acquired disorders of metabolism. The functional systems of the body or metabolism include eating, sleeping, hunger and temperature control. Disorders of metabolism can affect many systems in the body and over time result in significant and severe effects on multiple organs.

Diabetes is a common metabolic disorder in which there is under-secretion of insulin that regulates the utilisation of sugar and fats by the body. Complications of diabetes include renal damage, cardiovascular events, cerebrovascular events and blindness. The global prevalence of diabetes has increased from 4.7% in 1980 to 8.5% in 2014 [137]. Similar increases can be expected in people with ID, but the prevalence of diabetes in this

population remains unknown [138]. There is evidence to support the assertion that people with ID are at high risk of diabetes, and the risk of diabetes in people with certain genetic syndromes such as Prader–Willi is approximately 25% for non-insulin-dependent diabetes mellitus with the mean age at onset as early as 20 years [139]. The risk of diabetes in people with Down syndrome has been debated on account of the autoimmune nature of diabetes, but the risk is considered high as evidenced in a Dutch study in children where the risk is threefold higher in children with Down syndrome compared to those without the syndrome [140].

Thyroid diseases, especially hypothyroidism, are over-represented in people with ID [141] especially in people with Down syndrome who have a high rate of thyroid disorders primarily of autoimmune origin. The lifetime prevalence of thyroid disease in people with Down syndrome is estimated at 63% with the incidence of primary congenital hypothyroidism in infants with Down syndrome approximately 28 times more than in the general population [142]. Cheung and colleagues [143] have reported a lifetime prevalence of hypocalcaemia of 80% in people with 22q11.2DS which is one of the commonest microdeletions and is typically attributable to hypoparathyroidism in this group.

Respiratory Disorders

Respiratory conditions are higher in people with ID but studies on the prevalence of asthma in people with ID have shown mixed findings. Gale and colleagues [144] reported the prevalence of asthma in people with ID is double that of the general population in the United Kingdom. Similar findings were reported from studies in Scotland [125], while others report no difference in prevalence between ID and the general population [141]. Irrespective of that, a case–control study has shown that people who died as a result of severe asthma following hospital admission were more likely to have ID [145] emphasising the importance of effective treatment of asthma in people with ID.

Even though Chronic Obstructive Pulmonary Disease (COPD) is a common respiratory condition secondary to smoking in the general population, there are no studies on the prevalence of COPD in people with ID. Recurrent chest infections, on the other hand, are commonly seen among children with severe ID [146] that increase morbidity and mortality in people with ID. There are multiple reasons for recurrent chest infections that include aspiration secondary to swallowing difficulties and gastro-oesophageal reflux, decreased cough efficacy due to expiratory muscle dysfunction and/or kyphoscoliosis, and malnutrition leading to respiratory muscle weakness. The presence of cerebral palsy further increases the risk. Almost 50% of people with Prader–Willi syndrome across different age groups reported a history of recurrent respiratory infections [139].

Obstructive Sleep Apnoea (OSA) is another common condition especially affecting certain groups of people with ID. People with Down syndrome are at a higher risk of OSA due to hypotonic upper airway muscles. Obesity itself is a risk factor that further increases the risk of OSA in people with Down syndrome and Prader–Willi syndrome.

Cardiovascular Disorders

Congenital cardiac abnormalities are more prevalent in certain genetic syndromes, especially in Down syndrome. A Swedish cohort study examining cardiovascular diseases showed that 54% of infants with Down syndrome had congenital cardiac defects compared with the risk of congenital heart disease of 1% in the general population. The most common congenital heart conditions in people with Down syndrome are atrioventricular septal defects (42%), ventriculo-septal defects (22%) and atrial septal defects (16%) [147].

Velocardiofacial syndrome or 22q11 Deletion syndrome (22q11DS) is a relatively common microdeletion syndrome, with an incidence estimated to be between 1 in 4000 and 1 in 6000 [148, 149], causing ID with various physical and mental health conditions. Cardiac abnormalities are commonly found

in this syndrome that includes interrupted aortic arch type B, persistent truncus arteriosus, tetralogy of Fallot and isolated ventricular septal defect or transposition [150].

Gastrointestinal Disorders

Dysphagia, or difficulty in swallowing, is highly prevalent in people with ID. Hypertonia or hypotonia of the swallowing muscles along with poor coordination during swallowing are considered to be among potential aetiologies. Dyspepsia and gastro-oesophageal reflux are also common [151]. Constipation is a frequent health condition in people with ID where nearly 70% of institutionalised adults with ID had constipation [152] and in children with severe ID, the prevalence rate is as high as 50%. People with ID are at a higher risk of constipation as a side effect of the various medications they are prescribed (e.g. antipsychotics), reduced mobility and poor fluid intake. Cerebral palsy and Down syndrome are strongly associated with constipation.

Cancers

It was previously thought that people with ID had a lower prevalence of cancers, but more contemporary analysis of data appears to show rates comparable to the general population [153]. There are some differences in the relative frequencies of types of cancer, for example, people with ID are at a much higher risk of gastrointestinal cancer. Rates and patterns of cancers may be changing with increased longevity. A significant challenge in the diagnosis and treatment of cancer is the variability in access to and uptake of screening programmes. Women with ID have a much lower participation rate in cervical and breast screening programmes than women without ID.

In the United Kingdom, figures from the Joint Health and Social Care Self-Assessment Framework demonstrated variability in uptake across three national screening programmes for cervical, breast and bowel cancer. For the bowel screening programme, 41.6% of people with ID were screened compared with 50.4% for the general population. Breast cancer screening was carried out on 39% of women with ID (general population 55.9%) and cervical cancer screening was the lowest with 29% compared with 69.1% [127].

Barriers to uptake of screening include the lack of routine use of accessible materials including invitations to screening, lack of reasonable adjustments to appointment systems, availability of adequate time and adaptations for restrictions in mobility. Professionals cite communication difficulties as a significant barrier and the awareness and attitudes of the professionals themselves have a significant impact. People with ID themselves may have limited knowledge and understanding of cancers and the need and benefits of screening [154].

Sensory Impairment

In a Dutch study of people with ID under the age of 50 years in an institutional setting, nearly 21% had hearing problems and 4% had visual problems. Such prevalence rates are significantly higher compared to the general population. The prevalence rate is higher with increasing severity of ID where 50% of people with severe and profound ID have visual impairments. The prevalence of hearing impairments was significantly high in people with Down syndrome and people with ID over the age of 50 [155]. Some of these conditions are treatable or steps can be taken to reduce the impairment due to sensory deficits, but they are often difficult to detect in people with severe ID.

Nutrition and Weight

Overweight is defined as a Body Mass Index (BMI) ratio of 25–29.9 and obesity BMI > 30 and are currently major health concerns for the general population. Obesity is one of the biggest risk factors for cardiovascular and cerebrovascular events. There has been a marked increase in the number of people with ID with obesity with a higher prevalence than the general population [156–158].

Multiple factors are thought to contribute to overweight and obesity in people with ID, and there is an association with certain genetic syndromes, for example, Down syndrome [158] and Prader–Willi syndrome [139].

Genetic studies have shown that genetic deletions and certain copy number variants are linked to obesity supporting the hypothesis that it is a heritable and highly heterogenous set of conditions [159]. Interestingly, the rate of obesity is lower with increasing severity of ID [158].

Many external factors lead to obesity that include a lack of healthy food choices, the side effects of medications such as antipsychotic drugs, a lack of exercise [156, 160], physical limitations and pain, little motivation and few resources and support to engage in activities. The environment in which a person lives has an impact on maintaining physical activity where people with ID living in less supervised settings are at higher risk of obesity compared to people who live in closely supervised ones [161]. Gender disparity in obesity is an interesting factor in its development. Kanter and Caballero [162] identified socio-cultural factors leading to gender disparity where in developing countries there are more obese women than men and that women with ID are at greater risk of obesity [156, 163, 164]. Such factors are larger body sizes considered as signs of healthiness and happiness alongside sex differences in metabolism and adipose tissue distribution.

- **Musculoskeletal Disorders**

People with ID experience musculoskeletal problems that cause significant functional impairment by reducing mobility and impairing ability to engage in educational and other activities which require fine and gross motor skills. Hypotonia is a common finding in Down syndrome and Prader–Willi syndrome and in people with cerebral palsy. People with ID are at a higher risk of low bone mineral density, osteoporosis and osteopenia often secondary to the use of antiepileptic medication to control seizures that reduces Vitamin D absorption. These factors along with reduced mobility predispose people to bone fractures that may also go unnoticed if they are immobile. Almost 50% of people with ID meet the criteria for screening of osteoporosis and osteopenia [165].

3.2.4.1 Prevention

Primary, secondary and tertiary prevention strategies are important in managing physical health conditions in people with ID. Examples of primary prevention interventions in childhood are screening for visual defects, hearing disorders and musculoskeletal disorders to prevent morbidity and/or to reduce the risk of impairment. Screening every person with ID for common health conditions and specific screening tests in people with congenital disorders is important, for example, testing for hypothyroidism in people with Down syndrome annually as per the guidelines from Down Syndrome Medical Interest Group. Secondary prevention is the detection and treatment of a condition prior to developing complications that involve recognising people at high risk and taking the necessary steps to test and treat. Tertiary prevention is reducing harm from a condition, for example, interventions to prevent a person with cerebral palsy from developing contractures. The biggest challenge with preventative strategies in people with ID is the paucity of research and policies and guidelines on screening and managing health conditions.

- Conditions related to central nervous system, metabolic system, respiratory system, cardiovascular system, gastrointestinal system and musculoskeletal system are commonly seen in people with ID.
- Improving physical health care of people with ID includes early identification and support to access health care.

3.2.5 Improving Health Care and Reducing Physical Vulnerabilities

To reduce health inequalities in people with ID, it is essential to recognise the obstacles in the person and in the system to them receiv-

ing appropriate care. Providing health services for people with ID can be challenging for many reasons not least the multi-morbidity affecting people with ID. In England, General Practitioners have responsibility to offer Annual Health Checks to their patients with ID. Despite various measures to increase uptake of Annual Health Checks only 50% had one [166].

One of the main challenges with improving health care for people with ID is the lack of research often due to multiple barriers such as funding, ethical issues and little interest by researchers in this area. As a result, issues relevant to diagnosis and treatment of physical health issues in people with ID are often not specifically addressed in guidelines with the potential of not identifying health problems as their presentations may be different to people in the general population. In addition, people with ID at high risk may not be recognised as "high risk" or clinicians may not be trained to examine and suspect health issues.

People with ID often express pain or distress through behavioural changes on account of poor communication skills. The behaviour can be perceived as "challenging" to carers and clinicians who may fail to understand the underlying physical cause of the behaviour. This may lead to inadequate assessment and inappropriate treatment. To overcome such difficulties, joint working between mental health clinicians and generalists is recommended. A lack of mental capacity to make decisions about physical health care can be an issue for some people with ID. Legal frameworks to support assessing mental capacity and making best interest decisions are important to support people with ID to access health care [167].

- **Summary**

People with ID are prone to physical health difficulties either directly related to the level of ID or as a consequence of treatments they receive. It is essential that clinicians working with people with ID are alert to unusual presentations, the impact of treatments, and are familiar with the health needs of this population in order to avoid greater morbidity. People with ID are a heterogenous group who experience a range of physical disorders as they grow older including long-term conditions. Skilled interventions by carers and clinicians can help to prevent the onset of physical health problems or to ameliorate their impact through education and support.

3.3 Lifespan and Transitions

3.3.1 Introduction

In the last decade, lifespan issues appear to have received increasing attention. There has been a growth in research and policies. Transition planning and supports for community inclusion, independent living and employment have become key areas of interest. Among many factors that have contributed to this development, a major role has been played by deinstitutionalisation, which created greater access to community-based services and living arrangements. Furthermore, educational advocacy and legislations have facilitated the access to educational opportunities. Provision of behavioural intervention programmes has produced dramatic increases in language, social and practical skills, with many individuals achieving skills necessary to adapt in community living. As of 2012, approximately 50,000 individuals with ID/autism spectrum disorder (ASD) per year turn 18 years old in the United States [168, 169]. Therefore, the challenges of transition to adulthood in ASD are now a significant public health issue [170, 171].

3.3.2 Adolescence

Deterioration in behavioural is seen in approximately one-third to one-fourth of adolescents with ID and ASD [172]. A major causal factor for such deterioration is postulated to be due to hormonal changes and associated sexual desires, especially in the context of limited knowledge and skills around safety and

relationship issues. In females with ID/ASD, this seems to be linked to menarche. The age of onset for menarche is often significantly earlier compared to women in the general population. Adolescence is also marked by various other changes in psychosocial development, educational and life activities, participation to community living and the related safety issues.

3.3.3 Education

Literature shows that adolescents with ID and ASD have lower levels of academic achievement in high school, and the majority of them have post-school services as part of their transition plan [173]. The data in the scientific literature indicate that 40% of individuals with ID/ASD attend college, and a smaller percentage graduate from College, with lower attendance rates among those with more severe symptoms or lack of access to services [168, 174–178]. Those young adults who are attending College or University or trying to pursue professional education may encounter various problems. Living away from home, managing one's daily life and finances, managing the unpredictable stresses of more independent living and navigating the relatively complex social environment of higher education are some of the challenges. However, there are several organisations that provide professional support staff and peer mentoring during College education. Furthermore, there are an increasing number of programmes designed to prepare and support young adults with ID/ASD prior to and during the University studies.

3.3.4 Sexuality

Sexuality encompasses more than just sexual behaviour. It includes self-image, emotions, values, attitudes, beliefs, behaviours and relationships. There are many wrongly held beliefs about ID/ASD individuals, referring to them as sexually immature and sparsely interested in romantic relationships or as asexual [179]. In contrast to these stereotypes, several studies have shown that sexuality is an important part of life for individuals with ASD and that they have general interest in solitary and dyadic sexual behaviours [180]. In fact, people with ID/ASD typically mature physically and sexually according to normal developmental stages. However, a young person with ASD can develop normally in some areas of social and emotional understanding and have difficulties in others. Difficulties in initiating and maintaining relationships appear to be the main difficulty that most people with ID/ASD experience than the lack of interest. The success or failure encountered by young people during their sexual development impacts their ability to effectively transition into adulthood.

Moreover, lack of understanding of rules of dating and romantic relationships, of social skills and also poor social decision-making in adults with ID/ASD may lead these individuals to engage in behaviours that are misinterpreted or get them into trouble, such as "stalking" behaviours [180]. This can have severe consequences, including loss of opportunities for employment, social isolation or even criminal prosecution. Moreover, individuals with ID/ASD report problematic sexual behaviours, including hypersexuality, paraphilic disorders, asexuality and gender-nonconforming feelings [181].

There has been a growing interest in this area recently. Some authors have suggested that specialised sexual education combined with social and communication skills training for adolescents may be beneficial. Such education would focus on improving knowledge so that inappropriate activity can be avoided [182, 183]. However, relatively few interventions and services have been developed and rigorously tested to improve social functioning for late adolescents and adults with ASD.

3.3.5 Adulthood

The transition to adulthood is one of the periods characterised by considerable stress and adjustment for people with ID/ASD and

their families [184]. One of the major difficulties in addressing transition to adulthood adequately is the tremendous heterogeneity of ID/ASD, including heterogeneity of underlying aetiology, clinical manifestations, levels of cognitive and adaptive functioning [185]. This heterogeneity makes essential thorough clinical evaluation and tailored transition plans, services, interventions to the goals and needs of the particular individuals. One of the major challenges is to help individuals, families and schools to plan the transition to adulthood in advance. Transitional issues are numerous and complex and often take time and planning to address these complexities [173].

Transition work should include several issues: helping to find appropriate jobs, providing support to progress in their work placement, considering options for housing, helping to gain more independent living skills and finding appropriate legal and financial counselling for longer term planning regarding financial and healthcare decision-making. Ideally, the individual, parents, teachers and other professionals should all participate in formulating the transition plan. There should be coordination between efforts of school and community agencies [173, 186].

One of the most complex transitions, which generally occur in adulthood, is represented by moving from the parental home to another setting such as independent, shared, supported or residential livings. Many skills are involved in independent living, including managing safety, cooking, cleaning, laundry, dressing and personal finances. In general, teaching and practice of these skills should be part of a transition plan to gain such skills relatively early, so that there is sufficient time for these skills to be acquired. Housing and residential issues are treated in ▶ Chap. 37.

Finding and maintaining a job is a priority during the transition to adulthood as it plays an important role in developing a sense of purpose and well-being, self-esteem, social and mental engagement, and financial independence. The several issues related to vocation and employment are treated in ▶ Chap. 38. Furthermore, young adults have substantial difficulties in meeting the increasing social subtlety of adolescent interactions relative to childhood social interactions.

Most adults with ASD tend to remain socially isolated [187, 188]. Several studies have found that a high percentage of people with ASD have no friendships or have only one friend [189–191]. Another critical transitional issue is the increased risk for periods of aggravation of behavioural symptoms (e.g. aggression, hyperactivity and insistence on sameness), seizures [192, 193] and mental health problems. The psychotropic medication usage tends to increase in individuals with ASD as they enter adolescence and adulthood [194], despite the fact that the evidence base for use of medications in adults with ASD is very limited [26, 195, 196].

The relatively poor outcomes for adults with ASD may be attributable, at least in part, to the relative lack of services for adults. This is further increased by limited research on adults with ASD. In many countries, mandated services and supports for individuals with ASD either disappear or are dramatically reduced after the age of 18–21 years [178, 191, 197]. The transition to adulthood is often a period of considerable stress and adjustment for close family members of persons with ASD\ID [184].

Main difficulties encountered by family members concern the coordination of many types of health, educational and other services. Parents often have longer term concerns about the capacity to move out of the home and to function in post-secondary education, employment and activities of daily living, what will happen to their child when the parents become older, sick or pass away. They have considerable worries about how to address legal issues about guardianship and financial and health decision-making [198]. In addition, these parents tend to experience higher levels of stress, more mental health symptoms, higher divorce rates than parents of typically developing children and higher demands for assistance [199, 200].

When necessary, the transition to adult services must be adequately prepared, not

only through the collaboration of services professionals for the two ages but also by providing young people with the necessary indications about the interventions they will need, where and from whom receive them. It is necessary for the young person and, when appropriate, the parents or caregivers to be involved in the treatment planning. Similar methods should be applied – mutatis mutandis – also to the transition, more gradual but also more subtle, from adulthood to senescence.

3.3.6 Ageing

Life expectancy of people with ID has increased over the last few decades although it is still lower than that of the general population by about 10–15 years. Increase in life expectancy has been linked with an increase in the prevalence of mental and physical ill-health disorders associated with ageing.

- There have been significant changes over the last few decades in the ways people with ID live following deinstitutionalisation and community inclusion.
- As a result, there have been changing expectations from people with ID in different aspects of life.
- Transitioning from one stage of life to another can lead to different challenges for people with ID.

Key Points

- Psychological distress is commonly seen among people with intellectual disabilities (ID)/autism spectrum disorder (ASD).
- Similarly, high rate of physical disorders are seen among people with ID/ASD associated with high mortality.
- People with ID/ASD are further vulnerable due to different stages of transition that they have to go through in their lives.

References

1. Ridner SH. Psychological distress: concept analysis. J Adv Nurs. 2004;45(5):536–45. https://doi.org/10.1046/j.1365-2648.2003.02938.x.
2. The Centers for Disease Control. Non-specific Psychological Distress. 2011. Retrieved from https://www.cdc.gov/mentalhealth/data_stats/nspd.htm.
3. Rai D, Kosidou K, Lundberg M, Araya R, Lewis G, Magnusson C. Psychological distress and risk of long-term disability: population-based longitudinal study. J Epidemiol Community Health. 2012;66(7):586–92. https://doi.org/10.1136/jech.2010.119644.
4. Bramston P, Fogarty GJ. The assessment of emotional distress experienced by people with an intellectual disability: a study of different methodologies. Dev Disabil Res Rev. 2000;21:487–500.
5. Bramston P, Bostock J. Measuring perceived stress in people with intellectual disabilities: the development of a new scale. Aust NZ J Dev Disabil. 1994;19:149–57. https://doi.org/10.1080/07263869400035181.
6. Bramston P, Fogarty GJ, Cummins RA. The nature of stressors reported by people with an intellectual disability. J Appl Res Intellect Disabil. 1999;12:1–10. https://doi.org/10.1111/j.1468-3148.1999.tb00046.x.
7. Hartley SL, Maclean WE. Stressful social interactions experienced by adults with mild intellectual disability. Am J Intellect Dev Disabil. 2009;114(2):71–84. https://doi.org/10.1352/2009.114.71-84.
8. Lunsky Y, Benson BA. Social circles of adults with mental retardation as viewed by their caregivers. J Dev Phys Disabil. 1999;11:115–29. https://doi.org/10.1023/A:1021843003671.
9. Khemka I, Hickson L. Empowering women with intellectual and developmental disabilities to resist abuse in interpersonal relationships: promising interventions and practices. In: Johnson A, Nelson J, Lund E, editors. Religion, disability, and interpersonal violence. New York: Springer; 2017.
10. Hughes K, Bellis MA, Jones L, Wood S, Bates G, Eckley L, McCoy E, Mikton C, Shakespeare T, Officer A. Prevalence and risk of violence against adults with disabilities: a systematic review and meta-analysis of observational studies. Lancet. 2012;379(9826):1621–9. https://doi.org/10.1016/S0140-6736(11)61851-5.
11. Jones L, Bellis MA, Wood S, Hughes K, McCoy E, Eckley L, Bates G, Mikton C, Shakespeare T, Officer A. Prevalence and risk of violence against children with disabilities: a systematic review and meta-analysis of observational studies. Lancet. 2012;380(9845):899–907. https://doi.org/10.1016/S0140-6736(12)60692-8.
12. Sobsey D, Doe T. Patterns of sexual abuse and assault. Sex Disabil. 1991;9(3):243–59.

13. Lovallo WR. Behavioral medicine and health psychology series, Vol. 1. Stress & health: biological and psychological interactions. Thousand Oaks, CA: Sage Publications, Inc; 1997.
14. Porges SW. The polyvagal perspective. Biol Psychol. 2007;74(2):116–43. https://doi.org/10.1016/j.biopsycho.2006.06.009.
15. Sroufe LA. Attachment and development a prospective, longitudinal study from birth to adulthood. Attach Hum Dev. 2005;7:349–67. https://doi.org/10.1080/14616730500365928.
16. Schuengel C, de Schipper JC, Sterkenburg PS, Kef S. Attachment, intellectual disabilities and mental health: research, assessment and intervention. J Appl Res Intellect Disabil. 2013;26(1):34–46. https://doi.org/10.1111/jar.12010.
17. Schuengel C, Sterkenburg PS, Jeczynski P, Janssen CGC, Jongbloed G. Supporting affect regulation in children with multiple disabilities during psychotherapy: a multiple case design study of therapeutic attachment. J Consult Clin Psychol. 2009;77:291–301. https://doi.org/10.1037/a0014274.
18. Sterkenburg PS, Janssen CGC, Schuengel C. The effect of an attachment-based behaviour therapy for children with visual and severe intellectual disabilities. J Appl Res Intellect Disabil. 2008;21(2):126–35. https://doi.org/10.1111/j.1468-3148.2007.00374.x.
19. Jonker D, Sterkenburg PS, Van Rensburg E. Caregiver-mediated therapy for an adult with visual and intellectual impairment suffering from separation anxiety. Res Dev Disabil. 2015;47:1–13. https://doi.org/10.1016/j.ridd.2015.08.005.
20. Van Nieuwenhuijzen M, Vriens A. (Social) cognitive skills and social information processing in children with mild to borderline intellectual disabilities. Res Dev Disabil. 2012;33(2):426–34. https://doi.org/10.1016/j.ridd.2011.09.025.
21. Ebensen AJ, Benson BA. Diathesis-stress and depressed mood among adults with mental retardation. Am J Intellect Dev Disabil. 2006;111(2):100–12. https://doi.org/10.1352/0895-8017(2006)111[100:DADMAA]2.0.CO;2.
22. Ali A, Strydom A, Hassiotis A, Williams R, King M. A measure of perceived stigma in people with intellectual disability. Br J Psychiatry. 2008;193(5):410–5. https://doi.org/10.1192/bjp.bp.107.045823.
23. Ali A, King M, Strydom A, Hassiotis A. Self-reported stigma and symptoms of anxiety and depression in people with intellectual disabilities: findings from a cross sectional study in England. J Affect Disord. 2015;187:224–31. https://doi.org/10.1016/j.jad.2015.07.046.
24. De Knegt NC, Lobbezoo F, Schuengel C, Evenhuis HM, Scherder EJA. Self-reported presence and experience of pain in adults with Down syndrome. Pain Med. 2017;18(7):1247–63. https://doi.org/10.1093/pm/pnw226.
25. Coiffait FMM, Leedham AT. Psychological well-being of children and adults with severe and profound intellectual and developmental disabilities. In: Rubin IL, Merrick J, Greydanus DE, Patel DR, editors. Health care for people with intellectual and developmental disabilities across the lifespan. New York: Springer; 2016.
26. Deb S, Bethea T, Havercamp S, Rifkin A, Underwood L. Disruptive, impulse-control, and conduct disorders. In: Fletcher R, Barnhill J, Cooper S-A, editors. Diagnostic manual – intellectual disability: a textbook of diagnosis of mental disorders in persons with intellectual disability. 2nd ed. Kingston: NADD Press; 2016. p. 521–60.
27. Bakken TL, Kildahl AN, Gjersøe V, Matre E, Kristiansen T, Ro A, et al. Identification of PTSD in adults with intellectual disabilities in five patients in a specialised psychiatric inpatient unit. Ad Ment H Intel Disabil. 2014;8:91–102. https://doi.org/10.1108/AMHID-01-2013-0002.
28. Reeve A. Anxiety: challenges of normal and abnormal responses. In: Rubin IL, Merrick J, Greydanus DE, Patel DR, editors. Health care for people with intellectual and developmental disabilities across the lifespan. New York: Springer; 2016.
29. American Psychiatric Association. Diagnostic and statistical manual of mental disorders (DSM-5). 5th ed. Washington, DC: American Psychiatric Association; 2013.
30. Hartley SL, Lickel AH, MacLean WE. Reassurance seeking and depression in adults with mild intellectual disability. J Intellect Disabil Res. 2008;52:917–29. https://doi.org/10.1111/j.1365--2788.2008.01126.x.
31. Wigham S, Emerson E. Trauma and life events in adults with intellectual disability. Curr Dev Disord Rep. 2015;2:93–9. https://doi.org/10.1007/s40474-015-0041-y.
32. De Knegt NC, Pieper MJC, Lobbezoo F, Schuengel C, Evenhuis HM, Passchier J, Scherder EJA. Behavioural pain indicators in people with intellectual disabilities: a systematic review. J Pain. 2013;14:885–96. https://doi.org/10.1016/j.jpain.2013.04.016.
33. Hulbert-Williams L, Hastings RP, Crowe R, Pemberton J. Self-reported life events, social support and psychological problems in adults with intellectual disabilities. J Appl Res Intellect Disabil. 2011;24:427–36. https://doi.org/10.1111/j.1468--3148.2011.00624.x.
34. Fogarty, GJ, Bramston, P, Cummins, RA. Validation of the Lifestress Inventory for people with a mild intellectual disability. Res Dev Disabil. 1997;18(6):435–456. https://doi.org/10.1016/s0891-4222(97)00021-8.
35. Hall JC, Jobson L, Langdon PE. Measuring symptoms of post-traumatic stress disorder in people with intellectual disabilities: the development and psychometric properties of the Impact of Event

Scale-Intellectual Disabilities (IES-IDs). Br J Clin Psychol. 2014;53(3):315–32. https://doi.org/10.1111/bjc.12048.
36. Wigham S, Hatton C, Taylor JL. The Lancaster and Northgate Trauma Scales (LANTS): the development and psychometric properties of a measure of trauma for people with mild to moderate intellectual disabilities. Res Dev Disabil. 2011;32(6):2651–9. https://doi.org/10.1016/j.ridd.2011.06.008.
37. Hatton C, Emerson E. The relationship between life events and psychopathology amongst children with intellectual disabilities. J Appl Res Intellect Disabil. 2004;17:109–17.
38. American Psychiatric Association. Diagnostic and statistical manual of mental disorders-IV ed.-TR Author, Washington, DC; 2000.
39. Dosen A. Integrative treatment in persons with intellectual disability and mental health problems. J Intel Disabil Res. 2007;51(1):66–74.
40. Emerson E. Poverty and people with intellectual disabilities. Ment Retard Dev Disabil Res Rev. 2007;13(2):107–13. https://doi.org/10.1002/mrdd.20144.
41. Emerson E. Childhood exposure to environmental adversity and the well-being of people with intellectual disabilities. J Intel Disabil Res. 2013;57(7):589–600.
42. Sullivan PM, Knutson JF. Maltreatment and disabilities: a population-based epidemiological study. Child Abuse Negl. 2000;24:1257–73.
43. Hartley SL, MacLean WE. Perceptions of stress and coping strategies among adults with mild mental retardation: insight into psychological distress. Am J Ment Retard. 2005;110(4):285–97.
44. Jahnsen R, Villien L, Stanghelle LH, Hoim I. Coping potential and disability-sense of coherence in adults with cerebral palsy. Disabil Reahabilit. 2002;24:511–8.
45. Hollins S, Esterhuyzen A. Bereavement and grief in adults with learning disabilities. Br J Psychiatry. 1997;170:497–501.
46. Levitas A, Gilson SF. Predictable crises in the lives of persons with mental retardation. Ment Healt Asp Dev Disabil. 2001;4:89–100.
47. Martorell A, Tsakanikosc E. Traumatic experiences and life events in people with intellectual disability. Cur Op Psych. 2008;21:445–8.
48. Mevissen L, De Jongh A. PTSD and its treatment in people with intellectual disabilities: a review of the literature. Clin Psych Rev. 2010;30(3):308–16.
49. Hulbert-Williams L, Hastings R, Owen DM, Burns L, Day J, Mulligan J, Noone SJ. Exposure to life events as a risk factor for psychological problems in adults with intellectual disabilities: a longitudinal design. J Intellect Disabil Res. 2014;58(1):48–60. https://doi.org/10.1111/jir.12050. Epub 2013 Apr 30
50. Annison JE. Towards a clearer understanding of the meaning of "home". J Intellect Develop Disabil. 2000;25(4):251–62.
51. Feldman M, Varhese J, Ramsay J, Rajska D. Relationships between social support, stress and mother-child interactions in mothers with intellectual disabilities. J Appl Res Intellect Dis. 2002;15(4):314–23.
52. Lippold T, Burns J. Social support and intellectual disabilities: a comparison between social networks of adults with intellectual disability and those with physical disability. J Intellect Disabil Res. 2009;53(5):463–73.
53. Rosen JW, Burchard SN. Community activities and social support networks: a social comparison of adults with and without mental retardation. Ed Train Ment Retard. 1990;25:193–204.
54. Lunsky Y, Havercamp SM. Distinguishing low levels of social support and social strain: implication for dual diagnosis. Am J Ment Retard. 1999;104:200–4.
55. Emerson E, Brigham P. The developmental health of children of parents with intellectual disabilities: cross sectional study. Res Develop Disabil. 2014;35(4):917–21.
56. Hyman I, Cohen I, Mahon M. Student alienation syndrome: a paradigm for understanding the relation between school trauma and school violence. Cal Sc Psychol. 2003;8:73–86.
57. Maes M, Mylle J, Delmeire L, Janca A. Pre- and post-disaster negative life events in relation to the incidence and severity of post-traumatic stress disorder. Psych Res. 2001;105:1–12.
58. Ehlers A, Clark DM. A cognitive model of post-traumatic stress disorder. Behav Res Ther. 2000;38:319–45.
59. Rush AJ, Frances A, editors. Expert consensus guideline series: treatment of psychiatric and behavioral problems in mental retardation [Special Issue]. Am J Ment Retard. 2000;105(3):159–226.
60. Friedman NP, Miyake A, Corley RP, Young SE, Defries JC, Hewitt JK. Not all executive functions are related to intelligence. Psychol Sci. 2006;17:172–9.
61. Johnson SL, Cueller AK, Ruggero C, Winett-Perlman C, Goodnick P, White R, Miller I. Life events as predictors of mania and depression in bipolar I disorder. J Abnorm Psychol. 2008;117(2):268–77. https://doi.org/10.1037/0021-843X.117.2.268. Erratum in: J Abnorm Psychol. 2008;117(3):698. Cueller, Amy K [corrected to Cuellar, Amy K]. PMID: 18489203; PMCID: PMC2862221.
62. Smiley E, Cooper SA, Finlayson J, Jackson A, Allan L, Mantry D, McGrother C, McConnachie A, Morrison J. Incidence and predictors of mental ill-health in adults with intellectual disabilities: prospective study. Br J Psychiatry. 2007;191:313–9. https://doi.org/10.1192/bjp.bp.106.031104.
63. Moss S, Emerson E, Kiernan C, Turner S, Hatton C, Alborz A. Psychiatric symptoms in adults with learning disability and challenging behaviour. Br J Psychiatry. 2000;177:452–6. https://doi.org/10.1192/bjp.177.5.452.

64. Shabalala N, Jasson A. PTSD symptoms in intellectually disabled victims of sexual assault. SA J Psychol. 2011;41:424–36.
65. Taggart L, Taylor D, McCrum-Gardner E. Individual, life events, family and socio-economic factors associated with young people with intellectual disability and with and without behavioural/emotional problems. J Intel Disabil. 2010;14(4):267–88.
66. Hermans H, Evenhuis HM. Life events and their associations with depression and anxiety in older people with intellectual disabilities: results of the HA-ID study. J Affect Dis. 2012;138:79–85.
67. Totman R, Kiff J, Reed SE, Craig JW. Predicting experimental colds in volunteers from different measures of recent life stress. J Psychosom Res. 1980;24:155–63.
68. Craig TK, Brown GW. Goal frustration and life events in the aetiology of painful gastrointestinal disorder. J Psychosom Res. 1984;28:411–21.
69. Levenson JL, Bemis C. The role of psychological factors in cancer onset and progression. Psychosomatics. 1991;32:124–32.
70. Niaura R, Goldstein MG. Psychological factors affecting physical condition: cardiovascular disease literature review. Psychosomatics. 1992;33:146–55.
71. Bebbington P, Marsden L, Brewin CP. The need for psychiatric treatment in the general population: the Camberwell needs for care survey. Psychol Med. 1997;27:821–34.
72. Kessler R. The effects to stressful life events on depression. Annu Rev Psychol. 1997;48:191–214.
73. Hastings RP, Hatton C, Taylor JL, Maddison C. Life events and psychiatric symptoms in adults with intellectual disabilities. J Intel Disabil Res. 2004;48:42–6.
74. Hamilton D, Sutherland G, Lacono T. Further examination of relationships between life events and psychiatric symptoms in adults with intellectual disability. J Intel Disabil Res. 2005;49(11):839–44.
75. Patti PJ, Amble KB, Flory MJ. Life events in older adults with intellectual disabilities: differences between adults with and without Down syndrome. J Policy Pract Intellect Disabil. 2005;2(2):149–55. https://doi.org/10.1111/j.1741-1130.2005.00023.x.
76. Esbensen AJ, Benson BA. A prospective analysis of life events, problem behaviours and depression in adults with intellectual disability. J Intel Disabil Res. 2006;50:248–58.
77. Tsakanikos E, Bouras N, Costello H, Holt G. Multiple exposure to life events and clinical psychopathology in adults with intellectual disability. Soc Psychiatry Psychiatr Epidemiol. 2007;42:24–8.
78. Hulbert-Williams L, Hastings RP. Life events as a risk factor for psychological problems in individuals with intellectual disabilities: a critical review. J Intellect Disabil Res. 2008;52(11):883–95. https://doi.org/10.1111/j.1365-2788.2008.01110.x.
79. Martorell A, Tsakanikos E, Pereda A, Gutiérrez-Recacha P, Bouras N, Ayuso-Mateos JL. Mental health in adults with mild and moderate intellectual disabilities: the role of recent life events and traumatic experiences across the life span. J Nerv Ment Dis. 2009;197(3):182–6. https://doi.org/10.1097/NMD.0b013e3181923c8c.
80. Allen JG, Huntoon J, Evans RB. A self-report measure to screen for trauma history and its application to women in inpatient treatment for trauma-related disorders. Bull Menn Clin. 1999;63(3):429–42.
81. Moss S, Prosser H, Costello H, Simpson N, Patel P, Rowe S, Turner S, Hatton C. Reliability and validity of the PAS-ADD checklist for detecting psychiatric disorders in adults with intellectual disability. J Intellect Disabil Res. 1998;42(Pt 2):173–83. https://doi.org/10.1046/j.1365-2788.1998.00116.x.
82. World Health Organization. The ICD-10 classification of mental and behavioural disorders: diagnostic criteria for research. Geneva: WHO; 1993.
83. Wigham S, Taylor JL, Hatton C. A prospective study of the relationship between adverse life events and trauma in adults with mild to moderate intellectual disabilities. J Intellect Disabil Res. 2014;58(12):1131–40.
84. Berger R, Gelkopf M, Versano-Mor K, Shpigelman C-N. Impact of exposure to potentially traumatic events on individuals with intellectual disability. Am J Intellect Dev Disabil. 2015;120(2):176–88.
85. Cooper SA, Smiley E, Jackson A, Finlayson J, Allan L, Mantry D, Morrison J. Adults with intellectual disabilities: prevalence, incidence and remission of aggressive behaviour and related factors. J Intellect Disabil Res. 2009;53(3):217–32. https://doi.org/10.1111/j.1365-2788.2008.01127.x.
86. Mevissen L, Lievegoed R, Seubert A, De Jongh A. Do the persons with intellectual disability and limited verbal capacities respond to trauma treatment? J Intellect Disabil Res. 2011;36(4):278–83.
87. Owen DM, Hastings RP, Noone SJ, Chinn J, Harman K, Roberts J, et al. Life events as correlates of problem behavior and mental health in a residential population of adults with developmental disabilities. Res Develop Disabil. 2004;25:309–20.
88. Machale R, Carey S. An investigation of the effect of bereavement on mental health and challenging behavior in adults with learning disability. Br J Learn Disabil. 2002;30(3):113.
89. Tsakanikos E, Costello H, Holt G, Bouras N, Sturmey P, Newton T. Psychopathology in adults with autism and intellectual disability. J Autism Dev Disord. 2006;36(8):1123–9.
90. Reiter S, Bryen DN, Shachar I. Adeolescents with intellectual disabilities as victims of abuse. J Intellect Disabil. 2007;11:371–87.
91. Murphy GH, O'Callaghan AC, Clare IC. The impact of alleged abuse on behaviour in adults with

severe intellectual disabilities. J Intellect Disabil Res. 2007;51(Pt 10):741–9. https://doi.org/10.1111/j.1365-2788.2007.00973.x.
92. Lovell A. Learning disability against itself: the self-injury/self-harm conundrum. Br J Learn Disabil. 2008;36(2):109–21.
93. Peckham NG. The vulnerability and sexual abuse of people with learning disabilities. Br J Learn Disabil. 2007;35(2):131–7.
94. Firth H, Balogh R, Berney T, Bretherton K, Graham S, Whibley S. Psychopathology of sexual abuse in young people with intellectual disability. J Intellect Disabil Res. 2001;6:193–2016.
95. Mitchell A, Clegg J. Is post-traumatic stress disorder a helpful concept for adults with intellectual disability? J Intellect Disabil Res. 2005;49:552–9.
96. Hove O, Havik OE. Development level and other factors associated with symptoms of mental disorders and problem behaviour in adults with intellectual disabilities living in the community. Soc Psychiatry Psychiatr Epidemiol. 2010;45:105–13.
97. Tomasulo DJ, Razza NJ. Post-traumatic stress disorder. In: Fletcher R, Loschen E, Stavrakaki C, First M, editors. Diagnostic manual: intellectual disability (DM-ID). A textbook of diagnosis of mental disorders in persons with intellectual disability. Kingston: NADD Press; 2007. p. 365–78.
98. Lunsky Y, Neely L. Interpersonal conflict in a relationships context. Paper presented at International Association for the Scientific Study of Intellectual Disability World Congress. Seattle; 2000.
99. Sarason IG, Johnson JH, Siegel JM. Assessing the impact of life change: development of the life experiences survey. J Consult Clin Psychol. 1978;46:932–46.
100. Turk V, Brown H. The sexual abuse of adults with learning disabilities: results of a two year incidence survey. Ment Handicap Res. 1993;6:193–216.
101. Westcott HL, Jones DPH. Annotation: the abuse of disabled children. J Child Psychol Psychiatry. 1999;40(4):497–506.
102. Balogh R, Bretherton K, Whibley S, Berney T, Graham S, Richold P, Worsley C, Firth H. Sexual abuse in children and adolescents with intellectual disability. J Intellect Disabil Res. 2001;45(Pt 3):194–201. https://doi.org/10.1046/j.1365--2788.2001.00293.x.
103. Bramston P, Bostock J, Tehan G. The measurement of stress in people with an intellectual disability: a pilot study. Intl J Disabil Dev Educ. 1993;40:95–104.
104. Bramston P, Fogarty GJ. Measuring stress in the mildly intellectually handicapped: the factorial structure of the subjective stress scale. Res Dev Disabil. 1995;6:117–31.
105. Fogarty GJ, Bramston P, Cummins RA. Validation of life stress inventory for people with mild intellectual disability. Res Dev Disabil. 1997;18:435–56.
106. Lunsky Y, Bramston PA. Preliminary study of perceived stress in adults with intellectual disabilities according to self-report and informant ratings. J Intellect Disabil. 2006;31:20–7.
107. Wigham S, Hatton C, Taylor JL. The effects of traumatizing life events on people with intellectual disabilities: a systematic review. J Ment Health Res Intellect Disabil. 2011;4:19–39.
108. Little M, Paul K, Jordens CFC, Sayers E. Vulnerability in the narratives of patients and their carers: studies of colorectal cancer. Health. 2000;4:495–510.
109. Grabovschi C, Loignon C, Fortin M. Mapping the concept of vulnerability related to health care disparities: a scoping review. BMC Health Serv Res. 2013;13:94. https://doi.org/10.1186/1472-6963-13-94.
110. Perera B, Audi S, Solomou S, Courtenay K, Ramsay H. Mental and physical health conditions in people with intellectual disabilities: comparing local and national data. Br J Learn Disabil. 2020;48(1):19–27.
111. Emerson E, Glover G, Hatton C, Wolstenholme J. Trends in age-standardised mortality rates and life expectancy of people with learning disabilities in Sheffield over a 33-year period. Tizard Learn Disabil Rev. 2014;19(2):90–5. 17107573
112. Bittles AH, Glasson EJ. Clinical, social, and ethical implications of changing life expectancy in Down syndrome. Dev Med Child Neurol. 2004;46:282–6.
113. Patja K, Iivanainen M, Vesala H, Oksanen H, Ruoppila I. Life expectancy of people with intellectual disability: a 35-year follow-up study. J Intellect Disabil Res. 2000;44(Pt 5):591–9. https://doi.org/10.1046/j.1365-2788.2000.00280.x.
114. Janicki MP, Dalton AJ, Henderson CM, et al. Mortality and morbidity among older adults with intellectual disability: health services considerations. Disabil Rehabil. 1999;21:284–94.
115. Tyrer F, Smith LK, McGrother CW. Mortality in adults with moderate to profound intellectual disability: a population-based study. J Intellect Disabil Res. 2007;51:520–7.
116. Hollins S, Attard MT, von Fraunhofer N, Sedgwick P. Mortality in people with learning disability: risks, causes, and death certification findings in London. Dev Med Child Neurol. 1998;40:50–6.
117. Mencap 2007. Death by Indifference. London: Mencap. www.mencap.org.uk/deathbyindifference06/02/09.
118. Michael J. Health care for all: independent inquiry into access to healthcare for people with learning disabilities. London: Aldrick Press; 2008.
119. CIPOLD Team. Confidential Inquiry into premature deaths of people with learning disabilities. 2013. http://www.bris.ac.uk/cipold/reports/.
120. Heslop P, Blair PS, Fleming P, et al. The confidential inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. Lancet. 2014;383:889–95.
121. O'Leary L, Cooper S-A, Hughes-McCormack L. Early death and causes of death of people with

intellectual disabilities: a systematic review. J Appl Res Intellect Disabil. 2017;00:1–18.
122. New South Wales Ombudsman. Report of Reviewable Deaths in 2010 and 2011. Volume 2: Deaths of people with disabilities in care. Sydney: NSW Ombudsman; 2013. p. 21–60.
123. Haveman M, Heller T, Lee L, Maaskant M, Shooshtari S, Strydom A. Major health risks in aging persons with intellectual disabilities: an overview of recent studies. J Policy Pract Intellect Disabil. 2010;7:59–69. https://doi.org/10.1111/j.1741-1130.2010.00248.x.
124. Tyrer F, McGrother C. Cause-specific mortality and death certificate reporting in adults with moderate to profound intellectual disability. J Intellect Disabil Res. 2009;53:898–904.
125. Cooper SA, McLean G, Guthrie B, McConnachie A, Mercer S, Sullivan F, Morrison J. Multiple physical and mental health comorbidity in adults with intellectual disabilities: population-based cross-sectional analysis. BMC Fam Pract. 2015;16:110.
126. Berney T, Deb S. Epilepsy in learning disability. In: Shorvon S, Guerrini R, Cook M, Lahtoo S, editors. Oxford textbook of epilepsy and epileptic seizures: Oxford textbooks in clinical neurology. Oxford, UK: Oxford University Press; 2012. p. 195–9.
127. Marriot A, Turner S. Making reasonable adjustments to cancer screening: an update of the 2012 report. Public Health England; 2015.
128. Sheehan R, Hassiotis A, Walters K, Osborn D, Strydom A, Horsfall L, et al. Mental illness, challenging behaviour, and psychotropic drug prescribing in people with intellectual disability: UK population based cohort study. BMJ (Clinical researched.). 2015;351:h4326. https://doi.org/10.1136/bmj.h4326.
129. McGrother CW, Bhaumik S, Thorp CF, Hauck A, Branford D, Watson JM. Epilepsy in adults with intellectual disabilities: prevalence, associations and service implications. Seizure. 2006;15:376–86.
130. Robertson J, Hatton C, Emerson E, Baines S. Prevalence of epilepsy among people with intellectual disabilities: a systematic review. Seizure. 2015;29:46–62.
131. Vadlamudi L, Andermann E, Lombroso CT, Schachter SC, Milne RL, Hopper JL, Andermann F, Berkovic SF. Epilepsy in twins: insights from unique historical data of William Lennox. Neurology. 2004;62:1127–33.
132. Thibert RL, Conant KD, Braun EK, Bruno P, Said RR, Nespeca MP, Thiele EA. Epilepsy in Angelman syndrome: a questionnaire-based assessment of the natural history and current treatment options. Epilepsia. 2009;50(11):2369–76. https://doi.org/10.1111/j.1528-1167.2009.02108.x.
133. Uppal H, Chandran S, Potluri R. Risk factors for mortality in Down syndrome. J Intellect Disabil Res. 2015;59:873–81.
134. Kiani R, Tyrer F, Jesu A, Bhaumik S, Gangavati S, Walker G, Kazmi S, Barrett M. Mortality from sudden unexpected death in epilepsy (SUDEP) in a cohort of adults with intellectual disability. J Intellect Disabil Res. 2014;58(6):508–20.
135. Robertson J, Hatton C, Emerson E, Baines S. Mortality in people with intellectual disabilities and epilepsy: a systematic review. Seizure. 2015;29:123–33. https://doi.org/10.1016/j.seizure.2015.04.004.
136. van Karnebeek CDM, Stockler S. Treatable inborn errors of metabolism causing intellectual disability: a review and diagnostic approach. In: eLS. Chichester: John Wiley & Sons Ltd. 2014. http://www.els.net. https://doi.org/10.1002/9780470015902.a0024466.
137. Mathers CD, Loncar D. Projections of global mortality and burden of disease from 2002 to 2030. PLoS Med. 2006;3(11):e442.
138. McVilly K, McGillivray J, Curtis A, Lehmann J, Morrish L, Speight J. Diabetes in people with an intellectual disability: a systematic review of prevalence, incidence and impact. Diabet Med. 2014;31(8):897–904.
139. Butler J, Whittington J, Holland A, Boer H, Clarke D, Webb T. Prevalence of, and risk factors for, physical ill-health in people with Prader-Willi syndrome: a population-based study. Dev Med Child Neurol. 2002;44(4):248–55.
140. Ruwaard D, Hirasing RA, Reeser HM, van Buuren S, Bakker K, Heine RJ, Geerdink RA, Bruining GJ, Vaandrager GJ, Verloove-Vanhorick SP. Increasing incidence of type I diabetes in The Netherlands. The second nationwide study among children under 20 years of age. Diabetes Care. 1994;17(6):599–601. https://doi.org/10.2337/diacare.17.6.599.
141. Morin D, Mérineau-Côté J, Ouellette-Kuntz H, et al. Comparison of the prevalence of chronic disease among people with and without intellectual disability. Am J Intellect Dev Disabil. 2012;117:455–63.
142. Fort P, Lifshitz F, Bellisario R, Davis J, Lanes R, Pugliese M, Richman R, Post EM, David R. Abnormalities of thyroid function in infants with Down syndrome. J Pediatr. 1984;104(4):545–9. https://doi.org/10.1016/s0022-3476(84)80544-2.
143. Cheung EN, George SR, Costain GA, et al. Prevalence of hypocalcaemia and its associated features in 22q11·2 deletion syndrome. Clin Endocrinol. 2014;81:190–6.
144. Gale L, Naqvi H, Russ L. Asthma, smoking and BMI in adults with intellectual disabilities: a community-based survey. J Intellect Disabil Res. 2009;53:787–96.
145. Sturdy PM, Victor CR, Anderson HR, et al. Psychological, social and health behaviour risk factors for deaths certified as asthma: a national case-control study. Thorax. 2002;57:1034–9.
146. Mahon M, Kibirige MS. Patterns of admissions for children with special needs to the paediatric assessment unit. Arch Dis Child. 2004;89:165–9.

147. Bergström S, Carr H, Petersson G, Stephansson O, Bonamy AK, Dahlström A, Halvorsen CP, Johansson S. Trends in congenital heart defects in infants with Down syndrome. Pediatrics. 2016;138(1):e20160123. https://doi.org/10.1542/peds.2016-0123.
148. Botto LD, May K, Fernhoff PM, Correa A, Coleman K, Rasmussen SA, Merritt RK, O'Leary LA, Wong LY, Elixson EM, et al. A population-based study of the 22q11.2 deletion: phenotype, incidence, and contribution to major birth defects in the population. Pediatrics. 2003;112:101–7.
149. Oskarsdottir S, Vujic M, Fasth A. Incidence and prevalence of the 22q11 deletion syndrome: a population-based study in Western Sweden. Arch Dis Child. 2004;89:148–51.
150. Lodewyk HS, Mierop V, Kutsche L. Cardiovascular anomalies in DiGeorge syndrome and importance of neural crest as a possible pathogenetic factor. Am J Cardiol. 1986;58(1):133–7.
151. Bohmer CJ, Niezen-de Boer MC, Klinkenberg-Knol EC, Deville WL, Nadorp JH, Meuwissen SG. The prevalence of gastroesophageal reflux disease in institutionalized intellectually disabled individuals. Am J Gastroenterol. 1999;94:804–10.
152. Ohmer CJ, Taminiau JA, Klinkenberg-Knol EC, Meuwissen SG. The prevalence of constipation in institutionalized people with intellectual disability. J Intellect Disabil Res. 2001;45:212–8.
153. Patja K, Eero P, Livanainen M. Cancer incidence among people with learning disability. J Intellect Disabil Res. 2001;45(4):300–7.
154. Turner S, Emerson E, Glover G, Cornwall Cancer Screening Team. Making reasonable adjustments to cancer screening. Durham: Improving Health & Lives: Learning Disabilities Observatory. 2012. https://www.ndti.org.uk/uploads/files/Cancer_screening.pdf.
155. Evenhuis HM, Theunissen M, Denkers I, Verschuure H, Kemme H. Prevalence of visual and hearing impairment in a Dutch institutionalized population with intellectual disability. J Intellect Disabil Res. 2001;45(Pt 5):457–64. https://doi.org/10.1046/j.1365-2788.2001.00350.x.
156. Beange H, McElduff A, Baker W. Medical disorders of adults with mental retardation: a population study. Am J Ment Retard. 1995;99:595–604.
157. Hove O. Weight survey on adult persons with mental retardation living in the community. Res Dev Disabil. 2004;25:9–17.
158. Melville CA, Cooper S-A, Morrison J, Allan L, Smiley E, Williamson A. The prevalence and determinants of obesity in adults with intellectual disabilities. J Appl Res Intellect Disabil. 2008;21(5):425–37.
159. Walley AJ, Asher JE, Froguel P. The genetic contribution to non-syndromic human obesity. Nat Rev Genet. 2009;10:431–42.
160. Emerson E. Underweight, obesity and exercise among adults with intellectual disabilities in supported accommodation in Northern England. J Intellect Disabil Res. 2005;49:134–43.
161. Rimmer JH, Yamaki K. Obesity and intellectual disability. Dev Disabil Res Rev. 2006;12(1):22–7.
162. Kanter R, Caballero B. Global gender disparities in obesity: a review. Adv Nutr. 2012;3(4):491–8. https://doi.org/10.3945/an.112.002063.
163. Rimmer JH, Braddock D, Fujiura G. Cardiovascular risk factor levels in adults with mental retardation. Am J Ment Retard. 1994;98:510–8.
164. Fujiura GT, Fitzsimons N, Marks B. Predictors of BMI among adults with Down syndrome: the social context of health promotion. Res Dev Disabil. 1997;18:261–74.
165. Srikanth R, Cassidy G, Joiner C, Teeluckdharry S. Osteoporosis in people with intellectual disabilities: a review and a brief study of risk factors for osteoporosis in a community sample of people with intellectual disabilities. J Intellect Disabil Res. 2011;55(1):53–62. https://doi.org/10.1111/j.1365--2788.2010.01346.x.
166. NHS Digital, Health and Care of People with Learning Disabilities. 2016. https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/health-and-care-of-people-with-learning-disabilities-experimental-statistics-2015-to-2016. Accessed 4 Sept 2020.
167. Department of Health Mental Capacity Act. London, HMSO. 2005. https://www.legislation.gov.uk/ukpga/2005/9/contents. Accessed 4 Sept 2020.
168. Shattuck PT, Narendorf SC, Cooper B, Sterzing PR, Wagner M, Taylor JL. Postsecondary education and employment among youth with an autism spectrum disorder. Pediatrics. 2012;129(6):1042–9. https://doi.org/10.1542/peds.2011-2864.
169. Shattuck PT, Roux AM, Hudson LE, Taylor JL, Maenner MJ, Trani JF. Services for adults with an autism spectrum disorder. Can J Psychiatr. 2012;57(5):284–91. https://doi.org/10.1177/070674371205700503.
170. Gerhardt P, Lainer I. Addressing the needs of adolescents and adults with autism: a crisis on the horizon. J Contemp Psychother. 2011;41(1):37–45. https://doi.org/10.1007/s10879-010-9160-2.
171. Howlin P. Redressing the balance in autism research. Nat Clin Pract Neurol. 2008;4:407. https://doi.org/10.1038/ncpneuro0860.
172. Knickmeyer R, Baron-Cohen S, Raggatt P, Taylor K, Hackett G. Fetal testosterone and empathy. Horm Behav. 2006;49(3):282–92. https://doi.org/10.1016/j.yhbeh.2005.08.010.
173. Hendricks DR, Wehman P. Transition from school to adulthood for youth with autism spectrum disorders. Focus Autism Other Dev Disabl. 2009;24:77–88. https://doi.org/10.1177/1088357608329827.

174. Cederlund M, Hagberg B, Billstedt E, Gillberg IC, Gillberg C. Asperger syndrome and autism: a comparative longitudinal follow-up study more than 5 years after original diagnosis. J Autism Dev Disord. 2008;38(1):72–85. https://doi.org/10.1007/s10803-007-0364-6.
175. Eaves LC, Ho HH. Young adult outcome of autism spectrum disorders. J Autism Dev Disord. 2008;38(4):739–47. https://doi.org/10.1007/s10803-007-0441-x.
176. Howlin P, Alcock J, Burkin C. An 8 year follow-up of a specialist supported employment service for high-ability adults with autism or Asperger syndrome. Autism. 2005;9(5):533–49. https://doi.org/10.1177/1362361305057871.
177. Howlin P, Mawhood L, Rutter M. Autism and developmental receptive language disorder–a follow-up comparison in early adult life. II: social, behavioural, and psychiatric outcomes. J Child Psychol Psychiatry. 2000;41(5):561–78. https://doi.org/10.1111/1469-7610.00643.
178. Taylor JL, Seltzer MM. Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. J Autism Dev Disord. 2011;41(5):566–74. https://doi.org/10.1007/s10803-010-1070-3.
179. Sullivan A, Caterino LC. Addressing the sexuality and sex education of individuals with autism spectrum disorders. Educ Treat Children. 2008;31:381–94. https://doi.org/10.1353/etc.0.0001.
180. Stokes M, Newton N, Kaur A. Stalking, and social and romantic functioning among adolescents and adults with autism spectrum disorder. J Autism Dev Disord. 2007;37(10):1969–86. https://doi.org/10.1007/s10803-006-0344-2.
181. Turner D, Briken P, Schöttle D. Autism-spectrum disorders in adolescence and adulthood: focus on sexuality. Curr Opin Psychiatry. 2017;30(6):409–16. https://doi.org/10.1097/YCO.0000000000000369.
182. Stokes MA, Kaur A. High-functioning autism and sexuality: a parental perspective. Autism. 2005;9(3):266–89. https://doi.org/10.1177/1362361305053258.
183. Konstantareas MM, Lunsky YJ. Sociosexual knowledge, experience, attitudes, and interests of individuals with autistic disorder and developmental delay. J Autism Dev Disord. 1997;27(4):397–413. https://doi.org/10.1023/a:1025805405188.
184. Seltzer MM, Krauss MW, Orsmond GI, Vestal C. Families of adolescents and adults with autism: uncharted territory. Int Rev Res Ment Ret. 2001;23:267–94. https://doi.org/10.1016/S0074-7750(00)80014-2.
185. Taylor JL. Chapter One – the transition out of high school and into adulthood for individuals with autism and their families. Int Rev Res Ment Ret (Academic Press). 2009;38:2–28. https://doi.org/10.1016/S0074-7750(08)38001-X.
186. Reid DH, Everson JM, Green CW. A systematic evaluation of preferences identified through person-centered planning for people with profound multiple disabilities. J Appl Behav Anal. 1999;32(4):467–77. https://doi.org/10.1901/jaba.1999.32-467.
187. Billstedt E, Gillberg IC, Gillberg C. Autism in adults: symptom patterns and early childhood predictors. Use of the DISCO in a community sample followed from childhood. J Child Psychol Psychiatry. 2007;48(11):1102–10. https://doi.org/10.1111/j.1469-7610.2007.01774.x.
188. Howlin P, Moss P, Savage S, Rutter M. Social outcomes in mid- to later adulthood among individuals diagnosed with autism and average nonverbal IQ as children. J Am Acad Child Adolesc Psychiatry. 2013;52(6):572–81.e1. https://doi.org/10.1016/j.jaac.2013.02.017.
189. Baron-Cohen S, Wheelwright S. The Friendship Questionnaire: an investigation of adults with Asperger syndrome or high-functioning autism, and normal sex differences. J Autism Dev Disord. 2003;33(5):509–17. https://doi.org/10.1023/a:1025879411971.
190. Howlin P. Psychiatric disturbances in adulthood. In: Autism and Asperger syndrome: preparing for adulthood. 2nd ed. New York: Routledge; 2004. p. 270–99.
191. Howlin P, Moss P. Adults with autism spectrum disorders. Can J Psychiatr. 2012;57:275–83. https://doi.org/10.1177/070674371205700502.
192. Gillberg C, Steffenburg S. Outcome and prognostic factors in infantile autism and similar conditions: a population-based study of 46 cases followed through puberty. J Autism Dev Disord. 1987;17(2):273–87. https://doi.org/10.1007/BF01495061.
193. Seltzer MM, Shattuck P, Abbeduto L, Greenberg JS. Trajectory of development in adolescents and adults with autism. Ment Retard Dev Disabil Res Rev. 2004;10(4):234–47. https://doi.org/10.1002/mrdd.20038.
194. Aman MG, Lam KSL, Collier-Crespin A. Prevalence and patterns of use of psychoactive medicine among individuals with autism in the Autism Society of Ohio. J Autism Dev Disord. 2003;33:527–34. https://doi.org/10.1023/A:1025883612879.
195. Dove D, Warren Z, McPheeters ML, Taylor JL, Sathe NA, Veenstra-VanderWeele J. Medications for adolescents and young adults with autism spectrum disorders: a systematic review. Pediatrics. 2012;130(4):717–26. https://doi.org/10.1542/peds.2012-0683.
196. Doyle CA, McDougle CJ. Pharmacotherapy to control behavioral symptoms in children with autism. Expert Opin Pharmacother. 2012;13(11):1615–29. https://doi.org/10.1517/14656566.2012.674110.
197. Taylor JL, Seltzer MM. Changes in the autism behavioral phenotype during the transition to adulthood. J Autism Dev Disord. 2010;40(12):1431–46. https://doi.org/10.1007/s10803-010-1005-z.

198. Unwin G, Le Mesurier N, Bathia N, Deb S. Transition for adolescents and young adults with learning disabilities and mental health problems/challenging behaviours: the parent carers' views. Adv Ment Health Intellect Disabil. 2008;2(1):22–8. https://doi.org/10.1108/17530180200800004.
199. Abbeduto L, Seltzer MM, Shattuck P, Krauss MW, Orsmond G, Murphy MM. Psychological well-being and coping in mothers of youths with autism, Down syndrome, or fragile X syndrome. Am J Ment Retard. 2004;109(3):237–54. https://doi.org/10.1352/0895-8017(2004)109<237:PWACIM>2.0.CO;2.
200. Brodkin Edward S. Adults with Autism spectrum disorder: transition issues. In: McDougle C, editor. Autism spectrum disorder. Oxford University Press; 2016. p. 429–47. https://doi.org/10.1093/med/9780199349722.003.0023.