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REVIEW ARTICLE

Autism spectrum disorder in older adults with intellectual disability: a scoping review

E. Maguire[1,*], N. Mulryan[2,3], F. Sheerin[3], P. McCallion[3,4] and M. McCarron[3]

[1] *Department of Liaison Psychiatry, James Connolly Memorial Hospital, Dublin, Ireland*
[2] *Daughters of Charity Disability Support Services, St. Vincent's Centre, Dublin, Ireland*
[3] *Trinity Centre for Ageing and Intellectual Disability (TCAID), Trinity College, University of Dublin, Dublin, Ireland*
[4] *Temple University College of Public Health, Philadelphia, PA, USA*

Introduction: Ireland has an ageing population of persons with intellectual disability (ID), autism spectrum disorder (ASD) and both (ID/ASD). Despite this, little is known about the prevalence of ASD and its effect on functional outcomes, psychiatric comorbidity or diagnostic issues in an older population with ID. This article reviews the literature on older adults with ID/ASD and identifies opportunities for future research in this population.

Method: The authors searched the Medline, Pubmed, Embase, CINAHL and PsychInfo databases using the search terms using key words: (older adults) AND (ID OR mental retardation OR learning disability) AND (autism OR ASD). After excluding articles for relevance, a scoping review was carried out on the results retrieved.

Results: Of the 1227 articles retrieved from the literature on ID and autism/ASD in older adults, 85 articles were relevant to an adult population with ID/ASD. The data were collated and are presented covering domains of diagnosis, prevalence, psychiatric comorbidities and functional outcomes.

Conclusions: Despite increased prevalence in childhood ASD in the last 20 years, there is a lack of research regarding adults, especially older adults, with ASD, up to half of whom will have some level of ID. The existing literature suggests that older adults with ID/ASD may have reduced functional independence, increased psychiatric comorbidity and psychotropic prescribing and more behavioural presentations than the older population generally or those with ID only. There is a need for longitudinal data to be collected on this ageing population so that care and management needs can be met in the future.

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Keywords: Intellectual disability, older adults, later life, ageing, autism, autism spectrum disorder, ASD, learning disability.

Introduction

Adults with intellectual disability (ID) are living longer than previously. Figures from the National Intellectual Disability Database show an increasing percentage in those with moderate to profound ID aged 35 years and over, from 28.5% in 1974 to 48.7% in 2015 (Doyle & Carew, 2015). While adults with autism spectrum disorder (ASD) have a slightly decreased life expectancy compared with the neurotypical population (Perkins & Berkman, 2012), anywhere between 8% and 40% of the adult population with ID will also have ASD (Bhaumik et al., 2008; Cooper, et al., 2007; de Bildt et al., 2005; La Malfa et al., 2004; Arvio & Sillanpää, 2003; Matson & Shoemaker, 2009). The knowledge base on life expectancy for this cohort with both ID and ASD is limited. Behavioural presentations (McCarthy et al., 2010), decreased adaptive functioning (Matson et al., 2009b), increased psychiatric (Totsika et al., 2010; Dunn et al., 2020) and medical (Perkins & Berkman, 2012; Dunn et al., 2020) comorbidities are common to both disorders and have implications for multi-disciplinary care needs. Age-related risk factors within the general population are still present and some groups are at higher risk, for example those with Trisomy 21 who develop early-onset dementia, on average, in their mid-fifties (Lai & Williams, 1989; Visser et al. 1997; McCarron et al., 2014; McCarron et al., 2017). Even in those individuals with ID and without Down syndrome, dementia is more common compared with the general population (Cooper & van der Speck, 2009). This article looks at the evidence base for screening, diagnosis, management and outcomes for older adults with both ID and ASD (ID/ASD) and where future research might be directed to optimise their care.

Method

Research databases Medline, Pubmed, Embase, CINAHL and PsychInfo (inception to 4 August 2020)

*Address for correspondence: E. Maguire, Department of Liaison Psychiatry, James Connolly Memorial Hospital, Blanchardstown, Dublin 15, Ireland.
(Email: Erica.maguire@hse.ie)

were searched using key words: (older adults) AND (ID OR mental retardation OR learning disability) AND (autism OR ASD).

1989 results were reduced to 1227 after duplicates were removed.

Studies or articles focusing on children, adolescents, under 35s only or their parents or caregivers ($n = 467$) were firstly excluded, apart from those studying children for estimates of current ASD prevalence. The following were excluded: genetic, metabolic or other aetiological studies ($n = 199$); studies relating to ASD (adult spinal disorder or atrial septal defect) ($n = 3$); studies not in English ($n = 51$); case reports or small case studies (<5 subjects) ($n = 13$) and studies or articles concerning specific syndromes only were excluded (e.g. Fragile X Syndrome, Smith Magenis Syndrome) as being outside the scope of this article, given that these studies tended to focus on anomalies and characteristics specific to these genotypes and were not relevant to a broader scoping review on ageing in ID and autism ($n = 175$).

The abstracts of 319 remaining results of possible interest to an adult population with ID/ASD were then screened for relevance and the full text was consulted if relevance was questionable. Ten papers concerning dental or anaesthetic techniques in this population were excluded as being outside the scope of this article. Sixty-seven results were excluded as not identifying a study group or subgroup with ASD. Forty-three results were excluded as not identifying a study group or subgroup with an ID. Nineteen results were excluded as pertaining to the family members or carers of adults with ID or ASD only, as the carer perspective is outside the scope of this article. Seventy-eight articles of possible interest were deemed irrelevant – examples include focus on metabolic markers for ID/ASD, older papers that refer to defunct diagnostic categories like 'autistic psychosis' or 'idiots-savants', validation of scales and subscales in foreign language populations, trials of medication for challenging behaviours and neuroimaging characteristics of adults with ID or ASD, among others. The full-text article was not available in ten results of possible interest.

Eighty-five articles of interest were included for appraisal and the data are presented covering domains of diagnosis, prevalence, psychiatric comorbidities and functional outcomes in adults with ID/ASD. Seven articles were also included as relating to current childhood prevalence of ASD, in order to estimate future generations of an ageing population with ASD.

PRISMA Guidelines were followed in the conduct of this review (Tricco, 2018). Additional sources of information were identified from websites of governmental and non-governmental organisations, e.g. Irish Department of Health and National Institute for Health and Care Excellence (U.K.), where relevant.

Sixteen further papers of interest were identified from references of those included within the study. Six articles of interest to the Irish population were personally identified by the authors of this study. One article of interest regarding ageing in autism was personally identified by an author of this study.

Results

On examining extant literature, the data were collated and are presented covering domains of diagnosis, prevalence, psychiatric comorbidities and functional outcomes.

Diagnosis

Older people are less likely to have been diagnosed with ASD for various reasons, mainly that 'childhood autism' (Kanner, 1943) was largely ignored in adulthood for decades. Diagnostically, DSM-IV required that symptoms were present before 3 years which presented some difficulty in establishing a reliable history for adult subjects, although this requirement has since been dispensed with in DSM-V. Public awareness of ASD has grown, but much of the research continues to focus on children. Yet, the estimated prevalence of 1% in the community has been found across all age groups (Brugha et al., 2011), so autism is no longer only a disorder of childhood.

Defining 'ageing' in ID and ASD is somewhat arbitrary, given that the evidence base largely emerged in the last decade. A wide range of cutoffs has been used in different studies on ageing in this context, from 30 years (Wise et al., 2019) to 65 years (Cooper, 1997).

This review selected 35 years as a cut-off for selecting studies of interest, given that national figures in this jurisdiction (Doyle & Carew, 2015) demonstrate an increase in adults with ID living over this age in recent decades and that a mean age of death of 39.5 years in 'low-functioning ASD' was noted in one Swedish study (Hirvikoski et al., 2016).

Overall, mortality is increased in ASD (Hirvikoski et al., 2016; Hwang et al., 2019), probably owing to medical comorbidity associated with ID and genetic syndromes. However, it has not been proven that autism *per se* reduces life expectancy (Gillberg et al., 2010). One review notes that low case identification in an adult population and a relatively poor research focus on ageing in autism means that it is unclear whether autism in itself can predict certain trajectories of mortality (Janicki et al., 2008).

There is a lack of consensus on what ASD screening, diagnostic and neuropsychological evaluations to use in an adult cohort (Roestorf et al., 2019). Table 1 summarises findings in this regard.

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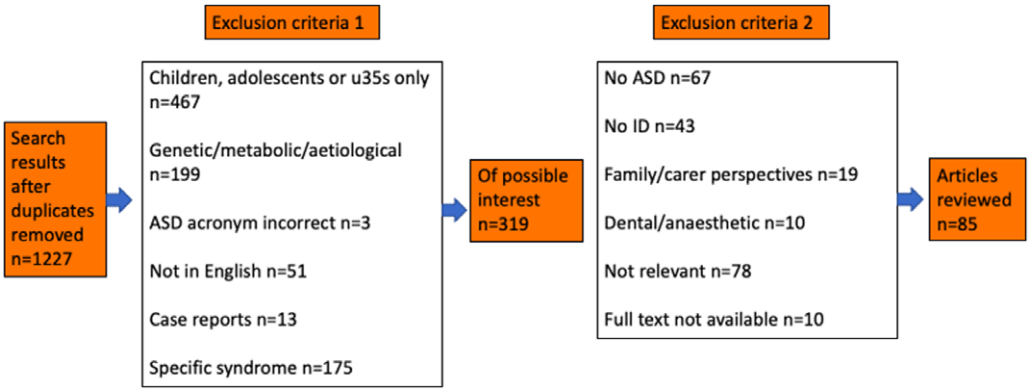

Fig. 1. Study flow chart.

Some self-report questionnaires may not be appropriate for those with an ID due to cognitive ability (Roestorf et al., 2019). The prevailing need for a reliable informant history to make an accurate diagnosis of ASD in those with ID (Bhaumik et al., 2010; Matson et al., 2012) is also recommended in an older population (van Niekerk et al., 2011). The latter authors warn that the probable under-identification of ASD in an older population may lead to iatrogenic harm, if incorrectly treated as psychiatric disorder.

Prevalence

In the last two decades, with more comprehensive assessments and increased public awareness, the estimated prevalence of ASD has increased. While an earlier study (Brugha et al., 2011) found no evidence of a statistically significant reduction in the prevalence of ASD as a function of age, another noted a small decrease in ASD prevalence with age, perhaps due to decreased longevity in those with moderate to profound ID (Wise, 2020).

Table 2 summarises recent findings regarding estimates of prevalence of ASD, ID and both.

The prevalence of ID in adults with ASD is being revised. Recent data from the US SPARK cohort (Fombonne et al., 2020) shows that most of those with ASD aged 30 and over received their diagnosis in adulthood. Changes in diagnostic criteria (e.g. the removal of the 'early onset' requirement in DSM-V) and overall increased public awareness of ASD have reduced the proportion of those with ASD who are believed to also have an ID (Table 2).

From the perspective of those with ID, the estimated prevalence of ASD in adults with ID varies (Table 2), depending on the screening tools or diagnostic criteria used. Innovative tools are emerging, such as music-based screening tool MUSAD (Bergmann et al., 2015). One study identified a doubling of the previously recognised prevalence of ASD when 256 adults with severe ID were recruited for screening and diagnosis, suggesting a tendency towards underestimation (Saemundsen et al., 2010). The known prevalence of ID in Ireland is 5.96/1,000 (or 3.49/1,000 with moderate to profound ID) (Hourigan et al., 2018). Unfortunately, the National Intellectual Disability Database (NIDD) in Ireland does not capture data on ASD at present (Dept. of Health, 2018).

Finally, autistic traits may be present in those with ID who do not meet the diagnostic criteria for ASD. One study (Bhaumik et al., 2010) found that 69% of an adult population with ID displayed at least one autistic trait and that therefore autistic traits in people with ID were not specific to ASD. Those with two or more autistic traits without an ASD diagnosis tended to be older, suggesting that some traits e.g. elaborate routines or reduced social interaction may develop or become more prominent with age. A previous study (Shah et al., 1982) found strongly autistic traits in 38% of adult inpatients with ID. Matson et al. (2008) assessed IQ level as a moderator for expression of the ASD triad of impairments in adults with ID. ASD traits in those with ID only were affected by IQ level, but symptoms were not significantly moderated by IQ level in the ID/ASD group. They also noted that the domain of repetitive behaviours caused the most functional impairment for those with ID/ASD, followed by social interaction, then communication.

Psychiatric comorbidity

People with an ID have a significantly higher rate of comorbid psychopathology than the general population (Matson & Shoemaker, 2009; Horovitz et al., 2011). Difficulties in identifying psychiatric disorder in subjects with ASD include the diagnostic overlap between the triad of impairments in autism and symptoms of major psychiatric disorders (Bakken et al., 2010). The presence of complex behavioural presentations, or 'challenging behaviours', may also affect

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Table 1. *Summary of findings regarding screening, diagnostic and evaluation tools in an older population with ASD/ID*

Tools used	Study	Comments
Screening		
PPD-MRS – Screening	Kraijer & de Bildt (2005)	Screening for pervasive developmental disorder in children and adults (aged 2–55) with mild to profound ID
Autism-spectrum Quotient (AQ) – Screening	van Niekerk et al. (2011)	Screening for ASD in an older population with or without ID AQ developed by Baron-Cohen et al. (2001) NB – Recommends caregiver also completing the autism questionnaire for relatives (AQ-R)
DiBAS-R – Screening	Heinrich et al. (2018)	Screening for ASD in adults with mild-moderate ID
DASH-II – Screening	Matson et al. (1999)	Screening for depression adults with severe-profound ID, with or without comorbid ASD
Social communication questionnaire (SCQ)-current – Screening	Sappok et al. (2015)	Screening for ASD in adults with ID. May be more accurate than the SCQ-lifetime version
DiBAS-R & ACL – Combined tool screening	Mutsaerts et al. (2016)	Screening for ASD in adults with ID May improve accuracy
Diagnostic		
ADOS; ADI-R – Diagnostic	Sappok et al. (2013b)	Diagnosis of ASD in adults with ID. Limitations – lack of empirical data for use in an old age population
ADOS – Diagnostic	Berument et al. (2005)	Diagnosis of ASD in older adults with severe-profound ID; adapted Pilot study with positive reliability and validity results
OASID – Diagnostic	de Vaan et al. (2016)	Behavioural assessment of ASD in adults with moderate-profound ID Observational tool developed for those with a sensory impairment
ADI-R, ADOS-G – Diagnostic	NICE (2012)	Recommends these tools for diagnosis of ASD in adults with ID
Miscellaneous		
Standard neuropsychological tests – Profiling (Theory of mind, central coherence and executive functioning)	van Niekerk et al. (2011)	Identification of ASD traits in older adults with or without ID NB – In evaluating theory of mind, central coherence and executive dysfunction deficits in older people, these 'strengths and weaknesses' are non-specific to ASD
Executive functioning – Profiling (Tower of London test, Mazes task, Knock and Tap task, Verbal Conflict task, modified Wisconsin Card Sorting Task, COWA task of verbal fluency, Spatial Span task)	Barnard et al. (2008)	Identifying executive dysfunction as a primary indicator of ASD in adults with ID/ASD NB Significant difference in working memory and planning tasks when comparing an ID/ASD group to one with ID only
WHOQOL-BREF – Short Form; Personal Well-being Index (PWI) – Quality of Life Assessment	Roestorf et al. (2019)	Assessing the quality of life in older adults with ASD with or without ID

Table 2. *Estimates of prevalence*

Study	Denominator	Numerator	Prevalence estimate
Kogan et al. (2018); Dietz et al. (2020)	Child population (U.S.)	ASD in child population (U.S.)	2–2.5%
Boilson et al. (2016); Dept. of Health (2018)	Child population (Ireland)	ASD in child population (Ireland)	1.5%
Brugha et al. (2016)	General population, inclusive of all IQ levels	ASD in the general population, inclusive of all IQ levels	1.1%
Dietz et al. (2020)	Adults (aged 18–84) (U.S.)	ASD in adults (aged 18–84) (U.S.)	2.2%
Gillberg (1995)	Adults and children with ASD	ID in adults and children with ASD	75% NB – author later revised this – see below
de Bildt et al. (2005); Gillberg & Soderstrom (2003)	Adults and children with ASD	ID in adults and children with ASD	15–17%
Bhaumik et al. (2008)	Adult population with ASD	ID in adult population with ASD	8.8%
Cooper et al. (2007)	Adult population with ID	ASD in adult population with ID	2–7.5% Depending on diagnostic method used
Sandhu & Tomlins (2017)	Specialist treatment and assessment units for adults with ID	ASD in adults with ID in a specialist inpatient unit	40%
de Bildt et al. (2005)	Children and adults (aged 2–55) with ID	ASD in children and adults (aged 2–55) with ID	16.7% Based on DSM-IV-TR
La Malfa et al. (2004)	General adult population with ID	ASD in general adult population with ID	40%
	General adult population with ASD	ID in general adult population with ASD	70%
Bryson et al., (2008)	Adolescents with ID	ASD in adolescents with ID	28%

assessment for psychiatric disorder (O'Dwyer et al., 2018). Table 3 summarises the literature relating to ID/ASD and these comorbidities.

Prescribing for adults with ID/ASD

Concerns have been raised about the inappropriate prescribing (Matson & Neal, 2009; O'Dwyer et al., 2019) and monitoring of side effects (Paton et al., 2016) of psychotropics in a population with ID. There is a lack of quality evidence regarding the prescription of psychotropics in a population with ASD, as much of the research focuses on children and ethical issues arise in relation to carrying out randomised controlled trials. The importance of correctly differentiating psychiatric disorder from ASD impairment or behavioural problems lies in the risk of inappropriate prescribing (e.g. benzodiazepines, antipsychotics) and iatrogenic harm in a population already at risk of polypharmacy (O'Dwyer et al., 2016; Schoufour et al., 2018). Table 4 summarises the literature in this regard.

Functional outcomes

All older adults have the added complications of age-related cognitive decline, frailty and medical comorbidity to contend with. One of the hopes for older adults with ID is that functional independence is maintained as much as possible. Objective measurement of functioning might be used to assess activity limitations, such as the Waisman Activities of Daily Living (W-ADL) scale, validated in a longitudinal study for adults with autism and ID (Maenner et al., 2013). Functional outcomes may be affected by medical comorbidity and care setting factors (Table 5).

Discussion

Research on the ageing of people with ID in general has been challenging given that ageing with a known diagnosis of ASD has been a relatively recent phenomenon, ageing services and policies have not included people with ID, and the prevalent services philosophy in ID services has been focused upon building independence rather than maintaining function (McCallion et al., 2017). Available research confirms patterns of comorbid conditions are often different, onset of conditions may be at earlier ages, there are fewer natural supports such as spouses and one's own children in older years, and access to needed healthcare is often difficult and not suitable for needs (Burke et al., 2019; McCarron et al., 2013,2017; McCausland et al., 2021). Yet there are reports of people with ID who are living fulfilling lives as they age maintaining valued relationships and community connections (McCausland et al., 2018). There are also examples of ageing in place and of housing and programming options that have lessons for the general population (Jokinen et al., 2013; McCallion et al., 2017). As research develops on the ageing of people with ASD, there must be attention to understand the similarities to and differences from people with ID and without ASD, as much as attention to those issues compared to the general population.

Firstly, research is needed to assess the prevalence of adults with ID/ASD in Ireland and in other jurisdictions. The effect of ageing on ASD prevalence should be observed, in both the neurotypical population and in those with ID, especially as there is some evidence for a decreased life expectancy with those with ASD. The benefits of attentive medical and nursing care in residential care facilities may not be as easily accessible to those who are able to live independently, but who may be isolated or socially avoidant in the context of autistic traits.

Any research in the area of ID/ASD, psychiatric comorbidity and behavioural problems is hampered by the overlap between the symptoms of many major mental illnesses, the decreased cognitive and adaptive functioning associated with an ID and the triad of impairments classically observed in ASD. Studying these symptoms in an ageing population may be further complicated by age-related cognitive impairment, a lack of reliable informants (particularly regarding early developmental history) and medical comorbidity. Awareness of these difficulties, which are demonstrated consistently in the literature to date, may better inform future study design. The drive to validate specific screening and diagnostic tools for psychiatric and neuropsychological comorbidity within a population with ID/ASD is one positive trend which may contribute to the growing evidence base. Longitudinal observation of the effect of ageing on cognitive ability and mental health conditions in ID and ASD has been deemed the foremost priority in data collection by many researchers.

Appropriate screening and diagnostic tools should be validated for those with ID and used as a matter of best practice. Ideally, screening for ASD would be carried out on all adults registered with the NIDD, although it is acknowledged that this would be an onerous task. The correct identification of ASD, or even autistic traits, in an ID population may save some patients from being labelled unfairly as having 'challenging behaviours' or misdiagnosed with major mental illness. Psychotropic medication may be inappropriately prescribed in these situations. If increased medical comorbidity cannot be avoided (e.g. epilepsy, age-related cardiovascular changes), a prudent diagnostic approach for psychiatric symptoms might reduce the drug burden in an ageing population.

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Table 3. *Summary of findings regarding ID/ASD and psychiatric comorbidity/challenging behaviours*

Study	Summary of findings
Dunn et al. (2020)	OR of 25.55 for psychiatric comorbidity in people with ID/ASD (*v.* general population)
Cooper (1997)	Over 65s with ID/ASD more likely to have comorbid psychiatric disorder (*v.* under 65s with ID)
Deb et al. (2001)	Prevalence of psychiatric comorbidity in individuals with ID – 10–40%
Nylander et al. (2018)	Comorbid ID increased the likelihood that a patient with ASD was in receipt of specialised psychiatric care (*v.* those with ASD alone)
Horovitz et al. (2011)	Regarding suitability of screening tools for psychiatric comorbidity in older populations – noted that scores in the DASH-II (mental disorder) subscales remain relatively stable over time
Buck et al. (2014); Bishop-Fitzpatrick & Rubenstein (2019); Hollocks et al. (2019)	Lower rates of diagnosis of anxiety and depressive disorders in ID/ASD (*v.* adults with ASD only) NB rates may be underestimated due to communication difficulties in ID/ASD group
Tsakanikos et al. (2006)	No difference in the rate of psychiatric disorder in adults with ID/ASD (*v.* adults with ID only)
Cervantes & Matson (2015); Bakken et al. (2010)	Higher rates of psychiatric comorbidity in adults with ID/ASD (*v.* adults with ID only).
Totsika et al. (2010)	Psychiatric comorbidity not proportionately higher among older adults with ID/ASD (*v.* older adults with ID only) Older adults with ID/ASD have fewer behavioural problems (*v.* younger adults with ID/ASD) suggesting a decrease in behavioural problems over time
Hand et al. (2019b)	Greater odds of a suicide attempt in adults with ID/ASD (*v.* adults with ASD only) Lower odds of suicidal ideation in adults with ID/ASD (*v.* adults with ASD only)
O'Dwyer et al. (2018)	Challenging or 'problem' behaviours are found in approximately half of older Irish adults (over 40) with intellectual disability
Sappok et al. (2013a); Sappok et al. (2014)	Lower level of emotional development in adults with ID/ASD (*v.* adults with ID only) which may predict challenging behaviours
Lundqvist (2013)	Comorbid ASD and severity of ID were risk factors for 'challenging behaviours' in an adult population with ID Aggressive/destructive behaviour peaked in older age group (≥70 years)
McClintock et al. (2003); Felce & Kerr (2013)	Noted an association between adults with ID/ASD and self-injury, property destruction and aggression (*v.* adults with ID only)
Tsiouris et al. (2011)	Association between ASD and aggression in a large cohort of adults receiving ID services
McCarthy et al. (2010)	Adults with ID/ASD had four times the rate of 'behavioural issues' (*v.* adults with ID only)
Roy & Balaratnasingam (2010)	Revised diagnosis of ASD given to 13 out of 14 indigenous Australian adult subjects originally diagnosed with schizophrenia
Kats et al. (2013)	Adults with ID/ASD had double the prevalence of self-injurious behaviour and behavioural problems; (*v.* adults with ID only) Adults with ID/ASD twice as likely to be prescribed medications for behavioural problems (*v.* adults with ID only)
Matson & Rivet (2008)	Frequency of challenging behaviours increases with severity of autistic symptoms in adults with ID
Folch et al. (2018); Tureck et al. (2013); Collacott et al. (1998)	Self-injurious behaviour more frequent in adults with ID/ASD (*v.* adults with ID only)
Cohen et al. (2010)	Higher rates of aggression and self-injury in females with ID/ASD (*v.* females with ID only)
Cooper et al. (2009)	No association with higher rates of self-injurious behaviour in adults with ID/ASD (*v.* adults with ID only)
Baudewijns et al. (2018)	Higher prevalence of major depressive disorder in adults with ID/ASD and 'behavioural problems' (*v.* adults with ID/ASD and no 'behavioural problems') NB Depressive symptomatology may be incorrectly labelled as 'behavioural problems'
Felce et al. (2009)	Discusses general difficulties in accurately diagnosing mental illness in those with ID/ASD and with challenging behaviours

Table 4. *Summary of literature regarding prescribing of psychotropics in ID/ASD*

Study	Summary of findings
LoVullo & Matson (2009)	15.8% of ID/ASD subgroup prescribed psychotropic medications (*v.* 0% of ID only group)
Esler et al. (2019); Tsakanikos et al. (2007); Sheehan et al. (2015)	ID/ASD group more likely to be prescribed psychotropics (*v.* those with ID only) ID/ASD status predicts a higher number of psychotropics prescribed (*v.* ID only)
Axmon et al. (2017a)	ID or ASD *and* dementia group more likely to be prescribed psychotropics (*v.* ID or ASD group without dementia) ID or ASD *and* dementia group less likely to be prescribed acetylcholinesterase inhibitors (*v.* general population with dementia)
de Kuijper & Hoekstra (2017); de Kuijper & Hoekstra (2018)	Physicians may be less likely to discontinue off-label psychotropic prescribing for those with ID/ASD (*v.* those with ID only) Discontinuation may be more likely to fail in those with ID/ASD (*v.* those with ID only)

Table 5. *Summary of findings regarding physical and mental health outcomes in adults with ID/ASD*

Study	Findings
Magiati et al. (2014)	In a population with ASD, higher childhood IQ is a consistent predictor of cognitive ability, social outcomes and adaptive functioning in adulthood
Wise et al. (2019)	In an adult population with ASD, those with IQ >55 have a higher degree of functional independence. ASD impairments may explain variation in functioning
Wilkins & Matson (2009)	Adults with ID/ASD group have greater social impairment on seven global measures of social behaviour (*v.* adults with ID only)
Matson et al. (2009a)	Adaptive behaviour capacity in those with ID decreases as ASD features increase
Lord et al. (2015)	Developmental trajectories of children with ASD to young adulthood, with and without ID Noted that some features of ASD may improve over time, but trajectory of change for those with IQ<70 is less positive
Bishop-Fitzpatrick & Rubenstein (2019)	In a population of adults (over 40) with ASD, a higher prevalence of physical and mental health conditions was noted (*v.* general population), regardless of ID Higher rates of epilepsy and lower rates of depression in anxiety in ID/ASD group (*v.* ASD only)
Flygare Wallén et al. (2018)	Higher rates of obesity and diabetes mellitus in adults with ID or ASD (*v.* general population) Rates between the groups comparable in over 50s
Mouridsen et al. (2017)	Higher rate visual disorder in adults with ASD or ID/ASD (*v.* general population)
Miot et al. (2019)	Higher burden of medical comorbidity in adults with ID/ASD; (*v.* general population) positive correlations with age, reduced independence and polypharmacy noted
Chaplin et al. (2011)	Lower rates of alcohol and illicit substance use in adults with ID/ASD (*v.* ID only; *v.* general population)
Axmon et al. (2017b)	Lower rates of COPD in adults with ID and ID/ASD (*v.* general population)
Beadle-Brown et al. (2009)	Comorbid ASD does not predict reduced subjective quality of life in those with ID
Totsika et al. (2010)	Comborbid ASD does not predict any significant difference in quality of life in those with ID
Gerber et al. (2011)	Specific residential programmes for adults with ID/ASD may improve quality of life over time (linked to a decrease in challenging behaviours)
Felce & Perry (2012)	No significant advantage to housing adults with ID/ASD separately from those with ID only
Durbin et al. (2018)	Individuals with ID more likely than individuals without ID to visit the emergency department (ED); may be reduced by improved continuity of primary care
Hand et al. (2019a)	Presence of ID in adults (with or without co-occurring ASD) increases the risk for preventable hospitalisations
Rubenstein & Bishop (2019)	Adults with ID/ASD claim a higher proportion of public health resources (*v.* adults with ID or ASD only)
Shin et al. (2018)	Lower cancer screening rates among subjects with ID or ASD (*v.* general population)
Kiani et al. (2013)	Higher proportion of ASD among adults with ID in rural settings (UK) (*v.* adults with ID in an urban setting)

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Currently, many older adults with ID live in residential or supported care facilities and State funding is allocated for their social, occupational and healthcare needs. The increasing prevalence of ASD in children is of relevance for future resource planning, as ageing may lead from a family-based care model in childhood/early adulthood to residential care in later years. However, those who continue to live with family or who live independently must also have their comorbid medical and psychiatric conditions appropriately managed, potentially allied to day centre or work placement attendance. Some ID service providers have developed specific day and residential services for people with ASD, but not always in a purpose-built fashion. We need to optimise independence and acquisition of daily living skills in adults with ID/ASD. There is a challenge in improving and maintaining adaptive functioning in additional ways to that of the neurotypical ageing population.

Limitations

This review leads to a discussion on what we know, and what is as yet unknown, about an older population with ID/ASD. Most of the evidence is drawn from cross-sectional study designs. A longitudinal study measuring social and occupational functioning, residential and care needs and healthcare data is indicated to provide for future generations with ID/ASD.This review is best categorised as a scoping review, a type of systematic knowledge synthesis which identifies the main concepts, theories, sources and knowledge gaps within the evidence base for a particular topic (Tricco et al., 2018). It is therefore a brief and broad overview which the reader may use to identify topics of more specific interest for systematic appraisal or meta-analysis. It is possible, for example, that the planner of a residential facility for adults with ID/ASD may wish to consult the view of family or caregivers, the evidence base on which has been excluded from the scope of this paper for expedience. Different studies use different cutoffs to define 'ageing' or 'older' and employ different stratifications of age groups which limit direct comparability of subjects. Ten papers of possible interest were not included as the full text could not be retrieved, and the 51 papers not in English may have added a different perspective, given the global burden of ID and ASD and the cultural and socioeconomic differences between international healthcare systems.

Conflict of interest

Author [EM] has no conflicts of interest to disclose.

Ethical standards

The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committee on human experimentation with the Helsinki Declaration of 1975, as revised in 2008. The authors assert that ethical approval for publication of this review was not required by their local Ethics Committee.

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