

ORIGINAL ARTICLE



Ageing, osteoporosis and intellectual disability; risks differ, and diagnosis can be missed

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Abstract

Background: People with intellectual disability often present atypically for various health conditions, making it challenging to identify concerns, particularly when communication challenges are also considered. Additionally, they may face barriers to healthcare access, resulting in many conditions going unnoticed. Health screening inequities are also evident in this population, and osteoporosis, a silent condition often only diagnosed postfracture, requires screening; however, if this does not happen, it may result in unnecessary fracture. Therefore the aim of this study is to identify predictors of osteoporosis in older adults with intellectual disability and examine potential inequity in the diagnosis of the condition.

Methods: The study used data from the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA). Bone quality was measured using quantitative ultrasound (QUS). Logistic regression was performed to identify significant predictors of poor bone quality, including chronic health conditions, dietary intake, medication use and activity levels.

Results: Out of 575 participants who completed QUS, osteoporosis prevalence was objectively measured at 41%, with a further 33.2% measured within the osteopenic range, but less than 2 in 10 had a doctor's diagnosis of osteoporosis. Reported Dual-Energy X-ray Absorptiometry screening uptake was low at 18.2%. Three major predictor variables of osteoporosis and osteopenia were found significant: difficulty walking 100 yards, taking antiepileptic drugs medicines and taking proton pump inhibitors. The model achieved an overall classification accuracy of 70.8% for osteopenia and 72.5% for identifying osteoporosis.

Conclusion: The study highlights the different risk factors in people with intellectual disability, the potential for missed diagnoses and the likelihood there is inadequate screening. There is an urgent need for robust risk assessment and reasonable adjustments to ensure equitable screening and targeted preventive strategies. Clinicians must consider specific concerns for this population to avoid missed

diagnoses and reduce the adverse effects of osteoporosis/osteopenia, such as an increased risk of fragility fractures.

KEYWORDS

assessment inequalities, intellectual disability, osteoporosis, risk factors

Keypoints

- People with intellectual disability can have different ways of showing health problems, which makes it hard for doctors to know when something is wrong, especially when they cannot speak or find it hard to say how they feel.
- Sometimes, they also face difficulties in getting proper healthcare assessments, so some health issues may not be known. Poor bone health can go unnoticed, which could lead to people experiencing a broken bone.
- We tried to find out why some older adults with intellectual disability may have poor bone health and are at risk of breaking bones. We also looked at whether these individuals might not get examined for these problems.
- We studied information on 575 people in the study, and we found that 7 out of 10 people had poor bone health. Less than 2 out of 10 of them had it diagnosed by a doctor. Many of them had not been screened properly for this condition.
- We found three important things to help expect poor bone health: if someone has difficulty walking 100 yards, if they are taking certain medicines for their epilepsy, and if they are using certain types of medications for stomach problems. This is different to people without intellectual disability.
- It is important for healthcare providers to carefully assess the risks and make necessary changes to ensure everyone gets the right screenings and preventative care. By doing this, we can avoid problems like fractures, and we can close the gap of health inequalities between people with intellectual disability and those without.

1 | INTRODUCTION

Global ageing has seen an unprecedented increase in older adults over the last number of decades, and the United Nations estimate these trends to continue with forecasts such as an estimated two billion of the world's population will be over 60 years by 2050 (Gu et al., 2021). Similar increases have been observed for individuals with intellectual disability (Hourigan et al., 2018), which is a great success attributed to better education, housing, healthcare and social support (Schepens et al., 2019). However, longevity for individuals with intellectual disabilities starts from a low base whereby, for example, as recently as 1983, the average lifespan for those with Down syndrome was 25 years (Manickam, 2021; Presson et al., 2013) and whilst this lifespan has now increased to over 60 years, people with intellectual disability continue to die on average 20 years earlier than their peers without intellectual disability (Doyle et al., 2021; McCarron et al., 2015). Possible contributing factors rest with the increased burden of chronic health conditions and multimorbidity as they age (Hussain et al., 2020; Kinnear et al., 2018; McCarron

et al., 2013; Tyrer et al., 2019), along with noted healthcare inequalities such as lack of reasonable adjustments or inequity of access to healthcare (Doherty et al., 2020; Northway, 2017; Shady et al., 2022). It is estimated that the burden of multimorbidity (the coexistence of two or more chronic health conditions) consistent with ageing, ranges between 60% and 90%, respectively (Kinnear et al., 2018; Tyrer et al., 2019). The burden and negative impact on individuals with intellectual disabilities' independence increases with age and is especially felt by those who live in lower socioeconomic circumstances (Furler et al., 2002). People's health is influenced by a multitude of factors, including limited access to primary care, extended waiting times, short appointment durations, insufficient assessments or specific screenings and challenges with conveying health information due to communication barriers, all commonly faced by people with intellectual disability (Burke et al., 2023; Doherty et al., 2020; Hussain et al., 2020; Shady et al., 2022). Additionally, healthcare providers may lack understanding of intellectual disability, leading to complications with diagnosis due to atypical presentation of symptoms, and attitudinal issues from healthcare

professionals (Heslop et al., 2013; Martin et al., 2001; Robertson et al., 2011). This can result in disparities in care and diagnostic overshadowing (Javaid et al., 2019), where symptoms are attributed solely to intellectual disability without proper investigation. Culminating in many health conditions going unrecognised, and unmet, far too often, this results in unnecessary poor outcomes for the individuals with intellectual disability (Heslop et al., 2013). Overall, people with intellectual disability present with more complex and adverse health conditions as they age, and experience more health challenges and inequalities engaging in healthcare and health promotion, resulting in unmet health needs. One area frequently overlooked is musculoskeletal health (Srikanth et al., 2011).

2 | BACKGROUND

Musculoskeletal disorders are the second highest cause of years lost due to disability worldwide, and they account for 21% of all years lost to disability. They have the fourth greatest impact on overall health, and it is estimated that worldwide 1.7 billion people suffer from musculoskeletal disorders, with an estimated 45% increase likely over the next 20 years (Murray et al., 2012). In contrast to the traditional health burdens of cardiovascular disease, cancer and diabetes, musculoskeletal disease is on the increase (Cooper, 2014). Part of this family of conditions are osteoporosis and osteopenia. Both insidious and initially symptom-free conditions, with many people not realising they have osteoporosis/osteopenia until they are diagnosed, perhaps post a fracture. Fracture is the most common clinical outcome leading to pain, increased morbidity and loss of independence.

Ensuring strong bone health throughout life starts early, during childhood and adolescence. This critical phase lays the foundation for robust bone formation and strength (Vasanwala et al., 2022). Incorporating weight-bearing exercises and resistance training during these formative years stimulates bone growth, contributing significantly to reaching peak bone mass (Santos et al., 2017). Supporting this development requires a bone-healthy diet rich in essential nutrients. Adequate intake of calcium, vital for bone structure, along with vitamin D facilitating calcium absorption, forms the cornerstone. Protein and other nutrients complement this framework, supporting ongoing bone formation and maintenance; however, for people with intellectual disability, challenges such as complex health conditions, or poor dietary intake often manifest in early childhood (Bandini et al., 2019), and the opportunities to pave the way for stronger more resilient bones later in life is interrupted.

It is increasingly recognised and of urgent concern that osteoporosis/osteopenia (poor bone health) is underdiagnosed and undertreated in the older population of people with intellectual disability (Burke et al., 2019, 2021; Fritz et al., 2021; Jasien et al., 2012; Nguyen et al., 2004; Winterhalder et al., 2022). In fact, Nguyen et al. (2004) report up to 75% of women and 90% of men with increased risk of poor bone health are not investigated, and they go on to report that more than 75% who are diagnosed are not treated. These findings are supported more recently by Frighi et al. (2022) who report the lack of inclusion of people with intellectual disability in guidelines and note

that major osteoporotic fractures, particularly hip rates, were occurring 15–30 years earlier in men and women with intellectual disability compared to their nondisabled peers pointing to a lack of diagnosis and treatment for poor bone health.

International studies suggest that people with intellectual disability have an increased loading of risks for poor bone health (Fritz et al., 2021; Lin et al., 2015; Srikanth et al., 2011). Indeed the prominent risks may differ and may not be factors that are commonly recognised or considered during the assessment of people with intellectual disability (Burke et al., 2021; Winterhalder et al., 2022). Factors such as high levels of antiepileptic medication use, for example, phenytoin or sodium valproate, a high prevalence of early menopause, failure to reach optimal bone mass as in the case of those with Down syndrome, complex mobility issues, multiple health conditions or, syndrome specific complexity, for example, Prader–Willis syndrome (Burke et al., 2021, 2017, 2018; Frighi et al., 2019) all can lead to poor bone health; however these are frequently not considered. A possible explanation for this is the fact that no policy guidelines for osteoporosis/osteopenia assessment among people with intellectual disability exist, in fact considering that people with intellectual disability frequently present atypically, have multiple complex health needs and complex challenges with communication, a disparity exists in what to assess and when to assess.

All too often, diagnosis of poor bone health is dependent on dual-energy X-ray absorptiometry (DXA) scanning, an assessment that may prove too difficult for people with intellectual disability or indeed may not be offered (Frighi et al., 2019; Fritz et al., 2021; Walsh et al., 2022). There is often a lack of access to this type of assessment for individuals with intellectual disability, particularly with mobility difficulties as well as difficulty in complying with instruction; they may experience fear, present with behaviours that challenge or may simply be too scared with an unfamiliar environment (Brodtkorb et al., 2016; Gillis et al., 2009; Iacono et al., 2014), factors that pose challenges for diagnosis. Therefore, reliance on DXA contributes to inequity in healthcare provision. If people do not engage in DXA, there is a risk that they will not receive treatment. Alternate means of assessment are established; however, they are not widely used or recognised by clinicians (Burke et al., 2018; Walsh et al., 2022). FRAX™, a validated recognised assessment tool utilised by healthcare professionals to establish bone health and risk of fracture, is also widely used in healthcare. FRAX™ includes items such as the parental history of hip fracture, smoking, alcohol intake of >3 units/day, glucocorticoids and BMI. However, because of the FRAX™ construct, it could possibly miss specific risks attributed to individuals with intellectual disability and, therefore, may not be suitable for this cohort (van Geel et al., 2014). That many risk calculators do not have specific intellectual disability health-related risk factors further encourages caution with their use in this cohort. Another example of inadvertent inequity is experienced by those with intellectual disability when it comes to their health management.

Given the expanding demographic of older adults with intellectual disabilities, coupled with the severe clinical implications of poor bone health and its substantial influence on overall well-being, a compelling case emerges for a comprehensive investigation into bone

health within this specific population. Such an enquiry is poised to yield invaluable insights that can substantially mitigate the risk of inequality and inequity during the assessment and care of bone health for individuals with intellectual disability.

3 | METHODS AND MATERIALS

Data for this paper was obtained from the second wave [2014] of the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA). IDS-TILDA is a longitudinal study examining the health and well-being of adults with intellectual disability (Burke et al., 2014). The data is drawn from the response information to the preinterview questionnaire and main face-to-face interview; see elsewhere for a full description of IDS-TILDA methodology (McCarron et al., 2022). Data is collected every 3 years, which represents a wave. The data collected entails the doctor's diagnosed chronic health conditions (e.g., osteoporosis, heart disease, metabolic conditions, neurological and mental health), current medications prescribed, behavioural lifestyle (smoking, alcohol use, physical activity), activities of daily living and parental history of fracture. This data was combined with a suite of objective health measures (OM) at wave 2 [2014] that included height, weight, grip strength, mid-upper arm circumference, waist circumference, and quantitative heel ultrasound (QUS). See Burke et al. (2020) for the full methodology applied to the collection of the health measures.

3.1 | Determining contributing factors

From extensive general and intellectual disability literature searches, the World Health Organisation (WHO) guidelines and the International Osteoporosis Foundation guidelines, a comprehensive list of risk factors was identified and matched to data collected by IDS-TILDA. For reporting clarity and consistency, these were categorised into three groups (1) demographics, (2) non-modifiable risk factors and (3) modifiable risk factors. Classifications are presented below in Table 1.

3.2 | Data analysis, quality and integrity

SPSS v24 was used for this analysis. Initial descriptive analyses were conducted to identify prevalence, mean and standard deviation ($\pm$ SD) where appropriate. Attendance at DXA was self-reported, as was the doctor's reported diagnosis of osteoporosis. Bivariate analysis (chi-squared) was conducted to determine significant associations between the dependent variable (bone health status) and independent risk factor variables (predictors). Binary logistic regression was conducted to determine the relative size and magnitude of these bivariate relationships. Variables that violated assumptions were not included in further analysis. The demographic variables, along with the candidate variables, that is, those statistically significant non-modifiable and modifiable risk factors that emerged from the chi-squared analysis, were entered into the final

multinomial logistic regression model to identify factors influencing bone status. In this model, the dependent variable had three possible outcomes: normal, osteopenia and osteoporosis. The individuals who had a QUS t-score within the normal range were the reference group for this analysis. Due to the large number of clinical and behavioural variables, multicollinearity was investigated, including variance inflation factor (VIF) and variance proportions. The maximum VIF found in this analysis was below 2 (implying the minimum tolerance found was greater than 0.5), indicating that multicollinearity is not of concern.

3.3 | Explaining variable construct

Age: Dates of birth enabled age calculations which were then categorised into three groups: 40–49, 50–64 and 65 years+.

Barthel's index: Was calculated using the daily activities of living, for example, dressing, washing, grooming, transfer, mobility, stairs negotiation, bowel and bladder, to determine a range of assistance required from independent to dependent.

QUS: For the purposes of this study, the t-score calculated from the stiffness index identified by the GE Lunar Achilles device is divided into three outcome categories and is utilised to classify people into the following categories (Hans et al., 2003). These classifications are utilised for research purposes only and not in a diagnostic capacity:

1. Normal: QUS T-score > -1.2 (at low risk of fracture).
2. Osteopenia: QUS T-score $-2.49 < \text{t-score} < -1.2$ (moderate risk of fracture).
3. Osteoporosis < -2.5 (at high risk of fracture).

Dietary calcium intake: This included total dairy and milk consumption according to portion size, fluid quantity (200 mL glass) and frequency (number of times per day/week/month/not at all) based on the Irish recommendations of the food pyramid (Food Safety Authority, 2011). These were then matched according to the recommended portion intake per day and further collapsed into three categories, namely, above recommendations, below recommendations or meets recommended daily allowance.

Alcohol intake: People were asked to identify the amount and frequency of their alcohol consumption using a modified version of the Alcohol Use Disorders Identification Test (Babor et al., 2001). This was then converted to the Food Safety Authority of Ireland recommendations based on the WHO guidelines for hazardous drinking that affects health, stratified by gender and then classified by above or below recommended units of alcohol per week.

4 | RESULTS

4.1 | Study profile

In summary, 575 participants had quantitative heel ultrasound measurement (QUS). Of those participating, 57.6% were female

TABLE 1 Mapping the identified predictor variables for osteopenia and osteoporosis to the IDS-TILDA data.

Demographics		Non-modifiable predictors					Modifiable predictors			
Demographics	Genetics	Musculoskeletal conditions	Respiratory	Endocrine	GIT	Neurological	Medications	Motor function	Behavioural health	Medications
Age	Down syndrome	Scoliosis	Asthma	Hyperthyroidism	GERD	Stroke/TIA ^b	AEDs	Difficulty mobilising 100 yards	Physical activity level	Antipsychotics Barbiturates Lithium
Sex		Rheumatoid arthritis	COPD	Hypothyroidism		Dementia			Smoking	SSIs corticosteroids
Level of ID		Muscular dystrophy	Lung disease			Spina bifida		Grip strength	Alcohol consumption >3 units/day	
Living circumstance		Parental history of hip fracture	Cancer ^d	Diabetes	Peptic ulceration	Cerebral palsy ^a			Dietary intake of Ca	
				Menopause PKU ^c	Cancer ^d					
				Chronic constipation					Waist circumference	
				Coeliac disease						
					PKU ^c					

Abbreviation: AED, antiepileptic drugs.
Parathyroidism, no participant reported this condition.
Crohns disease, no participant reported this condition.
Ulcerative colitis, no participant reported this condition.
^aAnoxia at birth affects motor and skeletal development.
^bTrans ischaemic attack.
^cPhenylketonuria.
^dCancer is treated as one variable—all reported cancers are collapsed into one variable.

TABLE 2 Baseline profile of eligible study participants (N = 575).

Demographic profile and health variables ^a		Totals	n	%	Mean ± SD (range)
Sex		575			
	Male		244	42.4	
	Female		331	57.6	
Age (years)		575			56.6 ± 9.28 (92–44)
	40–49		163	28.3	
	50–64		292	50.8	
	65+		120	20.9	
Level of intellectual disability		528			
	Mild		123	23.3	
	Moderate		252	47.7	
	Severe/profound		153	29.0	
Living circumstances		569			
	Independent/with family		87	15.3	
	Community group home		243	42.7	
	Residential setting		239	42.0	
Type of intellectual disability		564			
	Down syndrome		104	18.4	
	Non-Down syndrome		460	81.6	
	History of fracture	554	116	20.9	
History of falls					
	In the past month	561	80	14.3	
	In the past year	561	161	28.7	
Epilepsy		566	187	33.0	
Mental health conditions		548	284	51.8	
Barthel index		567			
	Independent		91	16.0	
	Slight dependence		98	17.3	
	Moderate dependence		106	18.7	
	Severe dependence		272	48.0	
Medications					
	Antiepileptic medications	575	239	41.6	
	Proton pump inhibitors	575	146	25.4	
Mental health drugs contributing to bone loss		575	143	24.9	

^aNot all participants responded to all questions asked.

(n = 331). The mean age of participants was 56.6 years (±9.28). A total of 23.3% (n = 123/528) reported a mild level of intellectual disability, 47.7% (n = 252/528) reported a moderate level, and 29% (n = 153/528) reported a severe/profound level; 8.9% (n = 47/528) did not report a level of intellectual disability. Those living at home or independently made up the smallest residential grouping of the sample at 15.3% (n = 87/569), with almost equal proportions of participants living either in community group homes (CGH) or residential settings, 42% (n = 243/569) versus 42.7% (n = 239/569). One-third of the sample reported a doctor's diagnosis of epilepsy,

with almost half the sample being identified as having severe dependence on the Barthel index (48.0%, n = 272/567). A full demographical profile can be seen in Table 2 below.

4.2 | Skeletal health profile

In total, 14.4% (n = 81/562) reported a self-reported doctor's diagnosis of osteoporosis. Objectively measured QUS identified poorer rates of bone health overall, with over 70% indicating

TABLE 3 Skeletal health profile (N = 575).

Skeletal observations ^a	n	%	Total (N)
Self-reported doctor's diagnosis of osteoporosis	81	14.4	562
Objective measured QUS			575
Normal	148	25.8	
Osteopenia	191	33.2	
Osteoporosis	236	41.0	
Attended DXA scan			559
Yes, within 2 years	102	18.2	
Yes, over 2 years	40	7.2	
No	363	64.9	
Don't know	54	9.7	
History of fracture			554
Yes	116	20.9	
No	438	79.1	
Accident & emergency attendance			552
Fracture	13	2.4	
Sprain	8	1.4	
Multiple injuries	2	0.4	

Abbreviations: DXA, dual-energy X-ray absorptiometry; QUS, quantitative ultrasound.

^aNot all participants responded to all questions asked.

objective evidence of osteopenia (33.2%, $n = 191/575$) or osteoporosis (41%, $n = 236/575$). In relation to having DXA screening, 18.2% ($n = 102/559$) reported that they had had a DXA in the last 2 years, with 7.2% ($n = 40/559$) stating it was more than 2 years since their DXA scan; however, a further 9.7% ($n = 54/559$) of participants did not know if they had been for DXA, but the majority (65%, $n = 363/559$) reported they had never had a DXA. In total 20.9% ($n = 116/554$) reported a history of fracture. People provided information on Accident and Emergency attendance in the last year; the greatest reason for attendance was fracture (2.4%, $n = 13/552$) (Table 3).

4.3 | Prevalence of non-modifiable and modifiable predictors among the cohort

In total, over two-fifths of the sample (41.6%, $n = 238/575$) reported taking antiepileptic medicines, with 34.1% ($n = 193/566$) having difficulty walking 100 yards. Almost three-quarters of the females reported having gone through menopause, the mean age of menopause being 47.6 years (+4.37) for those who reported age at menopause ($n = 67/292$). In total, 3.5% ($n = 20/569$) reported a parental history of hip fracture, with 5.2% ($n = 29/561$) reporting asthma. Almost half the participants' dietary calcium consumption

was below the daily recommended allowance (49.2%, $n = 283/560$). Levels of engagement in physical activity were also low at 72.8% ($n = 410/563$), identifying within the low levels. Conditions such as chronic constipation were reported at 37.7% ($n = 212/562$) among the participants. Over half the participants were on medications that contribute to bone loss. Over 12%, ($n = 70/564$) reported that they currently were or previously had smoked, and alcohol consumption exceeding units per week was almost negligible. A full description of predictor variables can be viewed in Table 4.

4.4 | Demographic profile stratified by QUS measures

Four demographical variables were statistically associated with the objectively measured QUS results [osteopenia and osteoporosis], age ($p = 0.003$), Down syndrome ($p < 0.0001$), living circumstance ($p < 0.0001$) and level of ID ($p < 0.0001$). Those with more severe/profound levels of intellectual disability are more likely to present with OM osteoporosis (62.7%), whereas those with mild or moderate levels of intellectual disability are more likely to present with osteopenia (35% and 36.5%, respectively), according to QUS. Similarly, there is a greater presence of OM of osteoporosis among those with severe/profound levels of intellectual disability living in residential settings compared to those living independently/with family or living in a CGH where osteopenia has a higher observation. The remaining associations can be seen in Table 5.

4.5 | Bivariate associations between non-modifiable and modifiable predictors and, QUS measures

In total, five non-modifiable predictors were highly statistically associated with poor bone health ($p < 0.0001$), namely, cerebral palsy, difficulty walking and being on antiepileptic medication. Scoliosis ($p = 0.003$) and diabetes ($p = 0.038$) were also found to be statistically significant. Of the modifiable conditions, five variables were statistically significant: chronic constipation, low levels of physical activity and proton pump inhibitors (PPI) ($p < 0.0001$) along with gastroesophageal reflux ($p = 0.001$) and low grip strength ($p = 0.003$). See Table 6 for the full examination of the non-modifiable and modifiable factors.

4.6 | Multinomial logistic regression of QUS measured osteopenia and osteoporosis

The model contained five demographics (of which living circumstance, level of intellectual disability and type of ID were significant) and three significant independent variables, [PPI, antiepileptic drugs (AEDs) and difficulty walking 100 yards] significantly predicting variables. The model as a whole explained between 22.7% (Cox

TABLE 4 Non-modifiable and modifiable predictors of osteopenia and osteoporosis (N = 575).

Non-modifiable predictors					Modifiable predictors					
Variables ^a		Totals	n	%	Mean (+SD) maximum –minimum	Variables	Total	n	%	Mean (+SD) maximum –minimum
Musculoskeletal	Rheumatoid arthritis (RA)	553	12	2.2		Have you ever smoked cigarettes, cigars, pipe or cigarillos daily for 1 year	564	70	12.4	
	Scoliosis	562	28	5.0		Alcohol consumption ^b	566	214	37.8	
	Parental history of hip fracture	569	20	3.5		>Recommended units per week ^b	1	0.5		
Neurological conditions	Stroke and/TIA	575	22	3.8		<Recommended units per week ^b	213	99.5		
	Muscular dystrophy	562	4	0.7		Dietary calcium intake	560			
	Spina bifida	562	3	0.5		Below recommendations	283	49.2		
	Cerebral palsy	562	37	6.6		Meets recommendations	67	11.7		
	Epilepsy	566	187	33.0		Above recommendations	210	36.5		
Respiratory conditions	Asthma	561	29	5.2		GIT conditions	562	57	10.1	
	Other lung disease	558	13	2.3		Chronic constipation	562	212	37.7	
Endocrine conditions	Hypothyroid disease	562	81	14.4		Peptic ulceration	536	26	4.5	
	Hyperthyroid disease	562	16	2.8		BMI	566			OM weight: 72.8 kgs ±15.1 (93.2–37.9)
	Diabetes	560	43	7.7		Underweight	18	3.2		
	Menopause	292	218	74.7		Normal	168	29.7		
	Age at menopause	67	-		47.6 years ±4.37 (35–54)	Overweight/obese	380	67.1		
	Menopause at >45 years	49	73.1			Physical activity level (IPAQ)	563			
	Early menopause ≤45 years	18	26.9			Low	410	72.8		
GIT conditions	Phenylketonuria (PKU)	562	7	1.2		Moderate	140	24.9		
	Coeliac disease	562	14	2.5		High	13	2.3		
All cancer		565	27	4.8		Grip strength (stratified by gender and age)	457			

(Continues)

TABLE 4 (Continued)

Non-modifiable predictors				Modifiable predictors				
Variables ^a	Totals			Mean (+SD) maximum –minimum	Variables	Total		Mean (+SD) maximum –minimum
	566	n	%	n		%		
Motor function	Difficulty walking 100 yards	193	34.1		Below	442	93.4	
Medications	Antiepileptic drugs (AED)	238	41.6		Normal	15	3.3	
					Above	15	3.3	
					Proton pump inhibitors (PPI)	146	25.4	
					Contributing mental health drugs ^c	143	24.9	
					Corticosteroids	5	0.9	

Abbreviation: MUAC, mid-upper arm circumference.

^aNot all participants provided responses to all questions asked.

^bAlcohol consumption stratified by gender: <17 units/week for males and <11 units/week for females.

^cContributing to bone loss, selective serotonin reuptake inhibitors (SSRIs), barbiturates, lithium.

and Snell R^2) and 31.3% (Nagelkerke R^2) of the variance and correctly classified 55.8% of cases overall; 73.7% for osteoporosis and 43.1% for osteopenia. The results demonstrate consistency across a number of factors discriminating osteopenia and osteoporosis from normal bone health. Statistically significant factors to emerge as influencing the presence of osteoporosis include those with difficulty walking being six times more likely to present with osteoporosis than those without difficulty walking (AOR: 6.175, 95% CI: 3.273–11.65, $p < 0.001$), those with severe/profound level of intellectual disability were four times more likely to present with osteoporosis than those with a mild level of ID (AOR: 4.239, 95% CI: 1.859–9.668, $p = 0.001$) and those on PPI had a twofold increased risk of osteoporosis than those who were not taking PPIs (AOR: 2.166, 95% CI: 1.139–4.118, $p = 0.018$). Those on AEDs were over three times more likely to present with osteoporosis (AOR: 3.504, 95% CI: 2.224–5.518, p -value < 0.0001). With regard to osteopenia, those living in a residential setting were two times more likely to present with this condition than those who lived independently or with family (AOR: 2.204, 95% CI: 1.038–4.678, $p < 0.0001$) and similarly AEDs increased the risk twofold (AOR: 2.147, 95% CI: 1.337–3.448, $p = 0.002$). The remaining predictors can be observed in Table 7.

5 | DISCUSSION

The intersection of intellectual disability and bone health presents a complex landscape that demands careful consideration. All too often, care and health outcomes for people with intellectual disability fail to meet acceptable standards compared with their nondisabled peers (White et al., 2023). Avoidable deaths continue to be a feature in the lives of people with intellectual disability since Heslop et al. (2014) raised these issues more than 10 years ago. It is safe to say that poor bone health could possibly contribute to these stark figures, and whilst there are no direct figures for individuals with intellectual disability-related deaths due to fragility, fracture in the wider general population is concerning (Brown et al., 2021). This study has highlighted a disconcerting contrast between clinical diagnoses and objective measurements of bone health in this population, with a striking divergence of 14% versus 41% for osteoporosis, coupled with an additional 33% within the osteopenia group. These findings unveil a hidden and undiagnosed cohort at risk of enduring the adverse consequences of compromised bone health, most notably fractures. Such disparities in bone health diagnosis resonate as a disquieting call for greater scrutiny, highlighting a broader concern that inequities in healthcare may be pervasive and not confined to bone health alone. The echoes of health disparity resonate loudly within the realm of intellectual disability, paralleling findings from studies focused on other aspects of healthcare. The research by Ouellette-Kuntz et al. (2015), for example, illuminates a disconcerting reality, where individuals with intellectual disabilities are less likely to engage in age and gender-specific cancer screenings compared to their counterparts without intellectual disabilities. Maltais et al. (2020) further underscore this point, advocating for targeted policies

TABLE 5 Bivariate association of demographic profile and QUS measures.

Demographic*	QUS t-score Normal n (%)	Osteopenia n (%)	Osteoporosis n (%)	χ^2	df	p Value**
Gender				4.752	2	0.093
Male	71 (29.0)	85 (34.7)	89 (36.3)			
Female	77 (23.3)	106 (32.1)	148 (44.7)			
Age (years)				16.015	4	0.003
43–49	54 (33.1)	56 (34.4)	53 (32.5)			
50–64	74 (25.3)	100 (34.4)	118 (40.4)			
65+	20 (16.7)	35 (29.2)	65 (54.2)			
Level of ID				47.173	4	0.0001
Mild	46 (37.4)	43 (35.0)	34 (27.6)			
Moderate	71 (28.2)	92 (36.5)	89 (35.3)			
Severe/profound	18 (11.8)	39 (25.5)	96 (62.7)			
Living circumstance				44.836	4	0.0001
Independent/family	40 (46.0)	25 (28.7)	22 (25.3)			
Community group home	68 (28.0)	91 (37.4)	84 (34.6)			
Residential setting	36 (15.1)	74 (31.0)	129 (54.0)			
Type of ID				18.267	2	0.0001
Down syndrome	43 (41.3)	33 (31.7)	28 (26.9)			
Non-Down syndrome	105 (22.3)	158 (33.5)	208 (44.2)			

Note: Bold values indicate statistical significance.

Abbreviation: QUS, quantitative ultrasound.

*denoted that not all participants responded to all demographic questions.

**denoted findings in bold are significant.

to enhance access to healthcare services for those with intellectual disabilities. This evidence compels us to question the broader implications of these inequities, potentially affecting various aspects of health and well-being within this vulnerable population.

The road to equitable healthcare is riddled with challenges, particularly when it comes to assessing the bone health of individuals with intellectual disabilities. Bone health, including for the general population, is often relegated to the periphery of annual health checks, exacerbating the potential for undiagnosed cases of osteoporosis/osteopenia (Fritz et al., 2021; Jasien et al., 2012; Martin et al., 2001). The advancing age of this population emphasises a pressing reality that bone health assessment, including annual height to monitor change, assessment of risk factors such as walking difficulty, presence of AEDs and PPIs and establishing vitamin D and calcium profile, is even more pivotal. The current study's revelation that a significant proportion, 65%, had never undergone DXA assessment, the gold standard for diagnosis, is concerning, even if DXA is not always suitable for this cohort. Other options must be considered and embraced, such as QUS, which has been noted as acceptable to people with intellectual disability (Burke et al., 2019, 2020; Walsh et al., 2022) to better ensure access and

comprehensive evaluation. Annual health assessment ought to include a comprehensive health history, including family history where possible, bone health assessment including height, weight, vitamin D and K, body shape or any change in posture, bowel health status and nutritional status; all need to be assessed, when concerns are raised bone health profile and markers ought to be ordered, including vitamin D, calcium, phosphate, albumin, alkaline phosphatase, c-telopeptide and then DXA where possible.

Objective assessment strategies, however, are only part of the solution. Traditional risk factors, such as smoking, alcohol consumption and corticosteroid use, do not consistently emerge as prime predictors in this population. Instead, factors like mobility issues, severity of intellectual disability, AED usage and PPI medications gain prominence. The heightened risk associated with PPI medication unveils the intricate interplay between gastrointestinal conditions prevalent in individuals with intellectual disabilities and their potential impact on bone integrity (Fattahi et al., 2019). Mobility issues, often intertwined with intellectual disabilities (Oppewal et al., 2014), emerge as a significant predictor of poor bone health, amplifying the susceptibility to fractures due to imbalanced bone turnover and increased risk of falls. AED usage, identified in this study as highly

TABLE 6 Bivariate associations between non-modifiable and modifiable predictors and QUS measures.

Non-modifiable predictors				Modifiable predictors									
Predictors present	QUS t-score			χ ²	df	p Value ^a	Predictors present	QUS t-score			χ ²	df	p Value ^a
	Normal n (%)	Osteopenia n (%)	Osteoporosis n (%)					Normal n (%)	Osteopenia n (%)	Osteoporosis n (%)			
Scoliosis	2 (7.1)	6 (21.4)	20 (71.4)	11.592	2	0.003	Smoked for at least a year	17 (24.3)	20 (28.6)	33 (47.1)	1.158	2	0.560
Parental history of hip fracture	6 (30.0)	10 (50.0)	4 (20.0)	4.170	2	0.124	Dietary calcium intake (RDA)						
Cerebral palsy	5 (13.5)	5 (13.5)	27 (73.0)	16.509	2	0.0001	Below RDA	74 (26.1)	85 (30.0)	124 (43.8)			
Asthma	11 (37.9)	5 (17.2)	13 (44.8)	4.389	2	0.111	Meets RDA	13 (19.4)	28 (41.8)	26 (38.8)			
Stroke &/TIA	3 (13.6)	9 (40.9)	10 (45.5)	1.675	2	0.433	Above RDA	56 (26.7)	74 (35.2)	80 (38.1)			
Hypothyroidism	19 (23.5)	26 (32.1)	36 (44.4)	0.404	2	0.817	GERD	12 (21.1)	11 (19.3)	34 (59.6)	9.42	2	0.009
Diabetes	15 (34.9)	18 (41.9)	10 (23.3)	6.561	2	0.038	Chronic constipation	32 (15.1)	61 (28.8)	119 (56.1)	34.356	2	0.0001
Menopause	50 (22.9)	70 (32.1)	98 (45.0)	0.295	2	0.863	Peptic ulceration	6 (23.1)	6 (23.1)	14 (53.8)	1.973	2	0.373
All cancers	11 (40.7)	5 (18.5)	11 (40.7)	4.413	2	0.110	Level of physical activity				29.149	2	0.0001
Waist circumference ^c				5.503	4	0.239	Low	82 (20.0)	135 (32.9)	193 (47.1)			
Normal	25 (29.4)	25 (29.4)	35 (41.2)				Moderate/high	61 (39.9)	52 (34.0)	40 (26.1)			
Increased risk	19 (22.4)	37 (43.5)	29 (34.1)				Grip strength ^b	105 (27.8)	134 (35.4)	139 (36.8)	13.817	2	0.001
Substantial increased risk	99 (30.7)	120 (37.2)	104 (32.2)				Mental health drugs	28 (19.6)	49 (34.3)	66 (46.2)	4.079	2	0.130
Difficulty walking 100 yards	19 (9.8)	44 (22.8)	19 (9.8)	85.348	2	0.0001	Proton pump inhibitors (PPIs)	20 (13.7)	38 (26.0)	88 (60.3)	31.699	2	0.0001
Antiepileptic medications (AEDs)	36 (15.1)	78 (32.6)	125 (52.3)	30.784	2	0.0001							

TABLE 7 Multinomial logistic regression model.

Model osteopenia and osteoporosis as measured and categorised by QUS t-score ^b						
Reference category = normal QUS t-score						
	Osteopenia			Osteoporosis		
	p Value	Adjusted odds ratio (OR)	95% confidence interval (CI)	p Value	Adjusted odds ratio (OR)	95% confidence interval (CI)
Gender (male) ^a						
Female	0.835	0.949	0.578–1.558	0.419	1.245	0.732–2.116
Age (43–49)						
50–64	0.896	1.038	0.591–1.825	0.48	1.246	0.677–2.29
65+	0.756	1.13	0.521–2.453	0.284	1.555	0.693–3.487
Level of ID (mild)						
Moderate	0.346	1.312	0.745–2.311	0.409	1.306	0.693–2.459
Severe/ profound	0.102	1.96	0.874–4.394	0.001	4.239	1.859–9.668
Living circumstance (Independent)						
Community group home	0.063	1.907	0.966–3.767	0.209	1.641	0.757–3.556
Residential	0.04	2.204	1.038–4.678	0.061	2.197	0.964–5.01
Proton pump inhibitors (PPI) (no)	0.587	1.198	0.624–2.299	0.018	2.166	1.139–4.118
Antiepileptic (AED) (no)	0.002	2.147	1.337–3.448	<0.0001	3.504	2.224–5.518
Walking 100 yards (no difficulty)						
Difficulty	0.056	1.897	0.985–3.653	<0.001	6.175	3.273–11.65

Abbreviations: AED, antiepileptic drug; QUS, quantitative ultrasound.

^aReference category in parenthesis with all statistically significant risks in bold ($p < 0.05$).

^bCox and Snell $R^2 = 0.277$, Nagelkerke $R^2 = 0.313$.

prevalent (41.6%), amplifies the risk further by negatively impacting bone health, and its implications may often be overlooked. These findings emphasise the need for tailored interventions that address the unique profile of risk factors specific to individuals with intellectual disabilities, informing more robust health planning (McCarron et al., 2017).

The cumulative effect of these findings is a clarion call for comprehensive and multidimensional interventions. Encouraging people to engage in weight-bearing physical activity, resistance and strengthening exercise, as well as improving diet and vitamin D intake in an effort to address poor bone health, is prudent. The startling contrast between risk factors highlighted in this study and those commonly observed in the general population further underscores the urgent need for tailored approaches, specifically considering those with severe/profound levels of intellectual disability and overall the challenges such as communication that all people with intellectual disability can experience. Therefore aspects such as augmented

communication to support comprehension, supporting medication use and individuals with intellectual disabilities are at a precarious juncture, with a heightened vulnerability to missed diagnoses and fragmented healthcare. Bridging this divide requires a collaborative effort from healthcare providers, individuals with intellectual disabilities and their caregivers. Heightened communication, awareness and education are pivotal. The educational gap among healthcare professionals, particularly in primary care such as physiotherapists, nurses, doctors and so forth, regarding reasonable adjustments for assessments looms large (Burke et al., 2020; Iacono et al., 2014). Reasonable adjustments such as hoists to support people engaged in DXA screening access, easy-read information so that people understand the importance of their bone health and social stories to provide people with exemplars of how physical activity can help. As the gatekeepers of healthcare, healthcare professionals, such as doctors, nurses, physiotherapists and so forth, bear a significant responsibility in ensuring equitable access to healthcare services

(Krahn & Fox, 2014). A crucial step is to enhance knowledge of intellectual disabilities and disability-related adjustments, particularly augmented communication, to facilitate assessments comfortably and confidently (Fleming et al., 2023; Kupzyk & Allen, 2019).

6 | CONCLUSION

The prolonged lifespan of individuals with intellectual disabilities, coupled with their susceptibility to age-related illnesses, mirrors the broader population's health challenges. The evidence here of discernible risk factor disparities, inadequate attention to bone health assessments and underlying healthcare inequalities presents a concerning outlook of inequity in healthcare for individuals with intellectual disabilities. The complexity of bone health assessment among people with intellectual disability resonates with broader healthcare complexities, shedding light on latent disparities spanning various health domains. The findings here highlight these challenges and offer direction for proactive measures encompassing informed healthcare policies, targeted interventions and unwavering commitment to equitable health outcomes. As healthcare progresses and evolves, individuals with intellectual disabilities, their caregivers and healthcare professionals must synergise efforts, fostering informed decision-making and collaborative initiatives to improve the health and well-being of people with intellectual disability. In this context, the imperative for comprehensive health assessments, particularly in cases like osteoporosis, is underscored. Distinct risk factors necessitate tailored approaches specifically for people with intellectual disability. Addressing these disparities mandates individualised considerations, heightened healthcare professional education, seamless communication and adaptable assessment methodologies. Through concerted efforts, the persistent threat of health disparities and inequity can be mitigated, fostering a future where every individual, regardless of their cognitive profile, can access healthcare on an equal footing.

6.1 | Limitations

Despite the study's valuable insights, certain limitations should be noted. First, the data utilised in this study is 10 years old, which pertains to objective health data collected and had not been included since 2014; however, the new Wave of data collected has included it and will afford future and comparative analysis to be conducted. Sample size constraints, a common challenge for researchers, were present in this study. Future investigations should prioritise larger sample sizes to enhance the generalisability of findings. Additionally, the measurements relied on, the GE Lunar Achilles QUS heel ultrasound, which, while not a diagnostic tool, holds validity as a significant predictor of osteoporosis and fractures. However, it is essential to acknowledge that these measurements were taken at a single time point, necessitating further longitudinal assessments for comprehensive comparison and an enhanced understanding of associations, without establishing causation.

AUTHOR CONTRIBUTIONS

All authors were responsible for the design of the study. Eilish A. Burke and Rachael Carroll undertook the analysis, and all authors were responsible for the interpretation of the data. Eilish A. Burke drafted the manuscript, and all authors were responsible for revised versions of the manuscript. All authors have approved the final version.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

Any researcher wishing to access data can do so following the criteria of the research data protection protocol as outlined by the data protection privacy notice associated with the study office.

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REFERENCES

- Babor, T., Higgins-Biddle, J., Saunders, J., & Monteiro, M. (2001). The alcohol use disorders identification test, guidelines for use in primary care. Department of Mental Health and Substance Dependence, World Health Organization. ©World Health Organization.
- Bandini, L. G., Curtin, C., Eliasziw, M., Phillips, S., Jay, L., Maslin, M., & Must, A. (2019). Food selectivity in a diverse sample of young children with and without intellectual disabilities. *Appetite*, 133, 433–440.
- Brodtkorb, E., Samsonsen, C., Sund, J. K., Bråthen, G., Helde, G., & Reimers, A. (2016). Treatment non-adherence in pseudo-refractory epilepsy. *Epilepsy Research*, 122, 1–6.
- Brown, J. P., Adachi, J. D., Schemitsch, E., Tarride, J. E., Brown, V., Bell, A., Reiner, M., Oliveira, T., Motsepe-Ditshego, P., Burke, N., & Slatkovska, L. (2021). Mortality in older adults following a fragility fracture: Real-world retrospective matched-cohort study in Ontario. *BMC Musculoskeletal Disorders*, 22, 105.
- Burke, É. A., Carroll, R., Ding, A. W., Yaman, M., Walsh, J. B., McCallion, P., & McCarron, M. (2021). Men's bones matter too, a cross sectional study examining bone health among men with intellectual disability in Ireland. *OBM Geriatrics*, 5(4), 1.
- Burke, É., Carroll, R., O'Dwyer, M., Walsh, J. B., McCallion, P., & McCarron, M. (2019). Quantitative examination of the bone health status of older adults with intellectual and developmental disability in Ireland: A cross-sectional nationwide study. *BMJ Open*, 9(4), e026939.

- Burke, É. A., Carroll, R., O'Dwyer, M., Walsh, J. B., McCallion, P., & McCarron, M. (2018). Osteoporosis and people with Down syndrome: A preliminary descriptive examination of the intellectual disability supplement to the Irish longitudinal study on ageing wave 1 results. *Health, 10*(9), 1233–1249.
- Burke, É. A., Fleming, S., Doyle, C., Henderson, K., Horan, P., Keenan, P., & Byrne, K. (2023). Using verbal and non-verbal communication to support people with learning disabilities. *Learning Disability Practice, 26*(3), 33–42.
- Burke, É. A., McCallion, P., Carroll, R., Walsh, J. B., & McCarron, M. (2017). An exploration of the bone health of older adults with an intellectual disability in Ireland. *Journal of Intellectual Disability Research, 61*(2), 99–114.
- Burke, É. A., McCallion, P., & McCarron, M. E. (2014). *Advancing years, different challenges: Wave 2 IDS-TILDA. Findings on the ageing of people with an intellectual disability*. Trinity College Dublin.
- Burke, É. A., Walsh, J. B., McCallion, P., & McCarron, M. (2020). Making reasonable adjustment to enable and support people with intellectual disability engage in objective health measures in a research study—The health fair in the intellectual disability supplement to the Irish longitudinal study on ageing. *Inclusion, 8*(2), 124–137.
- Cooper, C. (2014). The lifecourse epidemiology of musculoskeletal ageing. *Osteoporosis international* (Vol. 25, pp. S101–S102). Springer London Ltd.
- Doherty, A. J., Atherton, H., Boland, P., Hastings, R., Hives, L., Hood, K., James-Jenkinson, L., Leavey, R., Randell, E., Reed, J., Taggart, L., Wilson, N., & Chauhan, U. (2020). Barriers and facilitators to primary health care for people with intellectual disabilities and/or autism: An integrative review. *BJGP Open, 4*(3), bjgpopen20X101030.
- Doyle, A., O'Sullivan, M., Craig, S., & McConkey, R. (2021). People with intellectual disability in Ireland are still dying young. *Journal of Applied Research in Intellectual Disabilities, 34*(4), 1057–1065.
- Fattahi, M. R., Niknam, R., Shams, M., Anushiravani, A., Taghavi, S. A., Omrani, G. R., & Mahmoudi, L. (2019). The association between prolonged proton pump inhibitors use and bone mineral density. *Risk Management and Healthcare Policy, 12*, 349–355. <https://doi.org/10.2147/RMHP.S223118>
- Fleming, S., Burke, É. A., Doyle, C., Henderson, K., Horan, P., Byrne, K., & Keenan, P. (2023). Ensuring effective communication when undertaking a systematic health assessment. *Learning Disability Practice, 27*(1), 24.
- Food Safety Authority of Ireland. (2011). *Scientific recommendations for healthy eating guideline in Ireland*. : Available at <https://tinyurl.com/mr2vmjph>
- Frighi, V., Morovat, A., Andrews, T. M., Rana, F., Stephenson, M. T., White, S. J., Fower, E., Roast, J., & Goodwin, G. M. (2019). Vitamin D, bone mineral density and risk of fracture in people with intellectual disabilities. *Journal of Intellectual Disability Research, 63*(4), 357–367.
- Frighi, V., Smith, M., Andrews, T. M., Clifton, L., Collins, G. S., Fuller, A., Roast, J., & Holt, T. A. (2022). Incidence of fractures in people with intellectual disabilities over the life course: A retrospective matched cohort study. *EClinicalMedicine, 52*.
- Fritz, R., Edwards, L., & Jacob, R. (2021). Osteoporosis in adult patients with intellectual and developmental disabilities: Special considerations for diagnosis, prevention, and management. *Southern Medical Journal, 114*(4), 246–251.
- Furler, J. S., Chondros, P., Young, D. Y. L., Harris, E., Powell Davies, P. G., & Harris, M. F. (2002). The inverse care law revisited: Impact of disadvantaged location on accessing longer GP consultation times. *Medical Journal of Australia, 177*(2), 80–83.
- van Geel, T. A. C. M., Eisman, J. A., Geusens, P. P., van den Bergh, J. P. W., Center, J. R., & Dinant, G. J. (2014). The utility of absolute risk prediction using FRAX® and Garvan fracture risk calculator in daily practice. *Maturitas, 77*(2), 174–179.
- Gillis, J. M., Hammond Natof, T., Lockshin, S. B., & Romanczyk, R. G. (2009). Fear of routine physical exams in children with autism spectrum disorders: Prevalence and intervention effectiveness. *Focus on Autism and Other Developmental Disabilities, 24*(3), 156–168.
- Gu, D., Andreev, K., & Dupre, M. E. (2021). Major trends in population growth around the world. *China CDC Weekly, 3*(28), 604–613.
- Hans, D., Hartl, F., & Krieg, M. A. (2003). Device-specific weighted T-score for two quantitative ultrasounds: Operational propositions for the management of osteoporosis for 65 years and older women in Switzerland. *Osteoporosis International, 14*(3), 251–258.
- Heslop, P., Blair, P., Fleming, P., Hoghton, M., Marriott, A., & Russ, L. (2013). *Confidential inquiry into premature deaths of people with learning disabilities (CIPOLD)*. Norah Fry Research Centre.
- Heslop, P., Blair, P. S., Fleming, P., Hoghton, M., Marriott, A., & Russ, L. (2014). The confidential inquiry into premature deaths of people with intellectual disabilities in the UK: A population-based study. *The Lancet, 383*(9920), 889–895.
- Hourigan, S., Fanagan, S., & Kelly, C. (2018). Annual report of the national intellectual disability database committee 2017 main findings. *Health Research Board Dublin*. <https://tinyurl.com/y44n3rxh>
- Hussain, R., Wark, S., Janicki, M. P., Parmenter, T., & Knox, M. (2020). Multimorbidity in older people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 33*(6), 1234–1244.
- Iacono, T., Bigby, C., Unsworth, C., Douglas, J., & Fitzpatrick, P. (2014). A systematic review of hospital experiences of people with intellectual disability. *BMC Health Services Research, 14*(1), 505.
- Jasien, J., Daimon, C. M., Maudsley, S., Shapiro, B. K., & Martin, B. (2012). Aging and bone health in individuals with developmental disabilities. *International Journal of Endocrinology, 2012*, 1–10.
- Javid, A., Nakata, V., & Michael, D. (2019). Diagnostic overshadowing in learning disability: Think beyond the disability. *Progress in Neurology and Psychiatry, 23*(2), 8–10.
- Kinnear, D., Morrison, J., Allan, L., Henderson, A., Smiley, E., & Cooper, S. A. (2018). Prevalence of physical conditions and multimorbidity in a cohort of adults with intellectual disabilities with and without Down syndrome: Cross-sectional study. *BMJ Open, 8*(2), e018292.
- Krahn, G. L., & Fox, M. H. (2014). Health disparities of adults with intellectual disabilities: What do we know? What do we do? *Journal of Applied Research in Intellectual Disabilities, 27*(5), 431–446.
- Kupzyk, S., & Allen, K. D. (2019). A review of strategies to increase comfort and compliance with medical/dental routines in persons with intellectual and developmental disabilities. *Journal of Developmental and Physical Disabilities, 31*, 231–249.
- Lin, L. P., Hsu, S. W., Yao, C. H., Lai, W. J., Hsu, P. J., Wu, J. L., Chu, C. M., & Lin, J. D. (2015). Risk for osteopenia and osteoporosis in institution-dwelling individuals with intellectual and/or developmental disabilities. *Research in Developmental Disabilities, 36*, 108–113.
- Maltais, J., Morin, D., & Tassé, M. J. (2020). Healthcare services utilization among people with intellectual disability and comparison with the general population. *Journal of Applied Research in Intellectual Disabilities, 33*(3), 552–564.
- Manickam, M. (2021). *Down syndrome life expectancy is higher, but not for everyone*. Nationwide Children. <https://www.nationwidechildrens.org/family-resources-education/700childrens/2021/07/down-syndrome-life-expectancy>
- Martin, D. M., Cassidy, G., Ahmad, F., & Martin, M. S. (2001). Women with learning disabilities and the menopause. *Journal of Learning Disabilities, 5*(2), 121–132.
- McCarron, M., Carroll, R., Kelly, C., & McCallion, P. (2015). Mortality rates in the general Irish population compared to those with an intellectual disability from 2003 to 2012. *Journal of Applied Research in Intellectual Disabilities, 28*(5), 406–413.

- McCarron, M., Cleary, E., & McCallion, P. (2017). Health and health-care utilization of the older population of Ireland: Comparing the intellectual disability population and the general population. *Research on Aging*, 39(6), 693–718.
- McCarron, M., McCausland, D., McGlinchey, E., Bowman, S., Foley, M., Haigh, M., Burke, E., & McCallion, P. (2022). Recruitment and retention in longitudinal studies of people with intellectual disability: A case study of the intellectual disability supplement to the Irish longitudinal study on ageing (IDS-TILDA). *Research in Developmental Disabilities*, 124, 104197.
- McCarron, M., Swinburne, J., Burke, E., McGlinchey, E., Carroll, R., & McCallion, P. (2013). Patterns of multimorbidity in an older population of persons with an intellectual disability: Results from the intellectual disability supplement to the Irish longitudinal study on ageing (IDS-TILDA). *Research in Developmental Disabilities*, 34(1), 521–527.
- Murray, C. J. L., Vos, T., Lozano, R., Naghavi, M., Flaxman, A. D., Michaud, C., Ezzati, M., Shibuya, K., Salomon, J. A., Abdalla, S., Aboyans, V., Abraham, J., Ackerman, I., Aggarwal, R., Ahn, S. Y., Ali, M. K., AlMazroa, M. A., Alvarado, M., Anderson, H. R., ... Haring, D. (2012). Disability-adjusted life years (DALYs) for 291 diseases and injuries in 21 regions, 1990–2010: A systematic analysis for the Global Burden of Disease Study 2010. *The Lancet*, 380(9859), 2197–2223.
- Nguyen, T. V., Center, J. R., & Eisman, J. A. (2004). Osteoporosis: Underrated, underdiagnosed and undertreated. *Medical Journal of Australia*, 180(5), S18.
- Northway, R. (2017). *Equality and equity of access to healthcare for people with intellectual disabilities*. Retrieved from <http://www.intellectualdisability.info/changing-values/articles/equality-and-equity-of-access-to-healthcare-for-people-with-intellectual-disabilities>
- Oppewal, A., Hilgenkamp, T. I. M., van Wijck, R., Schoufour, J. D., & Evenhuis, H. M. (2014). Physical fitness is predictive for a decline in daily functioning in older adults with intellectual disabilities: Results of the HA-ID study. *Research in Developmental Disabilities*, 35(10), 2299–2315.
- Ouellette-Kuntz, H., Cobigo, V., Balogh, R., Wilton, A., & Lunskey, Y. (2015). The uptake of secondary prevention by adults with intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities*, 28(1), 43–54.
- Presson, A. P., Partyka, G., Jensen, K. M., Devine, O. J., Rasmussen, S. A., McCabe, L. L., & McCabe, E. R. B. (2013). Current estimate of Down syndrome population prevalence in the United States. *The Journal of Pediatrics*, 163(4), 1163–1168.
- Robertson, J., Roberts, H., Emerson, E., Turner, S., & Greig, R. (2011). The impact of health checks for people with intellectual disabilities: A systematic review of evidence. *Journal of Intellectual Disability Research*, 55(11), 1009–1019.
- Santos, L., Elliott-Sale, K. J., & Sale, C. (2017). Exercise and bone health across the lifespan. *Biogerontology*, 18, 931–946.
- Schepens, H. R. M. M., Van Puyenbroeck, J., & Maes, B. (2019). How to improve the quality of life of elderly people with intellectual disability: A systematic literature review of support strategies. *Journal of Applied Research in Intellectual Disabilities*, 32(3), 483–5210.
- Shady, K., Phillips, S., & Newman, S. (2022). Barriers and facilitators to healthcare access in adults with intellectual and developmental disorders and communication difficulties: An integrative review. *Review Journal of Autism and Developmental Disorders*, 11, 1–13. <https://doi.org/10.1007/s40489-022-00324-8>
- Srikanth, R., Cassidy, G., Joiner, C., & Teeluckdhar, S. (2011). 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. *Journal of Intellectual Disability Research*, 55(1), 53–62.
- Tyrer, F., Dunkley, A. J., Singh, J., Kristunas, C., Khunti, K., Bhaumik, S., Davies, M. J., Yates, T. E., & Gray, L. J. (2019). Multimorbidity and lifestyle factors among adults with intellectual disabilities: a cross-sectional analysis of a UK cohort. *Journal of Intellectual Disability Research*, 63(3), 255–265.
- Vasanwala, R. F., Gani, L., & Ang, S. B. (2022). It starts from the womb: Maximizing bone health. *Climacteric*, 25(1), 11–21.
- Walsh, N., Barr, O., Lang, D., Currid, M., & Hoey, C. (2022). Peripheral bone density measurement: An interdisciplinary initiative for improving health outcomes for people with learning disabilities. *Journal of Intellectual Disabilities*, 26(1), 18–28.
- White, A., Sheehan, R., Ding, J., Roberts, C., Magill, N., Keagan-Bull, R., Carter, B., Chauhan, U., Tuffrey-Wijne, I., & Strydom, A. (2023). Learning from lives and deaths: People with a learning disability and autistic people (LeDeR) report for 2022. *LeDeR Autism and Learning Disability Partnership*, King's College London. <https://tinyurl.com/33re3d8p>
- Winterhalter, R., McCabe, J., Young, C., Lamb, K., Sawhney, I., Jory, C., O'Dwyer, M., & Shankar, R. (2022). Bone health, intellectual disability and epilepsy: An observational community-based study. *Acta Neurologica Scandinavica*, 145(6), 753–761.

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