

## REVIEW

# Definition, assessment and management of frailty for people with intellectual disabilities: A scoping review

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## Abstract

**Background:** People with intellectual disabilities may experience frailty earlier than the general population. This scoping review aimed to investigate how frailty is defined, assessed, and managed in adults with an intellectual disability; factors associated with frailty; and the potential impact of COVID-19 on frailty identification and management.

**Method:** Databases were searched from January 2016 to July 2023 for studies that investigated frailty in individuals with intellectual disabilities.

**Results:** Twenty studies met the inclusion criteria. Frailty prevalence varied between 9% and 84%. Greater severity of intellectual disability, presence of Down syndrome, older age, polypharmacy, and group home living were associated with frailty. Multi-agency working, trusted relationships and provision of evidence-based information may all be beneficial in frailty management.

**Conclusion:** Frailty is common for people with intellectual disabilities and is best identified with measures specifically designed for this population. Future research should evaluate interventions to manage frailty and improve lives.

## KEYWORDS

ageing, frailty, intellectual disabilities, scoping review

## 1 | INTRODUCTION

There are ~1.5 million people with intellectual disabilities in the United Kingdom (Mencap, 2023) with a global prevalence of ~1% (Maulik et al., 2011). Many physical and mental health conditions are more common in people with intellectual disabilities than in the general population such as epilepsy, cerebral palsy, attention deficit hyperactivity disorder and anxiety disorders (Buckley et al., 2020; Hughes-McCormack et al., 2017; Liao et al., 2021), with high rates of polypharmacy (Haider et al., 2014; O'Dwyer et al., 2016). Median age of death has been estimated at 62 years (White et al., 2021) and avoidable and premature death is a significant international issue (Cooper et al., 2020; Doyle et al., 2021; Lin et al., 2023; Tyrer et al., 2021).

Notwithstanding the inequalities in premature mortality, the life expectancy of people with intellectual disabilities is increasing (Emerson et al., 2014), and there is greater attention on supporting healthy ageing. In the general population, there is a focus on frailty in later life and it is widely agreed that frailty is an age-related decline (World Health Organisation et al., 2016). A consensus statement defined frailty as 'a medical syndrome ... characterised by diminished strength, endurance, and reduced physiologic function that increases an individual's vulnerability for developing increased dependency and/or death' (Morley et al., 2013). While this definition largely adopts a physical approach to frailty, more researchers and clinicians are now focusing on an increasingly holistic approach to this concept (e.g., Gobbens & Uchmanowicz, 2023).

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Those categorised as frail in the general population have been found to be at higher risk of hospitalisation and mortality (Clegg et al., 2016), therefore in England, the National Health Service (NHS) aims to identify frailty in people aged 65 and older (NHS England, 2023). However, 60% of people with intellectual disabilities die before the age of 65 (White et al., 2021). These figures suggest that many may never receive an assessment of frailty in their lifetime, and therefore factors that could have contributed towards decline may not be detected. Furthermore, frailty may affect individuals with an intellectual disability on average 20–30 years earlier than what is expected in the general population (Schoufour et al., 2014; Ouellette-Kuntz, Stankiewicz, et al., 2018), and can result in earlier admission to long-term care (McKenzie, Martin, & Ouellette-Kuntz, 2016a) and early mortality (Schoufour, Mitnitski, et al., 2015). Therefore, it is paramount that this population is considered for frailty assessments at a much earlier age.

McKenzie, Ouellette-Kuntz, and Martin (2016a) conducted a scoping review into frailty and intellectual disabilities and noted a significant increase in research in this field over the 5 years prior to the review, specifically measurement of frailty. They found frailty to predict a range of negative outcomes including reduced mobility and survival rate, and increases in falls, medication use and hospitalisation. There was some evidence (Schoufour, Ehteld, & Evenhuis, 2015) that a more holistic approach to frailty measurement, capturing multiple areas of health, rather than focusing on physical deficits was preferable. In line with this, the most commonly used frailty measure across the identified papers was the ID-Frailty Index (Schoufour et al., 2013), which aims to be more holistic. All of the 17 articles included in their review were published since 2010, which suggests that the area is gaining significant interest for research. However, they highlighted that there was a lack of research regarding the validation and subsequent implementation of frailty measures in settings beyond research studies, along with the impact and predictors of frailty.

COVID-19 disproportionately affected people with intellectual disabilities in terms of their likelihood of contracting a serious illness and reduced overall support from an overburdened health and social system (Doody & Keenan, 2021; World Health Organisation, 2020). During the COVID-19 pandemic in the United Kingdom, the National Institute for Health and Care Excellence (NICE) initially recommended the use of the Clinical Frailty Scale (CFS) (Rockwood et al., 2005) to assess frailty in all adults on admission to hospital to aid decisions about critical care treatment. Following feedback about the lack of suitability of the CFS for people with intellectual disabilities, NICE updated their guidance to state that this tool should not be used for this population (NICE, 2020) as it was overestimating their level of frailty. This has further highlighted a need for frailty measures that consider population-specific factors in people with intellectual disabilities, such as needing support with daily skills (Tuffrey-Wijne, 2020), and the presence of multiple comorbidities from a young age (Young-Southward et al., 2017).

Given the increase in research into frailty in intellectual disabilities in recent years and the issues raised by COVID-19 for frailty assessment in this population, the present scoping review aims to provide an updated overview of the literature on frailty and intellectual disabilities

since McKenzie, Martin, and Ouellette-Kuntz's (2016a) review, and to identify any potential impact of the COVID-19 pandemic on assessing and managing frailty in individuals with an intellectual disability.

## 2 | METHOD

Scoping reviews aim to map all the relevant literature in a specific area of interest and consequently help to identify any gaps in existing research (Arksey & O'Malley, 2005). This review adopted the Arksey and O'Malley (2005) framework for scoping reviews which involves five stages; (1) identifying the research question; (2) identifying the relevant studies; (3) study selection; (4) charting the data; (5) collating, summarising, and reporting the results. The methods of this scoping review were pre-registered on the Open Science Framework (OSF) Registry (<https://osf.io/p9abf>). After developing the initial protocol, we expanded the research questions to incorporate research question 2.

### 2.1 | Stage 1: Identifying the research question

The overall aim of this scoping review was to conduct a review of the literature on frailty and intellectual disabilities that followed the approach of, and builds on, the McKenzie, Martin, and Ouellette-Kuntz (2016a) review.

Research questions:

1. How is frailty defined, assessed and managed in adults with an intellectual disability?
2. What factors are associated with the outcomes and characteristics of frailty?
3. What has been the impact of COVID-19 on frailty identification and management for adults with intellectual disabilities?

### 2.2 | Stage 2: Identifying relevant studies

On 29 July 2022, searches were conducted on the following databases: Scopus, PubMed, Cochrane Library and Medline. The search was repeated on 14 July 2023 to identify relevant papers published since July 2022. The search string was as follows: ('intellectual impairment' OR 'mental deficiency' OR 'multiple malformation syndrome' OR 'metabolic encephalopathy' OR 'congenital hypothyroidism' OR 'down syndrome' OR 'trisomy 21' OR 'learning disorder' OR 'autism' OR 'developmental disorder' OR 'learning disability\*' OR 'intellectual disability') AND (frail\*).

### 2.3 | Stage 3: Study selection

To be included in the scoping review, articles were to (a) explore frailty within the context of individuals with an intellectual disability, including (but not limited to) definition, assessment, and management

of frailty; (b) be published between 1 January 2016 and 14 July 2023. Studies were excluded from this scoping review if they met any of the following criteria:

1. Did not present data collection or analysis, for example, editorial letter, commentary.
2. Were not written in the English language (due to the time and cost involved in translating the article into English)
3. Not peer-reviewed

Results from database searches were extracted and imported onto Rayyan, a free web tool designed to support researchers in conducting systematic and other types of reviews (Ouzzani et al., 2016). One reviewer (Author 1) removed the duplicates. All articles were then screened by title and abstract independently by two researchers (Author 1, Author 3), using the inclusion and exclusion criteria. Where researchers were unsure about eligibility or there were disagreements ( $n = 35$ ), the researchers discussed and came to a mutual decision. Those not meeting the criteria were excluded. Full-text articles were then reviewed independently by the same two researchers.

The reference lists of included articles and excluded relevant review articles were examined to ensure all relevant studies had been identified.

## 2.4 | Stage 4: Charting the data

A data extraction form was developed in Excel by one of the reviewers (Author 1) and agreed by the team. The following column headings were used to chart the data from the relevant articles:

1. Author(s) and year of publication
2. Location
3. Aim(s)
4. Participants
5. Methodology
6. Measures of frailty
7. Frailty prevalence
8. Factors associated with frailty
9. Main findings
10. Other implications

## 2.5 | Stage 5: Collating, summarising and reporting the results

Following the framework of Arksey and O'Malley (2005), the narrative account was presented in two ways. First, the nature and distribution of the included studies, for example, country, study design, participant characteristics and setting. Secondly, the results were organised according to themes that were deemed most relevant according to the research questions.

## 3 | RESULTS

### 3.1 | Included studies and characteristics

The overall search yielded 194 records. After removing duplicates, 139 records were left to screen by title and abstract. Based on title and abstract screening, 112 articles were excluded. Twenty-seven articles were assessed by the researchers for inclusion. Five were excluded due to not meeting the inclusion criteria in terms of exploring frailty in people with intellectual disabilities, one was excluded as it did not provide novel data collection or analyses, and one was excluded, as the article was only available in Dutch. This left a total of 20 studies that met inclusion criteria and were therefore included within this scoping review. The study selection process was guided using PRISMA guidelines (Page et al., 2021) and can be seen below in Figure 1.

### 3.2 | Study location

Characteristics of the included studies are presented in Table 1, including the study location. There were high numbers of studies set in Canada and the Netherlands, reflecting the two key research teams in this area. There was some diversity in countries in the remaining articles although most were in Europe.

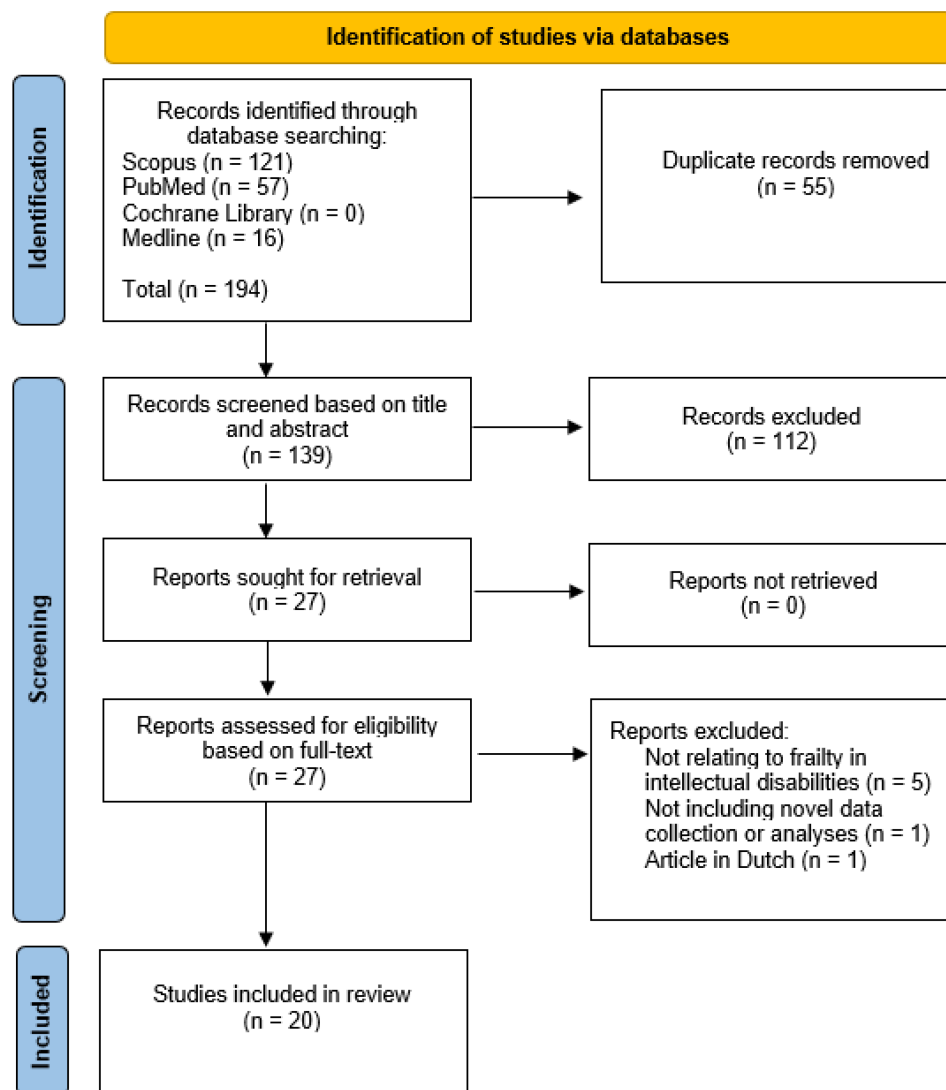
### 3.3 | Study design and setting

As shown in Table 1, 13 studies involved retrospective analysis, that is, they investigated previously collected data on various health factors in individuals with intellectual disabilities. The remaining studies varied, including qualitative, longitudinal and intervention designs.

### 3.4 | Study participants

It should be noted that some studies used data from the same participants. Schoufour et al. (2022), Festen et al. (2021), Schoufour et al. (2016) and Schoufour et al. (2017) all analysed data that was collected as part of a longitudinal study known as the 'Healthy Ageing and Intellectual Disability' study. Despite overlapping data, each study had different research aims and are therefore all included in this review. Six studies based in Canada also likely used data from the same participants (Martin et al., 2018; McKenzie, Ouellette-Kuntz, & Martin, 2016b; McKenzie et al., 2017; Ouellette-Kuntz et al., 2017; Ouellette-Kuntz, Martin, & McKenzie, 2018; Ouellette-Kuntz, Stankiewicz, et al., 2018).

The majority of people with intellectual disabilities included in these studies were in receipt of a range of health and social care. Many of the studies set in Canada were focused on individuals specifically in receipt of community-based care, or those who worked with or supported them (Ouellette-Kuntz, Martin, & McKenzie, 2018;



**FIGURE 1** PRISMA flow diagram of studies from identification to inclusion.

Ouellette-Kuntz, Stankiewicz, et al., 2018; Martin et al., 2018, 2020; Barabash et al., 2021). Hippiisley-Cox and Coupland (2017) included people on primary care registers, but it is not known what other health or care services they were receiving.

### 3.5 | Sample size

The size of the samples in the studies varied considerably from 85 (Lin & Tseng, 2022) to 51,138 (McKenzie et al., 2017). The studies with the larger sample sizes were retrospective studies in which previously collected healthcare data were analysed.

### 3.6 | Sex

Thirteen studies provided information on sex of participants with intellectual disabilities. Twelve of the included studies had similar

proportions, with between 46% and 52% being female (Ahlström et al., 2022; El Mrayyan et al., 2022; Hippiisley-Cox & Coupland, 2017; Lin, 2021; Lin & Tseng, 2022; Ouellette-Kuntz, Martin, & McKenzie, 2018; Ouellette-Kuntz, Stankiewicz, et al., 2018; McKenzie, Ouellette-Kuntz, & Martin, 2016b; Martin et al., 2018; Schoufour et al., 2016, 2017, 2022). O'Connell et al. (2020) had a slightly higher proportion of females at 58%.

### 3.7 | Age

The age of participants was reported in 15 studies and are shown in Table 1. There was variation with four studies analysing data from individuals between the ages of 18 and 99 years (Ouellette-Kuntz, Martin, & McKenzie, 2018; Ouellette-Kuntz, Stankiewicz, et al., 2018; Martin et al., 2018; McKenzie, Martin, & Ouellette-Kuntz, 2016b; McKenzie et al., 2017) and the remaining six studies had a higher minimum age ranging from 40 upwards.

TABLE 1 Data extraction of study characteristics and results presented by research group.

Author, year	Location	Study aim(s)	Design and methods	Participants	Main relevant findings
bMcKenzie, Martin, & Ouellette-Kuntz, 2016b	Canada	To use a frailty index to predict admission to long term care among persons with intellectual disability receiving home care services	Retrospective analysis; investigation of variables between the time of their first assessment and their admission to long term care	3034 adults with intellectual disabilities who had a home care assessment between April 2010 and March 2014 and who were not initially living in a residential care facility; mean age = 53.9 years (SD = 17.3)	<ol style="list-style-type: none"> <li>Prevalence of frailty at first assessment was 28.3%</li> <li>Those who were admitted to long-term care facilities during follow-up were more likely to be pre-frail or frail at first assessment.</li> <li>69% of participants who died before being admitted to long term care were either pre-frail or frail at first assessment</li> </ol>
McKenzie et al., 2017	Canada	To examine the occurrence of frailty among adults with and without intellectual disabilities to determine the utility of a common measure of frailty	Retrospective analysis; frailty was measured using the John Hopkins Frailty Marker in individuals with and without	51,138 adults with intellectual disabilities living in the community and a random sample of 20% of Ontarians (3.8 million) without intellectual disabilities; no information on age	<ol style="list-style-type: none"> <li>Prevalence of frailty was higher in those with intellectual disabilities (~9%) compared to those without an intellectual disability (~3%)</li> <li>In the youngest age group (18–24 years), the proportion of adults with intellectual disabilities identified as frail was similar to that found among 60–64-year-olds without intellectual disabilities.</li> </ol>
Ouellette-Kuntz et al., 2017	Canada	To examine patterns of admission to long-term care facilities in among adults with intellectual disabilities compared to those without	Retrospective analysis; investigation of admission to long-term care over a 4-year period	50,670 adults with intellectual disabilities living in the community and a random sample of 20% of Ontarians (3.2 million) without intellectual disabilities; no information on age	<ol style="list-style-type: none"> <li>Frailty was associated with admission to long-term care among adults with intellectual disabilities compared to those without</li> <li>Over the 4-year period, 4.5% of the individuals with ID were admitted to long term care compared with 0.9% of the comparison group without intellectual disabilities</li> </ol>
Martin et al., 2017	Canada	To describe the reaction of attendees to the presented results around frailty and ageing in individuals with intellectual disabilities at a webinar	Knowledge transfer webinar; attendees of the webinar were presented with and asked questions about research findings related to ageing and intellectual	Approximately 197 participants; family members, service providers, decision makers, researchers, and individuals from health and	<ol style="list-style-type: none"> <li>Insufficient cross-sector expertise and inadequate funding were believed to be the two main factors that contributed to services being unable to support the ageing</li> </ol>

(Continues)

TABLE 1 (Continued)

Author, year	Location	Study aim(s)	Design and methods	Participants	Main relevant findings
Martin et al., 2018	Canada	To describe the transitions in frailty status over a 1-year period and explore the association between baseline frailty status and worsening frailty or death over time.	Retrospective cohort study; frailty was measured using the HC-IDD Frailty Index at baseline and a year later to compare changes	2893 individuals with intellectual disabilities receiving community-based home care services; mean age = 49.5 years (no info on SD)	<p>population with intellectual disabilities.</p> <p>2. There was felt to be a lack of evidence-based information in ageing in this population</p> <p>1. Among those who were frail at baseline, 35.3% improved, 18.2% worsened and 9.6% died.</p> <p>2. Among those who were frail at baseline, 37.4% improved, 36.8% remained stable and 25.9% had died.</p> <p>3. Having controlled for other factors, being frail at baseline was predictive of worsening or dying.</p>
Ouellette-Kuntz, Martin, & McKenzie, 2018	Canada	To determine if adding an intellectual disability-specific measure of frailty to a list of predictors increases the ability to predict admission to long-term care or death within 1 year in this population	Retrospective cohort study; investigation of frailty-related variables between the time of their first assessment and either their admission to long term care or death using the HC-IDD Frailty Index and the John Hopkins Frailty Marker	6169 adults with intellectual disabilities receiving community-based home care services; mean age = 53.1 years (no info on SD)	<p>1. 6.9% of the cohort died and 20.6% were admitted to long-term care within a year of the assessment.</p> <p>2. Adding the HC-IDD Frailty Index along with the John Hopkins Frailty Marker improved the ability of the model to predict death within a year of a home care assessment by an additional 5.95%</p>
Ouellette-Kuntz, Stankiewicz, et al., 2018	Canada	To determine the factors associated with the rate of deficit accumulation in adults with intellectual disabilities	Longitudinal analysis of administratively held clinical data using the RAI-HC. Frailty was analysed using the HC-IDD Frailty Index	N = 5074; adults with intellectual disabilities who had at least one home care assessment between April 2003 and March 2015; mean age = 49.2 years (SD = 17.2)	<p>1. Increasing age, presence of Down syndrome and living in a group home appeared to significantly predict greater deficit accumulation.</p> <p>2. Non-frail individuals aged 40–49 years accumulated deficits 1.52 times faster than individuals of 18–29 years of age.</p> <p>3. For pre-frail individuals, the accumulation of deficits was 1.94 times faster in 40–49-year-olds than in 18-year-olds.</p>



TABLE 1 (Continued)

Author, year	Location	Study aim(s)	Design and methods	Participants	Main relevant findings
Ouellette-Kuntz et al., 2019	International (including Canada, The Netherlands, Northern Ireland, Sweden and the United States)	To undertake a consultation to produce a consensus statement regarding the best approaches to supporting individuals with intellectual disabilities as they become frail.	Nominal Group Technique, a National Institute of Health consensus conference approach, and a Delphi survey	37 individuals participated in the initial Nominal Group Task. 187 stakeholders from 20 countries were then invited to complete the survey which consisted of service providers, policy makers, researchers and family members.	<ol style="list-style-type: none"> <li>Frailty should be considered earlier in individuals with intellectual disabilities than those without</li> <li>Intersectoral collaboration is needed to coordinate assessments and actions.</li> <li>The needs of caregivers are particularly important</li> </ol>
Martin et al., 2020	Canada	To explore the collaboration between home care and disability services sectors in the context of supporting older adults with intellectual disabilities who are frail	Case study design involving interviews regarding known conditions for effective inter-sectoral collaboration (necessity, opportunity, capacity, relationships, planned actions and sustained outcomes).	23 individuals including family members, support workers, care co-ordinators, supervisors, managers, administrators, nurses and therapists and two individuals with intellectual disabilities; no information on mean age but the age range was 55–68 years	<ol style="list-style-type: none"> <li>Factors related to relationships were of particular importance to individuals with intellectual disabilities and family members.</li> <li>Many of the conditions were considered to be present and an important part of developing inter-sectoral collaboration.</li> </ol>
Barabash et al., 2021	Canada	To investigate the extent to which consensus statement principles (created by Ouellette-Kuntz et al., 2019) are present in care plans of older adults with intellectual disabilities	Review of care plans for adults with intellectual disabilities. Documented goals, actions and outcomes were coded according to the consensus statement's principles and recommendations.	23 care plans for adults with intellectual disabilities (no information on mean age)	<ol style="list-style-type: none"> <li>The recommendations 'improvement and maintenance are viable goals' and 'intersectoral collaboration is needed' were documented the most often.</li> <li>'Attention to the needs of formal and informal caregivers' was mentioned the least often in care plans.</li> </ol>
Schoufour et al., 2016	The Netherlands	To assess the association between frailty and a range of physical processes in older people with intellectual disabilities	Observational study; data was collected on frailty using the ID-Frailty Index and a range of biochemical measures to investigate associations of these	757 individuals from the HA-ID study (adults with intellectual disabilities aged 50+ from three Dutch care providers which included central residential settings, community-based homes, day activity centres and supported living); mean age of 61.7 years (SD = 8.0)	<ol style="list-style-type: none"> <li>Higher frailty scores were associated with lower levels of haemoglobin, cholesterol, glucose and albumin.</li> </ol>
Schoufour et al., 2017	The Netherlands	To compare the feasibility and validity of Fried's Frailty	Prospective cohort study; measured frailty using two		<ol style="list-style-type: none"> <li>Agreement between the three different Frailty Index</li> </ol>

(Continues)

TABLE 1 (Continued)

Author, year	Location	Study aim(s)	Design and methods	Participants	Main relevant findings
Festen et al., 2021	The Netherlands	Phenotype and the ID-Frailty Index (using three different scoring categorisations) in older adults with intellectual disabilities	different tools and compared frailty prevalence and other factors (age, sex, residential status, level of intellectual disability)	1050 individuals from the HA-ID study; mean age of 61.6 years (SD = 8.0)	<p>scoring versions and Fried's Frailty Phenotype ranged from 0.1 to 0.3 agreement based on Cohen's Kappa.</p> <p>2. People designated as frail by the ID-Frailty Index were more likely to die within 5 years following assessment than those categorised as frail with Fried's Frailty Phenotype.</p> <p>3. Criterion validity was stronger with the ID-Frailty Index compared to Fried's Frailty Phenotype</p>
		To compare the classification of individuals with intellectual disabilities using the CFS and the ID-Frailty Index	Retrospective cohort study; frailty was assessed using the two different assessment tools and investigated along with survival	982 individuals from the HA-ID study; no information on mean age for this specific cohort.	<p>1. When assessed using the ID-Frailty Index, those who were categorised as moderate or severe frailty had a much higher risk of mortality in the 5 years following assessment.</p> <p>2. In comparison to the ID-Frailty Index, 74.9% individuals would be incorrectly classified by the CFS as too frail to have a good probability of survival while they are in fact not moderately or severely frail.</p> <p>3. The ID-Frailty Index was found to predict mortality more accurately than the CFS.</p>
Schoufour et al., 2022	The Netherlands	To develop a shortened and more practical version of the ID-Frailty Index and to test its validity	Retrospective cohort study; the ID-FI Short Form was developed based on data from a set of participants and then its validity and precision was validated on a second set of participants	982 individuals from the HA-ID study. The first set of participants (n = 490) had a mean age of 61.4 years (SD = 8.2). The validation set of participants (n = 492) had a mean age of 61.9 years (SD = 8.0).	<p>1. The ID-FI Short Form was reduced to 17 deficits from 51 deficits in the original index.</p> <p>2. There was acceptable internal consistency of the ID-FI Short Form and a strong correlation between it and the original Frailty index.</p>



TABLE 1 (Continued)

Author, year	Location	Study aim(s)	Design and methods	Participants	Main relevant findings
Hippisley-Cox and Coupland, 2017	England	To develop an algorithm to estimate risk of death and be able to classify frailty	Prospective cohort study of general population; routinely collected data from general practices was used to evaluate risk of death at 1 year; frailty measures using the Electronic Frailty Index.	4982 adults with intellectual disabilities registered at GP practices included in the overall sample; no information on mean age, however, criteria were ages 65–100 years	<p>3. The ID-FI Short Form was associated with survival; with every 1 of 100 increase on the ID-FI Short Form, the mortality probability increased by 7%</p> <p>1. Having an intellectual disability was a key determinant of death and unplanned admission to hospital.</p> <p>2. Four 'QFrailty' groups were developed to classify patients on severity of frailty to aid with assessment and intervention, based on predicted on risk of death and unplanned hospital admission.</p>
Ahlinström et al., 2022	Sweden	To investigate social care support and how this may relate to frailty factors	Secondary analysis of longitudinal data from four Swedish registries (same as those in El Mrayyan et al., 2022). They investigated various frailty factors including age, polypharmacy and severity of intellectual disability.	7936 individuals with intellectual disabilities living in Sweden and receiving support services; mean age = 64.2 years (no info on SD)	<p>1. Age, polypharmacy and having a more severe intellectual disabilities were significantly associated with increased access to social care.</p> <p>2. Individuals who were in the age group of 65–79 and who had a severe intellectual disability and polypharmacy were the most likely to be receiving social care support</p>
El Mrayyan et al., 2022	Sweden	To describe the support available for older people with intellectual disabilities and affective or anxiety diagnoses and to investigate the association between support and various frailty factors	Secondary analysis of longitudinal data from four Swedish registries (same as those in Ahlinström et al., 2022). They investigated various frailty factors including multimorbidity, polypharmacy and severity of intellectual disability.	N = 871; individuals with affective and/or anxiety diagnoses and intellectual disability; median age = 61 years (no info on mean or SD)	<p>1. Residential arrangement, daily activities and personal contact were the most common support and social services.</p> <p>2. Those with polypharmacy were more likely to utilise residential arrangements and receive personal contact.</p> <p>3. Those with multimorbidity were less likely to participate in daily activities compared</p>

(Continues)

TABLE 1 (Continued)

Author, year	Location	Study aim(s)	Design and methods	Participants	Main relevant findings
O'Connell et al., 2020	Northern Ireland	To describe the prevalence of frailty and examine the association between medication exposure with frailty	Observational cross-sectional study; data drawn from a database used in a previous study and various factors (frailty, polypharmacy) were measured. Frailty was measured using a modified version of Fried's Frailty Phenotype.	570 adults with intellectual disabilities: 2 age groups (44–59 years and 60 years+), no information on mean age or SD	to those without multimorbidity. 1. No statistically significant association between sex and frailty status. 2. Frailty status was found to be significantly associated with polypharmacy. 3. Excessive polypharmacy (10 or more medications) was significantly associated with being pre-frail and being frail.
Lin, 2021	Taiwan	To compare the effects of two exercise programs and no intervention on frailty and muscle mass	Quasi-experimental design; the experimental group received a 10-week combined exercise program of muscle strengthening and resistance training, the comparison group did a 30-minute walk twice a week for 10 weeks, and the control group participated in usual exercise. Frailty was assessed using Fried's Frailty Phenotype.	103 adults with intellectual disabilities from six residential care and day care centres in southern Taiwan; mean age = 47.8 years (SD = 6.6)	1. The intervention group had the highest reductions in pre-frailty and frailty compared with the other two groups post-intervention. 2. 19% of participants in the intervention group changed from pre-frailty to robustness, and 8% changed from frailty to pre-frailty between baseline and after the intervention. 3. 6% of the comparison group changed from pre-frailty to robustness between baseline and after intervention. 4. The control group had the highest percentage of individuals becoming frail than the other groups
Lin and Tseng, 2022	Taiwan	To investigate short-term changes in frailty and identify predictors of frailty and disability over time	Prospective cohort study; various measurements including frailty (assessed using Fried's Frailty Phenotype) were taken at baseline and at least 1 year later (approx. follow-up period = 9 months)	85 adults with intellectual disabilities over the age of 40, and receiving day care or institutional services in the city of Kaohsiung, Taiwan; mean age = 48.9 years (SD = 6.8)	1. By follow-up, 62.4% of participants remained at the same frailty categorisation; 21.1% became less frail, and 16.5% became more frail. 2. Severity of intellectual disability and frailty condition significantly predicted impairments in undertaking activities of daily living between baseline and follow-up

### 3.8 | Severity of intellectual disability

Six studies reported on severity of intellectual disability (see Table 2). Schoufour et al. (2016) drew on the same participant pool as Schoufour et al. (2017) with a slightly smaller sample size and had very similar proportions regarding severity of intellectual disability. O'Connell et al. (2020) had broadly similar proportions to the Schoufour studies and as shown in Table 2, there was variability among the other studies.

### 3.9 | Diagnoses

Three studies reported the proportion of their sample with Down syndrome: 14% in Schoufour et al. (2017), 17.2% in Martin et al. (2018) and 16.6% in Ouellette-Kuntz, Stankiewicz, et al. (2018). One study only recruited individuals with affective and/or anxiety diagnoses and an intellectual disability (El Mrayyan et al., 2022). No other studies reported additional diagnoses.

### 3.10 | Frailty measures

The frailty definitions used by studies (where reported) are shown in Table 3, and Table 4 shows which frailty measures were adopted by which of the included studies. Ten of the studies assessed frailty using one measure and four studies used two different measures. Festen et al. (2021) compared the ID-Frailty Index and the CFS; Schoufour et al. (2022) compared the ID-Frailty Index and the ID-FI Short Form; Ouellette-Kuntz, Martin, and McKenzie (2018) examined the effectiveness of adding the HC-IDD Frailty Index to an existing list of predictors including the John Hopkins Frailty Marker; and Schoufour et al. (2017) compared the ID-Frailty Index and Fried's Frailty Phenotype.

The ID-Frailty Index was developed by Schoufour et al. (2013) and all the studies that investigated this index were from the same research team in the Netherlands. The ID-FI Short Form was developed and validated by Schoufour et al. (2022). The HC-IDD Frailty Index was created by McKenzie et al. (2015) and all the studies investigating this tool are by members of this research team based in Canada. Three studies used the John Hopkins Frailty Marker, all from the same Canadian team of researchers (McKenzie et al., 2017; Ouellette-Kuntz et al., 2017; Ouellette-Kuntz, Martin, & McKenzie, 2018). Four studies used Fried's Frailty Phenotype (Schoufour et al., 2017; O'Connell et al., 2020), including two from the same research team (Lin, 2021; Lin & Tseng, 2022). One study used the CFS (Festen et al., 2021) and one used the Electronic Frailty Index (Hippisley-Cox & Coupland, 2017). Two studies did not adopt a specific frailty measure and instead investigated factors independently including healthcare visits, multimorbidity, and polypharmacy (Ahlström et al., 2022; El Mrayyan et al., 2022).

The ID-Frailty Index, the ID-FI Short Form and the HC-IDD Frailty Index are all similar in that they take a holistic approach to frailty by

investigating social, psychological, and cognitive deficits as well as physical. Therefore, a definition such as that outlined in Table 3 by Barabash et al. (2021) is most appropriate for these measures: *the acquisition of age-related health deficits across multiple domains (e.g., biological, psychological, social and cognitive)*.

The CFS, John Hopkins Frailty Marker, Fried's Frailty Phenotype and the Electronic Frailty Index are all more focused on physical deficits within their assessment although also including some cognitive deficits, aligning with the definition of frailty by Clegg et al. (2013) in Table 3: *a complex cascade that involves several physiological alterations, eventually leading to loss of function and failure to respond to stressor events*.

Notably, the ID-Frailty Index and the ID-FI Short form were developed specifically with older adults with intellectual disabilities in mind. So far, studies have only investigated these measures in those aged 50 and older, therefore the suitability of their application to a younger population is unknown.

### 3.11 | Prevalence of frailty

Ten of the studies presented results on prevalence of frailty in individuals with an intellectual disability and can be seen in Table 5. Frailty prevalence varied considerably, from 9% to 84%. Studies adopting Fried's Frailty Phenotype varied the least of all measurements, with prevalence from 13% to 24%. Two of the studies that used the John Hopkins Frailty Marker (McKenzie et al., 2017; Ouellette-Kuntz et al., 2017) had much lower rates of frailty at 8.7% and 8.9% respectively, compared with Ouellette-Kuntz, Martin, and McKenzie (2018) who also used this measure and had a frailty rate of 54.1%. All of these studies involved participants living in community settings as opposed to long-term care facilities. Ouellette-Kuntz, Martin, and McKenzie (2018) had a significantly smaller sample size compared to the other studies. Interestingly, Lin and Tseng (2022) had a younger sample than other studies, with a mean age of 48.9 years, yet the pre-frail and frail scores were relatively high compared to other studies. However, it should be noted that their sample size was significantly smaller.

Schoufour et al. (2017) compared three different cut-offs to categorise pre-frailty and frailty for the ID-Frailty Index. They placed more emphasis on the first cut-off (non-frail <0.2, frail >0.35) and as can be seen from Table 5, the prevalence of frailty from cut-off 1 is more in line with other studies than the other cut-offs. However, it should be noted that the ID-Frailty Index is a continuous measure and although Schoufour et al. (2017) placed more emphasis on the first cut-off, none of them are officially recommended.

### 3.12 | Frailty over time

Martin et al. (2018) investigated frailty over a 1-year period and found that of the participants who were initially categorised as non-frail, 84.3% remained non-frail, 11.3% worsened and 3.9% died. They

**TABLE 2** Severity of intellectual disability for each study in which this was reported.

Study (date)	Severity of intellectual disability N (%)						Total sample size
	Borderline	Mild	Moderate	Severe	Profound	Unknown	
O'Connell et al. (2020)	-	123 (21.6)	252 (44.2)	153 (26.8) were severe or profound	-	42 (7.5)	570
Schoufour et al. (2017)	30 (2.9)	222 (21.2)	507 (48.2)	172 (16.4)	90 (8.6)	29 (2.7)	1050
Schoufour et al. (2016)	19 (2.5)	154 (20.3)	373 (49.3)	128 (16.9)	70 (9.2)	13 (1.8)	757
Ahlström et al (2021) <sup>a</sup>	-	611 (53.1)	540 (46.9) as mod, sev or profound				7936
Lin (2021)	-	42 (40.8) had mild or moderate		61 (59.2) had severe or profound			103
Lin and Tseng (2022)	-	8 (9.4)	27 (31.8)	28 (32.9)	22 (25.9)	-	85

<sup>a</sup>Level of intellectual disability only identified for 14.5% of the sample.

found that among those that were initially categorised as pre-frail, 37% remained pre-frail, 35.3% improved, 18.2% worsened and 9.6% died. Finally, they found that of those initially categorised as frail at baseline, 37.4% improved, 36.8% remained stable and 25.9% died. Therefore, those that were pre-frail and frail were more likely to deteriorate over time, although notably some people did improve. Lin and Tseng (2022) investigated frailty after a 9-month period and found that at baseline, 8.2% were categorised as robust, 68.3% were pre-frail and 23.5% were frail, and after 9 months, 9.4% were categorised as robust, 70.6% as pre-frail and 20% as frail. They found that 62.4% of participants remained stable in their condition, 21.1% improved and 16.5% became worse. Both studies included relatively young participants; participants in the Lin and Tseng (2022) study had an average age of 48.9 years, and the average age of those in the Martin et al. (2018) study was 49.5.

### 3.13 | Factors associated with frailty

#### 3.13.1 | Age

O'Connell et al. (2020) found frailty to be significantly associated with age, with those in the age group of 60+ years having higher rates of frailty compared to those in the 44–59 years age group. Ouellette-Kuntz, Stankiewicz, et al. (2018) found that among individuals who had been categorised as not frail and pre-frail, age was a predictor of increased accumulation of deficits starting at the age of 40. They also found that among those between the ages of 40 and 49 years, individuals who were pre-frail would accumulate deficits 1.94 times quicker than in those who were 18 years of age. Martin et al. (2018) found that participants falling into the pre-frail or frail categorisations were significantly older than those considered not frail.

#### 3.13.2 | Sex

O'Connell et al. (2020) found that females were twice as likely to be frail than males. McKenzie et al. (2017) reported that frailty was higher in women at 10.7% compared with males at 7.6%. Martin et al. (2018) found that of those that were categorised as frail, 55% were female.

#### 3.13.3 | Presence and severity of intellectual disability

McKenzie et al. (2017) found that approximately 9% of those with an intellectual disability were categorised as frail, compared to only 3% of those without. McKenzie and colleagues also found that the youngest age group of people with an intellectual disability (18–24 years) had frailty scores comparable to those in the 60–64-year-old group without an intellectual disability. O'Connell et al. (2020) and Lin and Tseng (2022) found frailty to be significantly associated with severity of intellectual disability.

#### 3.13.4 | Down syndrome

Martin et al. (2018) found that the overall prevalence of frailty was 16.8% for individuals with intellectual disabilities but for those with a specific diagnosis of Down syndrome, the prevalence of frailty was 26.7%. The presence of Down syndrome also increased the likelihood of worsening frailty or death. Ouellette-Kuntz, Stankiewicz, et al. (2018) found that in all three frailty categorisations (non-frail, pre-frail, and frail), having Down syndrome was a significant predictor of accumulating deficits faster than those without.

**TABLE 3** Definitions of frailty.

Definition	Adopted by
<i>the acquisition of age-related health deficits across multiple domains (e.g., biological, psychological, social and cognitive)</i>	Barabash et al. (2021))
<i>used to denote a multidimensional syndrome of loss of reserves (energy, physical ability, cognition, health) that gives rise to vulnerability. (Rockwood et al., 2005)</i>	Martin et al. (2018); O'Connell et al. (2020); Ouellette-Kuntz, Martin, and McKenzie (2018); Ouellette-Kuntz, Stankiewicz, et al. (2018); Lin and Tseng (2022)
<i>reflecting multi-system decline in physiological reserve capacity as change associated with ageing (Brehmer &amp; Weber, 2010)</i>	Lin (2021)
<i>a multi-dimensional state of vulnerability, with cognitive, social, psychological and biological deficits as well as environmental aspects associated with ageing and adverse outcomes (Clegg et al., 2013; Gale et al., 2015)</i>	Ouellette-Kuntz et al. (2019)
<i>a complex cascade that involves several physiological alterations, eventually leading to loss of function and failure to respond to stressor events (Clegg et al., 2013)</i>	Schoufour et al. (2016); Schoufour et al. (2017); Schoufour et al. (2022)
<i>a loss of resources in several domains of functioning, [leading] to a declining reserve capacity for dealing with stressors (Gobbens et al., 2010)</i>	McKenzie et al. (2017)
<i>a clinically recognisable state in which the ability of older people to cope with every day or acute stressors is compromised by an increased vulnerability brought by age-associated declines in physiological reserve and function across multiple organ systems (WHO, 2016)</i>	El Mrayyan et al. (2022)

### 3.13.5 | Other biological and health factors

Schoufour et al. (2017) found that frailty was associated with inflammation, anaemia, metabolic markers, and impaired renal functioning.

### 3.13.6 | Residential status

Martin et al. (2018) found that those who were categorised as frail were more likely to live in a group home setting than not. Ouellette-

Kuntz, Stankiewicz, et al. (2018) found that in those who were categorised as non-frail and pre-frail, living in a group home significantly predicted faster accumulation of deficits.

Ouellette-Kuntz et al. (2017) found that a higher percentage of individuals who were categorised as frail at baseline were admitted to long-term care within a year (13.4%) compared with those who were not frail (3.6%). Similarly, McKenzie, Martin, and Ouellette-Kuntz (2016b) found that those who were admitted to a long-term care facility during the follow-up period were more likely to be pre-frail or frail than those who were not admitted.

### 3.13.7 | Polypharmacy

It should be noted that the number of medications associated with the term 'polypharmacy' varied between studies, with Martin et al. (2018) defining this as seven or more, Ahlström et al. (2022) defining this as five or more, and O'Connell et al. (2020) defining this as between five and nine medications. 'Excessive polypharmacy' was defined by O'Connell et al. (2020) as 10 or more medications.

Martin et al. (2018) found frailty to be significantly associated with polypharmacy and O'Connell et al. (2020) found that being pre-frail or frail was significantly associated with excessive polypharmacy. Ahlström et al. (2022) considered polypharmacy as a frailty factor and found it to be significantly associated with increased social care.

### 3.13.8 | Mortality

Several studies found there to be a significant association between frailty score and mortality. Festen et al. (2021) found that those who were categorised as either moderately or severely frail had a considerably higher risk of mortality over the 5 years following assessment. Schoufour et al. (2017) found that those categorised as pre-frail or frail were respectively, at least twice as likely, and at least four times more likely to die during the follow-up period of 5 years than those who were categorised as not frail. Martin et al. (2018) found that those who were pre-frail or frail were 1.76- and 1.63-fold more likely to worsen or die within 12 months compared to those who were non-frail at baseline. McKenzie, Ouellette-Kuntz, and Martin (2016b) found that of those service users who died before admission to a long-term care facility, 69% had been categorised as either pre-frail or frail at their initial assessment. Schoufour et al. (2022) found that with every 1% on the ID-FI Short Form frailty assessment, there was a 7% increase of mortality probability.

The ID-Frailty Index was found to be superior than Fried's Frailty Phenotype (Schoufour et al., 2017) and the CFS (Festen et al., 2021) in predicting mortality, and Ouellette-Kuntz, Martin, and McKenzie (2018) found the HC-IDD frailty index was preferable to the John Hopkins Frailty Marker regarding mortality prediction.

## 3.14 | Management of frailty

Few studies discussed how to support frailty in individuals with intellectual disabilities. Ouellette-Kuntz et al. (2019) developed a

**TABLE 4** Frailty measures used in the included studies.

Measure	Description	Date of initial development	Studies in this review adopting this measure
ID-Frailty Index	A 51-item measure created specifically for individuals with intellectual disabilities. It includes physical, social, psychological and disease related deficits	Schoufour et al. (2013)	1. Festen et al. (2021) 2. Schoufour et al. (2022) 3. Schoufour et al. (2016) 4. Schoufour et al. (2017)
ID-FI Short Form	A shortened version of the ID-Frailty Index which has 17 items including physical, social, psychological and disease related deficits.	Schoufour et al. (2022)	1. Schoufour et al. (2022)
HC-IDD Frailty Index	A 42-item measure created specifically for individuals with intellectual disabilities. It includes physical, cognitive, psychological, and social deficits. Items were selected from the Resident Assessment Instrument-Home Care (Morris et al., 2009)	McKenzie (2015); McKenzie et al. (2015)	1. Ouellette-Kuntz, Martin, and McKenzie (2018) 2. Martin et al. (2018) 3. Ouellette-Kuntz, Stankiewicz, et al. (2018) 4. McKenzie, Martin, and Ouellette-Kuntz (2016b)
Clinical Frailty Scale	A measure of fitness and frailty involving domains including comorbidity, function, and cognition. An overall frailty score is generated from 1 (very fit) to 9 (terminally ill). This measure was not developed specifically for use with those with intellectual disabilities.	Rockwood et al. (2005)	1. Festen et al. (2021)
John Hopkins Frailty Marker	A measure which considers 81 diagnostic codes within clusters including dementia, malnutrition, impaired vision, incontinence and falls. This measure was not developed specifically for those with intellectual disabilities.	Bronskill et al. (2010)	1. Ouellette-Kuntz, Martin, and McKenzie (2018) 2. Ouellette-Kuntz et al. (2017) 3. McKenzie et al. (2017)
Fried's Frailty Phenotype	Assessment of weight loss, exhaustion, physical activity, walk time and grip strength. This measure was not developed specifically for those with intellectual disabilities.	Fried et al. (2001)	1. Lin (2021) 2. Schoufour et al. (2017) 3. Lin and Tseng (2022) 4. O'Connell et al. (2020)
Electronic Frailty Index	Involves 36 deficits including clinical signs, symptoms, diseases, disabilities and abnormal test values. This measure was not developed specifically for those with intellectual disabilities.	Clegg et al. (2016)	1. Hippisley-Cox and Coupland (2017)

Abbreviations: CFS, clinical frailty scale; FI, frailty index; HC-IDD, home-care intellectual and developmental disabilities.

consensus statement based on the views of stakeholders which provided recommendations when supporting individuals with intellectual disabilities who may be frail. The consensus statement consists of two principles ('a person-centered approach to planning' and 'ageing in place') and seven recommendations. Barabash et al. (2021) examined the applicability of this consensus statement within 23 care plans of individuals with intellectual disabilities who were frail. They found that the recommendations 'improvement and maintenance are viable goals' and 'intersectoral collaboration is needed' were most commonly evidently in care plans. The recommendation around increased attention to the needs of formal and informal caregivers was mentioned the least. They found that no new themes or additions to the consensus statement emerged during coding, however it should be

noted that it was the same research group that developed the statement and investigated its application.

Martin et al. (2020) investigated facilitators and barriers to implementing one of the consensus statement recommendations ('intersectoral collaboration') when supporting individuals with intellectual disabilities who are frail. They found that factors relating to relationships with service providers were most mentioned by individuals with intellectual disabilities and their families, and that the presence of trust and respect between providers and service users was identified as important by service users, families and service providers.

Regarding barriers to supporting individuals with an intellectual disability who are frail, Martin et al. (2017) found that many of the participants within their knowledge transfer webinar did not feel



TABLE 5 Prevalence of individuals as not frail, pre-frail and frail according to various measures.

Study (date)	Mean age (years)	Age range criteria	Measure used	Not frail n (%)	Pre-frail n (%)	Frail n (%)	Total sample size
Festen et al. (2021)	No data	50+	ID-Frailty Index (cut-off: <0.19 for relatively fit, 0.2–0.29 for pre-frail, 0.3–0.39 for mildly frail, 0.4–0.49 for moderately frail, and ≥0.5 for severely frail)	325 (33.1)	279 (28.4)	378 (38.5) Mild frailty: 192 (19.6) Moderate frailty: 130 (13.2) Severe frailty: 56 (5.7)	982
Schoufour et al. (2017)	61.6	50+	ID-Frailty Index (cut-off 1: non-frail <0.2, frail >0.35)	325 (33.1)	392 (37.3)	265 (25.2)	982 (for the ID-Frailty Index)
Schoufour et al. (2017)	61.6	50+	ID-Frailty Index (cut-off 2: non-frail <0.08, frail >0.25)	33 (3.4)	445 (45)	504 (51)	982 (for the ID-Frailty Index)
Schoufour et al. (2017)	61.6	50+	ID-Frailty Index (cut-off 3: non-frail < .10, frail >0.21)	65 (6.6)	285 (29)	632 (64)	982 (for the ID-Frailty Index)
Schoufour et al. (2017)	61.6	50+	Fried's frailty phenotype	230 (27)	508 (60)	110 (13)	848 (for Fried's Frailty Phenotype)
Lin (2021)	47.8	40+	Fried's frailty phenotype	0 (0)	86 (83)	17 (17)	103
Lin and Tseng (2022)	48.9	40+	Fried's frailty phenotype	7 (8.2)	58 (68.3)	20 (23.5)	85
O'Connell et al. (2020)	No data	44+	Fried's frailty phenotype (modified version)	102 (17.9)	365 (64)	103 (18.1)	570
Ouellette-Kuntz, Martin, and McKenzie (2018)	53.1	18–99	John Hopkins Frailty Marker	2831 (45.9)	N/A	3338 (54.1)	6169
Ouellette-Kuntz et al. (2017)	No data	18–99	John Hopkins Frailty Marker	46,262 (91.3)	N/A	4408 (8.7)	50,670
McKenzie, Martin, and Ouellette-Kuntz (2016b)	53.9	18–99	HC-IDD Frailty Index	1549 (51.1)	625 (20.6)	860 (28.3)	3034
McKenzie et al. (2017)	Mdn = 55.59	18–99	John Hopkins Frailty Marker	46,587 (90.1)	N/A	4551 (8.9)	51,138
Martin et al. (2018)	49.5	18–99	HC-IDD Frailty Index	1938 (67)	468 (16.2)	487 (16.8)	2893
Festen et al. (2021)	No data	50+	Clinical Frailty Scale	N/A	157 (16)	825 (84) Moderate frailty: 626 (63.7) Severe frailty: 199 (20.3)	982



services were ready for ageing in this population due to insufficient cross-sector expertise and lack of funding. Furthermore, they found that participants felt there was a lack of evidence-based information on ageing and frailty for people with intellectual disabilities.

The only study that conducted an intervention investigated frailty before and after a 10-week combined exercise intervention involving resistance training and aerobic exercise (Lin, 2021). They found that at baseline, 86.1% of participants in the intervention group were categorised as pre-frail and 13.9% were categorised as frail. At follow-up, 19.4% were categorised as robust, 75% were categorised as pre-frail and 5.6% were categorised as frail. This is preliminary evidence that indicates the potential for exercise interventions to be beneficial in managing or even reducing severity of frailty in this population.

### 3.15 | The impact of COVID-19 on frailty identification and management in this population

Out of the studies in the review, only one was in relation to COVID-19 (Festen et al., 2021). Conducting a retrospective analysis, they compared the outcome of the CFS with the ID-Frailty Index and found that 63.7% of the cohort would be considered moderately frail according to the CFS, however using the ID-Frailty Index 92% of this group would be incorrectly classified i.e., they either were considered relatively fit, prefrail or mildly frail. This suggests that the CFS is not suitable to investigate frailty in this population, and authors suggested instead adopting the ID-Frailty Index to calculate probability of survival during the pandemic.

## 4 | DISCUSSION

The aim of this scoping review was to examine the literature on frailty and intellectual disabilities following McKenzie, Martin, and Ouellette-Kuntz's (2016a) review. From the 194 articles identified through the four databases, 20 of these met the inclusion criteria and were included in this review.

The findings indicated considerable variation in frailty definitions, demonstrating the complexity of the concept and variety in stances that researchers take (Brehmer & Weber, 2010). Many definitions referred to frailty as 'multidimensional' or being across 'several domains' suggesting a consensus is that frailty affects multiple areas of functioning. From this, it makes sense that measures developed to assess frailty should focus on investigating a range of domains in order to capture the holistic nature of frailty as a concept.

Frailty measurement was first reported in people with intellectual disabilities through the Vienna Frailty Questionnaire for Persons with Intellectual Disabilities (Brehmer & Weber, 2010; Brehmer-Rinderer et al., 2013). However, since then, use of this tool has not been reported to our knowledge. A total of seven assessment tools were identified in our review, with four (CFS, John Hopkins Frailty Marker, Fried's Frailty Phenotype, Electronic Frailty Index) being largely physical in their approach to identifying frailty, whereas the other three

(ID-Frailty Index, ID-FI Short Form, HC-IDD Frailty Index) adopting a more holistic approach by also measuring psychological and social deficits. As previous literature has stated (Lifshitz & Merrick, 2004), measures that focus solely on physical health may not be the most suitable for people with intellectual disabilities, given that they often present with life-long physical health conditions (García-Domínguez et al., 2020) and inclusion of broader issues could provide a more accurate indication of frailty in this population.

Prevalence for frailty and pre-frailty for the studies in which this data were provided, varied considerably, from 9% to 84%, and 16% to 83%, respectively. Only one study adopted the CFS to measure frailty prevalence (Festen et al., 2021), and it was found that 84% of their sample were categorised as frail. This is considerably higher than studies with populations of the same age criteria of 50+ using the ID-Frailty Index (Festen et al., 2021; Schoufour et al., 2017), providing further evidence that the CFS is unsuitable for use with this population. While the ID-Frailty Index was recommended (Festen et al., 2021), the ID-FI Short Form may be a preferred option for use in clinical practice due to having fewer items, as well as having good internal consistency (Schoufour et al., 2022). Ouellette-Kuntz, Martin, and McKenzie (2018) concluded that the HC-IDD Frailty Index was preferable to the John Hopkins Frailty Marker, again due to it being more appropriate for the population in question, consistent with a paper in the McKenzie, Martin, and Ouellette-Kuntz (2016a) review (Schoufour, Ehteld, & Evenhuis, 2015).

Tools developed specifically for people with intellectual disabilities appear better able to predict mortality, are more accessible for this population and have stronger criterion validity (Festen et al., 2021; Ouellette-Kuntz, Martin, & McKenzie, 2018; Schoufour et al., 2017), potentially due to the other tools' lack of sensitivity to pre-existing factors associated with intellectual disability, rather than being due to frailty. However, all the studies investigating the tools specific to intellectual disability (ID-Frailty Index, ID-FI Short Form and HC-IDD Frailty Index) are by the same research teams in which they were created, limiting opportunities for replication in different contexts. Notably the number of research teams in this area was also limited in McKenzie, Martin, and Ouellette-Kuntz's (2016a) review, suggesting that diversification is still needed. Therefore, in order to replicate and extend findings to ascertain the validity of these tools, large scale studies in other countries and by diverse research teams are required that investigate a range of ages, severity of intellectual disabilities and residential status. For future research, we recommend focusing on those measures that were developed with this population in mind.

Identifying factors that are linked to frailty may enhance early identification and timely support. Polypharmacy was found to be associated with frailty and increased need for support for people with intellectual disabilities, (Ahlström et al., 2022; Martin et al., 2018; O'Connell et al., 2020) which has also been found consistently in older people without intellectual disabilities (Gutiérrez-Valencia et al., 2018). Another factor highlighted was the presence of Down syndrome and its association with higher frailty levels (Martin et al., 2018; Ouellette-Kuntz et al., 2018). Frailty has been found to

be linked with Alzheimer's Disease in the general population (Petermann-Rocha et al., 2020) and individuals with Down syndrome are at a higher risk of developing Alzheimer's Disease at an earlier age (Lott & Head, 2019) therefore this link may explain this increased risk of frailty. Several studies found frailty to be more common in females in this population, which is consistent with frailty in those without intellectual disabilities (Gordon et al., 2017). However, it should be noted that for each of these factors there were only several studies, and differences in frailty based on sex was not a consistent finding for McKenzie et al. (2016a), suggesting more research into this is needed.

In line with the findings of McKenzie et al. (2016a), the studies in this review (O'Connell et al., 2020; Ouellette-Kuntz et al., 2018) provide further evidence that frailty is age-related decline. Although increased frailty has been linked with ageing, several studies found improvements in frailty over time (Lin 2021; Lin & Tseng, 2022; Martin et al., 2018) implying that frailty may be able to be stabilised or even reversed, however, there was no information on interventions that participants may have received in these studies. Frailty has been found to be reversed or delayed in the general population when interventions including physical activity, health education and counselling are applied (Travers, Romero-Ortuno, Bailey & Cooney, 2019). Only one study in this review investigated management of frailty through an exercise intervention and found promising results (Lin, 2021). This highlights the fluid nature of frailty and perhaps emphasises that it should not be considered a permanent label. Further randomised controlled trials to examine the effectiveness of various exercises and other types of interventions and their impact on frailty are needed in future to explore potential improvements in frailty status.

Regarding management of frailty, Ouellette-Kuntz et al. (2019) created a consensus statement of seven recommendations which could be helpful for both clinicians and carers working with this population. It was also highlighted by Martin et al. (2017) that knowledge around ageing in individuals with intellectual disabilities is lacking among healthcare providers, indicating a need for further education and training to emphasise the importance of identifying and managing frailty in this population. It is important that if a label of 'frailty' is given to an individual with intellectual disabilities, then this should be accompanied with appropriate support. Given the lack of literature on managing frailty in people with intellectual disabilities and the importance of evidence-based practice, further investigation and research is warranted.

#### 4.1 | Strengths and limitations

One of the strengths of this review was the use of the Arksey and O'Malley (2005) five-stage framework, which enables transparency in the review process. A second strength was that although this review aimed to provide an update of the literature since McKenzie, Martin, and Ouellette-Kuntz's (2016a) review, we also investigated and reported on ways in which frailty could be managed in people with intellectual disabilities according to the available literature. This is a particularly important topic as frailty affects this population earlier

and therefore ways it can be managed are of considerable importance. However, the lack of published literature relating to management limits our conclusions in this area and highlights the need for further research.

Several limitations to this scoping review should also be acknowledged. Firstly, over half of the papers included are from two research groups in the Netherlands and Canada. These research groups also created and evaluated their own frailty measures. Therefore, more research is needed from teams that were independent in the development of these tools to investigate effectiveness. Furthermore, all the studies included in the review were conducted in high-income countries and therefore their results cannot be generalised to lower-income countries that may have differing health and social care provisions for individuals with intellectual disabilities. Another limitation was that there is considerable heterogeneity between the studies which assessed frailty, as the tools and their categorisations, populations and setting varied. Particularly the differences in categories and cut-off points between the tools made it not possible to determine the prevalence of frailty accurately.

It was not possible to discuss the impact of COVID-19 on this topic in detail as only one study had findings related to COVID-19 (Festen et al., 2021). This was due to the lack of published resources on this topic, likely due to the short timeframe since the pandemic began and the intense burden on the health and social care sectors during this time.

## 5 | CONCLUSION

This review identified 20 papers investigating frailty in people with intellectual disabilities since 2016, primarily restricted to research in the Netherlands and Canada. While there is clear evidence that adopting a measurement tool specifically developed for this population is preferable, tools had varied prevalence even with the same population of similar ages. As suggested by McKenzie et al. (2016a), further research is needed to determine the most appropriate tool to reliably assess frailty. In addition to this, further investigation of the factors associated with frailty are needed, particularly in residential settings and presence of other comorbidities such as Down syndrome as this may help to flag individuals who may be at higher risk of becoming frail. Clinical trials testing interventions that may help to slow onset of frailty or even reverse it are needed, and further guidance on how frailty can be managed in this population is required. The consensus statement developed by Ouellette-Kuntz et al. (2019) is a promising start. While more research is needed, the number of studies conducted in the last 8 years is encouraging and indicates increased interest that is likely to increase and progress the research field in the coming years.

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## CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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