Development and validation of a shortened and practical frailty index for people with intellectual disabilities

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Abstract

Background   There is no widely used instrument to detect frailty in people with intellectual disabilities (IDs). We aimed to develop and validate a shorter and more practical version of a published frailty index for people with IDs.
Method   This study was part of the longitudinal 'Healthy Ageing and Intellectual Disability' study. We included 982 people with IDs aged 50 years and over. The previously developed and validated ID-Frailty Index consisting of 51 deficits was used as the basis for the shortened version, the ID-FI Short Form. Content of the ID-FI Short Form was based on statistics and clinical and practical feasibility. We evaluated the precision and validity of the ID-FI Short Form using the internal consistency, the correlation between the ID-FI Short Form and the original ID-Frailty Index, the agreement in dividing participants in the categories non-frail, pre-frail and frail, and the association with survival.

Results   Seventeen deficits from the original ID-Frailty Index were selected for inclusion in the ID-FI Short Form. All deficits of the ID-FI Short Form are clinically and practically feasible to assess for caregivers and therapists supporting people with ID. We showed acceptable internal consistency with Cronbach's alpha of 0.75. The Pearson correlation between the ID-Frailty Index and the ID-FI Short Form was excellent ($r = 0.94$, $P < 0.001$). We observed a good agreement between the full and short forms in dividing the participants in the frailty categories, with a kappa statistic of 0.63. The ID-FI Short Form was associated with survival; with every 1/100 increase on the ID-FI Short Form, the mortality probability increased by 7% (hazard ratio 1.07, $P < 0.001$).
Conclusion   The first validation of the ID-FI Short Form shows it to be a promising, practical tool to assess the frailty status of people with ID.

Keywords   assessment, clinical practice, frailty, people with intellectual disabilities, screening

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Introduction

Frailty is generally considered a state of increased vulnerability for adverse health outcomes (Clegg *et al.* 2013). Assessing frailty can identify people at risk of health deterioration, monitor health trajectories over time and be used in treatment planning (Walston *et al.* 2018; Hoogendijk *et al.* 2019). In the last decade, frailty indices have been used more frequently to measure frailty in the general population and have been embedded in health practice and software to highlight people at risk of frailty and poor health for further assessment (Dent *et al.* 2016; Kojima *et al.* 2018). A frailty index is an instrument based on the accumulation of health-related deficits such as symptoms, signs, diseases, disabilities or laboratory measures. The more deficits one has, the more likely one is to be frail (Searle *et al.* 2008). These deficits represent different health domains. Frailty indices have demonstrated strong predictive value for adverse health outcomes and early mortality in several population-based and clinical settings (Mitnitski *et al.* 2001; Searle *et al.* 2008).

In recent years, frailty is increasingly recognised as a relevant health measure in people with intellectual disabilities (IDs) (McKenzie *et al.* 2016a; Ouellette-Kuntz *et al.* 2018). Yet instruments developed and evaluated in the general population may not be suitable or valid for people with ID (Evenhuis *et al.* 2013; Schoufour *et al.* 2017a). In addition to general ageing problems, people with ID have an increased risk of motor and sensory disabilities, chronic diseases, mental health problems and syndrome-specific complications starting at a young age (Evenhuis *et al.* 2013). We therefore developed the ID-Frailty Index, tailored to ageing people with ID, consisting of 51 deficits (Schoufour *et al.* 2013). The ID-Frailty Index was developed according to criteria formulated and validated for the general population by Searle *et al.* (2008). Based on data from our large-scale longitudinal Healthy Ageing and Intellectual Disability (HA-ID) study, we observed that people with ID at age 50 had mean frailty scores comparable with frailty scores of the general European population of 75 years and older (Schoufour *et al.* 2013). Among people with ID, the ID-Frailty Index proved a valid predictor for mobility decline and increased in disability, polypharmacy, care intensity and early mortality over a 3-year follow-up period (Schoufour *et al.* 2014a, 2014b, 2015a, 2015b). Similar results were observed by McKenzie *et al.* (2015, 2016b), who showed that a comparable frailty index developed for people with ID was able to predict institutionalisation among adults with ID and developmental disability.

Although the ID-Frailty Index is a valid instrument for the identification of frailty in people with ID, it is not very practical for use in practice and research as it consists of 51 deficits. These 51 deficits require completion of questionnaires by people with ID themselves or their families or other caregivers, diagnostic examinations by physicians, dieticians, physiotherapists and behavioural scientists, laboratory examinations, as well as detailed information from medical and behavioural files and information on care delivery (Schoufour *et al.* 2013). A shortened, clinically practical version is needed to allow quick screening and monitoring in clinical practice and for large-scale research into risks and effects on factors attributing to frailty.

In this study, we aimed to develop a shortened version of the original validated ID-Frailty Index that is more practical to use. Furthermore, we aimed to test the validity of this short form (ID-FI Short Form) by studying the internal consistency, the association with the original ID-Frailty Index and 5-year survival.

Methods

Study design and participants

This study was part of the longitudinal HA-ID study, performed in a consortium of the Erasmus MC, University Medical Center Rotterdam and three Dutch ID care organisations. The three care organisations are located throughout the Netherlands and offer a broad spectrum of support for people with ID, ranging from ambulatory support (home care) to residential care. Baseline data collection took place between February 2009 and July 2010. The Medical Ethics Committee of the Erasmus MC, University Medical Center Rotterdam (MEC-2008-234) and the ethics committees of the participating care organisations approved this study. Details about recruitment, design, inclusion criteria and representativeness of the HA-ID study have been published elsewhere (Hilgenkamp *et al.* 2011).

All clients aged 50 years and over who received support or care from the three care providers were invited to participate (*n* = 2322). Those capable of understanding the available information signed the consent form themselves. For those not able to make this decision, the legal representatives were approached. Written informed consent was provided for 1050 clients, forming a nearly representative study population for the Dutch population of older adults with ID aged 50 years and over using formal support or care (Hilgenkamp *et al.* 2011).

Data collection

In the HA-ID study, baseline data were collected within three subthemes: (1) physical activity and fitness; (2) nutrition and nutritional state; and (3) mood and anxiety. Within these themes, a broad diagnostic assessment was performed in addition to the collection of health records data. These data were used to develop the ID-Frailty Index previously (Schoufour *et al.* 2013). Additionally, information on the level of ID was provided by the behavioural therapist or psychologist involved. All-cause mortality data (time of death) were collected through the care organisations over a 5-year follow-up period, up to March 2015. If participants no longer received care from one of the care organisations, the date and reason of relocation were obtained. The mean follow-up period for mortality was 4.7 years (range 0 to 6.3). Generated data or analysed data from the current study are available from the corresponding author on reasonable request.

ID-Frailty Index (full version)

The previously developed ID-Frailty Index was taken as a starting point to create the ID-IF Short Form. The ID-Frailty Index was developed using 51 deficits from the baseline measurements of the HA-ID study and was calculated for 982 participants. All deficits fulfilled the criteria of Searle *et al.* (2008) and were (1) related to health; (2) positively associated with age; (3) frequently (>5%), but not too often (<80%) present in the population; and (4) measured in at least 70% of the participants. Furthermore, the deficits did not correlate too strongly with each other ($r < 0.7$), and together, they covered different health aspects. The 51 deficits included physical measurements (e.g. grip strength and walking speed), activities of daily living (e.g. bathing and housekeeping), social deficits (e.g. participates in organised day programming and reaches out to group mates), psychological related deficits (e.g. listless and panic attacks), diseases (e.g. cancer and asthma) and laboratory results (e.g. glucose and haemoglobin). The individual deficits and used cut-off values of the original ID-Frailty Index have been published elsewhere (Schoufour *et al.* 2013). Each deficit was recoded to a score ranging from 0 to 1, of which 0 indicated the complete absence of a deficit and 1 the complete presence of a deficit. A frailty index score was calculated taking the proportion of deficits present, resulting in a score between 0 and 1. Missing values were removed from both the numerator and the denominator.

Development of the ID-Frailty Index Short Form

We created the ID-FI Short Form based on two selection criteria: clinical and practical applicability and the independent explained variance of the individual deficits. By design, the Frailty Index allows for a relatively flexible inclusion of deficits. Therefore, a deficit that is selected by the statistical procedure can be replaced by a deficit from the same category if decided that the practical applicability of that deficit is better. An expert panel was created to discuss and develop the final ID-FI Short Form. Each step of the development of the ID-FI Short Form is explained in the succeeding text.

Practical applicability

To judge the practical applicability of the deficits, we asked 30 professionals providing support to people with ID within the HA-ID consort (one physician, four physical therapists, four behavioural therapists, four occupational therapists, six speech therapists, nine nurses and two professional caregivers) to evaluate all 51 deficits on clinical feasibility. All deficits were scored on a 5-point scale from *very easy to measure in practice* to *not feasible to measure in practice*, taking into account time and required instruments. In order to be included in the ID-FI Short Form, a deficit needed to be scored at least feasible by at least 75% of the professionals.

Statistical approach

To develop and later validate the ID-FI Short Form, the HA-ID dataset was split in two randomly created

sets, each consisting of approximately 50% of the participants. The first set was used to analyse which deficits explained most of the variance of the ID-Frailty Index score. We aimed to explain at least 90% of the variance of the complete ID-Frailty Index (adjusted R^2). Therefore, a stepwise forward linear regression analysis was performed using all 51 deficits as independent variables and the ID-Frailty Index score as the dependent variable. Deficits were selected for inclusion until at least 90% of all variance was explained. The second dataset was used to validate the ID-FI Short Form (see Validation of the ID-Frailty Index Short Form section).

To be able to include all participants in the analyses, we imputed the missing deficits using a multiple imputation procedure ($n = 10$ imputations with fully conditional specification and a maximum of 5000 iterations). All 51 deficits of the ID-Frailty Index and baseline characteristics (age, sex, level of ID and presence of Down syndrome) were used as predictors to estimate missing values. Imputation of missing values was shown to be a robust method to deal with missing values when constructing a frailty index (Schoufour *et al.* 2017b) Statistical analyses were performed using SPSS statistical software (IBM, version 24).

Expert panel

An expert panel evaluated the deficits that were selected with the statistical procedure and the clinical feasibility judged by the clinicians. This panel existed of movement scientists, nutritional scientist, physicians specialised in ID care and a physical therapist. All were experts in the field of ID research and/or clinical work with people with ID. If a deficit was selected in the statistical approach step but was judged as not clinically feasible by the 30 professionals, the expert panel replaced it with a similar deficit. This deficit came from the same health domain but with a higher feasibility. Thereafter, the panel discussed all deficits extensively and, if required, combined or replaced deficits.

Validation of the ID-Frailty Index Short Form

For the development of the ID-FI Short Form, we used the first half of the HA-ID dataset. The second half was used to validate the ID-FI Short Form. We calculated the ID-FI Short Form score (range 0–1) for

every individual and performed several analyses to evaluate the precision and validity of the instrument. First, Cronbach's alpha was calculated to estimate the internal consistency of the ID-FI Short Form, where an alpha of at least 0.7 was considered sufficient. Second, we compared the original ID-Frailty Index with the ID-FI Short Form. We compared the mean and the range of both scores. The original ID-Frailty Index score was used as a dependent variable in a linear regression model, and all deficits of the ID-FI Short Form were forced into the model as independent variables. The adjusted R^2 was used to assess the precision of the ID-FI Short Form. We calculated the Pearson correlation coefficient between the score on the original ID-Frailty Index and the Short Form. Furthermore, we applied the cut-off values of the full version to discriminate between non-frail (0 to <0.2), pre-frail (0.2–0.35) and frail (>0.35) participants and tested the agreement between the full and short forms with Cohen's kappa. We considered kappa values lower than 0.21 as poor, 0.21–0.40 as slight, 0.41–0.60 as moderate, 0.61–0.80 as good and 0.81–1 as excellent agreement.

Third, criterion validity of the ID-FI Short Form was determined by its association with survival (5-year follow-up). Data on participants who were lost to follow-up were censored for the survival analysis. Previously, we showed that the proportional hazard assumption was made and informative censoring was unlikely to influence the outcomes (Schoufour *et al.* 2018). The Cox proportional hazard model was used to evaluate the association between the score on the ID-FI Short Form and survival. We made a crude model (model 1) with only the ID-FI Short Form as the independent variable and a model that was adjusted for age, sex, level of ID and the presence of Down syndrome (model 2). Hazard ratios and corresponding confidence intervals were calculated. All survival analyses were repeated using the original ID-Frailty Index.

Results

Selection of the deficits for the ID-Frailty Index Short Form

All 51 deficits of the original ID-Frailty Index were evaluated on their clinical applicability (Table S1).

Table I Results of the forward regression method and clinical applicability

Variable name	Statistical approach		Practical applicability		Alternative deficit expert panel
	B	(SE)	Applicable yes, *n* (%)	Not applicable (score 4–5), *n* (%)	
Stair climbing	0.063	0.006	18 (78%)	5 (22%)	
Walking speed	0.039	0.005	15 (65%)	8 (35%)	Assistive devices
Is seeing group mates/reaching out	0.026	0.005	21 (95%)	1 (5%)	
Housekeeping	0.034	0.007	20 (87%)	3 (13%)	
Gastroesophageal reflux disease	0.032	0.005	20 (91%)	2 (9%)	Chronic disease
Sleeps more than regularly (trouble getting out of bed, falls asleep during the day)	0.037	0.008	21 (84%)	4 (16%)	
Grip strength	0.021	0.004	14 (61%)	9 (39%)	Weight loss
Calf circumference (CC) in cm	0.024	0.005	21 (91%	2 (9%)	
Getting dressed	0.048	0.007	21 (92%)	2 (8%)	
Fast fatigue easily fatigued/listless	0.057	0.007	21 (84%)	4 (16%)	
Medication use (polypharmacy)	0.055	0.005	21 (96%)	1 (4%)	
Groceries	0.039	0.007	17 (74%)	6 26%)	Bladder control
Decreased food intake, due to loss of appetite, digestive problems, chewing or swallowing difficulties	0.067	0.008	18 (82%)	4 (18%)	
Present at the care centre/job activity	0.034	0.005	21 (96%)	1 (4%)	
Knows which year it is	0.029	0.005	19 (79%)	5 (21%)	
Makes a sad/downcast impression	0.038	0.007	22 (88%)	3 (12%)	
Only eats selected types of food (e.g. pudding, rice)	0.037	0.009	19 (86%)	3 (14%)	

In the first set of participants [$n = 490$, mean age 61.4 years (SD = 8.2), 48% female], 17 deficits were selected based on the statistical approach, which explained 90.3% of the total variance (Table 1). These deficits represented all the categories that were included in the original ID-Frailty Index (Text S2). For three of these deficits, the clinical applicability was evaluated to be too poor to be included (a score of 3 or lower by at least 75% of the professionals) in the ID-FI Short Form: walking speed, grip strength and ability to do grocery shopping. The expert panel replaced these deficits with more practical deficits from the same health domain of the original ID-Frailty Index: use of assistive devices, weight loss and bladder control, respectively (Text S2). Thereafter, they evaluated all deficits and decided to replace gastroesophageal reflux disease with a more general deficit on diseases to cover a broader perspective on disease: *presence of chronic diseases*. The final deficits included in the ID-FI Short Form and their scoring are provided in Table 2.

Validation of the ID-Frailty Index Short Form

The validation set consisted of 492 participants [mean age 61.9 years (SD = 8.0), 49% female]. We observed Cronbach's alpha of 0.75 for the ID-FI Short Form. The 17 selected deficits for the ID-FI Short Form explained 89% (R^2 of 0.89) of the original ID-Frailty Index score in the validation set. The mean ID-FI Short Form score was 0.31 (SD = 0.16), versus a mean of 0.27 (SD = 0.13) for the original ID-Frailty Index. We observed a larger range for the ID-FI Short Form scores than for the original ID-Frailty Index: 0.0–0.84 and 0.04–0.67, respectively. The Pearson correlation between ID-FI Short Form and the ID-Frailty Index was 0.94 ($P < 0.001$). We observed a good agreement between both indices when comparing the classifications in the three frailty categories, with a kappa statistic of 0.63 (Table 3). Both the ID-Frailty Index and the ID-FI Short Form were predictive for survival. Based on 66 deaths, we found an adjusted hazard ratio of 1.09 ($P < 0.001$) for

Table 2 Deficits and scoring of the ID-Frailty Index Short Form

Deficit	Question	Scoring
Daily activities		
Stair climbing	Is the person able to climb a flight of stairs independently?	Needs support = 1 Needs partial support = 0.5 Independent = 0
Assistive devices	How does the person get around in familiar home environment, indoors, on level surfaces?	Wheelchair = 1 Walks with assistive device = 0.5 Walks independently = 0
Getting dressed	Is the person able to dress himself/herself? *Partial support = support with buttons and zippers etc., person can put on some of the clothes himself/herself* *No help = able to pick out and put on his/her own clothes*	Needs support = 1 Needs partial support = 0.5 Independent = 0
Housekeeping	Is the person able to do housekeeping chores? *With support = physical assistance or supervision*	Not able = 1 With support = 0.5 Independently = 0
Social functioning		
Reaching out	Is this person able to initiate social contact with other people?	Usually not = 1 Sometimes = 0.5 Usually yes = 0
Job/day activity program	How many times a week does the person work or participate in a day activity program?	<3 times/week = 1 ≥3 times/week = 0
Physical health		
Chronic disease	Does the person have a physical chronic disease? *Examples: Cardiovascular disease, COPD, cancer, diabetes mellitus, epilepsy*	Yes = 1 No = 0
Bladder control	In the past week, did the person have urinary incontinence? *Incontinent = incontinent and catheter. If the person can change and clean his/her own catheter, then score continent*	Incontinent = 1 Sometimes continent = 0.5 Continent = 0
Calf circumference	Measure the calf circumference in cm	Calf circumference <31 = 1 Calf circumference ≥31 = 0
Fatigued	In the past 6 weeks, was the person easily fatigued/lethargic?	Very often = 1 Often = 0.66 Sometimes = 0.33 Never/very rare = 0
Sleeping	In the past 6 weeks, has the person been sleeping more than regularly? *Examples: Trouble getting out of bed, falls asleep during the day*	Very often = 1 Often = 0.66 Sometimes = 0.33 Never/very rare = 0
Medication use/polypharmacy	How many types of regular medication for chronic/long term conditions in the person taking?	≥7 = 1 4–6 = 0.5 0–3 = 0
Nutrition		
Weight loss	Did the person lose weight over the past 3 months?	Greater than 3 kg = 1 Unknown = 0.5 1–3 kg = 0.5 No = 0
Decreased food intake	Did the person exhibit decreased food intake due to loss of appetite, digestive problems, chewing or swallowing difficulties?	Severe decrease = 1 Moderate decrease = 0.5 No decrease = 0
Abnormal food preferences	Does the person have non-normal food preferences? *Examples: only eats certain textures, only eats small amounts or only eats selected types of food*	Yes = 1 No = 0

Table 2. *(Continued)*

Deficit	Question	Scoring
Cognitive functioning		
Temporal orientation	Does the person know which year it is? *Can be 1 year off*	Usually not = 1 Sometimes = 0.5 Usually yes = 0
Sad/depressed	In the past 6 weeks, does the person make a sad or depressed impression?	Very often = 1 Often = 0.66 Sometimes = 0.33 Never/very rare = 0

Table 3 Agreement between original ID-Frailty Index and the ID-FI Short Form

		ID-FI Short Form				
n = 492		**Non-frail**	**Pre-frail**	**Frail**	**Total**	**Agreement**
Original ID-Frailty Index	Non-frail	123 (86%)	37 (22%)	1 (0.5%)	161	0.63
	Pre-frail	20 (14%)	129 (75%)	56 (32%)	205	*P* < 0.001
	Frail	0 (0%)	6 (3%)	120 (67%)	126	
	Total	143	172	177	492	

survival for every 1/100-point increase on the original ID-Frailty Index (e.g. from 0.3 to 0.31) and a hazard ratio of 1.07 (*P* < 0.001) for the ID-FI Short Form. A score below <0.2 was classified as non-frail, pre-frail score of 0.2–0.35 as pre-frail and score >0.35 as frail.

Discussion

To our knowledge, we are the first to develop and validate a short, clinically applicable and practical frailty instrument to assess frailty in most older person with ID. Using 17 deficits from the original 51-deficit ID-Frailty Index, a feasible ID-FI Short Form was developed. We found that the ID-FI Short Form had internal consistency and a good agreement with the original ID-Frailty Index and was able to predict survival very well.

The deficits for the ID-FI Short Form are based on clinical feasibility, the independently explained variance (statistical approach) and expert opinions. In these steps, a list of 17 deficits was composed, which represents different health domains and is clinically feasible for most health professionals working with people with ID. Overall, the original ID-Frailty Index showed stronger reliability, a smaller range and a higher correlation with survival than the short form. This is explained by the finding that the precision of frailty indices increases when adding more deficits (Mitnitski *et al.* 2005; Searle *et al.* 2008). Nevertheless, in order to make the ID-Frailty Index practical applicable, it was necessary to reduce the number of deficits. Even though only 17 deficits were included in the ID-FI Short Form, characteristics were very similar to frailty indices with more deficits, and more importantly, we observed a strong association with survival.

The main strength of this study is that a large database with detailed health information was used to develop the short version of the ID-Frailty Index and that development and validation were based on separate split halves of that dataset. However, there are several limitations in our design that need future consideration and research. First, we only used the

HA-ID dataset to create and validate the ID-FI Short Form. Although we split the dataset in a development and validation set, it would be of importance to validate the ID-FI Short Form in another, non-Dutch, dataset. Specifically, it is of interest to apply the ID-FI Short Form to younger people with ID. Generally, frailty does not start before the age of 70–75. Yet in people with ID, high frailty levels are already observed at the age of 50, comparable with people in the general population aged 70 and above (Schoufour *et al.* 2013). Moreover, McKenzie *et al.* (2015) observed that frailty was already present in people with ID aged 18 years and over. Second, deficits selected for the ID-FI Short Form are based on full extensively questionnaires, such as the Mini Nutritional Assessment or Anxiety, Depression and Mood Scale. However, the reliability of using these deficits as single questions as we propose in the ID-FI Short Form is currently unknown. Investigation of the test–retest and inter-rater reliability of the ID-FI Short Form is required, also in non-Dutch populations. Third, we do not yet know whether the ID-FI Short Form is able to detect changes over time. Last, we studied the relation between frailty and survival – a non-arbitrary and easily verifiable outcome. Nevertheless, other health outcomes including healthcare costs, hospitalisation, transition to long care facilities and the onset of disabilities and diseases are required to obtain full insight in the predictive capacity of the ID-FI Short Form.

In the general population, frailty screening instruments are used frequently for different purposes, for example, to identify people who need additional support, to start an intervention or to advise against a certain procedure (Dent *et al.* 2019). Instruments that are developed for the general population are often not applicable or not valid for people with ID, because people with ID exhibit health problems from an earlier age. For example, the identification of frail individuals with the broadly used frailty phenotype is not suitable for people with ID, because to a large extent, it is based on the existence of mobility limitations, which are often lifelong in individuals with ID (Fried *et al.* 2001; Schoufour *et al.* 2017a). Another example of a quick screening list in the general population is the Clinical Frailty Scale (CFS) (Rockwood *et al.* 2005). The classification 'frail' highly depends on the ability one has to perform activities in daily life, which is a strong predictor for morbidity and mortality in the general population. However, people with ID often have lifelong disabilities in performing activities of daily living due to their cognitive and physical limitations, which does not necessarily make them frail.

Interest in a practical, valid and reliable frailty tool for people with ID was particularly apparent during the COVID-19 pandemic. Frailty screening lists, such as the CFS, have been used during the pandemic to highlight frailer people and inform individual treatment escalation decisions. Frailty assessment could also affect decision-making in situations when treatment resources are limited (Chong *et al.* 2020; Rockwood & Theou 2020). However, the CFS is not validated in people with ID and may not have the same meaning and prognosis as it has in the general population of older people (Rockwood & Theou 2020). Indeed, the use of these instruments could misclassify people with ID as frail, possibly resulting in denied access to care facilities in crisis situations (Festen-Meas *et al.* 2021). The current COVID-19 pandemic thereby increases the necessity for a frailty screening instrument, specifically for individuals with ID as they are at significant elevated risk of contracting and dying from COVID-19 (Gleason *et al.* 2021). The ID-FI Short Form can be used for individuals, to identify people who need more health support or can benefit from specific interventions. It could complement tools that assess health deterioration such RESTORE2 (Wessex AHSN 2019). More broadly, the ID-FI Short Form could be used to monitor and evaluate the effects of policy and interventions and might even be used to provide an indication of future care needs and associated costs. Potentially, frailty may also be useful as a participant baseline assessment in research studies.

In conclusion, although further studies are required to test the validity and reliability of the ID-FI Short Form, we present a promising practical tool to assess the frailty status of people with ID.

Ethics Statement

The Medical Ethics Committee of the Erasmus MC, University Medical Center Rotterdam (MEC-2008-234) and the ethics committees of the participating care organisations approved this study.

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Conflict of Interest

None of the authors have any financial, personal or potential conflicts of interest.

Data Availability Statement

Generated data or analysed data from the current study are available from the corresponding author on reasonable request.

References

Chong E., Chan M., Tan H. N. & Lim W. S. (2020) COVID-19: use of the Clinical Frailty Scale for critical care decisions. *Journal of the American Geriatrics Society* **68**, E30–2.

Clegg A., Young J., Iliffe S., Rikkert M. O. & Rockwood K. (2013) Frailty in elderly people. *Lancet* **381**, 752–62.

Dent E., Kowal P. & Hoogendijk E. O. (2016) Frailty measurement in research and clinical practice: a review. *European Journal of Internal Medicine* **31**, 3–10.

Dent E., Martin F. C., Bergman H., Woo J., Romero-Ortuno R. & Walston J. D. (2019) Management of frailty: opportunities, challenges, and future directions. *Lancet* **394**, 1376–86.

Evenhuis H., Schoufour J. & Echteld M. (2013) Frailty and intellectual disability: a different operationalization? *Developmental Disabilities Research Reviews* **18**, 17–21.

Festen-Meas D. A. M., Schoufour J. D., Hilgenkamp T. I. M. & Oppewal A. (2021) Determining frailty in people with intellectual disabilities in the COVID-19 pandemic. *Journal of Policy and Practice in Intellectual Disabilities* **18**, 203–6.

Fried L. P., Tangen C. M., Walston J., Newman A. B., Hirsch C., Gottdiener J. et al. (2001) Frailty in older adults: evidence for a phenotype. *The Journals of Gerontology. Series A, Biological Sciences and Medical Sciences* **56**, M146–56.

Gleason J., Ross W., Fossi A., Blonsky H., Tobias J. & Stephens M. (2021) The devastating impact of Covid-19 on individuals with intellectual disabilities in the United States. *NEJM Catalyst Innovations in Care Deliver*.

Hilgenkamp T. I., Bastiaanse L. P., Hermans H., Penning C., van Wijck R. & Evenhuis H. M. (2011) Study healthy ageing and intellectual disabilities: recruitment and design. *Research in Developmental Disabilities* **32**, 1097–106.

Hoogendijk E. O., Afilalo J., Ensrud K. E., Kowal P., Onder G. & Fried L. P. (2019) Frailty: implications for clinical practice and public health. *Lancet* **394**, 1365–75.

Kojima G., Iliffe S. & Walters K. (2018) Frailty index as a predictor of mortality: a systematic review and meta-analysis. *Age and Ageing* **47**, 193–200.

McKenzie K., Martin L. & Ouellette-Kuntz H. (2016a) Frailty and intellectual and developmental disabilities: a scoping review. *Canadian Geriatrics Journal* **19**, 103–12.

McKenzie K., Ouellette-Kuntz H. & Martin L. (2015) Using an accumulation of deficits approach to measure frailty in a population of home care users with intellectual and developmental disabilities: an analytical descriptive study. *BMC Geriatrics* **15**, 170.

McKenzie K., Ouellette-Kuntz H. & Martin L. (2016b) Frailty as a predictor of institutionalization among adults with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities* **54**, 123–35.

Mitnitski A., Song X., Skoog I., Broe G. A., Cox J. L., Grunfeld E. et al. (2005) Relative fitness and frailty of elderly men and women in developed countries and their relationship with mortality. *Journal of the American Geriatrics Society* **53**, 2184–9.

Mitnitski A. B., Mogilner A. J. & Rockwood K. (2001) Accumulation of deficits as a proxy measure of aging. *ScientificWorldJournal* **1**, 323–36.

Ouellette-Kuntz H., Martin L., Burke E., McCallion P., McCarron M., McGlinchey E. et al. (2018) How best to support individuals with IDD as they become frail: development of a consensus statement. *Journal of Applied Research in Intellectual Disabilities* **31**, 35–42.

Rockwood K., Song X., Macknight C., Bergman H., Hogan D. B., McDowell I. et al. (2005) A global clinical measure of fitness and frailty in elderly people. *CMAJ* **173**, 489–95.

Rockwood K. & Theou O. (2020) Using the Clinical Frailty Scale in allocating scarce health care resources. *Canadian Geriatrics Journal* **23**, 210–5.

Schoufour J. D., Echteld M. A., Bastiaanse L. P. & Evenhuis H. M. (2015a) The use of a frailty index to predict adverse health outcomes (falls, fractures, hospitalization, medication use, comorbid conditions) in people with

intellectual disabilities. *Research in Developmental Disabilities* **38**, 39–47.

Schoufour J. D., Echteld M. A. & Evenhuis H. M. (2017a) Comparing two frailty concepts among older people with intellectual disabilities. *European Journal of Ageing* **14**, 63–79.

Schoufour J. D., Erler N. S., Jaspers L., Kiefte-de Jong J. C., Voortman T., Ziere G. *et al.* (2017b) Design of a frailty index among community living middle-aged and older people: the Rotterdam study. *Maturitas* **97**, 14–20.

Schoufour J. D., Evenhuis H. M. & Echteld M. A. (2014a) The impact of frailty on care intensity in older people with intellectual disabilities. *Research in Developmental Disabilities* **35**, 3455–61.

Schoufour J. D., Mitnitski A., Rockwood K., Evenhuis H. M. & Echteld M. A. (2013) Development of a frailty index for older people with intellectual disabilities: results from the HA-ID study. *Research in Developmental Disabilities* **34**, 1541–55.

Schoufour J. D., Mitnitski A., Rockwood K., Evenhuis H. M. & Echteld M. A. (2015b) Predicting 3-year survival in older people with intellectual disabilities using a Frailty Index. *Journal of the American Geriatrics Society* **63**, 531–6.

Schoufour J. D., Mitnitski A., Rockwood K., Hilgenkamp T. I., Evenhuis H. M. & Echteld M. A. (2014b) Predicting disabilities in daily functioning in older people with intellectual disabilities using a frailty index. *Research in Developmental Disabilities* **35**, 2267–77.

Schoufour J. D., Oppewal A., Van Der Maarl H. J. K., Hermans H., Evenhuis H. M., Hilgenkamp T. I. M. *et al.*

(2018) Multimorbidity and polypharmacy are independently associated with mortality in older people with intellectual disabilities: a 5-year follow-up from the HA-ID study. *American Journal on Intellectual and Developmental Disabilities* **123**, 72–82.

Searle S. D., Mitnitski A., Gahbauer E. A., Gill T. M. & Rockwood K. (2008) A standard procedure for creating a frailty index. *BMC Geriatrics* **8**, 24.

Walston J., Buta B. & Xue Q. L. (2018) Frailty screening and interventions: considerations for clinical practice. *Clinics in Geriatric Medicine* **34**, 25–38.

Wessex AHSN (2019) *RESTORE2 Programme: Patient Safety Collaborative Improving Health in Care Homes.* Wessex Academic Health Science Network, Hampshire.

Supporting Information

Additional Supporting Information may be found online in the supporting information tab for this article.

Table S1. Clinical applicability scores of the ID Frailty Index
Text S2. List of included deficits in the original frailty index in health domains categories