**Frailty index for older people with intellectual disabilities –** Schoufour et al. 2013

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| **#** | **Deficit** | **Additional Information** | **Cut-off values and FI scores** |
| **1** | Bladder control | ADL, completed by professional caregivers of the participants | Incontinent = 1  Sometimes continent = 0.5  Continent = 0 |
| **2** | Dressing | ADL, completed by professional caregivers of the participants | Needs help =1  Partly with help = 0.5  No help = 0 |
| **3** | Walking stairs | ADL, completed by professional caregivers of the participants | Needs help = 1  Partly with help = 0.5  No help = 0 |
| **4** | Bathing | ADL, completed by professional caregivers of the participants | With help = 1  No help = 0 |
| **5** | Transfer bed to chair | ADL, completed by professional caregivers of the participants | Unable, no sitting balance = 1  Major help = 0.66  Minor help = 0.33  No help = 0 |
| **6** | Groceries | IADL, completed by professional caregivers of the participants | Not independently = 1  With help = 0.5  Can do groceries = 0 |
| **7** | Housekeeping | IADL, completed by professional caregivers of the participants | Not independently = 1  With help = 0.5  Can do housekeeping = 0 |
| **8** | Falling | Number of falls in the last three months. Information gathered via the professional care giver | >11 falls = 1  6–10 falls = 0.75  3–5 falls = 0.5  1–2 falls = 0.25  0 falls = 0 |
| **9** | Present at the care centre  (max 10 shifts per week) | Information gathered via the professional care giver | \_3 visits a week = 0  <3 visits a week = 1 |
| **10** | Fatigued | ADESS (Dutch translation of the Anxiety, Depression And Mood Scale) over the past six months. Completed by professional Caregivers | Very often = 1  Often = 0.66  Sometimes = 0.33  Never = 0 |
| **11** | Listless | ADESS (Dutch translation of the Anxiety, Depression And Mood Scale) over the past six months. Completed by professional Caregivers | Very often = 1  Often = 0.66  Sometimes = 0.33  Never = 0 |
| **12** | Panic attacks | ADESS (Dutch translation of the Anxiety, Depression And Mood Scale) over the past six months. Completed by professional Caregivers | Very often = 1  Often = 0.66  Sometimes = 0.33  Never = 0 |
| **13** | Decreased food intake, due to loss of appetite, digestive problems, chewing of swallowing difficulties | Mini Nutritional Assessment (MNA) over the past three months. Completed by professional caregivers | Severe decrease in food  intake = 1  Moderate decrease in food  intake = 0.5  No decrease in food intake = 0 |
| **14** | Weight loss | Mini Nutritional Assessment (MNA) over the past three months. Completed by professional caregivers | Weight loss greater than 3 kg = 1  Does not know = 0.5  Weight loss 1–3 kg = 0.5  No weight loss = 0 |
| **15** | Fluid intake per day  (water, juice, coffee, tea,  milk) | Mini Nutritional Assessment (MNA) over the past three months. Completed by professional caregivers | Less than 3 cups = 1  1–5 cups = 0.5  >5 cups = 0 |
| **16** | Calf circumference (CC)  in cm | Mini Nutritional Assessment (MNA) over the past three months. Completed by professional caregivers | CC < 31 = 1  CC \_ 31 = 0 |
| **#** | **Deficit** | **Additional Information** | **Cut-off values and FI scores** |
| **17** | Only eats selected types of food (e.g. pudding, rice) | Screening Tool of Eating Problems (STEP) over the last month. Completed by professional caregivers | >10 times = 1  Between 1 and 10 times = 0.5  Not at all/not a problem = 0 |
| **18** | Only eats small amounts of the presented food | Screening Tool of Eating Problems (STEP) over the last month. Completed by professional caregivers | >10 times = 1  Between 1 and 10 times = 0.5  Not at all/not a problem = 0 |
| **19** | Only eats foods of certain Textures | Screening Tool of Eating Problems (STEP) over the last month. Completed by professional caregivers | >10 times = 1  Between 1 and 10 times = 0.5  Not at all/not a problem = 0 |
| **20** | Mobility | Provided by professional  Caregivers | Wheelchair = 1  Walks with support = 0.5  Walks independently = 0 |
| **21** | CVA | Medical file, last 24 months | Yes = 1  No = 0 |
| **22** | Coronary heart diseases/heart failure/cardiac dysrhythmia/pacemaker | Medical file, last 24 months | Yes = 1  No = 0 |
| **23** | Cancer | Medical file, last 24 months | Yes = 1  No = 0 |
| **24** | Asthma/COPD | Medical file, last 24 months,  medication | Yes = 1  No = 0 |
| **25** | GERD | Medical file, last 24 months | Yes = 1  No = 0 |
| **26** | Obstipation | Medical file, last 24 months,  medication | Yes = 1  No = 0 |
| **27** | Risk for Diabetes Mellitus  (DM) or known DM | Medical file, blood glucose levels, medication | DM according to medical file or taking drugs for DM and/or serum glucose \_ 7 mmol/l = 1  No DM according to medial file, no DM drugs and blood glucose 6.1–6.9 = 0.5  No DM according to medial file, no DM drugs and blood glucose < 6.1 = 0 |
| **28** | Scoliosis | Medical file | Yes = 1  No = 0 |
| **29** | Visual/Hearing impairments  (V/H impairment) | Medical file | At least one severe V/H impairment = 1  Two moderate V/H impairment = 1  One moderate V/H impairment = 0.5  No V/H impairment = 0 |
| **30** | Medication use (polypharmacy) | Medical file | \_7 drugs = 1  4–6 drugs = 0.5  0–3 drugs = 0 |
| **31** | Over or under weight | Medical examination | BMI < 8.5 OR > 30 = 1  BMI 18.5–20 OR 25–30 = 0.5  BMI 20–25 = 0 |
| **32** | High blood pressure | Medical file | Yes = 1  No = 0 |
| **33** | Peripheral atherosclerosis | Medical examination | Ankle Arm index  >0.9 = 0  0.8–0.9 = 0.5  <0.8 = 1 |
| **34** | Osteoporosis (t-score) | Medical examination | <2.5 = 1  \_1 till \_2.5 = 0.5  >\_1 = 0 |

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| **35** | Manual Dexterity (BBT) | Fitness assessment. The participants were asked to move as many coloured blocks as possible in one minute. The  blocks were 2.5 cm3 and needed to be moved from one side of a wooden box to the other side | Lowest quartile = 1  Second quartile = 0.66  Third quartile = 0.33  Highest quartile = 0 |
| **36** | Walking speed | Fitness assessment. Comfortable walking speed was measured by the average of three records of the time needed to complete 5 m after 3 m for  acceleration | Slow walking speed was Stratified for height and gender:  Male height \_ 173 cm \_7 s = 1  Male height > 173 cm \_6 s = 1  Females height \_ 159 cm\_7 s = 1  Females > 159 cm \_6 s = 1  Faster = 0  Participant who were not able to succeed the walking speed assessment due to physical limitations were scored positive  (score 1) as well |
| **37** | Grip strength | Fitness assessment. Measured with a Jamar Hand Dynamometer (#5030J1,  Sammons Preston Rolyan, USA) | Grip strength was stratified for  gender and BMI  **Male**  BMI \_ 24: \_29 kg = 0  BMI 24.1–26: \_30 kg = 0  BMI 26.1–28: \_30 kg = 0  BMI > 28: \_32 kg = 0  **Female**  BMI \_ 23: \_17 kg = 0  BMI 23.1–26: \_17.3 kg = 0  BMI 26.1–29: \_18 kg = 0  BMI > 29: \_21 kg = 0  Below cut-off values = 1  Participant who were not able to succeed the grip strength assessment due to physical limitations were scored positive  (score 1) as well |
| **38** | Hypercholesterolemia | Medical dossier | Yes = 1  No = 0 |
| **39** | HDL | Blood examination | HDL was stratified for gender  **Male**  0–0.9 mmol/l = 1  0.9–1.55 mmol/L = 0.5  >1.55 mmol/L = 0  **Female**  0–1.1 mmol/l = 1  1.1–1.55 mmol/L = 0.5  >1.55 mmol/L = 0 |
| **40** | Haemoglobin | Blood examination | Stratified for gender  **Male**  8.6–10.5 mmol/L = 0  <8.6 OR >10.5 mmol/L = 1  **Female**  7.5–9.5 mmol/L = 0  <7.5 OR >9.5 mmol/L = 1 |

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| **#** | **Deficit** | **Additional Information** | **Cut-off values and FI scores** |
| **41** | Dysphagia | Diagnosis via DDS questionnaire | Severe dysphagia = 1  Moderate dysphagia = 0.5  No dysphagia = 0 |
| **42** | Hospitalization | Asked in informed consent form.  Hospitalization is the past 12 months | >2 = 1  1–2 = 0.5  No = 0 |
| **43** | Makes a sad/depressing Impression | SDZ, completed by professional caregivers. Last three months | Often = 1  Several times = 0.66  Sometimes = 0.33  Never/very rare = 0 |
| **44** | Has fun and interest  in daily activities | SDZ, completed by professional caregivers. Last three months | Never/very rare = 1  Sometimes = 0.66  Several times = 0.33  Often = 0 |
| **45** | Sleeps more than regularly (trouble getting out of bed,  falls asleep during the day) | SDZ, completed by professional caregivers. Last three months | Often = 1  Several times = 0.66  Sometimes = 0.33  Never/very rare = 0 |
| **46** | Fast fatigue easily fatigued/listless | SDZ, completed by professional caregivers. Last three months | Often = 1  Several times = 0.66  Sometimes = 0.33  Never/very rare = 0 |
| **47** | Is slow or passive in his/her movements | SDZ, completed by professional caregivers. Last three months | Never/very rare = 0  Sometimes = 0.33  Several times = 0.66  Often = 1 |
| **48** | Knows which year it is | The Dementia Questionnaire for  Mentally Retarded Persons  (DMR) | Normally No = 1  Sometimes = 0.5  Normally Yes = 0 |
| **49** | Knows the way to familiar places | The Dementia Questionnaire for | Normally No = 1  Sometimes = 0.5  Normally Yes = 0 |
| **50** | Is seeing group mates | Mentally Retarded Persons | Normally No = 1  Sometimes = 0.5  Normally Yes = 0 |
| **51** | Knows that today is a weekend or a week day | (DMR) | Normally No = 1  Sometimes = 0.5  Normally Yes = 0 |
| All deficits were scored between ‘0’ and ‘1’, ‘0’ - indicating the absence of the deficit and ‘1’ the complete presence of the deficit. | | | |

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| **Calculation of the Frailty Index** | | |
| **Sum of deficit scores (a)** | **\*Total number of deficits measured (b)** | **\*\*Frailty Index (c)**  **a/b =c** |
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| \*Unable to calculate frailty score for less than 30 deficits  Calculate a frailty score dividing the sum of deficit scores by the total  \*\*Number of deficits measured, resulting in a score between 0 (no deficits present) and 1 (all deficits present). | | |

**Reference:**

Schoufour, J.D., Mitnitski, A., Rockwood, K., Evenhuis, H.M. and 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*(5), pp.1541-1555.

Schoufour, J.D., Echteld, M.A. and Evenhuis, H.M., 2017. Comparing two frailty concepts among older people with intellectual disabilities. *European journal of ageing*, *14*(1), pp.63-79.