**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 = 0.5Continent = 0 |
| **2** | Dressing | ADL, completed by professional caregivers of the participants | Needs help =1Partly with help = 0.5No help = 0 |
| **3** | Walking stairs | ADL, completed by professional caregivers of the participants | Needs help = 1Partly with help = 0.5No help = 0 |
| **4** | Bathing | ADL, completed by professional caregivers of the participants | With help = 1No help = 0 |
| **5** | Transfer bed to chair | ADL, completed by professional caregivers of the participants | Unable, no sitting balance = 1Major help = 0.66Minor help = 0.33No help = 0 |
| **6** | Groceries | IADL, completed by professional caregivers of the participants | Not independently = 1With help = 0.5Can do groceries = 0 |
| **7** | Housekeeping | IADL, completed by professional caregivers of the participants | Not independently = 1With help = 0.5Can do housekeeping = 0 |
| **8** | Falling | Number of falls in the last three months. Information gathered via the professional care giver | >11 falls = 16–10 falls = 0.753–5 falls = 0.51–2 falls = 0.250 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 = 1Often = 0.66Sometimes = 0.33Never = 0 |
| **11** | Listless | ADESS (Dutch translation of the Anxiety, Depression And Mood Scale) over the past six months. Completed by professional Caregivers | Very often = 1Often = 0.66Sometimes = 0.33Never = 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 = 1Often = 0.66Sometimes = 0.33Never = 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 foodintake = 1Moderate decrease in foodintake = 0.5No 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 = 1Does not know = 0.5Weight loss 1–3 kg = 0.5No 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 = 11–5 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 = 1CC \_ 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 = 1Between 1 and 10 times = 0.5Not 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 = 1Between 1 and 10 times = 0.5Not 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 = 1Between 1 and 10 times = 0.5Not at all/not a problem = 0 |
| **20** | Mobility | Provided by professionalCaregivers | Wheelchair = 1Walks with support = 0.5Walks independently = 0 |
| **21** | CVA | Medical file, last 24 months | Yes = 1No = 0 |
| **22** | Coronary heart diseases/heart failure/cardiac dysrhythmia/pacemaker | Medical file, last 24 months | Yes = 1No = 0 |
| **23** | Cancer | Medical file, last 24 months | Yes = 1No = 0 |
| **24** | Asthma/COPD | Medical file, last 24 months,medication | Yes = 1No = 0 |
| **25** | GERD | Medical file, last 24 months | Yes = 1No = 0 |
| **26** | Obstipation | Medical file, last 24 months,medication | Yes = 1No = 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 = 1No DM according to medial file, no DM drugs and blood glucose 6.1–6.9 = 0.5No DM according to medial file, no DM drugs and blood glucose < 6.1 = 0 |
| **28** | Scoliosis | Medical file | Yes = 1No = 0 |
| **29** | Visual/Hearing impairments(V/H impairment) | Medical file | At least one severe V/H impairment = 1Two moderate V/H impairment = 1One moderate V/H impairment = 0.5No V/H impairment = 0 |
| **30** | Medication use (polypharmacy) | Medical file | \_7 drugs = 14–6 drugs = 0.50–3 drugs = 0 |
| **31** | Over or under weight | Medical examination | BMI < 8.5 OR > 30 = 1BMI 18.5–20 OR 25–30 = 0.5BMI 20–25 = 0 |
| **32** | High blood pressure | Medical file | Yes = 1No = 0 |
| **33** | Peripheral atherosclerosis | Medical examination | Ankle Arm index>0.9 = 00.8–0.9 = 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. Theblocks were 2.5 cm3 and needed to be moved from one side of a wooden box to the other side | Lowest quartile = 1Second quartile = 0.66Third quartile = 0.33Highest 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 foracceleration | Slow walking speed was Stratified for height and gender:Male height \_ 173 cm \_7 s = 1Male height > 173 cm \_6 s = 1Females height \_ 159 cm\_7 s = 1Females > 159 cm \_6 s = 1Faster = 0Participant 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 forgender and BMI**Male**BMI \_ 24: \_29 kg = 0BMI 24.1–26: \_30 kg = 0BMI 26.1–28: \_30 kg = 0BMI > 28: \_32 kg = 0**Female**BMI \_ 23: \_17 kg = 0BMI 23.1–26: \_17.3 kg = 0BMI 26.1–29: \_18 kg = 0BMI > 29: \_21 kg = 0Below cut-off values = 1Participant 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 = 1No = 0 |
| **39** | HDL | Blood examination | HDL was stratified for gender**Male**0–0.9 mmol/l = 10.9–1.55 mmol/L = 0.5>1.55 mmol/L = 0**Female**0–1.1 mmol/l = 11.1–1.55 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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| **41** | Dysphagia | Diagnosis via DDS questionnaire | Severe dysphagia = 1Moderate dysphagia = 0.5No dysphagia = 0 |
| **42** | Hospitalization | Asked in informed consent form.Hospitalization is the past 12 months | >2 = 11–2 = 0.5No = 0 |
| **43** | Makes a sad/depressing Impression | SDZ, completed by professional caregivers. Last three months | Often = 1Several times = 0.66Sometimes = 0.33Never/very rare = 0 |
| **44** | Has fun and interestin daily activities | SDZ, completed by professional caregivers. Last three months | Never/very rare = 1Sometimes = 0.66Several times = 0.33Often = 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 = 1Several times = 0.66Sometimes = 0.33Never/very rare = 0 |
| **46** | Fast fatigue easily fatigued/listless | SDZ, completed by professional caregivers. Last three months | Often = 1Several times = 0.66Sometimes = 0.33Never/very rare = 0 |
| **47** | Is slow or passive in his/her movements | SDZ, completed by professional caregivers. Last three months | Never/very rare = 0Sometimes = 0.33Several times = 0.66Often = 1 |
| **48** | Knows which year it is | The Dementia Questionnaire forMentally Retarded Persons(DMR) | Normally No = 1Sometimes = 0.5Normally Yes = 0 |
| **49** | Knows the way to familiar places | The Dementia Questionnaire for | Normally No = 1Sometimes = 0.5Normally Yes = 0 |
| **50** | Is seeing group mates | Mentally Retarded Persons | Normally No = 1Sometimes = 0.5Normally Yes = 0 |
| **51** | Knows that today is a weekend or a week day | (DMR) | Normally No = 1Sometimes = 0.5Normally 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 deficitsCalculate 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.