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# Predicting disabilities in daily functioning in older people with intellectual disabilities using a frailty index

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ABSTRACT

Frailty is a state of increased vulnerability to adverse health outcomes compared to others of the same age. People with intellectual disabilities (ID) are more frequently and earlier frail compared to the general population. Frailty challenges much of health care, which will likely further increase due to the aging of the population. Before effective interventions can start, more information is necessary about the consequences of frailty in this, already disabled, population. Here we report whether frailty predicts disabilities in daily functioning. Frailty was measured with a frailty index (FI). At baseline and follow-up activities of daily living (ADL), instrumental activities of daily living (IADL) and mobility were collected by informant report. For 703 older people with ID (≥50 yr) baseline and follow-up measures were known. Multivariate linear regression models were used to predict ADL, IADL and mobility at follow-up. The FI was significantly associated with disabilities in daily functioning independent of baseline characteristics (age, gender, level of ID, Down syndrome) and baseline ADL, IADL or mobility. The FI showed to be most predictive for those with relative high independence at baseline. These results stress the importance for interventions that limit the progression of frailty and, thereby, help to limit further disability.



## 1. Introduction

Frailty is a state of increased vulnerability to adverse health outcomes compared to others of the same age. The prevalence increases with age, even recognizing that older people in general are more vulnerable to adverse health outcomes as a result of decline in many physiological systems (Clegg, Young, Iliffe, Rikkert, & Rockwood, 2013). Frailty challenges much of health care, which has a single problem or single system focus (Clegg et al., 2013; Levers, Estabrooks, & Ross Kerr, 2006). People with intellectual disabilities (ID) typically are at greater risk to develop frailty than others of the same age. Because they have, in addition to general aging problems, an increased risk of motor and sensory disabilities, co-morbidities, mental health

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problems, and syndrome specific aging problems (for example Down syndrome; Coppus et al., 2006; Evenhuis, Henderson, Beange, & Chicoine, 2001; Malt et al., 2013; Meuwese-Jongejeugd et al., 2006; van Splunder, Stilma, Bernsen, & Evenhuis, 2006). The construct of frailty has been developed (Schoufour, Mitnitski, Rockwood, Evenhuis, & Echteld, 2013) and validated in relation to the risk of death in older people with ID (Schoufour, Mitnitski, Rockwood, Evenhuis, & Echteld, 2014). Here we report on whether frailty also predicts for disabilities in daily functioning. This information provides insight into the consequences of frailty in this specific population, which is necessary to design effective interventions.

Which method captures frailty the best is still a matter of discussion. Several frailty instruments have emerged in recent years (Bouillon et al., 2013). One broadly used method is the frailty index which is a multifactorial measure for frailty. The frailty index is based on accumulation of a broad spectrum of non-specific age-related impairments (deficits), including symptoms, signs, diseases, disabilities or laboratory measurements (Mitnitski, Mogilner, & Rockwood, 2001; Rockwood & Mitnitski, 2007). Inasmuch as the administration of the frailty index does not necessarily involve self-report and the measure is multifactorial, which means that it is not focused on specific problems, this approach appears to offer a suitable measure for people with ID (Evenhuis, Schoufour, & Echteld, 2013). Therefore, we developed a frailty index for older ($\geq$50 year) people with ID (Schoufour et al., 2013) according to a standardized procedure (Searle, Mitnitski, Gahbauer, Gill, & Rockwood, 2008). This frailty index showed the same characteristics (frequency distribution, correlation with age) but frailty seemed to start at a younger age compared to the general population (Rockwood & Mitnitski, 2007; Romero-Ortuno & Kenny, 2012; Schoufour et al., 2013; Schoufour, Mitnitski, et al., 2014; Schoufour, van Wijngaarden, et al., 2014). The frailty index showed a clear relationship with 3-year mortality. Those classified as frail were at least 8 times (95%CI 7.7–17.3) more likely to die compared to those classified as non-frail (Schoufour, Mitnitski, et al., 2014; Schoufour, van Wijngaarden, et al., 2014).

The relationship between the frailty index and survival underlined the problem of frailty in people with ID. It is however not yet clear whether frailty also has an impact on disability in this already disabled population. In the general population it has been shown that frail individuals have a higher risk for disabilities in activities of daily living (ADL), instrumental activities of daily living (IADL) and mobility compared to non-frail individuals (Abizanda et al., 2013; Daniels, van Rossum, Beurskens, van den Heuvel, & de Witte, 2012; Ensrud, Ewing, Cawthon, et al., 2009; Ensrud, Ewing, Taylor, et al., 2008; Gobbens, van Assen, Luijkx, & Schols, 2012; Theou, Rockwood, Mitnitski, & Rockwood, 2012; Vermeulen, Neyens, van Rossum, Spreeuwenberg, & de Witte, 2011; Woo, Goggins, Sham, & Ho, 2006). In people with ID, activities of daily living were found, in addition to aging, to be related to cognitive functioning and mobility limitations (Hilgenkamp, Bastiaanse, et al., 2011; Hilgenkamp, van Wijck, & Evenhuis, 2011; Janicki & Jacobson, 1986; Maaskant et al., 1996). As a result, people with ID often experience lifelong dependence. The relationship between frailty and increasing dependence can therefore not be assumed to be the same as that observed in the general population. If frailty is a risk factor, frailty instruments that can identify those at risk can help selecting those who benefit from intervention programs aiming at maintaining independence and mobility. Maintaining as much independence as possible can increase the quality of life and diminish the burden for individuals, family, caregivers, and health care facilities (Andersen, Wittrup-Jensen, Lolk, Andersen, & Kragh-Sorensen, 2004; Manini, 2011). Therefore, the primary objective of this study was to analyze the association between the frailty index score and deterioration of ADL, IADL and mobility over a 3-year follow-up period in older people with ID.

## 2. Methods

### 2.1. Design and participants

This study was part of the 'Healthy Ageing and Intellectual Disability' (HA-ID) study. The observational HA-ID study collected information on the general health status of older people with ID. The HA-ID study focused on (1) physical activity and fitness, (2) nutrition and nutritional state, and (3) mood and anxiety. The study was conducted in three care organizations throughout The Netherlands (Hilgenkamp, Bastiaanse, et al., 2011). The Medical Ethics Committee of the Erasmus Medical Center Rotterdam (MEC-2008-234) and the ethics committees of the participating care organizations approved this study. The three care organizations together provided care to 2322 clients with borderline to profound ID aged 50 years and over, who were all invited to participate. Those capable of understanding the available information signed the consent form themselves. Legal representatives were approached for those not able to make this decision. Written informed consent was provided for 1050 clients. They formed a nearly representative study population for the Dutch population of older adults (aged 50 and above) with ID who receive formal care, albeit with a slight underrepresentation of men ($\chi^2[1, N = 2322] = 0.53$, $p = .03$), people aged 80 and over ($\chi^2[8, N = 2322] = 27.41$, $p = .001$), and people living independently ($\chi^2[3, N = 2237] = 50.55$, $p < .001$). Three years after the baseline measurements a follow-up study evaluated health, dependence, and mobility. The follow-up study was approved by the Medical Ethics Committee of the Erasmus Medical Center Rotterdam (MEC-2011-309) and the ethics committees of the participating care organizations. All participants, or their legal representatives, who still received care from one of the care organizations were asked again to provide written informed consent for the follow-up study.

### 2.2. Data collection

Baseline data collection has been described in detail elsewhere (Hilgenkamp, Bastiaanse, et al., 2011). The broad spectrum of data collected included physical assessments, a fitness test battery, actigraphy, pedometer measurements, mealtime