Elders gepubliceerd: interessante literatuur

17 juni 2026 · J. Voeten - Van de Louw

In de TAVG-rubriek ‘Elders gepubliceerd’ zetten we relevante nieuwe literatuur voor artsen VG op een rij. Deze editie bundelt onder andere onderzoek naar fysieke fitheid bij oudere volwassenen met een verstandelijke beperking, innovatieve inzet van immersive virtual reality bij middelengebruik en lichte verstandelijke beperkingen, herstel en uitval in klinische verslavingszorg, melatoninespiegels bij Smith-Magenis-syndroom, sterfte en overleving bij ouder wordende volwassenen met Downsyndroom, kwaliteit van leven bij ernstige gedragsproblemen, de voorspellende waarde van een kwetsbaarheidsindex en prioriteiten in gezondheidskennis voor begeleiders.

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Feasibility of Physical Fitness Measurements in Older Adults With Intellectual Disabilities Within Two Large Cohort Studies: The HA-ID and IDS-TILDA Study

Oppewal A, Lynch L, Burke E. Feasibility of Physical Fitness Measurements in Older Adults With Intellectual Disabilities Within Two Large Cohort Studies: The HA-ID and IDS-TILDA Study. J Intellect Disabil Res. 2026 Jul;70(7):688-699. doi: 10.1111/jir.70103. Epub 2026 Apr 9. PMID: 41956913; PMCID: PMC13238373.

Background: Research has shown significant underdiagnoses in adults with intellectual disabilities, highlighting the need for objective health measurements to prevent overshadowing. Physical fitness, crucial for health and functioning, is consistently poor in this population, increasing the risk of adverse outcomes. Fitness tests are promising but to date lack specific reference values from large datasets for broader applicability. This study examines the feasibility of four physical fitness tests in two large European cohort studies, IDS-TILDA in Ireland and the HA-ID study in the Netherlands, to address barriers and improve inclusion in research and care.

Method: This study used data from IDS-TILDA (40+ years) and HA-ID (60+ years) cohort studies. Static balance was measured by the capability of maintaining three stances; muscle strength was measured as grip strength; muscular endurance was measured with the Five-Times Chair Stand; and cardiorespiratory fitness was measured with the Two-Minute Step Test. Reasons for non-compliance were documented. The feasibility of these tests and reasons for non-successful performance were described for the total group and across participant characteristics.

Results: The IDS-TILDA sample was younger than the HA-ID sample, with more participants being independent in mobility. All fitness tests showed moderate to good feasibility, except the Full-Tandem stance in the IDS-TILDA sample. Lower feasibility was found in adults with severe and profound intellectual disabilities, walking aids and

wheelchair users. Key barriers for participation were physical limitations and difficulties understanding the task.

Conclusions: This study showed overall moderate to good feasibility. Physical limitations and difficulties understanding the task were important barriers, emphasising the need for the person-centred approach taken by both studies. Feasibility for including standardised physical fitness assessments, with a person-centred approach, in large cohort studies is shown. Including physical fitness assessment is recommended to allow for comparability and combining of data for more knowledge on physical fitness in adults with intellectual disabilities.

Immersive Virtual Reality-Supported Cognitive-Behavioral Therapy for Patients With Mild to Borderline Intellectual Disabilities and Substance Use Disorders: Two Exploratory Studies

Murray S, Langener S, Kip H, Klaassen R, Kelders SM, Heylen D, VanDerNagel J. *Immersive Virtual Reality-Supported Cognitive-Behavioral Therapy for Patients With Mild to Borderline Intellectual Disabilities and Substance Use Disorders: Two Exploratory Studies.* *JMIR XR Spat Comput. 2026 May 4;3:e82601. doi: 10.2196/82601. PMID: 42205233; PMCID: PMC13202510.*

Background: Substance use disorders (SUDs) are prevalent and characterized by high relapse rates. Individuals with mild to borderline intellectual disability (MBID) are more likely to develop SUDs and face barriers within treatment related to difficulties they experience with abstract thinking, verbal skills, and generalizing learned strategies to real-world contexts. Therefore, experiential, context-rich approaches are needed that reduce reliance on retrospective verbal reflection, support in-context identification of triggers, and allow the rehearsal of coping responses. Immersive virtual reality (IVR) may provide realistic, safe environments where patients with SUD and MBID can practice cognitive and behavioral skills with visual and practice-oriented materials.

Objective: This study aimed to generate design input for the development and clinical integration of IVR-supported therapy for individuals with MBID and SUD. Specifically, Study 1 explored alcohol-related triggers in patients with alcohol use disorder, whereas Study 2 examined the feasibility and acceptability of practicing nicotine-related coping strategies in patients with nicotine dependence (ND).

Methods: Two explorative studies were conducted at an inpatient clinic for patients with MBID and SUD in the Netherlands. Study 1 included 10 adults with alcohol use disorder and MBID who participated in interviews to determine relevant risk situations,

triggers, and therapeutic goals for IVR-cognitive behavioral therapy (CBT). Study 2 included 10 adults with MBID and nicotine dependence who practiced coping strategies within an existing IVR featuring craving-inducing and craving-reduction scenarios. A multiple-method approach was used to gather input for IVR-CBT development and to explore feasibility and acceptability (user evaluation interviews, the Questionnaire of Smoking Urges, and Visual Analog Scale ratings).

Results: In study 1, we identified high-risk situations, including at-home routines (eg, sitting on the couch watching football), supermarkets (eg, confrontation with alcohol and advertisements), social gatherings (eg, invitations and peer pressure), and being outside or traveling (eg, public transport or passing alcohol-related places). Triggers clustered into multisensory cues (eg, seeing or smelling alcohol), social influences (peer pressure and interpersonal conflict), affective states (tension, distress, boredom, or euphoria), and personal habits (eg, rewarding oneself or associations with money). Participants expressed interest in using IVR to identify triggers, discuss affective states, and train refusal skills. In study 2, IVR elicited nicotine craving, which increased during cue exposure and decreased during tutorial and coping phases. The coping elements embedded in IVR included relaxation (eg, mindfulness or breathing exercises), distraction (eg, virtual pets and interactive games), and physical activity (eg, walking or sports).

Conclusions: IVR-CBT elements appear feasible and acceptable in inpatient MBID care with appropriate support. Findings provide patient-derived design insights for integrating trigger identification and coping rehearsal within IVR. Future work should use an iterative, user-centered design approach based on validated CBT-related techniques (eg, functional analysis or coping, or skills training) and compare IVR-CBT with CBT as usual to understand benefits and risks for patients and therapists.

Recovery Outcomes and Treatment Dropout in Patients with Complex Problems Undergoing Inpatient Addiction Treatment: A Naturalistic Prospective Cohort Study

Pars E, Dijkstra BAG, VanDerNagel JEL, Schellekens AFA. Recovery Outcomes and Treatment Dropout in Patients with Complex Problems Undergoing Inpatient Addiction Treatment: A Naturalistic Prospective Cohort Study. Eur Addict Res. 2026;32(1):56-68. doi: 10.1159/000550485. Epub 2026 Jan 13. PMID: 41528956; PMCID: PMC12908947.

Introduction: Recovery from substance use disorder (SUD) spans clinical, functional, and personal dimensions. However, research covering these domains, particularly in populations with complex problems such as those with mild to borderline intellectual

disabilities (MBIDs), remains limited. This study explored different recovery outcomes and their relationship with treatment dropout during the first 12 weeks of inpatient treatment, while also examining whether the presence of MBID affected the outcomes.

Methods: A naturalistic, prospective cohort study was conducted with patients undergoing inpatient SUD treatment at a Salvation Army Clinic in The Netherlands. Recovery outcomes (clinical, functional, personal) and predictors of dropout were assessed over 12 weeks. MBID (yes/no) was determined using the SCIL screening tool. Data were analyzed using repeated measures (M)ANCOVA to evaluate recovery trajectories and logistic regression to explore associations between recovery levels and dropout.

Results: Of the 157 participants, 66% screened positive for potential MBID, and 40% dropped out within 12 weeks. For completers, significant improvements were observed across all recovery domains over time (all $p < 0.001$). Psychological problems decreased by a mean of 9.6 points (95% CI: 7.5-11.8), physical problems by a mean of 3.7 points (95% CI: 2.0-5.4), and craving by a mean of 7.5 points (95% CI: 6.4-8.6). Functional recovery increased by a mean of 5.1 points (95% CI: -1.4 to 11.7), and personal recovery by a mean of 5.7 points (95% CI: 3.5-7.9). Lower baseline recovery levels were associated with greater relative improvements but lower endpoint scores. Lower baseline functional recovery was a small but significant predictor of dropout. MBID status did not affect recovery trajectories.

Conclusions: The findings suggest a multidimensional recovery process during early phases of inpatient treatment, irrespective of MBID status. Baseline recovery levels play a crucial role in shaping outcomes, underscoring the importance of early assessments. Importantly, these findings indicate that those worst off at baseline profit most from treatment.

Melatonin Levels in 89 Individuals With Smith Magenis Syndrome

Braam W, Smith ACM. Melatonin Levels in 89 Individuals With Smith Magenis Syndrome. Am J Med Genet A. 2026 May 17. doi: 10.1002/ajmg.a.70167. Epub ahead of print. PMID: 42144698.

In patients with Smith-Magenis syndrome (SMS), an inverted circadian rhythm of melatonin (MT) contributes to the sleep disturbance. Standard treatment of sleep disturbance with MT often leads to extremely high daytime MT levels, resulting in even more sleep disorders. We therefore retrospectively evaluated the MT data of 89 SMS patients. Mean MT levels in participants on exogenous MT were significantly higher than in participants that did not use MT ($p = < 0.0001$). In 9 participants with very

high MT levels, these dropped significantly after discontinuation of exogenous MT ($p = 0.0037$). In 12 participants, MT levels were significantly higher after MT therapy start compared to MT levels before MT start ($p = 0.028$). MT is catabolized principally by the CYP1A2 enzyme, with a half-life of about 40 min. CYP1A2 genotyping was performed in five participants with high MT levels during MT use. Although clinically suspected to be a poor CYP1A2 metabolizer, all five turned out to have haplotype CYP1A2*1F, which is associated with increased enzyme activity. This shows that genotyping of CYP1A2 is not suitable to estimate the level of CYP1A2 enzyme activity. When prescribing MT, it is strongly recommended to measure a MT level prior to treatment in order to determine the dose to be given. Checks of the MT level during treatment are necessary due to the frequent occurrence of poor CYP1A2 metabolism. Since CYP1A2 genotyping does not provide adequate information about the level of CYP1A2 enzyme activity, we propose a simple way to determine CYP1A2 phenotype.

Immediate and Underlying Causes of Death and Survival Rates in Aging Adults With Down Syndrome

*Hilgenkamp TIM, Oppewal A, Chien LC, Maes-Festen DAM***.** *Immediate and Underlying Causes of Death and Survival Rates in Aging Adults With Down Syndrome . J Appl Res Intellect Disabil. 2026 May;39(3):e70246. doi: 10.1111/jar.70246. PMID: 42126823; PMCID: PMC13170638.*

Background: To describe immediate and underlying causes of mortality (using ICD-10 codes) and survival rates of aging adults with Down syndrome (Ds).

Method: This secondary analysis used the Healthy Aging and Intellectual Disabilities cohort. Adults with Ds (n = 149, ≥ 50 years at baseline) were matched 1:1 to adults with intellectual disabilities without Ds on age, sex and level of intellectual disability. Follow-up was ~10 years post-baseline, or at death.

Results: The most common immediate and underlying causes of death in adults with Ds were respiratory diseases/infections, followed by cardiovascular disease and neuropsychiatric conditions. Unknown causes accounted for 29%-50% of deaths. Adults with Ds had higher mortality than matched comparators (HR = 5.05, 95% CI 3.10-7.47), increasing significantly with each year of age (HR = 1.08/year, 95% CI 1.04-1.11).

Conclusion: Respiratory diseases, cardiovascular and neuropsychiatric conditions are important contributors to mortality in older adults with Ds, but large numbers of missing causes warrant cautious interpretation.

Mental Health Classification and Care for Individuals With Intellectual Disability and Severe Challenging Behaviour: A Three-Year Follow-Up on Quality of Life

Migchelsen I, Dijkxhoorn YM, de Sonneville LMJ, Swaab H. *Mental Health Classification and Care for Individuals With Intellectual Disability and Severe Challenging Behaviour: A Three-Year Follow-Up on Quality of Life.* *J Appl Res Intellect Disabil. 2026 May;39(3):e70243. doi: 10.1111/jar.70243. PMID: 42117796; PMCID: PMC13164824.*

Background: Individuals with intellectual disability and severe challenging behaviour (CB) often need intensive support. The present study examines whether mental health classification (MHC) makes interventions aimed at improving quality of life (QoL) more effective.

Method: A three-year follow up of 122 men and 62 women with intellectual disability and severe CB, aged 18-70 years, compared number and type of support goals and development of QoL (San Martin Scale) and CB (Developmental Behaviour Checklist for Adults) of individuals with (N = 124) and without (N = 60) MHC.

Results: MHC was associated with setting more support goals. This had no differential effect on the development of QoL or CB. Improvement in QoL was associated with lower initial QoL, higher cognitive functioning and a lower number of support goals set.

Conclusion: MHC was not related to better outcomes. Overall, setting fewer support goals and higher cognitive functioning are positively related to the effectiveness of treatment.

The Intellectual Disability Frailty Index Predicts 10-Year Mortality Within the HA-ID Cohort

van Maurik MC, Böhmer MN, Bindels PJE, Festen DAM, Oppewal A. *The Intellectual Disability Frailty Index Predicts 10-Year Mortality Within the HA-ID Cohort.* *J Intellect Disabil Res. 2026 Jul;70(7):725-733. doi: 10.1111/jir.70111. Epub 2026 May 8. PMID: 42101161; PMCID: PMC13238440.*

Background: Adults with intellectual disability (ID) experience frailty up to 20 years earlier than the general population, potentially increasing their risk of age-related comorbidities and mortality at a younger age. This study investigates the relationship between frailty, assessed with the Intellectual Disability Frailty Index (ID-FI) and its Short Form, and all-cause mortality over 10 years in older adults with ID. Accurate mortality prediction may help identify high-risk individuals and assist in creating

targeted interventions for adults with ID.

Methods: Data from 982 participants aged ≥ 50 years (mean age = 61.6 ± 8 years) with borderline to profound ID were analysed over a 10-year follow-up within the Healthy Ageing and Intellectual Disabilities (HA-ID) cohort. Frailty was assessed using the 51-item ID-FI and the 17-item ID-FI Short Form, which measure frailty scores that can be classified into five categories: relatively fit, prefrail, mildly frail, moderately frail and severely frail. Cox proportional hazards models were used to assess the predictive validity of both indices for all-cause mortality.

Results: Of 982 study participants, 433 (44.1%) were deceased during 10-year follow-up. Higher frailty scores were significantly associated with increased mortality risk, independent of age, sex, level of ID and Down syndrome. Compared to relatively fit participants, the hazard ratios (HRs) for mortality for the ID-FI were as follows: 1.53 (95% CI = 1.14-2.05) for prefrail, 3.17 (95% CI = 2.31-4.36) for mildly frail, 5.37 (95% CI = 3.66-7.89) for moderately frail and 10.00 (95% CI = 6.49-15.43) for severely frail participants. A similar pattern was demonstrated for the ID-FI Short Form. Both indices demonstrated fair predictive accuracy (AUC = 0.72) for 10-year all-cause mortality.

Conclusions: Both the ID-FI and ID-FI Short Form are predictive for 10-year mortality risk in adults with ID. Future research should investigate how frailty changes over time and develop strategies to improve care for adults with ID.

Health-related knowledge essential for support workers in providing daily care for people with intellectual disability: Dutch health professionals' priority topics

Nijhof K, Bevelander KE, Boot FH, Leusink GL, Naaldenberg J. *Health-related knowledge essential for support workers in providing daily care for people with intellectual disability: Dutch health professionals' priority topics.* *Patient Educ Couns. 2026 Aug;149:109677. doi: 10.1016/j.pec.2026.109677. Epub 2026 May 5. PMID: 42102514.*

Objectives: To gain insight into priority health topics for support workers in daily care for people with intellectual disability from healthcare professionals' perspectives.

Methods: A three-round modified Delphi study was conducted with 22 healthcare professionals working in intellectual disability care settings. In round 1, participants identified and elaborated on relevant health-related topics. These were merged into a list of distinct topics rated for relevance in round 2. Topics with high-rated relevance were ranked in round 3.

Results: In round 1, 63 health-related topics were identified. In round 2, 17 topics met the criterion for relevance. In round 3, the highest-prioritized topics addressed supporting healthy living and combining health-related knowledge with an understanding of the individual.

Conclusions: The high relevance ratings for all topics emphasize support workers' important role in health support for people with intellectual disability. Rather than a strict set, the topics can be used as building blocks that are adaptable to different contexts to guide staff tasks and training efforts.

Practice implications: This study provides a comprehensive overview of priority health topics relevant for support workers. Their practical prioritization and integration into training and care practices should ideally involve stakeholders within their specific contexts.

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