

## **Staf**

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## **Doel**

De leerstoel bestaat sinds april 2000 en heeft als centraal doel kennisvermeerdering op het gebied van de gezondheid van mensen met een verstandelijke handicap. Dit gebeurt door middel van wetenschappelijk onderzoek, onderwijs en nascholing en brede landelijke en internationale contacten. Het onderzoek bestaat primair uit epidemiologisch onderzoek ten behoeve van evidence-based preventie, diagnostiek en behandeling. Daarnaast houdt de leerstoel zich bezig met zorgvernieuwing en implementatie.

De bijdrage aan de specialistische opleiding tot AVG betreft vooral het onderwijs in wetenschappelijke vaardigheden ten behoeve van een kritisch-analytische attitude en een evidence-based vakuitoefening. Een leeronderzoek maakt hiervan deel uit.

## **Onderzoek**

### **1. Visuele en gehoorstoornissen**

Deze onderzoekslijn bestaat sinds 1998 en wordt in de loop van 2012 afgerond. Promoties:

- Dhr. J. van Splunder (oogarts). Prevalence and causes of visual impairment in adults with intellectual disabilities. 2003.
- Mevr. A. Meuwese-Jongejeugd (AVG). Hearing impairment in adults with an intellectual disability: epidemiology and rehabilitation. 2006.
- Mevr. L. Sjoukes (AVG). The impact of visual impairment on adults with an intellectual disability. 2008.
- Mevr. Y. van der Zee (neuropsycholoog). Diagnosing cerebral visual dysfunctions in children: looking beyond visual acuity and visual fields. 2012.
- Mevr. F. Boot (AIOS-AVG). Quantification of visual orienting responses to form and motion stimuli in children. 2012.

### **2. Bijkomende aandoeningen bij kinderen met ernstige meervoudige beperkingen**

Deze onderzoekslijn bestaat sinds 2001 en wordt in de loop van 2012/13 afgerond. Promoties:

- Mevr. R. Veugelers (SHE-arts). A population-based study on comorbidity in children with severe motor and intellectual disabilities: focus on feasibility and prevalence. 2006.
- Dhr. R. Rieken (AIOS-psychiatrie). Assessing body composition and energy expenditure in children with severe neurological impairment and intellectual disability. 2010.
- Mevr. E. Calis (AIOS-psychiatrie). Correlates of lower respiratory tract infections and nutritional state in children with severe generalized cerebral palsy and intellectual disability. 2011.
- Mevr. S. Mergler (AVG). Diagnosis of bone quality in children with severe neurological impairment and intellectual disability. 2012.
- Mevr. S. Mensch. Development of motor functioning in children with severe neurological impairment and intellectual disability: the MOVAKIC measurement instrument. 2013.

### **3. Dementie bij Down syndroom**

In deze lijn werd sinds 1998 samengewerkt met de afdeling Epidemiologie & Biostatistiek van het Erasmus MC (Prof Dr CM van Duijn). Promotie:

- Mevr. T. Coppus (AVG). Predictors of dementia and mortality in Down's syndrome. 2008.

### **4. Gezond ouder met een verstandelijke beperking (GOUD)**

Deze lijn is gestart in 2008 met grootschalig onderzoek in een consortium van drie zorgaanbieders. Promoties:

- Mevr. H. Hermans. Depression and anxiety in older people with intellectual disabilities: results of the Healthy Ageing and Intellectual Disability Study. 2012.
- Mevr. T. Hilgenkamp. Physical activity and its correlates in older people with intellectual disabilities: results of the Healthy Ageing and Intellectual Disability Study. 2012.
- Dhr. L. Bastiaanse (AVG). Nutrition and nutritional state in older people with intellectual disabilities: results of the Healthy Ageing and Intellectual Disability Study. 2013.

- Mevr. M. van Schijndel-Speet. Effects of a structured movement programme in older people with intellectual disabilities: results of the Healthy Ageing and Intellectual Disability Study. 2013.
- Mevr. E. van Dijk. Circadian rhythm and sleeping problems in older people with intellectual disabilities: results of the Healthy Ageing and Intellectual Disability Study. 2013.
- Mevr. C. de Winter (AVG). Epidemiology of cardiovascular disease in older people with intellectual disabilities: results of the Healthy Ageing and Intellectual Disability Study. 2014.
- Mevr. J. Schoufour. Frailty and healthy/unhealthy life years in older people with intellectual disabilities: results of the Healthy Ageing and Intellectual Disability Study. 2014.
- 5. Elders (2e promotor)
- Mevr. G. de Kuijper (AVG). Discontinuation of long-term antipsychotic agents for behavioural indications in individuals with intellectual disability: a randomised controlled study (UMCG Prof Minderaa). 2013.
- Mevr. N. de Knecht. Chronic pain experience in adults with Down syndrome and the relationship with cognitive functioning (VU Prof Scherder). Gestart 2010.
- Mevr. N. Jelluma (AIOS-AVG). Etiology of intellectual disability: results of new diagnostic techniques in adults (LUMC Prof Breuning). Gestart 2011.

### Onderwijs

Professor Evenhuis en de senior-onderzoeker zijn beiden stafid en docent bij de AVG-opleiding. Zij hebben in de periode 2001-2011 totaal 41 leeronderzoeken begeleid.

Een structurele bijdrage wordt geleverd aan de opleiding van studenten aan het Erasmus MC (bachelor en master colleges, afstudeeronderzoeken) en de specialistische opleiding van artsen voor verstandelijk gehandicapten (AVG), die tegelijkertijd met de leerstoel in 2000 is gevestigd aan het Erasmus MC. Daarnaast worden incidenteel AVG's of andere professionals begeleid bij kleinschalige onderzoeksprojecten.

Van 2001 t/m 2011 hebben 31 geneeskunde studenten hun keuze-onderzoek (vijf maanden) verricht bij de leerstoel, waaronder ook studenten uit Leiden, Nijmegen en Groningen. Drie van hen zijn daarna bij de leerstoel doorgegaan als promovendus, en zes hebben besloten de AVG-opleiding te volgen.

Daarnaast worden er regelmatig research masterstudenten van andere disciplines en andere universiteiten (Neuropsychologie Leiden, Fysiotherapiewetenschap Utrecht, Orthopedagogiek Utrecht) begeleid, evenals HBO-studenten in de fysiotherapie (Rotterdam, Den Haag) en diëtetiek (Den Haag).

### Publicaties

1. Evenhuis HM, Henderson CM, Beange H, Chicoine B. Healthy ageing – adults with intellectual disabilities: physical health issues. *J Applied Res Intell Disabil* 2001;14:175-94.
2. Evenhuis HM, Hilgeman IS, Bosman AJ & Laat JAPM de. De Fluisterkaart voor verstandelijk gehandicapten. *Evaluatie van een aangepaste fluisterspraaktest. Huisarts & Wetenschap* 2004;47:142-6.
3. Evenhuis HM, Splunder J van, Vink M, Weerdenburg C, Zanten B van & Stilma J. Obstacles in large-scale epidemiological assessment of sensory impairments in a Dutch population with intellectual disabilities. *J Intell Disabil Res* 2004;48:709-18.
4. Evenhuis H, Graaf G van der, Walinga M, Bindels-de Heus K, Genderen M van, Verhoeff M, Lantau K, Meulen-Ennema H van der, Meester N, Wiene L & Schalij-Delfos N. Detection of childhood visual impairment in at-risk groups. *J Policy Practice Intel Disabil* 2007;4:165-9.
5. Evenhuis HM, Sjoukes L, Koot HM & Kooijman AC. Does visual impairment lead to extra disability in adults with intellectual disabilities? A cross-sectional study. *J Intellect Disabil Res* 2009;53:19-28.
6. Evenhuis HM & Penning C. Eight years of specialist training of Dutch intellectual disability physicians: results of scientific research education. *J Policy Practice Intellect Disabil* 2009;6: Dec.
7. Evenhuis HM. Gezondheid van ouderen met verstandelijke handicaps. *Ned T Geneeskd* 2011;155:A2598.
8. Evenhuis et al. Frailty and disability in the older population with intellectual disabilities: results from the Healthy Ageing and Intellectual Disability Study (HA-ID). Submitted.
9. Splunder J van, Stilma JS & Evenhuis HM. Visual performance in specific syndromes associated with intellectual disability. *Eur J Ophthalmol* 2003;13:568-74.
10. Splunder J van, Stilma JS & Evenhuis HM. Refractive errors and visual impairment in 900 adults with intellectual disabilities in the Netherlands. *Acta Ophthalmol* 2003; 81:123-9.

11. Splunder J van, Stilma JS, Bernsen RMD & Evenhuis HM. Prevalence of ocular diagnoses found on screening 1,539 adults with intellectual disabilities. *Ophthalmology* 2004;111:1457-63.
12. Splunder J van, Stilma JS, Bernsen RMD & Evenhuis HM. Prevalence of visual impairment in adults with intellectual disabilities in the Netherlands: cross-sectional study. *Eye* 2006 Sep;20:1004-10.
13. Meuwese-Jongejeugd A, Harteloh P, Verschuure H, Nijs L, Koot H & Evenhuis H. Audiological rehabilitation in adults with intellectual disability: why does it fail? *J Policy Practice Intellect Disabil* 2005;2:66-67.
14. Meuwese-Jongejeugd A, Vink M, Zanten B van, Verschuure H, Bernsen R & Evenhuis H. Prevalence of hearing impairment in adults with an intellectual disability: cross-sectional population study. *International J Audiology* 2006;45:660-9.
15. Meuwese-Jongejeugd A, Verschuure H, Evenhuis HM. Hearing aids: expectations and satisfaction of people with an intellectual disability, a descriptive pilot study. *J Intell Disabil Res* 2007;51:913-22.
16. Meuwese-Jongejeugd A, Splunder J van, Vink M, Stilma JS, Zanten GA van, Verschuure J, Bernsen R & Evenhuis HM. Epidemiology of dual sensory impairment (deafblindness) in adults with intellectual disabilities. *Am J Ment Retard*. 2008 Jul;113(4):254-62.
17. Sjoukes L, Harteloh P & Evenhuis H. Is concept-mapping an effective method of introducing complex interventions into intellectual disability services? *J Policy Practice Intell Disabil* 2006;3:133-5..
18. Sjoukes L, Kooijman A, Koot H & Evenhuis HM. Rehabilitation of low vision in adults with intellectual disabilities: the influence of staff. *J Applied Res Intellect Disabil* 2009, Epub. May 1.
19. Boot FH, Pel JJM, Steen J van der, Evenhuis HM. Cerebral visual impairment: which perceptive visual dysfunctions can be expected in children with brain damage? A systematic review. *Res Dev Disabil* 2010;31:1149-59.
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21. Veugelers R, Calis EAC, Penning C, Verhagen AP, Bernsen RMD, Bouquet J, Benninga MA, Merkus PJFM, Arets HGM, Tibboel D & Evenhuis HM. A population-based nested case-control study on recurrent pneumonias in children with severe generalized cerebral palsy: ethical considerations of the design and representativeness of the study sample. *BMC Pediatrics* 2005;5:25.
22. Veugelers R, Penning C, Gulik ME van, Tibboel D & Evenhuis HM. Feasibility of bioelectric impedance analysis in children with a severe generalized cerebral palsy. *Nutrition* 2006 Jan;22(1):16-22.
23. Veugelers R, Penning C, Grootscholten SPJ, Merkus PJFM, Arets HGM, Rieken R, Brussee JE, Jilderda-Janssen M, Tibboel D & Evenhuis HM. Should we use criteria or eyeballing to reject post-interruption tracings? *Pediatric Pulmonology* 2006;4:937-46.
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53. Hermans H, Pas FH van der & Evenhuis HM. Instruments assessing anxiety in adults with intellectual disabilities: a systematic review. *Res Develop Disabil* 2011;32:861-70.
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