

**Symposium: Assessment****Non-specific learning disabilities compared to specific learning disabilities**

**H. Nikkanen** (hanna.nikkanen@nmi.fi), **V. Närhi**, **T. Ahonen**, **H. Numminen** & **H. Seppälä**

*Niilo Mäki Institute Jyväskylä Finland*

**Aim:** To compare people with non-specific learning disability (NSLD) to those with reading disability (RD) to see whether they show a distinctive cognitive, emotional and behavioural pattern. **Method:** Adolescents with RD were classified into two groups on the basis of general ability level and were administered reading, spelling, arithmetic, general cognitive functioning and neurocognitive tasks. Information about school history and emotional and behavioural problems was gathered by questionnaire. **Results:** Whether there are differences between the groups in reading related background skills, general level of academic achievement, executive function skills, attributional style and externalizing and internalizing symptoms. **Conclusions:** The results will be discussed in the light of the following questions: Which are the most central neurocognitive traits in NSLD and what is the relevance of general ability level in the definition of RD?

**An instrument for the diagnostics of a child's constitution**

**M. Niemeijer, MD** (mhn@planet.nl) & **E. Baars**

*Heilpädagogisch Verbond Zeist The Netherlands*

**Aim:** An instrument has been developed for descriptive diagnostics, as an addition to classifying diagnostics, for children with intellectual disabilities and psychiatric problems. It is based on assumptions in holistic care, that illness is a disturbance of balance and wholeness. It is an anthroposophic typology on constitutional features. It comprises analytical and synthetic elements and consists of 3 sets of 12 items each in polar arrangement and 3 VAS scales of bio-psychological functioning on three levels: thinking and memory, feeling and experience, and willing and doing. The test result is a profile over the three levels.

**Method:** After several trial versions, the instrument has a provisional final shape. Research on its validation started at the end of 2004. It is being used with approx. 300 children with general and more specific developmental problems such as Down syndrome, autism, child-abuse and ADHD. **Results:** The first results will be presented: test-retest and inter-rater reliability in groups of children with different developmental problems and disorders. **Conclusions:** The first steps towards validation have been taken. The instrument provides additional insights into treatment choice and after-care.

**Working memory and memory in everyday situations in children with mild intellectual disabilities**

**M. van der Molen** (M.vandermolen@fss.uu.nl), **J.E.H. van Luit**, **M.J. Jongmans** & **M.W. van der Molen**

*Utrecht University Utrecht The Netherlands*

**Aim:** Previous research into working memory of individuals with intellectual disabilities (ID) has established clear deficits. It is difficult to generalize those findings to real life: do people with ID have memory problems in daily life? The study examined everyday memory and working memory (following Baddeley's 1986 framework) in children with mild ID (IQ 55 - 85). **Method:** Working memory and everyday memory was investigated in three groups: 60 children with mild ID (mean age 15 years), 30 chronological age-matched control children (mean age 15 years) and 30 mental age-matched control children (mean age 10 years). The groups were given multiple assessments of everyday and working memory. **Results:** Children with mild ID performed poorly on aspects of everyday and working memory when compared with children matched for chronological age while there were only minimal differences relative to the performance of children matched for mental age. **Conclusions:** Results are consistent with a developmental delay account of mild ID. Delays in specific aspects of everyday and working memory have important implications for the remedial training of children with mild ID.

**A comparative study of loneliness and depression in adolescents with or without intellectual disabilities**

**H. Gascon** (hubert\_gascon@uqar.qc.ca) & **M.C. Haelewyck**

*Université du Québec à Rimouski Lévis Canada*

**Aim:** Having very few or no friends represents a risk factor for adolescents' social and emotional maladjustment. A great deal of research has indicated that individuals with intellectual disabilities (ID) have a more limited social networks than individuals without disabilities. This study aimed to compare loneliness between adolescents with ID attending special classes in a regular school environment and adolescents without ID. The relationship between loneliness and depression was also examined. **Method:** A total of 108 adolescents coming from ten different schools participated in the study, 48 with ID and 60 without ID. Data were collected with French versions of the Children's Loneliness and Social Dissatisfaction Scale (Asher *et al.* 1984) and Kovac Child Depression Inventory. **Results:** There were no differences in depression between the two groups. However, adolescents with ID were significantly lonelier than adolescents without ID ( $p < .001$ ). We noted a significant relationship between loneliness and depression ( $p < .001$ ). **Conclusions:** Findings will be discussed in terms of the importance of raising awareness in schools about loneliness experienced by adolescents with ID, its consequences, and ways to prevent it.

**Symposium: Healthy behaviour****Health knowledge and expected outcomes of risky behaviour: A comparative study of young people with physical and intellectual disabilities (ID)**

**J. Pownall** (J.Pownall.I@research.gla.ac.uk)

*University of Glasgow Glasgow UK*

**Aim:** As young people with disabilities are more likely to experience social exclusion, opportunities to talk about health may be fewer and this may impact upon knowledge. This may be more marked for sensitive topics like sexual health.

**Method:** Questionnaires and semi-structured interviews were used to elicit quantitative and qualitative data regarding knowledge of healthy eating, alcohol consumption, contraception and AIDS. 65 young people aged 15-21 years participated: 36 with a mild/moderate ID and 29 with a physical disability. Information was also collected on participants' social networks and sources of health knowledge. **Results:** Young people with ID had poorer knowledge overall, although this only reached statistical significance for alcohol ( $z = -2.73$ ,  $p < .01$ ) and AIDS ( $z = -2.17$ ,  $p < .05$ ). There were no significant within-group differences (across topics). The qualitative data also revealed major misunderstandings for both groups although this was more pronounced for the ID group. **Conclusions:** If young people are to make sensible and informed decisions about their health, we must take into account their lay theories of health, including both understandings and misunderstandings. By starting with people's own meanings of health and illness we are better positioned to design effective education strategies.

**The prevalence and determinants of obesity amongst adults with intellectual disabilities**

**C. Melville** (c.melville@clinmed.gla.ac.uk) **A. Jahoda** & **S.A. Cooper**

*Section of Psychological Medicine University of Glasgow Glasgow Scotland UK*

**Aim:** To determine the prevalence and determinants of obesity in adults with intellectual disabilities (ID). **Method:** All adults with ID living in Greater Glasgow were identified and offered a comprehensive health screen, to measure their health status including physical health and disability, health promotion needs, mental ill-health and problem behaviours. Participants had their height and weight measured, from which Body Mass Index (BMI) was calculated. **Results:** Women had significantly greater BMI than men ( $t = 4.5$ ,  $p < .001$ ). 39.3% of women and 27.8% men with ID were in obese, based on BMI. In a backwards stepwise logistic regression, only gender and level of ID had a significant, independent association with BMI. **Conclusions:** Adults with ID experience increased rates of obesity. The determinants of obesity are different for adults with ID, and require further investigation to inform the development of effective interventions and services.

**The Body Mass Index and eating behaviour in people with intellectual disability**

**A. van Knijff** (a.vanknijff@pepijnepaulus.nl), **M. Maaskant**, **C. Jansen**, **P. Freens**, **J. Hoekman**, **M. van den Akker**, **H. van Schroyenstijn Lantman**, **S. Kremers**, **S. Hartong** & **M. van Kordenoord**

*Stichting Pepijn en Paulus Echt/Sittard The Netherlands*

**Aim:** As in the general population, being overweight in people with intellectual disability (ID) is an increasing problem. **Method:** Three studies were carried out to examine: (a) the Body Mass Index of 744 adults with ID, (b) whether moving to community living was related to an increase in BMI in 405 people with ID, and (c) eating behaviours in 25 people with ID. **Results:** Almost half of the population is overweight. Risk groups are elderly people, people with mild/moderate ID, women and people with Down syndrome. Change in BMI was not related to change in living circumstances. Overweight people with ID show more restricted eating behaviour than people with ID and healthy weight. External eating behaviour is higher in people with ID compared to people without ID. **Conclusions:** A substantial proportion of people with ID are overweight. Health promotion programmes are usually not fit for people with ID. The friction between the autonomy of people with ID and good professional support needs to be discussed.

**The dietary intakes and physical activity levels of adults with intellectual disabilities**

**S. Hamilton** (s.hamilton@clinmed.gla.ac.uk), **C. Melville**, **S. Boyle**, **C. Pert**, **C. Mochan**, **N. Robinson**, **S. Miller** & **C. Hankey**

*Section of Psychological Medicine University of Glasgow Glasgow Scotland*

**Aim:** To develop reliable research instruments to measure the dietary intakes and physical activity levels of adults with intellectual disabilities (ID). **Method:** Two research instruments were developed: a three-day participant diary and a food frequency and physical activity carer questionnaire. Agreement between the diary and participant 24-hour recall of dietary intake and physical activity was examined. Two carers independently completed the questionnaire to examine inter-rater reliability. Data were gathered for 40 participants. **Results:** The carer questionnaire had good inter-rater reliability. The level of agreement between the three-day diary and 24-hour participant recall was limited. Participants had low levels of physical activity and dietary intakes that did not meet public health targets for healthy eating. Significant barriers to facilitating healthy lifestyles were identified by carers. **Conclusions:** The carer questionnaire is a reliable instrument for the measurement of dietary intakes and physical activity levels. Adults with ID require targeted interventions to address barriers to healthy lifestyles.

**Symposium: Pomona 2 - Data about health****Monitoring the health of adults with intellectual disabilities in Europe**

**C. Linehan** (christine.linehan@ucd.ie), **S. Buono**,  
**D. Moravec-Berger**, **L. Salvador-Carulla** & **J. Tossebro**  
*University College Dublin Dublin Ireland*

**Aim:** This presentation will outline the background and preliminary data from a European project, Pomona, that aims to develop a set of health indicators for adults with intellectual disabilities (ID). **Method:** Partners from 14 European countries have provided information on the current systems for health monitoring among those with ID. In addition, findings from a survey examining the inclusion of people with ID in national health information surveys and health evaluation surveys currently active throughout Europe will be presented. **Results:** To date, no systematic monitoring of the health of people with ID is undertaken. Information regarding the health of this population is not currently integrated into public health programmes within the European Union. Nor may health status and outcomes for the population with ID be compared with those of the general population. **Conclusions:** The Pomona project provides a first step in gathering information systematically about the health of adults with ID and placing this within the wider EU public health strategy.

**Applying a set of health indicators for people with intellectual disabilities across 14 European countries: Implementing a pilot study**

**M. Kerr** (mp\_kerr@yahoo.com), **A. Germanavicius**, **M. Haveman**  
& **C. Linehan**  
*Cardiff University Cardiff Wales UK*

**Aim:** Partners in a 14 country European project, Pomona, implemented a pilot study of an instrument developed to gather health-related information about people with intellectual disabilities (ID). **Method:** A survey protocol comprising measures of a set of 18 evidence-based health indicators for people with ID was developed, revised and tested through application to a small number of participants in the 14 countries. **Results:** Findings reflected diverse health and social systems in the participating countries and were used to inform revisions to the final instrument. **Conclusion:** Results are discussed in the context of identifying optimal strategies for researchers, health professionals and policy-makers to compare the health of populations of persons with ID within and across countries.

**Gathering information about the health of people with intellectual disabilities: Ethical issues**

**G. Weber** (germain.weber@univie.ac.at), **G. van Hove** & **P.N. Walsh**  
*University of Vienna Vienna Austria*

**Aim:** One aim of the Pomona project was to identify and document ethical issues arising from gathering health information in 14 countries. **Method:** All members of the project group identified and discussed the key ethical issues that arose during project activities at a plenary meeting of partners in Rome in May 2005 and a series of smaller, regional meetings held in autumn 2005 in Barcelona, Graz and Ljubljana. Evidence from both published literature and national practices across participating countries was documented. **Results:** Partners identified ethical issues that were, first, related to the definition and ascertainment of intellectual disabilities (ID) in the countries participating in the Pomona project. Second, some issues related to the management of and access to data about the status, living arrangements and health of people with ID. Third, partners identified questions related to recruiting participants and gaining informed consent or other forms of agreement. **Conclusions:** There was considerable variation in national practices related to managing health or other data gathered about people with ID. Implications for gathering, storing and disseminating information about their own health to individuals with ID are discussed.

**Applying a set of health indicators for people with intellectual disabilities across 14 European countries: Developing a survey instrument**

**M. Veenstra** (marja.veenstra@HAG.unimaas.nl), **H.M.J. van Schroyen**,  
**B. Lantman-de Valk**, **B. Azema**, **A. C. Cara** & **T. Maatta**  
*University of Maastricht Maastricht The Netherlands*

**Aim:** To operationalise the final set of health indicators for people with intellectual disabilities (ID) so as to compare health data of people with ID with those of the general population within and amongst the 14 participating EU countries. **Method:** Information on individual indicators will be gathered through interviews with participants and/or informants using a questionnaire. To allow comparison between the health of people with ID and the general population, items from generic health surveys were used, mostly standardized, validated and reliable scales. For characteristic problems, standardized disability scales were used. Information on organisational indicators will be collected through publications and national registers. A protocol was developed for the process of translation into ten European languages of the 14 countries. **Results:** The presentation will identify the methodological challenges involved in developing this instrument and the decisions that consortium partners took during development of the survey protocol. **Conclusion:** Lessons learned from developing a single instrument to apply across 14 countries will be presented.

**Symposium: Health inequalities and people with intellectual disabilities****Social determinants of the general health status of adults with intellectual disabilities in England**

**E. Emerson** (eric.emerson@lancaster.ac.uk) & **C. Hatton**  
*Institute for Health Research Lancaster University Lancaster UK*

**Aim:** To investigate the possible importance of social factors (poverty, neighbourhood deprivation, social support) on the general health status of adults with intellectual disabilities (ID). **Method:** Multivariate analysis of results of cross sectional survey of 2,898 adults with ID in England **Results:** Social factors were significantly associated with variation in the general health status of adults with ID. **Conclusions:** Social factors which have been linked to health inequalities in the general population are also linked to variations in general health status among adults with ID.

**Barriers to mammography screening for women with cerebral palsy**

**G. Llewellyn** (g.llewellyn@fhs.usyd.edu.au)  
*University of Sydney Sydney Australia*

**Aim:** Approximately 400,000 women with disability are missing out on the regular screening mammograms that assist in early detection of breast cancer. The aim was to explore how radiographers view mammography screening for women with cerebral palsy. **Method:** Radiographers from Breast Screen NSW were asked to participate in focus group discussions about barriers to mammography screening for women with cerebral palsy. **Results:** The barriers identified included: (a) a lack of accessible information in a variety of modes, (b) poor access to the mammography machine due to space constraints, (c) problems with maneuverability of mobility aids, and (d) technical issues associated with mammography positioning. **Conclusions:** Radiographers identified communication during the mammography as a major concern and the time constraints for attending to the individual needs of women with disability. Barriers to mammography screening are not only physical in nature. Opinions, beliefs and attitudes also impact on perpetuating health inequalities for women with disability. Such attitudes may be difficult to modify.

**Impact of repeated health checking on identification of health needs, access to health promotion and consultation and referral rates**

**D. Felce** (felce@cf.ac.uk) & **M. Kerr**  
*Welsh Centre for Learning Disabilities Cardiff University Cardiff UK*

**Aim:** In an earlier study, 51% of 181 adults with intellectual disabilities who received a health check in primary care had newly recognised morbidity. The aim was to assess the impact of repeated health checks on the identification of new needs, access to health promotion and consultation and referral rates. **Method:** Of 108 adults who had an initial check: 39 (Group 1) had a repeat after 28 mths, 36 (Group 2) had a repeat after 44 mths and 33 (Group 3) had no further check. 30 of Group 1 (Group 4) had a second repeat check 14 mths later. Medical records were audited to determine newly identified health needs. Data on consultation, referral and health promotion over 7.5 years were abstracted. **Results:** The number and nature of new health needs identified at subsequent checks was similar to the initial check. The correlation between needs identified and the interval between checks was non-significant. There was no difference in consultation or referral rates before and after the initial health check but health promotion increased. **Conclusions:** Repeat health checking has continuing utility in identifying unmet health needs. Annual health checking appears justifiable.

### Symposium: Health inequalities & people with intellectual disabilities 2

#### Health problems of people with intellectual disabilities (ID): The implications for general practice?

**J. Straetmans** josstraetmans@hotmail.com, **H.M.J. van Schrojenstein Lantman-de Valk & G.J. Dinant**

*Department of general practice - Maastricht University Maastricht The Netherlands*

**Aim:** People with ID have more health problems than those without ID and these frequently remain undetected. People with ID are increasingly registered with general practitioners (GPs). Data about consultation rates, the nature of their health problems and prescriptions by GPs become relevant. Exact figures are rare. This study examines consultation rates of people with ID, the nature of their health problems and prescriptions. **Method:** Within the Second Dutch National Survey of General Practice, GPs selected patients with ID. Each individual with ID was matched with five controls without ID. Consultation rates, the nature of health problems and prescriptions were analysed. **Results:** People with ID paid 70% more visits to their GPs. The profile of morbidity differed substantially from controls. They received more prescriptions, including four times as many repeat prescriptions. **Conclusions:** GPs spend more time on people with ID in their practice, even outside direct contacts. People with ID increase GP workload. Results have implications for planning adequate primary care for people with ID and for training GPs about characteristic health problems.

#### Hospital utilization among persons with intellectual disabilities: What the stats tell us about health inequalities

**H. Ouellette-Kuntz** oulette@post.queensu.ca, **R. Balogh & D. Hunter**

*Queen's University Kingston Canada*

**Aim:** To: (a) describe the hospital utilization patterns among people with an intellectual disability (ID) living in Ontario Canada, and (b) examine whether improved primary care for certain conditions could delay the progression of the disease or prevent serious complications and thus prevent hospitalization.

**Method:** A retrospective analysis of routinely collected hospitalization data for people living in Ontario with ID, between 1995 and 2001. **Results:** A substantial proportion of hospitalizations of people with ID were for mental disorders such as schizophrenia and depression (one-third of in-hospital stays) and dental diseases (40% of day-surgery admissions). The study also identified high ambulatory care-sensitive condition hospitalization rates. In-hospital surgical procedure rates, however, were low. **Conclusion:** Large discrepancies between findings for people with ID and published findings in the general population. A significant number of people with ID may not be receiving the health care that they are entitled to in Ontario. Further research is needed to explore causes for discrepancies in health care.

#### The economic impact of a health screening intervention in the UK: Policy implications

**R. Romeo** r.romeo@iop.kcl.ac.uk, **M. Knapp, S.A. Cooper, J. Morrison, C. Melville & L. Allan**

*King's College London London UK*

**Aim:** To examine the economic implications of a health-screening programme for people with intellectual disabilities (ID) who were screened and those who were not. The research will also present the policy implications associated with health screening for people with ID. **Method:** Using primary and secondary data, we examined service use patterns and costs over a 12-month period for 50 participants who have been offered a screening intervention and 50 who were not. Multivariate regression analyses were used to derive a best fitting model and generalised linear modelling was used to test the robustness of the results.

**Results:** Participants took part in a range of formal and informal community activities. Mean cost of care was over 70 per cent greater for those that were not screened. The extra costs were largely due to carer support costs. **Conclusions:** There are benefits to governments and carers from health screening programmes for people with ID. However, health interventions such as these are not widely available in the UK. Greater attention needs to be paid to the implementation of effective interventions, which not only produce health gains in the short term but also have the potential to provide a wide range of economic gains in the longer term.

### Symposium: Developments in intellectual disability medicine

#### Education for general practitioners by changing care for people with intellectual disability (ID)

**M. Wullink** (magda.wullink@hag.unimaas.nl), **H.M.J. van Schrojenstein Lantman-de Valk, J.F.M. Metsemakers & G.J. Dinant**

*Maastricht University Dept of General Practice Maastricht The Netherlands*

The aim is to develop a post-graduate education for general practitioners (GPs) to provide good quality care for people with ID. A literature search in Medline revealed no existing educational provision, only recommendations. Subsequently, a practice-based course was developed in cooperation with the Dutch College of General Practitioners (NHG). 50 GPs participated in small groups in this course on health care for people with ID. The evaluation of it and feedback on a draft version from clients, parents, ID physicians and staff from NHG was used to produce an individual (electronic) course for GPs. The main issues covered by the GP course were: (a) presentation of complaints and communication, (b) different co-morbidity of people with ID compared to peers, (c) specific co-morbidity and (d) cooperation between GPs and medical specialists, including ID physicians. Case examples were: coughing, constipation, troubles with food intake and epilepsy. The backgrounds of the described persons with ID in the cases were: Down syndrome, autistic spectrum disorder, Sanfilippo B syndrome, severe or unknown level of ID. The presentation will deal with the strengths and weaknesses of the module and recommendations for further implementation.

#### Developments in the profession of intellectual disability physician in the Netherlands

**H. Veeren** (h.veeren@debanjaard.com)

*De Compaan/NVAVG Den Haag/Rotterdam The Netherlands*

In February 2000, the Dutch Minister of Health recognised the physician for people with intellectual disability (ID) as a medical specialist. In December 2005, 177 physicians were registered in the specialist register of the Registration Council. In the years before the recognition of the ID specialist, physicians working in this field encountered many challenges in the justification of their profession. Due to the recognition of this new medical specialism, the appointment of the Chair of Prof. H.Evenhuis and the start of the specialist training programme, both at the Erasmus Medical Centre in Rotterdam, the medical profession has made enormous progress. In this presentation, recent developments in the profession of ID specialist and the field of medical care for people with ID are illustrated. Outreach activities, development of management guidelines, development of a competency profile for the ID specialist and arrangements for collaboration with general practitioners and other medical professions are being discussed.

#### Developments in the Dutch specialist training for physicians for people with intellectual disability

**M. Meijer** (m.meijer@erasmusmc.nl)

*Erasmus MC Rotterdam The Netherlands*

In this presentation the developments in the Dutch specialist training for physicians for people with intellectual disability, in existence since December 2000, will be demonstrated. The three year postgraduate course for physicians is organised by the Erasmus Medical Centre in Rotterdam. Changes in the content and structure of the training programme are illustrated, in response to didactical and organisational developments. The curriculum of the training programme will be competency-based and is better adapted to the individual learning goals of the students. In the first five years of its existence, 58 physicians entered the training, 26 are graduated and found a job in the specialised medical care for people with ID. Other figures about the training programme, such as student backgrounds, their motivation and some student characteristics are demonstrated. Current and future changes in the role of ID physicians in the Netherlands are a major motive for adaptation of the training programme.

#### The perceived challenges encountered by nurses in accident and emergency care for adults with intellectual disabilities

**M. Sowney** (ma.sowney@ulster.ac.uk) & **O. Barr**

*University of Ulster Londonderry Northern Ireland*

**Aim:** To explore the impact of a perceived lack of knowledge of the nature of intellectual disability (ID) on nurse's competence to assess and provide care to adults with ID within the accident and emergency service. **Method:** Five focus group discussions were conducted with 26 accident and emergency nurses from 5 hospitals in Northern Ireland. Data were analysed using Colaizzi's (1978) procedural steps. **Results:** Six interrelated themes emerged: good practice, respect for individuals, lack of knowledge, dependence on carers, and gaining consent. This paper focuses on two themes, lack of knowledge of the nature of ID and dependence on carers. Participants' fear and vulnerability was associated with a lack of knowledge of ID. **Conclusions:** A lack of knowledge and understanding is known to create fear and vulnerability. This emotion was expressed by the participants as a consequence of a lack of knowledge of ID which impacted on their confidence to care and increased their reliance on carers. A framework demonstrating the impact of a lack of knowledge on people with ID, families/carers and nurses has been developed.

**Symposium: Outcomes of small-scale research as part of Dutch specialist training of intellectual disability physicians****Co-morbidity in children and adolescents with profound intellectual and multiple disabilities (PIMD) in Surinam**

**M. Mastebroek, L. Tack** (m.mastebroek@tiscali.nl; letske@hotmail.com), **L. Tack, C. Netten & H.M. Evenhuis**  
*Intellectual Disability Medicine | Dept. of General Practice Erasmus MC Rotterdam The Netherlands*

**Aim:** To evaluate the prevalence rates and severity of health problems in children and adolescents with PIMD in Surinam. **Method:** We obtained information on 35 people with PIMD (mean age 13 years, range 2-31 years) - ethnic background, developmental level, aetiology, medical history, medications used, growth parameters, feeding and swallowing problems, epilepsy, airway infections, visual, hearing, dental, skin and orthopedic problems, communicative abilities, sleep patterns, self-injury, constipation and gastro-oesophageal reflux - from medical files, interviews with family and carers, diaries and physical examination. We interviewed the day centre staff and other health workers about the centre's medical network. **Results:** Prevalence rates and severity of health problems will be reported, with special attention to known versus newly diagnosed medical problems. **Conclusions:** Prevalence rates will be compared to those from the literature. We will give describe the medical network of the centre.

**Prevalence of 9 microdeletions among Dutch adults with intellectual disability (ID) of unknown aetiology, determined using a non-invasive screening technique**

**D. Peppink, E. de Rooij-Askes** (dpeppink@hotmail.com), **I. van Zoest, D. Douma-Kloppenburger, A. van Hagen, H. Gille & H.M. Evenhuis**  
*Intellectual Disability Medicine | Dept. of General Practice Erasmus MC Rotterdam The Netherlands*

**Aim:** To determine the prevalence of 9 microdeletions among adults with ID of unknown aetiology with a new non-invasive technique and to evaluate the method's feasibility. Determining aetiology can help provide a health watch programme for specific aetiology-related morbidity and mortality. **Method:** Informed consent was obtained from 299 (68%) of 436 randomly selected adults with ID of unknown aetiology, and/or their representatives. DNA was collected using oral swabs. Multiplex Ligation Dependent Probe Amplification was used to screen for 9 microdeletions related to ID syndromes (Williams-Beuren, 22q11-deletion, 1p-deletion, Miller-Dieker, Smith-Magenis, Prader-Willi, Alagille, Saethre-Chotzen and Sotos). **Results:** Preliminary data (299 participants): in 2 participants oral swabs failed due to resistant behaviour, 47 swabs were unsuccessful due to insufficient DNA (a second swab will be obtained). We have diagnosed 5/250 participants with a microdeletion syndrome. **Conclusions:** Oral swabs are feasible for DNA sampling in people with ID. Prevalence of an undiagnosed microdeletion syndrome among adults with ID of unknown aetiology is at least 2%.

**Prevalence of celiac disease in adults with Down Syndrome**

**A. van Eeghen** (agnies.van.eeghen@abrona.nl), **B. Tinselboer, A. van Rooijen, M. Fai-Hau, C. Penning & H. Evenhuis**  
*Erasmus University Medical Center Intellectual Disability Medicine Rotterdam The Netherlands*

**Aim:** Children with Down syndrome (DS) have an increased risk of celiac disease (6.0-8.3%). Regular serological screening is advised. No research exists on adults with DS. The aim was to estimate the prevalence of celiac disease in adults with DS. **Method:** We performed serological assessments (IgA-AGA, IgA-EMA, IgA-tTGA, IgG-EMA) on 158 adults with DS. **Results:** Analysis has not been completed for all participants. Four patients tested serologically positive for IgA-tTGA, of whom two also had a positive anti-EMA. This gives a prevalence of at least 2.5% undiagnosed celiac disease and an overall prevalence of 5.1% (95% CI 2.2-9.7%). **Conclusions:** The complete analysis will be presented. Prevalence of celiac disease in adults with DS may be comparable to published prevalences in children.

**Problem behaviour in patients with Down syndrome and dementia**

**D. Konz** (dnkonz@hotmail.com), **C. Jansen-Jacobs, M. Houben, C. Penning & H. Evenhuis**  
*Erasmus University Medical Center Intellectual Disability Medicine Rotterdam The Netherlands*

**Aim:** Disturbance of the cholinergic system might lead to attention deficit, anxiety, restlessness and hallucinations in Alzheimer dementia (Lemstra *et al.* 2003). The aim was to determine how cholinergic deficiency influences problem behaviour in persons with Down syndrome (DS) and dementia. **Method:** Case-control study (42 cases, 55 controls). Problem behaviour and signs of clouded consciousness, disorientation, restlessness and anxiety measured by validated Dutch behavioural checklists, completed by staff. Analysis: comparison of scores of cases and controls, and relationship between problem behaviours and cholinergic deficiency symptoms. **Results:** Cases displayed significantly more physically aggressive behaviour ( $p < .05$ ) and more clouded consciousness ( $p < .001$ ), disorientation ( $p < .001$ ), restlessness ( $p < .01$ ) and anxiety ( $p < .001$ ) than controls. Positive correlation between symptoms of cholinergic deficiency and problem behaviour in cases ( $r = .354$ ,  $p = .051$ ) and controls ( $r = .372$ ,  $p < .01$ ). **Conclusions:** Results support use of cholinesterase inhibitors to influence problem behaviour in people with DS and dementia displaying signs of cholinergic deficiency.

**Symposium: Promoting health improvement****The contribution of socio-economic deprivation to health inequalities for adults with intellectual disabilities**

**C. Melville** (c.melville@clinmed.gla.ac.uk), **S.A. Cooper, A. Williamson, L. Allan, E. Smiley & J. Morrison**  
*Section of Psychological Medicine University of Glasgow Glasgow Scotland UK*

**Aim:** To examine the association between socio-economic deprivation and health status for adults with intellectual disabilities (ID). **Method:** A detailed method of case ascertainment identified 3.15 adults per 1,000 general population. Participants received a comprehensive health screening assessment, designed to measure the health status including physical health and disability, health promotion needs, mental ill-health and problem behaviours. **Results:** For the 1,023 participants, smoking was associated with living in more deprived areas but none of the other health, disability or mental health variables were associated with deprivation. Although the uptake of health promotion programmes was low across all deprivation categories, participants living in more deprived areas were more likely to have up-to-date polio immunisation, tetanus immunisation and cervical screening status. **Conclusions:** In contrast to the general population, there is a lack of association between health status and level of deprivation for adults with ID. Current public health efforts focused on the most deprived communities will not benefit adults with ID with the greatest health needs.

**Injuries, accidents and falls among adults with intellectual disabilities**

**J. Finlayson** (jff96v@clinmed.gla.ac.uk), **S.A. Cooper, J. Morrison & A. Jackson**  
*Section of Psychological Medicine University of Glasgow Glasgow Scotland UK*

**Aim:** To describe the frequency, types and characteristics of injuries experienced by adults with intellectual disabilities (ID). **Method:** A population-based sample of adults with ID was interviewed and asked about any injuries they had experienced over a 12-month period. **Results:** Men and women with ID experienced a greater number and different types of injuries, when compared with carers, and published general population data. 24% of men and 18% of women with ID had experienced at least one injury, compared to 11% of male and 11% of female carers, and 17% of men and 11% of women in the general population. Comparison between the participant and carer groups was highly significant (Chi-square=53.85,  $df=1$ ,  $p < .001$ ). **Conclusions:** Findings demonstrate the magnitude, scope and characteristics of the problem of injuries, accidents and falls in adults with ID. Risk factors were identified, some of which are potentially modifiable.

**Uptake of cervical screening among women with intellectual disabilities**

**L. Allan** (linda.allan@glacomen.scot.nhs.uk), **J. Morrison, S.A. Cooper, E. Smiley & A. Williamson**  
*Glasgow Learning Disability Partnership Greater Glasgow NHS Glasgow Scotland UK*

**Aim:** To compare the uptake of cervical screening by women with intellectual disabilities (ID) with uptake by all women in one Scottish Health Board area, and to identify factors contributing to the variation in uptake. **Method:** Population based cohort study. 400 eligible women with ID aged 18-60 years undertook a comprehensive health screen where uptake of cervical screening was noted. **Results:** 54 women with ID (13.5%) had an up to date smear. Marital status, living circumstances, pregnancy history, contraceptive usage, smoking and level of ID were significantly associated with smear status while age, deprivation status, ethnic origin, having autistic spectrum disorder or problem behaviours were not. Using contraception, having been pregnant, having a milder ID and living independently were positively associated with having had a smear. **Conclusions:** The uptake of cervical screening by women with ID is markedly lower than for all women in the Health Board area (74%). Some women with ID are more disadvantaged than others. The reasons for the poor uptake are likely to be related to the multiple barriers to access experienced by this group.

**National guidelines for screening dementia in people with intellectual disabilities in the Netherlands**

**R. Meeusen** (r.meeusen@meare.nl), **H. Uurlings, R. Dautzenberg, M. der Kinderen, I. Veugen & A. Verhagen**  
*Meare Eindhoven The Netherlands*

**Aim:** is to develop standardized guidelines to diagnose dementia in people with intellectual disabilities (ID). Specific guidelines have been developed for people with different levels of ID. A network of psychologists and educational specialists collaborated to develop national guidelines for the diagnosis of dementia in people with intellectual disabilities. The definition of dementia was derived from ICD-10. All available scales for diagnosing dementia in people with ID (national and international) were studied with regard to their validity, reliability and practical use. This overview led to a new dementia-protocol. The guidelines describe the complete diagnostic process, including the inventory of premorbid status and describing the cause of the dementia. The guidelines pay attention to differences in diagnosing dementia for all levels of ID. The contribution to the diagnostic process of psychology and educational specialists and physicians is regarded as valuable.