

Managing health problems in people with intellectual disabilities

Henny M J van Schrojenstein Lantman-de Valk,^{1,2} Patricia Noonan Walsh³

¹Department of General Practice and Governor Kremers Centre, Maastricht University, PO Box 616, 6200 MD Maastricht, Netherlands

²Pepijn and Paulus Centre, PO Box 40, 6100AA Echt, Netherlands

³Centre for Disability Studies (School of Psychology), University College Dublin, Dublin, Ireland

Correspondence to: H M J van Schrojenstein Lantman-de Valk henny.lantman@hag.unimaas.nl

Cite this as: *BMJ* 2008;337:a2507
doi:10.1136/bmj.a2507

People with intellectual disabilities have a higher prevalence of health problems than the general public, and their health needs are often unrecognised and unmet.¹ People with intellectual and other disabilities are also more likely to develop secondary health conditions.^{w1} Improving the health of people with disabilities during their lives is a specific aim of the Healthy People 2010 initiative in the United States,² the Valuing People initiative in the United Kingdom,^{w2} and the Pomona project (www.pomonaproject.org),³ a public health initiative funded by the European Union to develop and test a set of health indicators for people with disabilities.

A recent randomised controlled trial on annual health screening in people with intellectual disabilities found an improvement in health in the intervention group.⁴ Nevertheless, epidemiological research on the health of people with intellectual disabilities is limited. We present here an up-to-date overview for medical generalists.

What is intellectual disability and how common is it?

Epidemiological research shows a prevalence of intellectual disability of about 0.7% (a figure mostly derived from service registrations—funding bodies or service providers).^{5w3}

In a recent conceptual review, Mont challenges the usefulness of a single summary indicator to capture disability,⁶ which is not a health condition borne by an individual. Rather, disability is, he says, “complex and multifaceted, with its roots in culture” (p 1662).⁶

Traditional society guidelines define intellectual disabilities as conditions characterised by substantial limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills, originating before age 18.^{w4} More specific classification or aetiological diagnoses are based on known reasons for the disability, applying criteria such as those contained in the text revision of the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM IV-TR)* or the American Psychiatric Association’s guidelines.^{w5} In many countries it is typically a psychologist who diagnoses intellectual disabilities.

What health problems might those with intellectual disabilities have?

Physical health problems

Intellectual disabilities are associated with a wide range of medical conditions that have effects on the person’s physical and/or mental health.⁷ These conditions are either associated (primary) or secondary conditions (table).

Primary conditions

The most common physical health problems are epilepsy, mobility problems, and sensory problems.^{8-10w6} Syndrome related health problems often occur in people with genetic syndromes. A small, general practice database study found that a quarter of people with intellectual disabilities and epilepsy were seizure-free and a third had poorly controlled seizures.^{w6} A cross sectional study (n=269) showed lower daily functioning in people with intellectual disabilities and untreated visual problems.^{w7} A 10 year cohort study in 200 people with Down’s syndrome established a prevalence of 11% and a 10 year incidence of 14% of hypothyroidism.⁹

TIPS FOR NON-SPECIALISTS

- Focus on abilities, not disabilities. Greet the person first before discussing things with the accompanying person. Communication is not only words but also pictures, gestures, and body language
- If the medical history cannot be obtained from the patient, ask the accompanying person. Also ask for available medical documentation and prescription lists to get a complete picture of current comorbidity
- If a person presents with challenging behaviour, assess for physical (for example, pain such as toothache, earache) and other sources of discomfort before treating the behaviour as psychiatric and prescribing psychotropic drugs
- Health management plans should be evaluated annually and should include case finding, appropriate monitoring of existing health needs, promotional activities, and disease prevention

SOURCES AND SELECTION CRITERIA

This review is based on searches of the Cochrane database, Medline, and PsycLIT. Key words were: *intell* disab* AND health OR prevalence*. We limited our search to the English language and the years 2006-8. We searched through reference lists of key articles and our personal archives.

Box 1 Key principles of communicating with people with intellectual disability*

- Focus on abilities, not disabilities. Talk respectfully; do not shout; explain what is happening; take time
- Greet the person first, before addressing the accompanying relative or support person
- Invite new patients to bring any existing personal health records. Paid support staff may be unaware of vital elements in a person's medical history; encourage them to make and keep notes and to bring these for subsequent consultations
- Check if your patient has verbal capacities. There may be an imbalance between receptive and expressive language skills. It may take time to realise that although a person is giving clear answers he or she does not understand the question. Even if a person has limited or absent verbal skills, assume competence, establish contact with the person first, and ask if he or she will allow the accompanying person to interpret
- Obtain the medical history as far as possible from the patient; otherwise an accompanying person should complete it
- Make clear that if the patient wants the accompanying person to leave at any moment during the consultation, he or she can indicate that
- For people who are non-verbal, there is a wealth of communication aids, varying from body language such as gestures and facial expressions to sign language and all kinds of pictorial materials and electronic devices. Establish if the patient normally uses these; if the patient does not use a communication system, ask the accompanying person how he or she knows what the patient wants—this could be through facial expressions, vocalisations, or challenging behaviour. If necessary ask for the help of a speech pathologist or a specialist in communication aids.

*Based on *Management Guidelines. Developmental Disability*²¹

Mental health problems

Although challenging behaviour is often interpreted as a means of communicating physical (such as pain), mental, or social discomfort, evidence suggests that psychiatric problems are more common among those with intellectual disability. A longitudinal cohort study showed a point prevalence of mental ill health of 41%. The most prevalent type was problem behaviour. Mental ill health seemed to be associated with life events.¹⁰ The same study found a point prevalence of 2.6% for psychosis in adults with intellectual disability and a standardised incidence ratio of 10.0 when compared with the general population.¹¹ In a cross sectional study in people with Down's syndrome, dementia (mostly Alzheimer's disease) was three times more common than in the general population.¹² At least a third of people with Down's syndrome can expect to develop Alzheimer's disease.^{w8}

Secondary health conditions

Evidence exists for obesity, fractures, poor oral health, constipation, and gastro-oesophageal reflux disease as

secondary health conditions in people with intellectual disability.^{13 14w9-w11} Although it might be assumed that people with intellectual disability would have increased risk factors for fractures (such as osteoporosis caused by many years of immobility or long term use of anticonvulsants), no such evidence exists. However, the higher prevalence of both epilepsy and mobility problems among those with intellectual disability⁸ indicates that further investigation is warranted.

Oral health is often poor, and toothache may manifest as challenging behaviour. A small cross sectional study in people with intellectual disability found a high prevalence of dental caries and toothlessness¹⁵; Nunn et al found a lack of access to adequate training in the dental needs of groups with disabilities.¹⁶

In a cross sectional study, constipation was significantly correlated with lack of mobility, cerebral palsy, the use of anticonvulsants, benzodiazepines, proton pump inhibitors, and refusal to eat.^{w10} Constipation may remain unreported and undetected for a long time and may cause severe problems such as ileus.

Gastro-oesophageal reflux disease often remains unnoticed. A cross sectional study found manifestations such as haematemesis, rumination, dental erosions,^{14w11} and hand-mouthing (putting your whole hand into your mouth).^{w12} If gastro-oesophageal reflux disease remains untreated, there is an increased risk of oesophageal carcinoma.¹⁷

A cross sectional survey in a general practice database found that sexually transmitted disease was eight times more common in people with intellectual disability than in controls.⁸

Many families and carers of people with intellectual disability ask for them to receive lifelong contraception or to have surgery to regulate fertility. A review of gynaecological and paediatric endocrinological literature concluded that little evidence exists to guide clinicians in this area.¹⁸ A cross sectional postal survey about menstrual problems in women with intellectual disability found that these problems were either the

Box 2 What a health management plan should include

- Case finding activities to identify new health needs
- Appropriate management interventions and monitoring for existing health needs—such as an annual check for long term medication used, clinical monitoring for diabetes, and (in people with Down's syndrome) an annual thyroid function check
- Health promotional activities such as establishing the need for nutritional and exercise advice and other lifestyle advice such as oral health needs (dental check) and sexual health needs; in risk groups, check for risk of osteoporosis and gastro-oesophageal reflux disorders
- Disease prevention such as immunisation against tetanus, poliomyelitis, influenza, and hepatitis B, and access to mainstream breast and cervical screening programmes

same as in other women or were related to inappropriate behaviour such as dislike of using pads, disposing of pads in the wrong place, or talking about menstruation in public.^{w13}

Why do people with intellectual disabilities have more health problems?

A case-control study showed that people with intellectual disability in the Netherlands visited their general practitioners 1.7 times as often and received four times as many prescriptions as people without intellectual disability.¹⁹ People with intellectual disability may not be able to understand the significance of their physical symptoms and may not report them early. Instead of somatic complaints, physical problems can manifest as challenging behaviour or loss of daily function. It may be as vague as, "John is not his usual self."

Furthermore, some challenging behaviours may be so intense that they adversely affect the physical health of the person. Physical disorders can also be a side effect of psychotropic drugs, prescribed for challenging behaviour.⁷

Health promotion and public health issues

A dearth of understandable health promotional material plays a role in the prevalence of some conditions, such as poor oral health^{w14} and sexually transmitted diseases.⁸ Poverty contributes to the health and social inequalities experienced by people with intellectual disability.²⁰ A cross sectional study in 1273 adults with intellectual disability in the UK showed that socioeconomic disadvantage, social exclusion, and the

A PATIENT'S STORY

An 18 year old woman (accompanied by her mother) presents because of unbearable pain in her left hip. Her mother makes a plea for intensive pain treatment, as her daughter screams and hits out when being washed and dressed in the morning. The daughter has a spastic tetraplegia and epilepsy. She was a premature and dysmature baby who left hospital at age 6 months. Her development was delayed. She does not speak but understands gestures and communicates by facial expressions and screaming. For her epilepsy she takes lamotrigine 100 mg twice daily, and she has a grand mal seizure about once a month.

At age 14 she had surgery (varisation osteotomy) for a left hip dysplasia. After some remission, two years later, the pain increased and she seemed to have osteoarthritis. Surgical revision did not result in improvement of her complaints. Her pain increased. By that time, she had moved from her parents' house into a community living facility with five other people with intellectual disabilities. The house had been recently renovated, adapted to the needs of the residents and it was staffed by 10 part time workers, all trained in support for people with intellectual disabilities.

One member of staff, experienced in working with people with autistic spectrum disorders wondered if she might have an autistic spectrum disorder in addition to her physical problems. Consultation with a psychologist confirmed the presence of an autistic spectrum disorder. Videotapes of individual staff members performing their morning routines with her showed great differences in behaviour—for example, in how they greeted her in the morning, moved her in the lifting device, or helped her to shower and to use a wheelchair. Subsequent training in total communication, including a consistent application of this approach, diminished the screaming and hitting greatly. In the following months, the dosage of analgesics was substantially reduced.

Associated (primary) and secondary health problems in people with intellectual disabilities

Health problem	Odds ratio	Prevalence (%)	No of study participants	Study design
Associated				
Epilepsy ^{8 w6}	15 ⁸	18 ^{w6}	318* ⁸ ; 318 ^{w6}	Cross sectional ^{8 w6}
Mobility problems including cerebral palsy ⁸	11		318*	Cross sectional
Hearing disorders ²³		8-100†	1598	Cross sectional
Visual problems ²⁴		2-67†	1598	Cross sectional
Mental ill health ¹⁰		41	1023	Longitudinal cohort
Psychosis (in adults) ¹¹		2.6	1023	Longitudinal cohort
Alzheimer's disease ¹²	3		258‡	Cross sectional
Syndrome related				
Hypothyroidism ⁹		11	200‡	Longitudinal cohort
Secondary				
Obesity ¹³		13-58		Review
Gastro-oesophageal reflux disease ^{w11}		48	386	Cross sectional
Constipation ¹⁴		70	215	Cross sectional
Fractures ^{w9}		32	93	Cross sectional
Untreated caries ¹⁵		58	50	Cross sectional
Edentulous ¹⁵		23	50	Cross sectional
Sexually transmitted diseases ⁸	8		318*	Cross sectional

The researchers of the studies for hearing disorders and visual problems studied the same group of patients.

*Part of a larger study of 48<thin>761 people (of whom 318 had intellectual disabilities).

†Prevalence increases with age and is higher in people with Down's syndrome.

‡Participants had Down's syndrome.

lack of social networks are associated with poorer self reported health status.^{w15}

From a public health perspective, misconceptions such as focusing only on prevention of disabling conditions or the idea that the environment does not play a role, lead to an under-emphasis on health promotion and on activities that prevent disease and an increase in the occurrence of secondary conditions.² In European health information systems, people with intellectual disability are rarely represented^{w16}; in the Pomona project, health indicators were developed so that comparable health information could be gathered to identify health inequalities in this vulnerable group.^{w17}

How can I communicate with patients with intellectual disabilities?

Excellent Australian guidelines on consulting with patients who have intellectual disabilities were published in 2005.²¹ Box 1 outlines techniques for communicating with patients who have intellectual disability.

Informed consent

When complex investigations, major surgery, or treatment are proposed, informed consent from the patient must be obtained. The process of assessing mental capacity was recently described.^{w18} A pitfall related to people with intellectual disability may be the incongruence between receptive and expressive verbal skills. It may take time to realise that although a person is giving clear answers he or she does not understand the question. For consent to be valid the person must be^{w19}:

- Capable of taking this particular decision. He must understand the information provided and be able to weigh this information for himself
- Capable of acting voluntarily and not under pressure from anybody
- Provided with sufficient and understandable information to enable him to make the decision.

Legislation on how to act when the person is unable to give informed consent varies among countries. In the UK, no one can give consent on behalf of another adult. The doctor then has to act in the best interest of the patient, having listened carefully to relatives or other people close to him.

Are there special considerations in treatment decisions?

It is discriminating and unlawful to assume that a particular treatment or care is inappropriate because the person has an intellectual disability.^{w19} Points to consider include communication problems as a cause of misunderstanding by the patient; comorbidity; and the possibility that treatment of one health problem interferes with another. Communication problems cannot be a reason not to give the patient the best possible treatment.

Behaviour can be a patient's method of communicating something, such as physical or psychic discomfort arising from various sources. Exploration of this should precede any treatment. A Cochrane meta-analysis of the treatment of challenging behaviour indicated that there is no evidence of benefit in using antipsychotic drugs, widely used to treat these

ADDITIONAL EDUCATIONAL RESOURCES

For healthcare professionals

- Intellectual Disabilities (www.intellectualdisability.info)—This website, maintained by St George's Hospital, London, provides information on health and intellectual disabilities for practitioners, students, and people with intellectual disabilities
- Centre for Developmental Disability Health (www.cddh.monash.org)—Provides fact sheets, information, and courses on health in people with intellectual disabilities
- International Association for the Scientific Study of Intellectual Disabilities (www.iasid.org)—Provides contacts, information about meetings, special interest research groups, fact sheets, guidelines
- American Association on Intellectual and Developmental Disabilities (www.aaid.org)—Provides information on meetings, contacts, fact sheets.
- International Society for Alternative and Augmentative communication (www.isaac-online.org)—Supports and encourages the best communication methods for people who find communication difficult
- Society for the Study of Behavioural Phenotypes (www.ssbp.co.uk)—Provides information sheets on genetic syndromes focusing on behavioural aspects
- Lennox N, Beange H, Davis R, Durvasula S, Edwards N, Graves P, et al. *Management guidelines. Developmental disability*. 2nd ed. (www.tg.com.au/index.php?sectionid=100)—Contains readable information on associated health problems, age related issues, syndrome related comorbidity, and other relevant topics

For people with intellectual disabilities

- *Beyond Words* and *Your Good Health* books are obtainable through www.bild.org.uk and www.intellectualdisability.info respectively. Relatives and care staff can obtain information through these two websites that is suited to their needs.
- Websites in other languages include www.lebenshilfe.de, www.emagister.com/discapacidad-fisica-psiquica-sensorial-tercera-edad-cursos-2331693.htm, www.intellicure.fr/index.cfm, <http://gehandicaptent-verstandelijk.startpagina.nl/>

SUMMARY POINTS

People with intellectual disabilities have twice as many health problems as the general population

The medical history should be obtained as far as possible from the patient; otherwise an accompanying person should complete it

Pictures, gestures, and body language are useful for communicating with the patient

The excess morbidity is related to the disabilities (such as epilepsy, mobility problems, sensory deficits), is syndrome related (such as related to hypothyroidism in people with Down's syndrome), or is secondary (such as obesity and reflux disease)

Accessible health promotion materials are scarce

behaviours.²² A recent randomised controlled trial showed no difference between antipsychotic drugs and placebo in managing difficult behaviour not related to a psychiatric illness.²³

A Cochrane meta-analysis of the treatment of epilepsy in people with intellectual disability showed that when patients participated in clinical trials a moderate reduction in seizure was possible, as well as occasional freedom from seizure. Side effects were no different from those in the general population. A key concern seemed to be the possible occurrence of behaviour disorders that may be a side effect of antiepileptic drugs; the few studies that measured behaviour showed little obvious impact.²⁴

When prescribing for people who already use several medications—for example, for epilepsy or psychiatric problems—considerations should be similar as for older people. Guidelines on good practice should be consulted so that any unnecessary prescriptions can be discontinued and side effects and interactions noted. An excellent overview was published recently.^{w20}

Exercise interventions may improve fitness and reduce obesity. A case-control study examined the effects of an exercise training programme in 52 adults with Down's syndrome (mean age 39.4 years) consisting of cardiovascular and strength exercises. The researchers found that after 12 weeks the training group improved significantly in cardiovascular fitness and muscular strength and endurance and had a slight but significant reduction in body weight.^{w21}

How to develop and sustain a health management plan?

A health management plan is a document that describes the health needs of an individual and the necessary actions to deal with these. A recent randomised controlled trial and a small case-control study (50 cases, 50 controls) showed the advantages of systematic (annual) health reviewing and a health action plan.^{3w22} Further studies will have to establish what is needed for good communication with people with intellectual disability and their carers and what the most appropriate roles are for trained specialist nurses and general practitioners.

People with intellectual disability often rely on health management by proxy and there are many barriers that prevent the identified health needs being met—such as limited or absent verbal and reading skills, communication barriers between support staff and healthcare staff. These barriers limit how well advice can be adhered to or causes a delay in making new appointments.^{w22} Box 2 lists the key components of a health management plan.

An existing and validated instrument for developing and sustaining a health management plan is the Comprehensive Health Assessment Programme.³ The “C21st Health Check” from the Glasgow University Centre for Excellence in Development Disabilities^{w22} is based on this model and adapted to the Scottish healthcare facilities.

Conclusion

People with intellectual disabilities have more health problems than their peers. Many factors—including communication abilities, masking of symptoms, lack of training among health professionals, and absence from generic screening programmes—mean that physical or mental health problems may go unrecognised and untreated. People with intellectual disabilities vary in characteristics, abilities, and preferences, but health professionals must not hold back from treating them.

Contributors: HMJvanSLV conceived the idea for the manuscript, collected literature and wrote the initial draft. PNW added references and contributed to design and interpretation of results. Both authors contributed to final paper. HMJvanSLV is the guarantor.

Competing interests: None declared.

Provenance and peer review: Commissioned; externally peer reviewed. Patient consent not required (patient anonymised, dead, or hypothetical).

- Cooper SA, Melville C, Morrison J. People with intellectual disabilities. *BMJ* 2004;329:414-5.
- US Government. *Healthy people 2010. Disability and secondary conditions*. <http://healthypeople.gov/document/HTML/Volume1/06Disability.htm>
- Pomona Project. *Health indicators for people with intellectual disabilities*. www.pomonaproject.org.
- Lennox N, Bain C, Rey-Conde T, Purdie D, Bush R, Pandeya N. Effects of a comprehensive health assessment programme for Australian adults with intellectual disability: a cluster randomized trial. *Int J Epidemiol* 2007;36:139-46.
- Wullink M, van-Schrojenstein-Lantman-de-Valk HM, Dinant GJ, Metsemakers JF. Prevalence of people with intellectual disability in the Netherlands. *J Intellect Disabil Res* 2007;51(pt 7):511-9.
- Mont D. Measuring health and disability. *Lancet* 2007;369:1658-63.
- Kwok H, Cheung PWH. Co-morbidity of psychiatric disorder and medical illness in people with intellectual disabilities. *Curr Opin Psychiatry* 2007;20:443-9.
- Van-Schrojenstein-Lantman-De-Valk HM, Metsemakers JF, Haveman MJ, Crebolder HF. Health problems in people with intellectual disability in general practice: a comparative study. *Fam Pract* 2000;17:405-7.
- Prasher V, Gomez G. Natural history of thyroid function in adults with Down syndrome—10-year follow-up study. *J Intellect Disabil Res* 2007;51(pt 4):312-7.
- Cooper SA, Smiley E, Morrison J, Williamson A, Allan L. Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *Br J Psychiatry* 2007;27:35.
- Cooper SA, Smiley E, Morrison J, Allan L, Williamson A, Finlayson J, et al. Psychosis and adults with intellectual disabilities. Prevalence, incidence, and related factors. *Soc Psychiatry Psychiatric Epidemiol* 2007;42:530-6.
- Strydom A, Livingston G, King M, Hassiotis A. Prevalence of dementia in intellectual disability using different diagnostic criteria. *Br J Psychiatry* 2007;191:150-7.
- Melville CA, Hamilton S, Hankey CR, Miller S, Boyle S. The prevalence and determinants of obesity in adults with intellectual disabilities. *Obes Rev* 2007;8:223-30.
- Bohmer CJ, Klinkenberg-Knol EC, Niezen-de-Boer MC, Meuwissen SG. Gastroesophageal reflux disease in intellectually disabled individuals: how often, how serious, how manageable? *Am J Gastroenterol* 2000;95:1868-72.
- Cumella S, Ransford N, Lyons J, Burnham H. Needs for oral care among people with intellectual disability not in contact with Community Dental Services. *J Intellect Disabil Res* 2000;44(pt 1):45-52.
- Nunn J, Freeman R, Anderson E, Carneiro LC, Carneiro MS, Formicola A, et al. Inequalities in access to education and healthcare. *Eur J Dental Educ* 2008;12:30-9.
- Patja K, Eero P, Iivanainen M. Cancer incidence among people with intellectual disability. *J Intellect Disabil Res* 2001;45(pt 4):300-7.
- Albanese A, Hopper NW. Suppression of menstruation in adolescents with severe learning disabilities. *Arch Dis Child* 2007;92:629-32.
- Straetmans JM, van-Schrojenstein-Lantman-de-Valk HM, Schellevis FG, Dinant GJ. Health problems of people with intellectual disabilities: the impact for general practice. *Br J Gen Pract* 2007;57:64-6.
- Emerson E. Poverty and people with intellectual disabilities. *Ment Retard Dev Disabil Res Rev* 2007;13:107-13.
- Lennox N, Beange H, Davis R, Durvasula S, Edwards N, Graves P, et al. *Management guidelines. Developmental disability*. 2nd ed. Melbourne, Australia: Therapeutic Guidelines, 2005. www.tg.com.au/index.php?sectionid=100
- Brylewski J, Duggan L. Anitpsychotic medication for challenging behaviour in people with learning disability. *Cochrane Database Syst Rev* 2004;(3):CD000377.
- Tyrer P, Oliver-Africano PC, Ahmed Z, Bouras N, Cooray S, Deb S, et al. Risperidone, haloperidol, and placebo in the treatment of aggressive challenging behaviour in patients with intellectual disability: a randomised controlled trial. *Lancet* 2008;371:57-63.
- Beavis J, Kerr M, Marson A. Pharmacological interventions for epilepsy in people with intellectual disabilities. *Cochrane Database Syst Rev* 2007;(3):CD 005399.