Health Evidence Bulletins Wales

Learning Disabilities
(Intellectual Disability)

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Introduction

The original series *Protocols for Investment in Health Gain* were written in the early 1990s to suggest areas where the introduction, or more widespread use, of certain practices could lead to worthwhile improvements in health for the people of Wales. This revision has been prepared by reviewing the earlier *Protocol for Investment in Health Gain: Learning Disabilities*[1] to provide some clear, updated statements with a precise indication of the strength of the evidence and its sources for each statement. The Bulletin also introduces new statements covering recent developments and subjects of important current interest.

The statements represent a methodical summary of the evidence in this area found through a formal literature search across a wide range of sources[2]. The evidence has been critically appraised using internationally accepted methods[2], compiled into this document under the direction of a public health physician, and reviewed by a multidisciplinary team who are directly involved in patient care[2]. The information in this document is also available electronically, via the NHS Cymruweb (http://cymruweb.wales.nhs.uk/hebw) and the Internet (http://hebw.uwcm.ac.uk). Information on the methodology adopted (including a copy of the documentation), the formats in which the document is issued and details of other publications in the series are available on request[3].

The convention used in this document to indicate the **type of evidence** is[4]:

'Type I evidence' - at least one good systematic review (including at least one randomised controlled trial)
'Type II evidence' - at least one good randomised controlled trial
'Type III evidence' - well designed interventional studies without randomisation
'Type IV evidence' - well designed observational studies
'Type V evidence' - expert opinion; influential reports and studies

Many health issues and interventions in the field of intellectual disability do not lend themselves to investigation by randomised controlled trial. Much of the quoted evidence is Type III, IV and V. There were very few randomised controlled trials to be found in the literature and even fewer systematic reviews. By valuing evidence from randomised controlled trials more highly than observational studies there is a danger that interventions with limited effectiveness might be judged to be more worthy than those based on observation. Similarly, those observational studies which clearly prove effectiveness (and make a randomised trial unethical) might be undervalued. Information assigned as Type V evidence may include expert opinion and important reports or recommendations which should rightly be highly regarded.

The health gain notation (used to indicate the potential **benefit** to health) is[5]:

(1) **'beneficial'** - effectiveness clearly demonstrated
(2) **'likely to be beneficial'** - effectiveness not so firmly established
(3) **'trade-off between beneficial and adverse effects'** - effects weighed according to individual circumstances
(4) **'unknown'**- insufficient/inadequate for recommendation
(5)**'unlikely to be beneficial'** - ineffectiveness is not as clearly demonstrated as for 6
(6)**'likely to be ineffective or harmful'** - ineffectiveness or harm clearly demonstrated

It should be stressed that these gradings, while aiming to be impartial, represent only the best advice of the professionals involved in preparing the Bulletin. Where possible the health gain notation reflects both the type of evidence and the small size of some of the samples. Although the statements are deliberately brief, statistically significant quantitative information has been provided where possible. Issues of cost-effectiveness or cost-benefit are considered where evidence is available.

In keeping with the original Protocols, these revised documents are designed to assist Health Authorities in developing local strategies and in commissioning high quality health care. It is anticipated that they will also be of value to all professionals involved in delivering services for people with intellectual disability in keeping abreast of the large and increasing body of literature in this field. It should be stressed that the publications will act as a supplement to, not a substitute for, skills and experience. Some of the conclusions reached in this Bulletin will inevitably be controversial. Every effort has been made to include the best evidence within a subject area. Readers who are aware of any important studies that have been overlooked are encouraged to contact the project team[3].

The prevalence rate in Western countries for moderate to severe intellectual disability is 30 per 1000 population[6]. As such it is a common condition affecting at least 3% of the population and not surprisingly, people with intellectual disability have many of the conditions found in the general population. This Bulletin therefore considers a number of medical conditions with a known association with intellectual disability. The areas covered include:

- Epidemiology;
- Communication;
- Psychiatric illness;
- Behavioural disturbance;
- Forensics;
- Training staff;
- Hypothyroidism and epilepsy;
- Dementia and Down Syndrome;
- Drug therapy;
- Caring and carers

A deliberate decision has been taken to leave out a number of areas from the Bulletin due to difficulties either in identifying adequate literature in those areas or because the area has been covered in detail in another Bulletin. Areas omitted include ethics, medical conditions (other than epilepsy, thyroid disease and mental illness) and communication and special education in adults. Carers and caring is also covered in the Healthy Living Bulletin[7] and cardiovascular disease is reviewed in the Cardiovascular Diseases Bulletin[8].

There is continuing confusion and complexity surrounding the classification of intellectual disability. With little agreement on terms, there is clearly a need for agreeing a common terminology[9]. There are a range of general titles used in public phraseology depending upon local fashion, public confusion and prejudice, issues of perceived stigma, offensiveness and correctness. In this Bulletin we have used the term 'Intellectual Disability' except where another term is used as part of a formal reference. Terms include:

- Intellectual Disability: starting to appear in much of the UK and international literature and currently used by the International Association for Scientific Studies of Intellectual Disability and in the *Journal of Intellectual Disability Research*.
- Learning Disability: The 'official' term used in the UK.
- Mental Retardation: The 'official' term used in North America and the ICD-10 Mental Handicap: A term used historically in the UK.
- Mental Subnormality and Feeble-mindedness: Now seriously outdated.
- Mental Impairment and Severe Mental Impairment: used in the UK 1983 Mental Health Act, although the Act is currently under revision.

Some authors propose a more innovative exploration of the potential of the multi-dimensional framework of the ICIDH-2[10]. The current ICD-10 classification is limited, based upon assessment of IQ and an additional fourth character to identify the extent of impairment of behaviour[11]:

- F70: Mild Mental Retardation, IQ 50-69.
- F71: Moderate Mental Retardation, IQ 35-49.
- F72: Severe Mental Retardation, IQ 20-34.
- F73: Profound Mental Retardation, IQ <20.
- F78: Other Mental Retardation.
- F79 Unspecified Mental Retardation.
- 0: no or minimal impairment of behaviour.
- 1: significant impairment of behaviour requiring attention or treatment.
- 8: other impairments of behaviour.
- 9: without mention of impairment of behaviour.

The statements made in this bulletin present a graded summary of the best available evidence of effectiveness across the spectrum of intellectual disability. The following information sources were systematically searched in the preparation of this Bulletin, according to the Project Methodology[2]: Cochrane Library, Medline, Pre-Medline, Embase, CINAHL, PsychINFO, ASSIA, Caredata, Rehabdata, National Research Register, Health Promis, the TRIP database, AMED, SIGLE. The full search strategies are available from the Project Office[3]. The date of completion of the literature search for each chapter is given. Some additional evidence, published since the date of the systematic literature search, has been added on the basis of recommendations by Authors and/or the Review Groups where this lends support to an existing statement.
The statements are intended to act as signposts to further sources of evidence, not as guidelines for the management of patients. It is hoped that this Bulletin will facilitate evidence-

based practice, which involves "integrating individual expertise with the best available external evidence from systematic research"[12].

Dr Laurence Hamilton-Kirkwood, Team Leader.
December 2000.

1. Welsh Health Planning Forum. *Protocol for Investment in Health Gain – Learning Disabilities.* Cardiff: Welsh Office NHS Directorate, August 1992.

2. Weightman AL, Barker J, Lancaster J. *Health Evidence Bulletins Wales. Project Methodology 3.* Cardiff: University of Wales College of Medicine, 2000. http://hebw.uwcm.ac.uk/methodology/index.html [accessed 8.12.00] See inside front cover for a full list of contributors to this Bulletin.

3. Contact: Health Evidence Bulletins Wales, Department of Information Services, UWCM, Cardiff CF14 4XN.

4. This table is adapted from the *Bandolier* system (derived from the work at McMaster University, Canada) using the NHS Centre for Reviews and Dissemination criteria for a systematic review. See p.18 in ref.2 or http://www.jr2.ox.ac.uk/Bandolier/band6/b6-5.html [accessed 8.12.00] and the Database of Abstracts of Reviews of Effectiveness (DARE) in the *Cochrane Library.*

5. This Notation is modified from the tables used in Enkin M, Keirse MJNC, Renfrew M and Neilson J. *A Guide to Effective Care in Pregnancy and Childbirth*. 2nd ed. Oxford: Oxford University Press, 1995 pp. 389-90.

6. Roeleveld N, Zielhuis GA, Gabreels F. The prevalence of mental retardation: a critical review of recent literature. *Developmental Medicine & Child Neurology*. 1997: 39(2): 125-32.

7. *Health Evidence Bulletins Wales: Healthy Living.* Cardiff: National Assembly for Wales, 2000. http://hebw.uwcm.ac.uk/healthyliving/index.html [accessed 8.12.00].

8. *Health Evidence Bulletins Wales: Cardiovascular Diseases*. Cardiff: Welsh Office, 1998. http://hebw.uwcm.ac.uk/cardio/index.html [accessed 8.12.00]

9. Fryers T. Epidemiology in relation to community and residential services. *Current Opinion in Psychiatry*. 1997: **10**: 340-53.

10. *ICIDH-2: International Classification of Functioning and Disability*. Beta-2 draft, Full Version. Geneva: World Health Organisation, July 1999

11. *ICD-10: International Classification of Diseases and Related Health Problems*. 10th Revision. Geneva: World Health Organisation, 1992

12. Sackett DL, Richardson WS, Rosenberg W, Haynes RB. *Evidence-based Medicine. How to Practice and Teach EBM*. Edinburgh: Churchill Livingstone, 1997.

1 EPIDEMIOLOGY, RISK FACTORS AND PREVENTION

This bulletin is a supplement to, not a substitute for, professional skills and experience. Users are advised to consult the supporting evidence for a consideration of all the implications of a recommendation.

"The field of intellectual disability continues to be plagued with inconsistent, uncritical and unscientific terminology, apparently hiding lax conceptualisation. Issues relating to deinstitutionalisation and community and home care services also continue to be addressed but the right questions are not always asked and, again, the complexities of methodology, the requirement of very large populations for epidemiological work in this field and the limitation of resources for research in all countries argue for better co-ordinated, collectively planned research programmes."
Fryers T. Epidemiology in relation to community and residential services.
Current Opinion in Psychiatry. 1997; **10**: 340-53

The *statements*	The *evidence*
1.1 Epidemiology	
1.1a. Classification of intellectual disability is a complex and confused area. There is still little agreement on terms and classes. There is a need for a general title for the field, a common terminology and taxonomy, and more innovative exploration of the potential of the multi-dimensional framework of the International Classification of Impairments, Disabilities and Handicaps (ICIDH)[i].	**i.** Fryers T. Epidemiology in relation to community and residential services. *Current Opinion in Psychiatry* 1997; **10**: 340-53 (Type V evidence – expert opinion with review of papers published during previous 12 months)
1.1b. ICIDH is under revision and is currently available in Beta-2 draft version[i].	**i.** World Health Organisation. *ICIDH-2: International Classification of Functioning and Disability. Beta-2 draft, Full Version.* Geneva: World Health Organisation, 1999 http://www.who.int/whosis/icidh/index.html [accessed 8.12.00] (Type V evidence – expert opinion)
1.1c. The prevalence rate in Western countries for **Severe Mental Retardation** (IQ <50) is 3-4 per 1000 population. The prevalence of **Moderate Mental Retardation** (IQ 50-70) is 30 per 1000 population[i,ii]. A typical District of 250,000 population would have 750 -1000 people with Severe Mental Retardation; 25-40 of these would have **severe behavioural problems**[ii]. *These minor differences in prevalence rates reflect the confusion in terminology pointed out in 1.1a	**i.** Roeleveld N, Zielhuis GA, Gabreels F. The prevalence of mental retardation: a critical review of recent literature. *Developmental Medicine & Child Neurology* 1997; **39(2)**: 125-32 (Type IV evidence - systematic review of 43 prevalence studies) **ii.** Felce D, Taylor D, Wright K. People with Learning Difficulties. pp.412-450 In Stevens A, Raftery J (eds). *Health Care Needs Assessment: The Epidemiologically Based Needs Assessment Review.* Oxford: Radcliffe Medical Press, 1994 (Type V evidence – expert opinion based on a survey of the field)

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The *statements*	The *evidence*
1.1d. The **expected birth prevalence*** of Down syndrome has increased from 1.67 (1996) to 1.84 per 1000 live births (1998). The **observed birth prevalence** has increased from 0.91 (1995) to 1.04 per 1000 live births (1998). **Antenatal diagnosis** has remained constant at 45-46%. This reflects a tendency for women to have babies at older ages and the greater use of antenatal screening[i]. (UK) **(assumes absence of antenatal screening and selective termination: to account for spontaneous foetal loss these figures also include 23% reduction in terminations after amniocentesis and 43% reduction in terminations after chorionic villus sampling)*	**i.** Huang T, Watt HC, Wald NJ, *et al*. Birth prevalence of Down's syndrome in England and Wales 1990 to 1997. *Journal of Medical Screening* 1998; **5**; 213-214 (Type IV evidence - observational study)
1.1e. **Down syndrome** is the commonest known cause of mild and severe intellectual disability. **Fetal Alcohol Syndrome** is the second commonest known cause in many countries[i].	**i.** Minns RA. Pre and perinatal conditions contributing to mental retardation. *Current Opinion in Psychiatry* 1997; **10(5)**: 354-59 (Type V evidence – expert opinion with review of 42 papers published during previous 12 months)
1.1f. **Endemic cretinism** caused by iodine deficiency is a common global cause of severe intellectual disability. Prevention with iodine is technically simple and cheap[i]. (Health gain notation – 1 *"beneficial"*)	**i.** Fryers T. Epidemiological concerns in current literature. *Current Opinion in Psychiatry* 1995; **8(5)**: 272-275 (Type V evidence – expert opinion with review of 21 papers published during previous 12 months)
1.1g. **Extremely low birth weight children**, even with optimal socio-economic environments, have a 50% chance of requiring **special educational services** and 20% are **significantly disabled***[i]. (USA) *(presence of one or more severe functional disabilities including autism, cerebral palsy, mental retardation, borderline intelligence with global intellectual problems). See also1.2e.	**i.** Halsey CL, Collin MF, Anderson CL. Extremely low-birth-weight children and their peers. A comparison of school-age outcomes. *Archives of Pediatrics & Adolescent Medicine* 1996; **150(8)**: 790-794 (Type IV evidence – an observational comparison, in the US, of 54 ELBW children matched for race, gender and socioeconomic status)
1.1h. Between 5 and 34 years of age, the prevalence of severe intellectual disability is three times higher among the **Asian community** compared to the non-Asian community[i].	**i.** Emerson E, Azmi S, Hatton C, *et al*. Is there an increased prevalence of severe learning disabilities among British Asians? *Ethnicity & Health* 1997; **2(4)**: 317-321 (Type IV evidence - observational studies with age specific prevalence rates for three Metropolitan Boroughs in the North East of England)

This document is a supplement to, not a substitute for, professional skills and experience. Users are advised to consult the supporting evidence for a consideration of all the implications of a recommendation.

The *statements*	The *evidence*
1.1i. For most children with intellectual disability, between 30-60%, the **cause is unknown**[i].	**i.** Minns RA. Pre and perinatal conditions contributing to mental retardation. *Current Opinion in Psychiatry* 1997; **10(5)**: 354-59 (Type V evidence – expert opinion with review of 42 papers published during previous 12 months)
1.1j. 80% of individuals with **autism** have significant intellectual disability. Conversely, autistic 'traits' are very common amongst people with intellectual disability: the full syndrome occurs in 17% overall and 27% of those with an IQ < 50[i,ii].	**i.** Berney TP. Autism – an evolving concept. *British Journal of Psychiatry* 2000; **176**: 20-6 (Type IV evidence – wide ranging review of 93 recent papers) **ii.** Deb S, Prasad KBG. The prevalence of DSM3-R autistic disorder among the children with a learning disability in the north-east of Scotland. *British Journal of Psychiatry* 1994; **165**: 395-399 (Type IV evidence – cross sectional study)
1.1k. **Fragile X syndrome** is not as common as was once thought with a revised prevalence of 1 in 5700 children of school age[i].	**i.** Morton JE, Bundey S, Webb TP, MacDonald F, Rindl PM, Bullock S. Fragile X syndrome is less common than previously estimated. *Journal of Medical Genetics* 1997; **34(1)**:1-5 (Type IV evidence – population study of school children in Coventry)
1.2 Risk Factors.	
1.2a. **Bacterial meningitis** in childhood may result in a lower IQ score but rarely gives rise to significant intellectual disability (IQ≤70)[i,ii]. There is significant variation in likelihood of sequelae dependent upon the **causative organism**. Lower IQ score occurs with Neisseria meningitidis (2.1%), Haemophilus influenzae (6.1%) and Streptococcus pneumoniae (17%)[ii].	**i.** Anderson V, Bond L, Catroppa C, Grimwood K, Keir E, Nolan T. Childhood bacterial meningitis: Impact of age at illness and acute medical complications on long term outcome. *Journal of the International Neuropsychological Society* 1997; **3(2)**: 147-158 (Type IV evidence - case-control study of 130 post meningitic children and 130 sex matched controls) **ii.** Baraff LJ, Lee SI, Schriger DL. Outcomes of bacterial meningitis in children: a meta-analysis. *Pediatric Infectious Disease Journal* 1993; **12(5)**:389-394 (Type IV evidence - meta analysis of 45 observational studies since 1955, with a total of 4920 children with acute bacterial meningitis)
1.2b Maternal **smoking in pregnancy** may be a preventable cause of intellectual disability (IQ≤70). Smoking one cigarette per day on five or more days per week in pregnancy may increase the risk of intellectual disability by 50%. There is evidence of a dose – response relationship[i]. (Health gain notation – 6 *"likely to be harmful"*)	**i.** Drews CD, Murphy CC, Yeargin-Allsopp M, Decouflé P. The relationship between idiopathic mental retardation and maternal smoking during pregnancy. *Paediatrics* 1996; **97(4)**. 547-553 (Type IV evidence - case control study, 221 children with idiopathic intellectual disability and 400 controls from local schools)

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The *statements*	The *evidence*
1.2c. Risk factors for intellectual disability need to be re-evaluated in the context of other important **maternal**, **perinatal** and **neonatal characteristics**[i]. Characteristics associated with intellectual disability include **low socio-economic status** of the family (44-50% of intellectual disability) and low level of maternal formal **education** (20%). Other significant associations include **maternal IQ≤70**, **multiple births**, **low weight gain in pregnancy** (<10 pounds), **maternal anaemia** and **maternal urinary tract infection**. * This relationship does not exist for severe/profound intellectual disability.	**i.** Camp BW, Broman SH, Nichols PL, Leff M. Maternal and neonatal risk factors for mental retardation: defining the 'at-risk' child. *Early Human Development* 1998; **50(2)**:159-73 (Type IV evidence - prospective cohort study, 35704 North American children followed up to 7 years of age with data on 12 neonatal factors)
1.2d. **Low Birth Weight** (LBW) (birth weight ≤2500g) affects intellectual, educational and health outcomes[i]. Children with a birth weight ≤2500g have a higher rate of health and educational problems at seven years of age. Children with a birth weight ≤1500g are more likely to have visited a GP, physiotherapist, speech therapist and eye specialist, and to require additional help in school.	**i.** Middle C, Johnson A, Alderdice F, Petty T, Macfarlane A. Birthweight and health and development at the age of 7 years. *Child: Care, Health & Development* 1996; **22(1)**: 55-71 (Type IV evidence - retrospective cohort study of 1169 UK children (aged 7) grouped by weight at birth)
1.2e. **Extremely Low Birth Weight** (ELBW) (birth weight ≤800g) affects intellectual, educational and health outcomes. ELBW survivors are three times more likely to demonstrate intellectual disability at school age compared to full term babies with a birth weight ≥2500g[i]. The most likely outcome for ELBW survivors at school age is a learning disorder, often multiple, or borderline intellectual functioning, combined with behavioural and motor risk factors rather than severe / multiple disability. But see also 1.1g.	**i.** Whitfield MF, Ekstein Grunau RV, Holsti L. Extremely premature (< or = 800 g) schoolchildren: multiple areas of hidden disability. *Archives of Disease in Childhood, Fetal & Neonatal Edition* 1997; **77(2)**: F85-90 (Type IV evidence - prospective cohort study of 115 extremely low birth weight North American children compared with 50 age and socio-demographic controls)
1.2f. **Cerebral ventricular dilatation** may be the strongest predictor of intellectual disability and cerebral palsy in ELBW babies[i].	**i.** Waugh J, O'Callaghan MJ, Tudehope DI, *et al*. Prevalence and aetiology of neurological impairment in extremely low birthweight infants. *Journal of Paediatrics & Child Health* 1996; **32(2)**: 120-124 (Type IV evidence - cross sectional study of 194 extremely low birthweight Australian children at 2 years of age)

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The *statements*	The *evidence*
1.3 Prevention	
1.3a Surgical correction of **single suture craniosynostosis** in the first year of life may not prevent intellectual disability* or improve global cognitive functioning at a later stage[i]. (* as defined by Bayley Scales of Infant Development and the McCarthy Scales of Children's Abilities) (Health gain notation – 5 *"unlikely to be beneficial"*)	**i.** Kapp-Simon KA. Mental development and learning disorders in children with single suture craniosynostosis. *Cleft Palate –Craniofacial Journal* 1998; **35(3)**: 197-203 (Type IV evidence - longitudinal evaluation of 84 consecutive children up to 50 months after initial assessment for surgery)
1.3b. The reduction or cessation of **smoking in pregnancy** may reduce the likelihood of learning disability in offspring[i]. See statement 1.2b. (Health gain notation – 2 *"likely to be beneficial"*)	**i.** Drew CD, Murphy CC, Yeargin-Allsopp M, Decouflé P. The relationship between idiopathic mental retardation and maternal smoking during pregnancy. *Paediatrics* 1996; **97(4)**: 547-553 (Type IV evidence - case control study, 221 children with idiopathic intellectual disability and 400 controls from local schools)

2 COMMUNICATION

This document is a supplement to, not a substitute for, professional skills and experience. Users are advised to consult the supporting evidence for a consideration of all the implications of a recommendation.

The *statements* | The *evidence*

2.1 Communication in Children

2.1a. Early Intervention has been shown to be important in fostering the development of **communication skills** in children[i,ii,iii,iv].
(Health gain notation – 2 *"likely to be beneficial"*)

i. Guralnick M. (ed.) *The Effectiveness of Early Intervention.* Baltimore: Brooks, 1997
(Type V evidence – expert overview of early intervention studies that concludes that there is a consensus from the research that early intervention makes a difference)

ii. Rogers SJ. Brief report: Early intervention in autism. *Journal of Autism and Developmental Disorders* 1996; **26(2)**: 243-6
(Type III evidence - Meta-analysis examining six published studies showing positive outcomes with children with autism. None were randomised controlled trials)

iii. Jordan R, Jones G, Murray D. *Educational Interventions for Children with Autism: A Literature Review of Recent and Current Research.* Sudbury: Department for Education and Employment, 1998
(Type V evidence – expert review of educational interventions for children with an autistic spectrum disorder indicating sufficient consistent evidence to suggest that early intervention is effective)

iv. Girolametto LE. Improving the social conversational skills of developmentally delayed children: an intervention study. *Journal of Speech and Hearing Disorders* 1988; **53**: 156-67
(Type II evidence – randomised controlled trial of 20 mother-child dyads. Following 11 weeks of intervention the experimental group showed greater improvement in communication skills than the control group)

2.1b. An extensive range of **interventions** has been proposed for children with **autistic spectrum** disorders over recent years. A number of approaches have some evidence of their effectiveness but this is variable in quality. There is no study with rigorous control of variables such as intensity. Thus the effectiveness of any single approach cannot be precisely isolated[i].
(Health gain notation – 4 *"unknown"*)

i. Jordan R, Jones G, Murray D. *Educational Interventions for Children with Autism: A Literature Review of Recent and Current Research.* Sudbury: Department for Education and Employment, 1998
(Type V evidence – expert review of interventions for children with an autistic spectrum disorder concluding that "*No approach has yet been entirely successful in producing a methodologically sound evaluation of its work.*")

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The *statements*	The *evidence*
2.2 Communication in Adults and Children	
2.2a. Advice and Training for **parents** and **carers** on how to facilitate communication skills is important in enabling people with intellectual disability to communicate[i,ii,iii,iv]. (Health gain notation – 2 *"likely to be beneficial"*)	**i.** Girolametto LE, Greenberg J, Manolsen HA. Developing dialogue skills: the Hanen Early Language Parent Program. *Seminars in Speech and Language* 1986; **7(4)**: 367-82 (Type III evidence - 78% of parents completing pre, post, and follow-up attitude questionnaires indicated that the group training enabled them to create a positive language- learning environment, and to continue as language facilitators after the training programme had ended) **ii.** Money D. A comparison of three approaches to delivering SLT services to people with learning disabilities. *European Journal of Disorders of Communication* 1997; **32**: 449-66 (Type III evidence - 36 carer-client dyads were randomly assigned to 3 intervention approaches: direct therapy, teaching carers, and a combination approach. The combination approach demonstrated statistically significant improvements following intervention. There was not a 'no treatment' control group) **iii.** Granlund M, Terneby J, Olsson C. Creating communicative opportunities through a combined in-service training and supervision package. *European Journal of Special Needs Education* 1992; **7(3)**: 229-51 (Type III evidence - a case controlled cross sectional study of 102 adults with a profound intellectual disability. The evidence supports the use of a combined staff training and supervision format in communication intervention) **iv.** Hodgkinson P. Communication in ALD- What do carers think? *Speech and Language Therapy in Practice* 1998; Spring: 5-7 (Type IV evidence - Structured interviews of 12 staff support the need for an approach which combines a consultative role to carers with direct intervention)
2.2b. A primary focus of intervention should be to ensure: ■ that a person with intellectual disability has maximum opportunities to communicate; ■ that all communicative initiatives, responses to communication and interactions should be rewarding experiences[i,ii,iii]. (Health gain notation – 2 *"likely to be beneficial"*)	**i.** Bradshaw J. Assessing and intervening in the communication environment. *British Journal of Learning Disabilities* 1998; **26**: 62-65 (Type IV evidence – an observational single case study. The data presented is limited but supports the notion that the quality of communication improves when staff know how to enable a person with intellectual disability to communicate meaningfully) **ii.** van der Gaag AD. The view from Walter's window; social environment and the communicative competence of adults with a mental handicap. *Journal of Mental Deficiency Research* 1989; **33**: 221-7 (Type IV evidence - case controlled observational study of 120 learning disabled adults. Community settings were more effective in facilitating communication and clients in the community were significantly better communicators) **iii.** Leuder I. Communicative Environments for Mentally Handicapped People. In M Beveridge, G Conti Ramsden, I Leuder (eds.) *Language Communication and Mentally Handicapped People*. London: Croom Helm, 1988 (Type IV evidence - cross sectional study suggesting that that the communicative environments of mentally handicapped persons become distorted and limit opportunities for communication)

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The *statements*	The *evidence*
2.2c. Intensive interaction approaches are shown to be effective in promoting early communication skills in adults and children[i,ii,iii,iv]. (Health gain notation – 2 *"likely to be beneficial"*)	**i.** Nind M. Efficacy of intensive interaction: developing sociability and communication in people with severe and complex learning difficulties using an approach based on care-giver infant interaction. *European Journal of Special Needs Education* 1996; **11(1)**: 48-66 (Type IV evidence - observational study of six subjects suggesting that communication skills may be enhanced using intensive interaction based on typical care-giver - infant interaction) **ii.** Burford B. Action cycles: rhythmic actions for engagement with children and young adults with profound mental handicap. *European Journal of Special Needs Education* 1988; **3(4)**: 189-206 (Type IV evidence - cross sectional observational study. Analysis of video records identifies crucial common timing factors in effective interaction behaviours) **iii.** Prevezer W. *Evaluation of an Alternative Approach. Musical Interaction with Children who were Considered Unable to Benefit from Conventional Speech and Language Therapy*. Nottingham: Nottingham Community NHS Trust, 1994 (Type IV evidence - overview of 6 case studies) **iv.** Wimpory DC, Nash S. Musical Interaction Therapy - therapeutic play for children with autism. *Child Language Teaching and Therapy* 1999; **15(1)**: 17-28 (Type IV evidence - a single case study. Video-taped evidence suggests that musical interaction therapy enables interactive patterns that are intrinsically rewarding and self perpetuating beyond therapy sessions)
2.2d. Alternative and **augmentative** (**AAC**) communication systems (high and low technology) may be helpful to adults and children with intellectual disability[i,ii,iii]. (Health gain notation – 2 *"likely to be beneficial"*)	**i.** Jago JL, Jago AG, Hart M. An evaluation of the total communication approach for teaching language skills to developmentally delayed preschool children. *Education and Training of the Mentally Retarded* 1984; **19(3)**: 175-82 (Type III evidence - a case controlled study of 24 children supports the use of total communication with pre-school, language delayed children) **ii.** Bondy AS, Frost LA. The Delaware autistic program. in Harris SL, Handleman JS. (eds.) *Pre-School Education Programs for Children with Autism*. Austin: Pro-Ed, 1994 (Type IV evidence - three case studies of pre-school children with autism) **iii.** Park K. How do objects become objects of reference?: A review of the literature on objects of reference and a proposed model for the use of objects in communication. *British Journal of Special Education* 1997; **24(3)**: 108-14 (Type V evidence - expert opinion)

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The *statements*

2.2e. Focussing on **functional communication**, **social** and **pragmatic** aspects of communication is effective whatever approach is used or whether AAC support is provided[i,ii,iii].
(Health gain notation – 2 *"likely to be beneficial"*)

The *evidence*

i. Angelo DH, Goldstein H. Effects of a pragmatic teaching strategy for requesting information by communication board users. *Journal of Speech and Hearing Disorders* 1990; **55**: 231-43
(Type IV evidence - observational study of 4 non-speaking children. Independent rater perceived significant differences when viewing before and after training video tapes)

ii. Calculator SN. Evaluating the effectiveness of AAC programmes for persons with severe handicaps. *Augmentative and Alternative Communication* 1998; **4**: 177-9
(Type V evidence - expert opinion. A position paper which stresses the importance of teaching useful communication skills and in providing opportunities to express choice and preference)

iii. Murphy J, Markova I, Collins C, Moodie E. AAC systems: Obstacles to effective use. *European Journal of Disorders of Communication* 1996; **31(1)**: 31-44
(Type IV evidence - cross sectional study of 93 AAC users. Results indicated the importance of: aids being accessible; opportunities for a wide range of social contacts; training which focuses on the communication partner; useful vocabulary; and encouragement for spontaneous modes of communication)

3 EPIDEMIOLOGY OF PSYCHIATRIC ILLNESS IN ADULTS WITH INTELLECTUAL DISABILITY

This document is a supplement to, not a substitute for, professional skills and experience. Users are advised to consult the supporting evidence for a consideration of all the implications of a recommendation.

The *statements* | The *evidence*

3.1 Psychiatric Illness

3.1a. Studies into the prevalence of **psychiatric illness** among **adults** with intellectual disability report a wide range, between 10% - 39%, depending on the sample selection; definition of psychiatric illness (some included and some excluded diagnoses such as behavioural disorders, pervasive developmental disorders, Rett syndrome and dementia); the diagnostic criteria used; and the diagnostic methods used[i].

i. Borthwick-Duffy SA. Epidemiology and prevalence of psychopathology in people with mental retardation. *Journal of Consulting & Clinical Psychology* 1994; **62(1)**: 17-27
(Type V evidence – expert review of 8 observational studies between 1975 and 1985 involving adults with intellectual disability in both the hospital and community settings)

3.1b. It is not clear whether or not the **rate** of psychiatric illness increases with the severity of intellectual disability[i,ii,iii].

It is difficult to decide with any degree of certainty whether mental illness in general but schizophrenia in particular is present in people with severe and profound intellectual disability[iv].

i. Corbett J. Psychiatric morbidity and mental retardation. In *Psychiatric Illness and Mental Handicap*. (eds. FE James and RP Snaith). London: Royal College of Psychiatrists, Gaskell Press, 1979. pp.11-25
(Type IV evidence – cross-sectional study of psychiatric morbidity in a population-based sample of 140 children and 402 adults with intellectual disability in London)

ii. Göstason R. Psychiatric illness among the mentally retarded. A Swedish population study. *Acta Psychiatrica Scandinavica, Supplementum* 1985; **318**:1-117
(Type IV evidence - cross sectional study of 51 severely and 64 mildly intellectually disabled adults and 64 control cases. Assessed using Comprehensive Psychopathological Rating Scale (CPRS) and DSM3 diagnostic criteria)

iii. Lund J. The prevalence of psychiatric morbidity in mentally retarded adults. *Acta Psychiatrica Scandinavica* 1985; **72(6)**: 563-70
(Type IV evidence – cross-sectional cohort study of 302 adults with intellectual disability, identified from the Danish National Register. It also draws comparisons with eight previous cross-sectional studies)

iv. Reid AH. Psychiatry and learning disability. *British Journal of Psychiatry* 1994; **164**: 613-8
(Type V evidence - expert opinion)

This document is a supplement to, not a substitute for, professional skills and experience. Users are advised to consult the supporting evidence for a consideration of all the implications of a recommendation.

The *statements*	The *evidence*
3.2 Psychiatric Illness in Elderly People	
3.2a. Psychiatric morbidity is found in 61.9% of adults with intellectual disability aged over 65 years[i]. Among adults aged 50 years and over, the prevalence of psychiatric disorder excluding dementia is 11.4% and the prevalence of dementia is 11.4%[ii]	**i.** Cooper S-A. Psychiatry of elderly compared to younger adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* 1997; **10(4)**: 303-311 (Type IV evidence - cross sectional study of 134 people over 65 years of age with intellectual disabilities) **ii.** Patel P, Goldberg D, Moss S. Psychiatric morbidity in older people with moderate and severe learning disability. II. The prevalence study. *British Journal of Psychiatry* 1993; **163**: 481-491 (Type IV evidence - cross sectional study of 105 people with intellectual disabilities aged 50 years and over, using PAS-ADD diagnostic interview)
3.3 Association of Psychiatric Illness with Other Disorders	
3.3a. The rates of psychiatric illness as well as behavioural disorder in adults with intellectual disabilities and **epilepsy** are not significantly different from those in non-epileptic adults with intellectual disabilities[i,ii].	**i.** Deb S. Mental disorder in adults with mental retardation and epilepsy. *Comprehensive Psychiatry* 1997; **38(3)**: 179-84 (Type IV evidence – case-controlled study of 150 epileptic and an age-, sex- and IQ-matched control group of 150 non-epileptic adults with intellectual disabilities) **ii.** Deb S, Joyce J. Psychiatric illness and behavioural problems in adults with learning disability and epilepsy. *Behavioural Neurology* 1998; **11(3)**: 125-9 (Type IV evidence - cross-sectional study of 143 adults with intellectual disabilities and epilepsy)
3.3b. The rate of functional psychiatric illness (excluding dementia and behavioural problems) in adults with severe intellectual disabilities but **not Down syndrome** is six times higher than adults with intellectual disabilities and Down syndrome[i]. Controversial evidence exists as to the higher rate of depressive illness reported among people with Down syndrome compared with non Down syndrome adults with an intellectual disability[i,ii].	**i.** Haveman MJ, Maaskant MA, van Schrojenstein HM, Urlings HFJ, Kessels AGH. Mental health problems in elderly people with and without Down's syndrome. *Journal of Intellectual Disability Research* 1994; **38(3)**: 341-55 (Type IV evidence - cross sectional study comparing 209 severely and 59 mildly intellectually disabled adults with Down syndrome with 477 severely and 1255 mildly intellectually disabled adults without Down syndrome) **ii.** Collacott RA. Cooper S-A. McGrother C. Differential rates of psychiatric disorders in adults with Down's syndrome compared with other mentally handicapped adults. *British Journal of Psychiatry* 1992; **161**:671-4 (Type IV evidence – case-controlled study of 371 adults with Down syndrome compared with 371 matched adults with intellectual disabilities of causes other than Down syndrome)

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The *statements*	The *evidence*
3.4 Prevalence of Specific Psychiatric Illnesses in Adults with Intellectual Disability	
3.4a. Studies into the prevalence of **specific psychiatric illnesses** amongst adults with intellectual disability indicate that some conditions are more prevalent than others in people with intellectual disability[i,ii,iii,iv]. The point prevalence of **schizophrenia** is reported as between 1.3% and 3.7%. The point prevalence of **affective disorders** including **depressive illness** and **mania** are reported as between 1.2% and 6%. The point prevalence **of anxiety related neurotic disorders** is found in around 16.4% adults (20-64 years).	**i.** Turner TH. Schizophrenia and mental handicap: an historical review, with implications for further research. *Psychological Medicine* 1989; **19(2)**: 301-14 (Type V evidence – expert review of 9 English language studies published between 1968 and 1985) **ii.** Lund J. The prevalence of psychiatric morbidity in mentally retarded adults. *Acta Psychiatrica Scandinavica* 1985; **72(6)**: 563-70 (Type IV evidence – cross-sectional cohort study of 302 adults with intellectual disability, identified from the Danish National Register. It also draws comparisons with eight previous cross-sectional studies) **iii.** Hagnell O, Öjesjö L, Otterbeck L, Rorsman B. Prevalence of mental disorders, personality traits and mental complaints in the Lundby study. *Scandinavian Journal of Social Medicine. Supplementum*. 1993; **21(Suppl.50)**: 1-76 (Type IV evidence – cross-sectional study of a geographically defined total population of 2612 over a 25 year period) **iv.** Cooper SA. Psychiatry of elderly compared to younger adults with intellectual disability. *Journal of Applied Research in Intellectual Disability* 1997; **10(4)**: 303-11 (Type IV evidence - cross sectional study of 134 people over 65 years of age with intellectual disability, and 73 people aged 20-64 years with intellectual disability)
3.4b. The prevalence of **attention deficit hyperactivity disorder (ADHD)** amongst adults with severe and profound intellectual disability (15%) is similar to children with severe intellectual disability (18%), but higher than in children with average intelligence (3%-5%)[i].	**i.** Fox RA, Wade EJ. Attention deficit hyperactivity disorder among adults with severe and profound mental retardation. *Research in Developmental Disabilities* 1998; **19(3)**: 275-80 (Type IV evidence - cross sectional study of 86 adults with severe to profound intellectual disability from a community setting, using the Conner's (1990) Hyperactivity Index)
3.4c. There is an association between **depression** and **aggression** with 40% of adults, adolescents and children with both intellectual disability and depression exhibiting aggression[i].	**i.** Reiss S, Rojahn J. Joint occurrence of depression and aggression in children and adults with mental retardation. *Journal of Intellectual Disability Research* 1993; **37(3)**: 287-94 (Type IV evidence - cross sectional study of 528 adults, adolescents and children using Reiss scale)

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The *statements*	The *evidence*
3.5 Services for people with Psychiatric Illness and Intellectual Disability	
3.5a. Up to 5 years after **community resettlement,** people with intellectual disability show little change in the prevalence of psychiatric diagnoses or behavioural disturbance[i]. (Health gain notation – 4 *"unknown"*)	**i.** Kon Y, Bouras N. Psychiatric follow-up and health services utilisation for people with learning disabilities. *British Journal of Developmental Disabilities* 1997; **43(1)**: 20-26 (Type IV evidence - cross sectional study with 1 and 5 year follow ups of 74 adults with intellectual disability following resettlement in the community)
3.5b. **Outreach treatment** represents an effective and efficient alternative to hospital treatment for people with intellectual disability and psychiatric disorders[i,ii]. (Health gain notation – 2 *"likely to be beneficial"*) **Assertive community outreach treatment** or intensive care (caseload, 10-15) significantly decreased the bed use and hospital admission in people with borderline intelligence and psychiatric illness when compared with those who received standard community care (caseload 25-35)[iii].	**i.** van Minnen A, Hoogduin CAL, Broekman TG. Hospital vs. outreach treatment of patients with mental retardation and psychiatric disorders: a controlled study. *Acta Psychiatrica Scandinavica* 1997; **95**: 515-22 (Type II evidence - 28 week follow-up of 50 patients with intellectual disability referred for psychiatric admission: patients randomly allocated to outreach or hospital inpatient treatment) **ii.** Holden P, Neff JA. Intensive outpatient treatment of persons with mental retardation and psychiatric disorder: a preliminary study. *Mental Retardation* 2000; **38(1)**: 27-32 (Type III evidence – non-randomised controlled study of 28 adults with intellectual disability and severe psychiatric disorder) **iii.** Tyrer P, Hassiotis A, Ukoumunne O, Piachaud J, Harvey K. UK 700 Group. Intensive case management for patients with borderline intelligence. *Lancet* 1999; **354**: 999-1000 (Type II evidence – randomised controlled trial of 708 patients, followed up for two years)
3.5c. 17% of all referrals to psychiatrists of people with intellectual disability were considered **emergencies**[i]. The majority of emergency referrals present as **behavioural problems** such as severe physical aggression and self-injurious behaviour.	**i.** Kohen D. Psychiatric emergencies in people with a mental handicap. *Psychiatric Bulletin* 1993; **17**: 587-9 (Type IV evidence - 12 month prospective study of referral patterns in a London borough)

4 BEHAVIOURAL DISTURBANCE

This document is a supplement to, not a substitute for, professional skills and experience. Users are advised to consult the supporting evidence for a consideration of all the implications of a recommendation.

The *statements* | The *evidence*

4.1 Background

4.1a. **Behavioural disturbance** is referred to under a number of different terms – behavioural disorders, behavioural problems and challenging behaviour. **Challenging behaviour** was coined to reflect the fact that such behaviour is not intrinsic to the individual but should be viewed as a response to environmental, social, individual and historical characteristics. Problem behaviour is interpreted as a challenge to the system rather than a manifestation of an individual symptom or characteristic[i,ii].

i. Emerson E. *Challenging Behaviour: Analysis and Intervention in People with Learning Disabilities.* Cambridge: Cambridge University Press, 1995
(Type V evidence - expert opinion)

ii. Jones RSP, Eayrs C. *Challenging Behaviour and Intellectual Disability: A Psychological Perspective.* Clevedon: BILD Publications, 1993
(Type V evidence - expert opinion)

4.1b. Recent studies suggest that between 12-17% of those administratively defined as having an intellectual disability will display challenging behaviour[i,ii,iii,iv,v].

Within a district of 500,000 general population, and assuming an administrative prevalence of intellectual disability of 0.45%, around 225-340 people will show challenging behaviour at any one point in time. Approximately 40-60% of these will show more severe problems.

Physical aggression, self-injury and destructiveness towards the environment tend to be the most commonly reported specific forms of challenging behaviour. Multiple forms are typically shown, and the behaviours concerned often appear to develop in childhood and remain highly persistent over time. Certain risk factors increase the likelihood of challenging behaviours. These include male gender; age between 15-35 years; having a more severe intellectual disability; having additional secondary impairments; reduced mobility and communication skills; and certain behavioural phenotypes[i,ii,iii,iv].

i. Emerson E. Working with people with challenging behaviour. In Emerson E, Hatton C, Bromley J and Caine A (eds.). *Clinical Psychology in People with Intellectual Disabilities.* Chichester: Wiley, 1998
(Type V evidence – expert opinion)

ii. Keirnan C, Alborz. Persistence and change in challenging and problem behaviours of young adults with intellectual disability living in the family home. *Journal of Applied Research in Intellectual Disabilities* 1996; **9**: 181-93
(Type IV evidence - cohort and cross sectional study)

iii. Emerson E, Alborz A, Reeves D, *et al. The Harc Challenging Behaviour Project Report II: the Prevalence of Challenging Behaviour.* Manchester: Hester Adrian Research Centre, University of Manchester, 1997
(Type IV evidence - well controlled cross sectional studies)

iv. Borthwick-Duffy S A. Prevalence of destructive behaviours. A study of aggression, self-injury and property destruction. In Thompson, T and Gray, D B (eds.). *Destructive Behaviour in Developmental Disabilities. Diagnosis and Treatment.* Sage: Thousand Oaks, 1994
(Type IV evidence - case registered study of 91,000 persons with intellectual disability)

v. Jacobson JW. Problem behaviour and psychiatric impairment within a developmentally disabled population. 1: Behaviour frequency. *Applied Research in Mental Retardation* 1982; **3**: 121-139
(Type IV evidence – observational study of a population-based sample of 32,112 people with intellectual disability of all ages and all degrees of severity of intellectual disability)

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The *statements*

4.1c. Classification of behavioural disturbance: One of the most enduring systems classifies aggressive behavioural problems into those which are directed towards other people (**aggression to others**), those which are directed towards objects in the environment (**destructiveness**) and **self-injurious behaviour.**

Non-aggressive behavioural disturbance include **withdrawal**, **anxiety and phobic reactions**. Self-injurious behaviour occurs in 14% of people with intellectual disability[i].

The *evidence*

i. Jacobson JW. Problem behavior and psychiatric impairment within a developmentally disabled population I: behavior frequency. *Applied Research in Mental Retardation* 1982; **3(2)**: 121-39
(Type IV evidence – review of challenging behaviour in a cohort of individuals with intellectual disability)

4.2 Assessment of Behavioural Disturbance

4.2a. Assessment with a view to treatment should be wide ranging and comprehensive. Information should include cognitive abilities, communication abilities, perceptual and motor abilities, social skills, domestic skills, self-care skills, community skills, family history, living arrangements, health and medical status.

Functional analysis appears critical to effective behavioural intervention. The products of functional analysis include: a clear topographical description of the target behaviours (including classes or sequences that occur together); the identification of events that predict the occurrence and non-occurrence of the target behaviours over the person's day; the identification of events that maintain the behaviours (i.e. the purpose or function served by the behaviour); the development of hypotheses that link specific behaviours with specific triggers and consequences; and the collection of observational data to confirm or refute these hypotheses. Data for functional analysis may be gathered by interview, by observation and by setting up analogue assessments to test specific behaviour and environmental relationships[i,ii].

Functional analysis enhances the **success rates** for behavioural intervention[iii,iv,v].

Reliability and **validity** is likely to be improved by the use of multiple methods[vi,vii].
(Health gain notation – 2 *"likely to be beneficial"*)

i. O'Neill RE, Horner RH, Albin RW, *et al. Functional Assessment of Programme Development for Problem Behaviour. A Practical Handbook*. Pacific Grove, CA: Brooks/Cole, 1997
(Type V evidence - expert opinion)

ii. Sturmey P. *Functional Analysis in Clinical Psychology*. London: Wiley, 1996
(Type V evidence - expert opinion)

iii. Carr EG, Horner RH, Turnbull AP, *et al. A Positive Behavioural Support for People with Development Disabilities. A Research Synthesis.* Washington: American Association on Mental Retardation, 1999
(Type I evidence - systematic review)

iv. Scotti JR, Evans IM, Mayer LH, Walker P. A meta analysis of intervention research with problem behaviour: treatment validity and standards of practice. *American Journal on Mental Retardation* 1991; 96: 233-56
(Type I evidence - systematic review)

v. Didden R, Duker PC, Korzilius H. Meta-analytic study on treatment effectiveness for problem behaviours with individual who have mental retardation. *American Journal on Mental Retardation* 1997; **101**: 387-99
(Type I evidence - systematic review)

vi. Toogood S, Timlin K. The functional assessment of challenging behaviour. *Journal of Applied Research and Intellectual Disabilities* 1996; **9**: 206-22
(Type IV evidence - experimental analysis of outcomes for different functional analysis methodologies)

vii. Yarbrough SC, Carr EG. Some relationships between informant assessment and functional analysis of problem behaviour. *American Journal on Mental Retardation* 2000; **105**: 130-51
(Type IV evidence - experimental analysis of outcomes for different functional analysis methodologies)

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The *statements*

4.2b. ABC Analysis stands for antecedents – behaviour – consequences. Behavioural problems should always be assessed in the context of their environment. **Antecedents** should be assessed with a view to determining the extent to which these antecedents or stimuli control the instigation of the behaviour. There should be a topographical description of the **behavioural** problem including the frequency, duration and intensity of the behaviour. Finally the **consequences** of the behaviour should be assessed to gauge their effect on the maintenance or otherwise of the problem[i,ii,iii].

Antecedent analysis considers a behaviour in relation to the setting and situation in which it occurs, the time of day, week, month or year, immediate preceding activities or events, any interactions or people who are present at the time. Antecedent analysis also considers the same variables in relation to non-occurrence or absence of the behaviour. The distinction should be made between setting events (establishing operations such as tiredness, illness, mood states etc) that act by altering the value of reinforcers thereby setting the scene for challenging behaviours to occur; and specific antecedents (such as demands made on the individual) that actually trigger the behaviours of concern[i,ii,iv,v].

Consequence analysis considers the effects of a behaviour on the environment, the effects on other people, previous and current attempts to manage the behaviour and consequences which seem to increase or reduce the frequency, intensity or duration of the behaviour.

The *evidence*

i. Kennedy CH, Mayer KA. Establishing operations and the motivation of challenging behaviour. Chapter15 In Luiselli, JK, Cameron MJ (eds.) *Antecedent Control. Innovative Approaches to Behavioural Support*. Baltimore: Paul H Brooks, 1998
(Type V evidence - expert opinion)

ii. Horner RH, Vaughn BJ, Day HD, Ard WR. The relationship between setting events and problem behaviour: expanding or understanding or behavioural support. Chapter 16 in Koegel L K, Koegel R L and Dunlap G (eds.). *Positive Behavioural Support. Including People with Difficult Behaviour in the Community*. Baltimore: Paul H Brooks, 1996
(Type IV evidence - observational study)

iii. LaVigna GW, Willis TJ, Donnellan AM. The role of positive programming in behavioural treatment. In *The Treatment of Severe Behaviour Disorders*. E Cipani (ed.). Washington DC: American Association on Mental Retardation, 1989
(Type V evidence - opinions of respected authorities based on clinical evidence)

iv. McGill P. Establishing operations: Implications for the assessment, treatment and prevention of problem behaviour. *Journal of Applied Behaviour Analysis* 1999; **32**: 293-418
(Type V evidence – expert opinion and review of important scientific studies)

v. Smith RG, Iwata BA. Antecedent influences on behaviour disorder. *Journal of Applied Behaviour Analysis* 1997; **30**: 343-375
(Type V evidence – expert opinion and review of important scientific studies)

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The *statements*	The *evidence*
4.2c. Observation of behavioural problems in relation to the environment is fundamental to the assessment of behavioural disturbance. The observational code should be relevant to the behaviour and environment in question, ensuring systematic objective reliable data recording. This data is crucial in developing functional analysis designed to identify controlling antecedents and consequences. Observation will inform and guide appropriate treatment, and will also provide baseline information on the frequency, duration and intensity of the behaviour disturbance with a view to gauging the effectiveness of the intervention through re-assessment after the implementation of treatment[i,ii]. (Health gain notation – 2 *"likely to be beneficial"*)	**i.** Repp AC, Roberts D, Slack D, *et al*. A comparison of frequency, interval and time sampling methods of data collection. *Journal of Applied Behaviour Analysis* 1976; **9**: 501-8 (Type II evidence - randomised control trial comparison of time sampling methods) **ii.** Thompson T, Felce D, Symons FJ. (eds.) *Behavioural Observation. Technology and Applications in Developmental Disabilities*. Baltimore: Paul H Brooks, 2000 (Type V evidence - review and expert opinion)
4.2d. Continuous recording of behaviour, its antecedents and consequences are the most valid methods of observation. This data will be comprehensive and relatively free from errors. However, since an individual may have to be observed over a lengthy period of time, continuous recording is mostly impractical because of the demands on the observers[i,ii]. (Health gain notation – 2 *"likely to be beneficial"*)	**i.** Repp AC, Roberts D, Slack D, *et al*. A comparison of frequency, interval and time sampling methods of data collection. *Journal of Applied Behaviour Analysis* 1976; **9**: 501-8 (Type II evidence - randomised control trial comparison of time sampling methods) **ii.** Thompson T, Felce D, Symons FJ. (eds.) *Behavioural Observation. Technology and Applications in Developmental Disabilities*. Baltimore: Paul H Brooks, 2000 (Type V evidence - review and expert opinion)
4.2e. Various observational methods have been assessed for comprehensiveness in relation to **continuing recording**. Methods include a record of the number of discreet events recorded, a measure of the total time spent engaged in the problem behaviour as a proportion of the total observation time, and various intervals of time sampling. This latter method allows the observer to watch the individual for a short period (for example, 10, 30 or 60 seconds) and then spend the next equivalent time interval recording whether or not the behaviour occurred and the circumstances surrounding the occurrence / non-occurrence of the behaviour[i,ii].	**i.** Repp AC, Roberts D, Slack D, *et al*. A comparison of frequency, interval and time sampling methods of data collection. *Journal of Applied Behaviour Analysis* 1976; **9**: 501-8 (Type II evidence - randomised control trial comparison of time sampling methods) **ii.** Thompson T, Felce D, Symons FJ. (eds.) *Behavioural Observation. Technology and Applications in Developmental Disabilities*. Baltimore: Paul H Brooks, 2000 (Type V evidence - review and expert opinion)

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The *statements*

4.2f. Functional analysis assumes behavioural problems have a function for the individual. Description of the problem should include any antecedent stimuli or setting events; consequences or reinforcement contingencies which may be maintaining the problem; description of the personal, social and environmental impact of the disturbance; an analysis of the history of the problem and motivating factors[i,ii,iii,iv,v,vi,vii,viii,ix,x].
(Health gain notation – 2 *"likely to be beneficial"*)
The most common behavioural processes are **positive reinforcement**. The disturbance results in social or other environmental reinforcement. The behaviour is likely to increase in frequency, duration or intensity when potential social contact is denied and reduce when this contact is available.

The second type of behavioural process is maintained by **negative reinforcement** (escape or avoidance). Behavioural disturbance increases where demands are placed on the individual and reduces when these demands are removed.

The third common behavioural disturbance is maintained by **automatic reinforcement** and appears uninfluenced by consequences. It occurs when there is little environmental stimulation and is controlled and maintained intrinsically by the automatic reinforcement provided by the behaviour.

Rating scales designed to identify these processes by considering events that affect frequency, duration or intensity of a behavioural disturbance are questionable and should not be used in the absence of additional information through interview of informants or observation.

cont.

The *evidence*

i. Iwata BA, Dorsey MF, Slifer KJ, *et al.* Towards a functional analysis of self-injury. *Journal of Applied Behaviour Analysis* 1994; **27**: 197-209
(Type IV evidence - well controlled case study)

ii. Iwata BA, Pace GM, Dorsey MF, *et al*. The functions of self-injurious behaviour: an experimental-epidemiological study. *Journal of Applied Behaviour Analysis* 1994; **27**: 215-40
(Type IV evidence - well controlled case study)

iii. Piazza CC, Fisher, WW, Hanley GP, *et al*. Treatment of pica through multiple analysis of its reinforcing functions. *Journal. of Applied Behaviour Analysis* 1998; **31**: 165-89
(Type IV evidence - well controlled case studies illustrating the importance of functional analysis in relation to pica)

iv. Demchak MA, Bossert KW. *Assessing Problem Behaviours.* Washington DC: American Association Mental Retardation, 1996
(Type IV evidence - systematic review covering the assessment of a range of challenging behaviours)

v. Durand VM, Crimmins DB. *The Motivation Assessment Scale*. Topeka KS: Monaco and Associates, 1992
(Type IV evidence - studies reporting good reliability assessing different reinforcing / maintaining conditions)

vi. Thomson S, Emerson E. Inter-observer agreement on the motivation assessment scale: another failure to replicate. *Mental Handicap Research (Journal of Applied Research in Intellectual Disabilities)* 1995; **8**: 203-8
(Type III evidence - controlled study on inter-observer agreement which found that the motivational assessment scale may have dubious reliability and validity)

vii. Piazza CC, Hanley GP, Fisher WW. Functional analysis and treatment of cigarette pica. *Journal of Applied Behaviour Analysis* 1996; **29**: 437-50
(Type IV evidence - well controlled case study)

viii. Lally JS, Livesey K, Kates K. Functional analysis and treatment of eye poking with response blocking. *Journal of Applied Behaviour Analysis* 1996; **29**: 129-32
(Type IV evidence - well controlled case study)

ix. Aman AG. *Assessing Psychopathology and Behaviour Problems in Persons with Mental Retardation*: *A Review of Available Instruments.* Rockville MD: US Department of Health and Human Services, 1991
(Type IV evidence - systematic review of 52 assessments of mental illness and challenging behaviour)

This document is a supplement to, not a substitute for, professional skills and experience. Users are advised to consult the supporting evidence for a consideration of all the implications of a recommendation.

The *statements*

4.2f cont.

Analogue assessments tests hypotheses by arranging artificial situations providing social reinforcement, tangible reinforcement, escape, avoidance or automatic reinforcement. Situations are individually tailored and the results can be used to identify appropriate individual treatment.

More recently studies have shown that less formal assessment including rating scales, informant interviews and some observational information can be valid and reliable ways of carrying out functional analysis[xi,xii].

The *evidence*

x. Matson JL, Bamburg JW, Cherry KE, *et al.* A validity study on the questions about behavioural function (QABF) scale: predicting treatment success for self-injury, aggression and stereotypies. *Research in Developmental Disabilities* 1999; **20**: 163-76
(Type III evidence - well designed interventional study deriving behavioural function for challenging behaviour in 398 subjects)

xi. Paclawskyj TR, Matson JL, Rush KS, Smalls Y, Vollmer TR. Questions about behavioral function (QABF): A behavioral checklist for functional assessment of aberant behavior. *Research in Developmental Disabilities* 2000; **21**: 223-229
(Type III evidence – well designed assessment study on 57 subjects showing good reliability and internal consistency for the QABF)

xii. Yarbrough SC, Carr EG. Some relationships between informant assessment and functional analysis of problem behavior. *The American Journal of Mental Retardation* 2000; **105**: 130-151
(Type IV evidence – well controlled study on 3 individual cases showing that informant assessment provided valid hypotheses about behavioural fuction only in situations likely to evoke challenging behaviour)

This document is a supplement to, not a substitute for, professional skills and experience. Users are advised to consult the supporting evidence for a consideration of all the implications of a recommendation.

The *statements*	The *evidence*
4.2g. Functional analysis is now considered in relation to a wide range of issues including its effectiveness in relation to healthcare problems, delivery by parents and carers and behavioural classification[i].	**i.** Cone JD. Issues and functional analysis in behavioural assessment. *Behaviour Research and Therapy* 1997; **35**: 259-75 (Type V evidence - expert opinion, review and synthesis of important studies)

4.3 Behavioural Treatments

4.3a. Behavioural treatments derived from the fact that most behaviours are governed by their antecedents and consequences. Antecedent management includes consideration of stimulus control, setting events and establishing operations. Consequences can be environmental (increasing or decreasing behavioural disturbance) or internal to the person (automatic or intrinsic reinforcement). Behavioural treatments manipulate these relationships to improve the behavioural disturbance. Behavioural interventions appear to produce superior outcomes when compared to pharmacological interventions for challenging behaviour[i]. (Health gain notation – 2 *"likely to be beneficial"*) Both positive and negative reinforcement increase the future frequency, duration or intensity of behaviour. In positive reinforcement, a desirable outcome (eg. food, drink, attention, activity etc.) is **presented** contingent upon the target behaviour; in negative reinforcement, it is the contingent **removal** of an undesirable outcome (pain, demands, social attention) that achieves this effect. Conversely, punishment decreases the future frequency, duration or intensity of behaviour. Positive punishment involves the contingent presentation of an aversive stimulus (eg pain, shock, forced exercise etc.), while negative punishment involves contingent removal of preferred stimuli (eg attention, activities, general access to positive reinforcement etc.)[ii,iii,iv].	**i.** Didden R, Duker PC, Corzilius H. Meta-analytic study on treatment effectiveness for problem behaviours with individuals who have mental retardation. *American Journal on Mental Retardation* 1997; **101(4)**: 387-99 (Type I evidence - systematic review and meta-analysis of 482 empirical studies on treatment of problem behaviours of individuals with intellectual disability) **ii.** Whitacker S. The reduction of aggression in people with learning disabilities: a review of psychological methods. *British Journal of Clinical Psychology* 1993; **32**: 1-38 (Type V evidence – expert opinion based on a review of 78 studies covering a range of interventions for the reduction of aggression) **iii.** Scotti JR, Evans IM, Mayer LH, Walker P. A meta-analysis of intervention research with problem behaviour: treatment validity and standards of practice. *American Journal on Mental Retardation* 1991; **96**: 233-56 (Type I evidence - systematic review and meta-analysis of 403 studies published from 1976-1987) **iv.** Repp AC, Singh NN (eds.) *Perspectives on the Use of Non-aversive and Aversive Interventions for Persons with Developmental Disabilities.* Sycamore, Illinois: Sycamore, 1990 (Type V evidence – expert opinion, review and synthesis of important studies)

This document is a supplement to, not a substitute for, professional skills and experience. Users are advised to consult the supporting evidence for a consideration of all the implications of a recommendation.

The *statements*

Positive Behavioural Approaches

4.3b. **Positive behavioural** approaches aim to change challenging behaviours by focussing on environmental manipulation (thus preventing the occurrence of the behaviours) and by teaching alternative adaptive responses (for example, skills that serve the same function as the target behaviour). In contingency management terms, positive reinforcement based approaches are favoured and aversive approaches rejected for technical and ethical reasons.

Using a criterion of 90% reduction in challenging behaviour from baseline levels, positive interventions are successful approximately 52% of the time; using an 80% reduction criterion, this rate increases to 68%. Using the 80% criterion, separate success rates for antecedent/stimulus based interventions was almost 70% and for reinforcement based interventions almost 72%. Success rates are generally not influenced by whether or not those procedures are implemented alone or in combination. Success rates for studies that combine positive behavioural approaches with aversive procedures produce a success rate of almost 64% using a 90% suppression criterion. Caution is urged in interpreting the latter finding in that it is based on a small number of studies. Intervention for combinations of challenging behaviours rather than single behaviours tends to be less successful. Interventions that involve systems/organisational change appear to be slightly more successful than those that do not (55% versus 42%). Some positive behavioural interventions may produce intervention effects that are at least as rapid as more aversive procedures[i,ii].

The *evidence*

i. Carr EG, Horner RH, Turnbull AP, *et al. Positive Behavioural Support for People with Developmental Disabilities. A Research Synthesis.* Washington: American Association on Mental Retardation, 1999
(Type V evidence - expert opinion and review of important studies)

ii. Carr EG, Robinson S, Taylor JC, Carlson JI. *Positive Behavioural Approaches to the Treatment of Severe Behaviour Problems in Persons with Developmental Disabilities: A Review and Analysis of Reinforcement and Stimulus Based Procedures.* Seattle: Association for Persons with Severe Handicaps, 1990
(Type V evidence - expert opinion and review of important studies)

This document is a supplement to, not a substitute for, professional skills and experience. Users are advised to consult the supporting evidence for a consideration of all the implications of a recommendation.

The *statements* | The *evidence*

Functional Communication Training

4.3c. **Functional communication training (FCT)** assumes that behavioural disturbance, rather than being seen as an aberrant activity, should be viewed as a means of communicating the needs of that individual to others. FCT is effective in helping the individual learn alternative ways of communicating needs without recourse to behavioural disturbance. FCT therefore increases adaptive communication and decreases maladaptive communication[i,ii].
(Health gain notation – 2 *"likely to be beneficial"*)

i. Carr EG, Durand VM. Reducing behaviour problem through functional communication training. *Journal of Applied Behaviour Analysis* 1985; **18**: 111-26
(Type IV evidence - well controlled case studies. This was one of the first papers to introduce the communication hypothesis and functional communications training)

ii. Durand VM. Functional communication training using assistive devices: recruiting natural communities of reinforcement. *Journal of Applied Behaviour Analysis* 1999; **32**: 247-67
(Type IV evidence - well controlled case studies)

4.3d Recent studies have found that **functional communication training** on its own may be of limited effectiveness without **concurrent extinction** of the target behaviour.
(Health gain notation – 5 *"unlikely to be beneficial"*)

Functional communication training with extinction (not delivering a consequence for problem behaviour) resulted in 90% reductions of problem behaviour in 50% of clients[i,ii,iii,iv].
(Health gain notation – 2 *"likely to be beneficial"*)

i. Thompson RH, Fisher WW, Piazza CC, *et al.* The evaluation and treatment of aggression maintained by attention and automatic reinforcement. *Journal of Applied Behaviour Analysis* 1998; **31**: 103-16
(Type IV evidence - well controlled case studies)

Other authors have found reinforcement of functional communication enhances the effectiveness of FCT.

ii. Fisher WW, Adelinis JD, Thompson RH, *et al.* Functional analysis and treatment of destructive behaviour maintained by termination of "don't" (and symmetrical "do") requests. *Journal of Applied Behaviour Analysis* 1998; **31**: 339-56
(Type IV evidence - well controlled case studies)

iii. Carr EG, Levin L, McConnachie G, *et al. Communication Based Intervention for Problem Behaviour: A Users' Guide for Producing Positive Change.* Baltimore, MD: PH Brookes, 1994
(Type V evidence - expert opinion, review of important studes and description of treatment methods)

iv. Fisher W, Piazza C, Cataldo, *et al.* Functional communication training with and without extinction and punishment. *Journal of Applied Behaviour Analysis* 1993; **26**: 23-36
(Type IV evidence - well controlled case studies)

This document is a supplement to, not a substitute for, professional skills and experience. Users are advised to consult the supporting evidence for a consideration of all the implications of a recommendation.

The *statements*	The *evidence*
4.3e. Functional communication training with **mild punishment** (e.g. time out in a room or a chair) directed at the target behaviour, resulted in 90% reduction in problem behaviour in 100% of clients[i]. (Health gain notation – 2 *"likely to be beneficial"*)	**i.** Hagopian LP, Fisher WW, Sullivan MT, *et al*. Effectiveness of functional communication training with and without extinction and punishment: a summary of 21 in-patient cases. *Journal of Applied Behaviour Analysis* 1998; **31**: 211-35 (Type IV evidence – a summary of data from well controlled case studies comparing functional communications training with extinction against functional communications training with mild punishment)
Extinction	
4.3f. Extinction is effective in reducing behavioural disturbance. By discontinuing any previous reinforcement of a behaviour, once the reinforcement is no longer available the behavioural disturbance reduces. No distinction is made between positive, negative, intrinsic or extrinsic reinforcement[i,ii,iii,iv]. A serious side effect is the occurrence of **extinction bursts** where individuals respond with an increased frequency of the behaviour in order to gain (the now unattainable) reinforcement. In cases of aggressive, destructive or self-injurious behaviour this will present a danger to the individual and others. Extinction should normally only be considered and used in conjunction with other methods and for non-dangerous behaviours. (Health gain notation – 3 *"trade off between beneficial and adverse effects"*)	**i.** Cooper JO, Heron TE, Heward WL. Applied behaviour analysis. Chapter 17 *Extinction*. New York: MacMillan, 1987 (Type V evidence - expert opinion with a review of some studies and methods) **ii.** Lerman DC, Iwata BA. Developing a technology for the use of operant extinction in clinical settings: an examination of basic and applied research. *Journal of Applied Behaviour Analysis* 1996; **29**: 345-82 (Type III evidence - systematic review of basic and applied research findings on variables that influence the direct and indirect effects of extinction. An expert evaluation of the general technology for the use of extinction) **iii.** Smith RG, Russo L, Le Duyd. Distinguishing between extinction and punishment effects of response blocking: a replication. *Journal of Applied Behaviour Analysis* 1999; **32**: 367-70 (Type IV evidence – well controlled case studies) **iv.** Vollmer TR, Progar PR, Lalli JS, *et al*. Fixed time schedules attenuate extinction induced phenomena in the treatment of severe abhorrent behaviour. *Journal of Applied Behaviour Analysis* 1998; **31**: 529-42 (Type IV evidence – well controlled case studies)
Aversive Consequences	
4.3g. There is extensive evidence that **aversive consequences** will produce short-term suppression of behavioural disturbance. Punishment techniques range from mild electric shock to cold water mist in the face and time out from positive reinforcement[i]. (Health gain notation – 2 "likely to be beneficial") **These techniques do not carry the same requirements for functional analysis of the variables controlling the problem behaviour. They do not fit comfortably with the systematic, analytic and educational features of the majority of research on behavioural treatment. They also pose significant ethical and legal concerns.**	**i.** Matson JL, DiLorenzo TM. *Punishment and its Alternatives: A New Perspective for Behaviour Modification*. New York: Springer, 1984 (Type V evidence – expert opinion and review of important studies)

This document is a supplement to, not a substitute for, professional skills and experience. Users are advised to consult the supporting evidence for a consideration of all the implications of a recommendation.

The *statements*	The *evidence*
4.3h. Punishment does not institute alternative adaptive responses. Punishment may also have severe side effects in eliciting aggressive behaviours and avoidance or escape behaviours and it can serve as a negative modelling procedure[i,ii]. Whereas more aversive procedures may produce greater levels of suppression (i.e. zero levels of target behaviour), the overall amount of change between baseline and treatment is not related to whether aversive or non-aversive approaches are used. The suppressive effect of more intrusive interventions is improved by the addition of Differential Reinforcement of Other behaviour (DRO) to intervention packages[iii]. Despite their obvious effectiveness, concerns about the **non-constructive nature of aversive interventions**, together with their lack of social validity, has resulted in these approaches being described as "default" technologies. It has been suggested their use is only indicated when alternative positive approaches have failed or are not feasible and when the costs of not intervening are greater than the costs of using aversive procedures[iv].	**i.** Plummer S, Bare DM, LeBlanc JM. Functional considerations in the use of procedural time out and an effective alternative. *Journal of Applied Behaviour Analysis* 1977; **10**: 689-706 (Type IV evidence – well controlled case study) **ii.** Hagopian LP, Fisher WW, Sullivan MT, *et al*. Effectiveness of functional communication training with and without extinction and punishment: a summary of 21 in-patient cases. *Journal of Applied Behaviour Analysis* 1998; **31**: 211-35 (Type IV evidence – a summary of data from well controlled case studes comparing functional communications training with extinction against functional communications training with mild punishment) **iii.** Scotti JR, Evans IM, Mayer LH, Walker P. A meta-analysis of intervention research with problem behaviour: treatment validity and standards of practice. *American Journal on Mental Retardation* 1991; **96**: 233-56 (Type I evidence - systematic review and meta-analysis of 403 studies from 1976-1987) **iv.** Emerson E. *Challenging Behaviour. Analysis and Intervention in People with Learning Difficulties.* Cambridge: Cambridge University Press, 1985 (Type V evidence: expert opinion based on clinical evidence)
4.3i. Time out, the loss of access to positive reinforcers to behaviour for a specific period of time, is effective in reducing future occurrences of abnormal behaviour. Time out is not simply removing an individual to a secluded setting (**seclusion**)[i,ii]. There is a distinction between "**time in**" and "**time out**". The greater the reinforcing properties of the time in situation so will be the greater effectiveness of the time out situation. Time out may simply be ineligibility to access reinforcers for a short period of time. Time out procedures can increase the effectiveness of positive programming procedures when used in conjunction with them. (Health gain notation – 2 *"likely to be beneficial"*) See also 4.4i.	**i.** Plummer S, Bare DM, LeBlanc JM. Functional considerations in the use of procedural time out and an effective alternative. *Journal of Applied Behaviour Analysis* 1977; **10**: 689-706 (Type IV evidence - well controlled case study) **ii.** Hagopian LP, Fisher WW, Sullivan MT, *et al*. Effectiveness of functional communication training with and without extinction and punishment: a summary of 21 in-patient cases. *Journal of Applied Behaviour Analysis* 1998; **31**: 211-35 (Type IV evidence – a summary of data from well controlled case studies comparing functional communications training with extinction against functional communications training with mild punishment)

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The *statements*	The *evidence*
4.4 Skills teaching	
4.4a. Skills' teaching is effective in people with and without behavioural disturbance in adapting to and overcome problems in their lives. A crucial aspect of positive programming, skills' teaching develops alternative functional behaviours that supplant behavioural problems and disturbances. Self-help skills, interpersonal skills, leisure skills, parenting skills and work skills can be developed using these methods. A meta analysis of 73 studies found that social skills training produced improvements in a broad repertoire of social skills, had effects lasting several months and had a greater effect for developmentally disabled groups than other clients[i]. (Health gain notation – 2 *"likely to be beneficial"*)	**i.** Corrigan PW. Social skills training in adults with psychiatric populations: a meta analysis. *Journal of Behaviour Therapy and Experimental Psychiatry* 1991; **22**: 203-10 (Type I evidence - systematic review and meta-analysis of 73 studies)
Behavioural Shaping, Prompting and Fading	
4.4b. Shaping is effective as an adjunct to training since subjects rarely achieve an adequate level of ability on their first attempt. Any approximation towards a reasonable level of skill is accepted by the therapist who then encourages subsequent attempts at improvement. The therapist may also establish one response and gradually shape it towards the desired end response[i]. In the early stages of training it is reasonable to **prompt** the desired response. Physical and verbal prompts can also help clients gain the confidence to begin a sequence of abilities[i]. An essential consideration when employing prompting is to build in the **fading** of prompts. It is unhelpful if the client becomes dependent on the therapists' prompts, so the therapist should have a plan to begin fading not only therapeutic prompts, but other aspects of the therapeutic situation, so that the client is able to function independently[i]. (Health gain notation – 2 *"likely to be beneficial"*)	**i.** Lindsay WR, Michie AM. Teaching new skills. in Fraser W, Sines D, Kerr M (eds.). *Hallas' The Care of People with Intellectual Disabilities*. 9th Edition. Oxford: Butterworth Heinemann, 1998 (Type V evidence - expert opinion including review of important studies)

This document is a supplement to, not a substitute for, professional skills and experience. Users are advised to consult the supporting evidence for a consideration of all the implications of a recommendation.

The *statements*	The *evidence*
4.4c. Behavioural Chaining: is useful once a sequence or **chain of skills** has been established. The therapist focuses training at one end of the chain, the next step in the sequence is trained and linked to the previous one and so on until the whole complex ability has been learned. When training begins with the first aspect in the sequence this is called **forward chaining**; when it begins with the last it is **backward chaining**[i]. (Health gain notation – 2 *"likely to be beneficial"*)	**i.** Carr J, Collins S. *Working Towards Independence: A Practical Guide to Teaching People with Learning Disabilities.* London: Jessica Kingsley, 1992 (Type V evidence - expert opinion, practical guidance including review of some important studies)
4.4d. Role-play uses important stimuli from a real setting whilst remaining under therapist control. It is effective in allowing the group or individual to practice various skills concerned before going into the real setting. Role-play can involve a whole sequence of skills or one small aspect of a behavioural sequence[i,ii]. (Health gain notation – 2 *"likely to be beneficial"*)	**i.** Langone J, Clees TJ, Oxford M, *et al*. Acquisition and generalisation of social skills by High School students with mild mental retardation. *Mental Retardation* 1995; **33**: 186-96 (Type III evidence - well designed controlled trial) **ii.** Baty FJ, Michie AM, Lindsay WR. Teaching mentally handicapped adults how to use a cafeteria. *Journal of Mental Deficiency Research* 1989; **33**: 137-48 (Type IV evidence - case controlled study)
4.4e. Modelling allows a series of complex skills to be demonstrated without going into confusing explanations of how the skill is sequenced together. Modelling will then be combined with role-playing in an effort to help clients achieve the skill of the model[i]. (Health gain notation – 2 *"likely to be beneficial"*)	**i.** Lindsay WR, Michie AM. Teaching new skills. in Fraser W, Sines D, Kerr M (eds.). *Hallas' The Care of People with Intellectual Disabilities.* 9th Edition. Oxford: Butterworth Heinemann, 1998 (Type V evidence - expert opinion including review of important studies)
4.4f. Social problem solving is a useful process whereby skills for determining an effective action strategy in a given situation are taught to patients. (Health gain notation – 2 *"likely to be beneficial"*) This is in addition to teaching the actual abilities to cope in specific situations. Results on the effectiveness of training social problem solving skills either on their own or as an adjunct to social skills training are equivocal[i].	**i.** Loumidis K, Hill A. Training social problem solving skills to reduce maladaptive behaviours in intellectual disability groups: the influence of individual difference factors. *Journal of Applied Research in Intellectual Disabilities* 1997; **10**: 217-37 (Type II evidence - controlled group study involving 46 subjects in two groups. Also includes an extensive review of social problem-solving skills training)

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The *statements*

Comprehensive systems based on behavioural principles

4.4g. Skills Training Systems: Group comparison studies suggest that gains produced by **social skills training** are consistent and effective when compared with alternative group therapies and no treatment controls. Early intervention systems directed at improvements in cognitive academic and social skills have been employed for some time in children with autism. Recent studies enlisting parents to implement procedures at home have found positive results[i,ii,iii,iv,v,vi].
(Health gain notation – 2 *"likely to be beneficial"*)

The *evidence*

i. Matson J, Senatore V. A comparison of traditional psychotherapy and social skills training for improving interpersonal functioning of mentally retarded adults. *Behaviour Therapy* 1981; **12**: 282-369
(Type III evidence - well designed controlled study comparing subjects receiving traditional psychotherapy and subjects receiving social skills training. Social skills training produced greater and more consistent improvements than psychotherapy)

ii. Fox R, McMorrow M, Schloss C. Stacking the deck: teaching social skills to retarded adults with a modified table game. *Journal of Applied Behaviour Analysis* 1983; **16**: 157-70
(Type IV evidence - a series of cases seen in a group and employing a highly innovative and engaging approach to social skills training)

iii. Michie AM, Lindsay WR, Smith AHW, Todman J. Changes following community living skills training: a controlled study. *British Journal of Clinical Psychology* 1998; **37**: 109-11
(Type II evidence - randomised controlled study comparing 29 subjects trained in community living skills using in vivo techniques, 13 using classroom techniques and 15 acting as a no treatment control. There was an overwhelming superiority in improvements for the skills training group)

iv. Ozomoff S, Cathcart K. Effectiveness of a home programme intervention for young children with autism. *Journal of Autism and Developmental Disorders* 1998; **28**: 25-32
(Type III evidence - a comparison of an experimental and control group with matched subjects. Significant improvements were found in the experimental cohort)

v. Sheinkopf SJ, Siegel B. Home based behavioural treatment of young children with autism. *Journal of Autism and Developmental Disorders* 1998; **28**: 15-23
(Type III evidence - a matched group comparison showing significant improvements in the experimental cohort)

vi. Gresham FM, MacMillan DL. Early intervention projects: can its claims be substantiated and its effects replicated? *Journal of Autism and Developmental Disorders* 1998; **28**: 5-13
(Type V evidence - expert opinion based on a review of early intervention projects where the authors acknowledge undoubted treatment successes but recommend a healthy scepticism concerning unqualified endorsement)

This document is a supplement to, not a substitute for, professional skills and experience. Users are advised to consult the supporting evidence for a consideration of all the implications of a recommendation.

The *statements*

4.4h. Services for people with challenging behaviour and intellectual disability:
Effective behavioural support for persons with challenging behaviour can be provided within community settings. Dependence on institutional provision can be reduced as a consequence[i,ii,iii,iv].
(Health gain notation – 2 *"likely to be beneficial"*)

The *evidence*

i. Allen D, Felce D. Service responses to challenging behaviour. Ch. 17 in Bouras N (ed). *Psychiatric and Behavioural Disorders in Developmental Disabilities and Mental Retardation.* Cambridge: Cambridge University Press, 1999
(Type V evidence - expert opinion based on scientific evidence)

ii. Emerson E, McGill P, Mansell J (eds.) *Severe Learning Disabilities and Challenging Behaviours: Designing High Quality Services.* London: Chapman & Hall, 1994
(Type V evidence – expert opinion based on scientific evidence)
including: McGill P, Emerson E, Mansel J. Individually designed residential provision for people with seriously challenging behaviours. Chapter 6
(Type V evidence – expert opinion and review of services for 22 clients)

iii. Homer RH, Close DW, Fredericks HD *et al.* Supported living for people with profound disabilities and severe problem behaviours. Chapter 9 in Lehr D, Brown F (eds.) *People with Disabilities who Challenge the System.* Baltimore: Paul Brookes, 1996
(Type V evidence – expert opinion and review of services for 12 clients)

iv. Mansell J. Specialised group homes for persons with severe or profound mental retardation and serious problem behaviour in England. *Research in Developmental Disabilities* 1994; **15**: 371-388
(Type III evidence – well designed interventional study in 13 people with severe or profound intellectual disability and challenging behaviour)

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The *statements*

4.4i. In addition to having strategies for changing behaviour, carers supporting people who display dangerous behaviour will require strategies for managing these behaviours safely and effectively. **Reactive behaviour management** strategies included distraction and diffusion, self-protective breakaway procedures and minimal restraint. Carers can effectively be taught a range of ethically acceptable techniques and their confidence increases as a result[i,ii].

Training may also lead to a reduction in restraint, use of emergency medication, and injuries[iii].
(Health gain notation – 2 *"likely to be beneficial"*)

It should be noted that all restraint procedures, however mild, carry the possibility of injury and should only be considered in conjunction with comprehensive policies for use and staff training.

The use of **seclusion** (the supervised containment of a person in a room to protect others from significant harm) for persons with a learning disability has been questioned. Its use may not bring about short-term improvements in behaviour as intended, may cause certain behaviours to worsen and elicit the appearance of new behaviours[iv].
(Health gain notation – 4 *"unknown"*)

The *evidence*

i. McDonnell A. Training care staff to manage challenging behaviour: an evaluation of a three day training course. *British Journal of Developmental Disabilities* 1997; **43**: 156-62
(Type IV evidence - case controlled study)

ii. Allen D, McDonald L, Dunn C, Doyle T. Changing care staff approaches to the management of aggressive behaviour in a residential treatment unit for persons with mental retardation and challenging behaviour. *Research and Developmental Disabilities* 1987; **18**: 101-12
(Type IV evidence - observational study)

iii. Allen D, Tynan H. Responding to aggressive behaviour: the impact of training on staff knowledge and confidence. *Mental Retardation* 2000; **38**: 97-104
(Type II evidence - controlled group comparison plus case controlled study)

iv. Mason T. Seclusion and learning disabilities: Research and deduction. *British Journal of Developmental Disabilities* 1996: **42**: 149-159
(Type IV evidence – survey of seclusion use over a 12 month period in a special hospital)

This document is a supplement to, not a substitute for, professional skills and experience. Users are advised to consult the supporting evidence for a consideration of all the implications of a recommendation.

The *statements* | The *evidence*

4.5 Relaxation

4.5a. Abbreviated progressive relaxation (APR) and **behavioural relaxation training** (BRT) are effective when used in individuals with moderate, severe and profound intellectual disability. BRT works more rapidly and reliably than APR, and is an established treatment approach for individuals with anxiety, agitation, restlessness and disruptiveness[i,ii,iii,iv].

Because BRT is an essentially passive technique, it does not appear to have the drawbacks inherent in APR. There is no paradoxical tensing of muscles in order to relax, and there appear to be no side effects whereby clients misconstrue the demands of training, becoming more rather than less excited. It is an effective enabling technique to allow individuals to become more accessible to their environment.
(Health gain notation – 2 *"likely to be beneficial"*)

i. Schilling D, Poppen R. Behavioural relaxation training and assessment. *Journal of Behaviour Therapy and Experimental Psychiatry* 1983; **14**: 99-107
(Type II evidence - randomised controlled study comparing four forms of relaxation. BRT was consistently effective across all measures)

ii. Lindsay WR, Baty FJ, Michie AM, *et al.* A comparison of anxiety treatments with adults who have moderate and severe mental retardation. *Research on Developmental Disabilities* 1989; **10**: 129-40
(Type II evidence - randomised controlled trial comparing BRT and APR against a control condition. Subjects in both conditions showed significant improvements over control subjects with BRT using more rapid improvement)

iii. Lindsay WR, Morrison FM. The effects of behavioural relaxation on cognitive performance in adults with severe intellectual disabilities. *Journal of Intellectual Disabilities Research* 1996; **40**: 285-290
(Type II evidence - randomised controlled trial. Subjects receiving BRT showed more significant improvements in cognitive functioning than control subjects on all tasks except those involving long term memory)

iv. Lindsay WR, Michie AM, Marshall I, *et al.* The effects of behavioural relaxation training on adults with profound multiple disabilities: a preliminary study on treatment effectiveness. *British Journal of Learning Disabilities* 1996; **24**: 119-23
(Type IV evidence - case controlled studies)

4.5b. Cue controlled relaxation (CCR) links the effects of relaxation to a cue word. In time the subject will be able to relax to the cue word only, rather than a time consuming relaxation procedure. CCR is effective at improving concentration and attention to an occupational task when used in individuals with moderate and severe intellectual disability[i,ii].
(Health gain notation – 2 *"likely to be beneficial"*)

i. Wells KC, Turner SM, Bellack AS, *et al.* Effects of cue control relaxation on psychomotor seizures: an experimental analysis. *Behaviour Research and Therapy* 1978; **16**: 51-3
(Type IV evidence - well designed case-study employing multiple measure across various conditions)

ii. Lindsay WR, Fee M, Michie AM, *et al.* The effects of cue control relaxation on adults with severe mental retardation. *Research in Developmental Disabilities* 1994; **15**: 425-37
(Type IV evidence - well designed series of case controlled studies for the sequence of introduction on a range of variables)

This document is a supplement to, not a substitute for, professional skills and experience. Users are advised to consult the supporting evidence for a consideration of all the implications of a recommendation.

The *statements*

The *evidence*

4.6 The Snoezelen environment

4.6a. The **Snoezelen** environment was developed in Holland to induce meditation, tranquillity and relaxation. It has been adopted in the UK for people with multiple handicap and severe or profound intellectual disability. The environment is artificial with a variety of soothing stimuli for all the senses including lights, textures, sounds and smells.

The original developers have explicitly resisted empirical assessment of the environment. Recent studies have found that, with individuals who have severe and profound intellectual disability, snoezelen is no less effective than relaxation techniques on a variety of measures. It was found to be more effective than other "alternative" or "complementary" techniques such as hand massage or physical activity. It is considerably more expensive than relaxation techniques[i,ii].

A controlled trial demonstrated a decrease in aggressive responding in anger management and control conditions with no significant differences in the conditions[ii].

While some studies have noted short term positive effects, one controlled study found no generalised effect outside the immediate results of the Snoezelen environment[iii].
(Health gain notation – 4 *"unknown"*)

i. Hulsugge J, Verheul A. *Snoezelen. Another World.* Chesterfield: Rompa, 1987
(Type V evidence – expert opinion)

ii. Lindsay WR, Pitcaithly D, Geelen N, *et al.* A comparison of the effects of four therapy procedures on concentration and responsiveness in people with profound learning disabilities. *Journal of Intellectual Disability Research* 1997; **41**: 201-7
(Type III evidence - controlled crossover group comparison employing 8 subjects who each received treatments involving Snoezelen, aromatherapy, relaxation and physical exercise)

iii. Martin NT, Gaffan EA, Williams T. Behavioural effects of long term multi-sensory stimulation. *British Journal of Clinical Psychology* 1998; **37**: 69-82
(Type II evidence – 27 adults with severe or profound intellectual disability were included in a randomised controlled trial employing a double cross-over design. The Snoezelen environment was compared with an ordinary environment)

4.7 Psychotherapy

4.7a. Reports of psychoanalytically informed **psychotherapies** have begun to appear over the last 10 years. In general these reports do not provide outcome data but where they do, the results are generally positive[i,ii].
(Health gain notation – 4 "unknown")

i. Frankish P. Meeting the emotional needs of handicapped people: a psychodynamic approach. *Journal of Mental Deficiency Research* 1989; **33**: 407-14
(Type IV evidence - case studies of 7 intellectually disabled children and adults)

ii. Beail N. Psychoanalytic psychotherapy with men with intellectual disabilities: a preliminary outcome study. *British Journal of Medical Psychology* 1998; **71**: 1-11
(Type IV evidence - case analysis of 25 men, 20 of whom completed treatment)

This document is a supplement to, not a substitute for, professional skills and experience. Users are advised to consult the supporting evidence for a consideration of all the implications of a recommendation.

The *statements*

The *evidence*

4.8 Cognitive Therapy

4.8a. There is a body of evidence, based on single case studies, demonstrating the effectiveness of **cognitive therapy** for people with mild intellectual disability and borderline intelligence[i,ii].

These reports maintain the essential principles, components and procedures of cognitive therapy (setting an agenda, developing an awareness of the role of underlying beliefs in determining thought, establishing the relationship between thoughts, feelings of anxiety and behaviour, monitoring automatic thoughts, challenging maladaptive beliefs and developing adaptive automatic thoughts) but simplify them considerably to allow for the linguistic and intellectual deficits of clients. As yet there have been no controlled treatment trials investigating long-term outcome.

(Health gain notation – 2 *"likely to be beneficial"*)

i. Stenfert Kroese B, Dagnan D, Loumidis K. *Cognitive Behaviour Therapy for People with Learning Disabilities.* London: Routledge, 1997
(Type V evidence - expert opinion and review of clinical case studies)

ii. Lindsay WR. Cognitive therapy. *The Psychologist* 1999; **12**: 238-41
(Type V evidence - expert opinion and presentation of over 50 case studies)

4.8b. Anger management training is an essentially cognitive therapy. The way in which an individual misconstrues a situation and their personal feelings of arousal is germane to the development of anger responses. The techniques help individuals appraise and reappraise situations for the extent to which they are in reality anger arousing, to identify their own emotions more accurately, to role-play adaptive ways of behaving in these situations and to practise them in real life[i,ii,iii].

One case-controlled study demonstrated a decrease in aggressive responding in anger management and control conditions with no significant differences between the conditions[i].

A further controlled trial demonstrated significant reductions in expressed anger for subjects receiving anger management training which maintained up to one year[iv].

(Health gain notation – 2 *"likely to be beneficial"*)

i. Benson BA, Rice CJ, Miranti SV. Effects of anger management training with mentally retarded adults and group treatment. *Journal of Consulting and Clinical Psychology* 1986; **54**: 728-9
(Type II evidence - although a controlled trial it lacks a no treatment control condition)

ii. Lawrenson H, Lindsay WR. The treatment of anger in individuals with learning disabilities. In W Fraser, D Sines and M Kerr (eds.) *Hallas' the Care of People with Intellectual Disabilities.* 9th Edition. Oxford: Butterworth Heinemann, 1998
(Type V evidence - expert opinion and case studies)

iii. Black L, Cullen C, Novaco R. Anger management training in people with intellectual disabilities. In B Stenfert Kroese, D Dagnan and K Loumidis (eds.) *Cognitive Behaviour Therapy for People with Learning Disabilities.* London: Routledge, 1997
(Type IV evidence - case controlled study)

iv. Rose J, West C, Clifford D. Group interventions for anger in people with intellectual disabilities. *Research in Developmental Disabilities* 2000; **21**: 171-181
(Type III evidence - an interventional study without randomisation comparing 25 individuals who completed anger management training with 19 individuals from a waiting list control. The interventions produced significant reductions in expressed anger which were maintained at 6 and 12 month follow-up)

5 DRUG THERAPY

This document is a supplement to, not a substitute for, professional skills and experience. Users are advised to consult the supporting evidence for a consideration of all the implications of a recommendation.

The *statements* | The *evidence*

5.1 Behavioural Disturbance

5.1a. **26.5%** of people with an intellectual disability can be **treated effectively**, 47.1% fairly effectively, 23.5% with intermittent success and 2.9% cannot be treated[i].

Pharmacological procedures are the **least** effective interventions. **Response contingent procedures** are significantly more effective than other procedures.
(Health gain notation – 2 *"likely to be beneficial"*)

Internally maladaptive and **socially disruptive** behaviors can be treated more effectively than **externally destructive** behaviors.
(Health gain notation – 2 *"likely to be beneficial"*)

Undertaking **functional analysis** prior to treatment is significantly associated with treatment success.
(Health gain notation – 2 *"likely to be beneficial"*)

i. Didden R, Duker PC, Korzilius H. Meta-analytic study on treatment effectiveness for problem behaviors with individuals who have mental retardation. *American Journal of Mental Retardation* 1997; **101(4)**: 387-99
(Type III evidence – systematic review and meta-analysis of 482 empirical studies (no randomised controlled trials) on treatment of problem behaviors of individuals with mental retardation)

5.1b. There is no good evidence that **antipsychotic medication** helps in managing behaviour, or harms people with intellectual disability. *Further research is required*[i].
(Health gain notation – 4 "unknown")

i. Brylewski J, Duggan L. Antipsychotic medication for challenging behaviour in people with learning disability (Cochrane Review). In: *The Cochrane Library.* 1999; **4**: Oxford: Update Software
http://www.update-software.com/ccweb/cochrane/revabstr/ab000377.htm
[accessed 8.12.00]
(Type I evidence - systematic review of 500 citations with 3 sound randomised controlled trials)

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The *statements*	The *evidence*
5.1c. It is possible to reduce or even withdraw **neuroleptics** in severely and profoundly intellectually disabled adults[i,ii,iii]. At least 60% of patients on long-term treatment can eventually be managed without psychoactive medication. Transient behavioural deterioration during drug reduction may be prolonged (up to two years), but then returns to baseline without further pharmacological intervention. Although 40% demonstrate persistent deterioration following drug withdrawal and require some type of psychoactive medication, very few will need to recommence neuroleptics. Those that do tend to be older and well controlled but receiving higher baseline doses of neuroleptics. (Health gain notation – 3 *"trade off between beneficial and adverse effects"*)	**i.** May P, London EB, Zimmerman T, *et al*. A study of the clinical outcome of patients with profound mental retardation gradually withdrawn from chronic neuroleptic medication. *Annals of Clinical Psychiatry* 1995; **7(4)**:155-60 (Type IV evidence - naturalistic study of 23 severely and profoundly intellectually disabled adult male patients undergoing slow "diagnostic" neuroleptic taper) **ii.** Branford D. Factors associated with the successful or unsuccessful withdrawal of antipsychotic drug therapy prescribed for people with learning disabilities. *Journal of Intellectual Disability Research* 1996; **40(4)**: 322-329 (Type III evidence – non-controlled study of 123 patients who had reduction of their antipsychotic medication) **iii.** Ahmed Z, Fraser W, Kerr MP, *et al*. Reducing antipsychotic medication in people with a learning disability. *British Journal of Psychiatry* 2000; **176**: 42-46 (Type II evidence – randomised controlled trial of 67 subjects in whom antipsychotic medication was used to treat behavioural problems. A 25% reduction in dosage per month led to one third of patients sucessfully coming off the medication and a further 19% having the dose reduced by half. Environmental factors influenced success in drug reduction rather than subject characteristics)
5.1d. Using multiple assessment measures, **Clomipramine** was effective in reducing the frequency and intensity of one or more stereotyped behaviour, hyperactivity and irritability[i]. 60% showed significant improvement, 30% had treatment limiting side effects and 10% showed no improvement. (Health gain notation – 2 *"likely to be beneficial"*)	**i.** Lewis MH, Bodfish JW, Powell SB, Golden RN. Clomipramine treatment for stereotype and related repetitive movement disorders associated with mental retardation. *American Journal of Mental Retardation* 1995; **100(3)**: 299-312 (Type II evidence - double blind placebo controlled cross- over study involving 10 severely or profoundly intellectually disabled adults)
5.1e. There is limited evidence that **Risperidone** is effective in improving a range of behavioural disturbances in people with varying levels of intellectual disability. *Further research is needed*[i]. (Health gain notation – 4 *"unknown"*)	**i.** Natarajan D, Martin AJ, Tesh D. Risperidone therapy in the control of behavioural disturbances in patients with learning disability. *Irish Journal of Psychological Medicine* 1997; **14(2)**: 69-71 (Type IV evidence - retrospective audit of seventeen long term inpatients with mild to severe intellectual disability: did not use recognised audit tool)

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The *statements*

5.1f **Antidepressants** with a specific 5-HT action should be used with caution in people with intellectual disability and **autism**. They may cause agitation, physical aggression and SIB and sleep disturbance related to the role of serotonin in autistic symptoms[i].
(Health gain notation – 5 *"unlikely to be beneficial"*)

In autistic adults **Fluvoxamine**, a selective serotonin reuptake inhibitor, results in a significant reduction in repetitive thoughts and behaviours, aggression and maladaptive behaviours compared to placebo. Fluvoxamine had a 53% response rate[ii].
(Health gain notation – 2 *"likely to be beneficial"*)

The *evidence*

i. Perry DW, Hinder S, Krishnan VHR, Roy A. The use of specific serotonin re-uptake inhibitors in people with learning disability, autism and depression: Letter to the Editors. *Human Psychopharmacology* 1996; **11**: 425-6
(Type IV evidence - case study of two patients)

ii. McDougle CJ, Naylor ST, Cohen DJ *et al* A double-blind, placebo-controlled study of Fluvoxamine in adults with autistic disorders. *Archives of General Psychiatry* 1996; **53**: 1001-1008
(Type II evidence randomised controlled trial of 30 adults with autism. Mean dose of Fluvoxamine, 277 ±42mg, was compared to placebo. A significant improvement with Fluvoxamine was seen after 4 weeks. Robust study design with standardised rating scales and thorough statistical analysis)

5.2 Self-Injurious Behaviour

5.2a. There is growing evidence that serotonergic drugs are effective in the reduction of **self-injurious** (SIB) and **aggressive behaviour** in people with intellectual disability. **Sertraline**, a serotonin reuptake inhibitor, has been shown to be more effective (when measured by Clinical Global Impressions) and have fewer side effects than traditional neuroleptics[i,ii,iii,iv]. *Further trials are recommended.*
(Health gain notation – 4 *"unknown"*)

i. Sandman CA, Matrick WP. Opiate mechanisms in self injury. *Mental Retardation and Developmental Disability Research Review* 1995; **1**: 130-136
(Type I evidence – systematic review showing a 35-75% reduction in self-injurious behaviour in adults with severe and profound intellectual disability after treatment with oral Naltrexone)

ii. Sandman CA, Metrick W, Taylor DV, *et al*. Dissociation of POMC peptides after self-injury preducts responses to centrally acting opiate blockers. *American Journal on Mental Retardation* 1997; **102(2)**: 182-199
(Type II evidence – double-blind, placebo controlled crossover study of 8 men and 2 women with self-injurious behaviour treated with Naltrexone following plasma measurement of beta-endorphin. The study showed that an elevated beta-endorphin level indicated a good response to Naltrexone, suggesting that such individuals may be addicted to endogenous opiates released following self-injury)

iii. Thompson T, Hackenberg T, Cerutti D, *et al*. Opioid antagonist effects on self-injury in adults with mental retardation: Response form and location as determinants of medication effects. *American Journal on Mental Retardation* 1994; **99(1)**: 85-102
(Type II evidence – double-blind randomised controlled trial of 8 adults with severe or profound intellectual disability treated with 50 mg and 100 mg of Naltrexone. Both doses significantly reduced self-injurious behaviour. Naltrexone showed no side effects at either dose including no effect on sleep pattern)

iv. Hellings JA, Kelley LA, Gabrielli WF, *et al*. Sertraline response in adults with mental retardation and autistic disorder. *Journal of Clinical Psychiatry* 1996; **57(8)**: 333-6
(Type III evidence - open trial, nine consecutively admitted adult intellectually disabled outpatients presenting with target behaviours of self-injury and/or aggression. Six were mildly or moderately mentally retarded by DSM-III-R criteria; five had comorbid autistic disorder)

This document is a supplement to, not a substitute for, professional skills and experience. Users are advised to consult the supporting evidence for a consideration of all the implications of a recommendation.

The *statements*	The *evidence*
5.2b. There is limited evidence that **Naltrexone** may be effective in reducing self-injurious behaviour (SIB) in adults with profound intellectual disability and that this benefit might be both durable to environmental changes and continue long after cessation of therapy[i]. (Health gain notation – 4 *"unknown"*)	**i.** Crews WD Jr, Rhodes RD, Bonaventura SH, *et al*. Cessation of long-term naltrexone administration: longitudinal follow-ups. *Research in Developmental Disabilities* 1999; **20(1)**: 23-30 (Type IV evidence - case study of one patient)
5.2c. There is limited evidence that **Risperidone** is effective in the management of aggressive and self-injurious behaviour (SIB) in people with moderate to profound intellectual disability. Side effects are mild and primarily those of sedation and restlessness[i]. (Health gain notation – 4 *"unknown"*)	**i.** Cohen SA, Ihrig K, Lott RS, Kerrick JM. Risperidone for aggression and self-injurious behavior in adults with mental retardation. *Journal of Autism & Developmental Disorders* 1998; **28(3)**:229-33 (Type IV evidence - tracking of maladaptive behaviours in 8 adult patients following initiation of risperidone)
5.3 Attention-Deficit Hyperactivity Disorder	
5.3a. **Amphetamine** is effective in the treatment of **attention-deficit hyperactivity disorder** (ADHD) in children[i]. It has been shown to reduce inattention, hyperactivity and other disruptive behavioural problems and tends to improve results in the Wechsler Intelligence Scale for Children. Measured benefits last at least one year and adverse effects are few and mild. (Health gain notation – 2 *"likely to be beneficial"*)	**i.** Gillberg C, Melander H, von Knorring AL, *et al.* Long term stimulant treatment of children with attention-deficit hyperactivity disorder symptoms. *Archives of General Psychiatry* 1997; **54(9)**: 857-64 (Type II evidence - multicentre double blind placebo controlled RCT involving 62 children aged between 6 & 11 years)
5.3b. There is limited evidence that both **Methylphenidate** and **Fenfluramine** may be effective treatments for attention-deficit hyperactivity disorder (ADHD) in children with intellectual disability or borderline IQ[i]. (Methylphenidate: Health gain notation – 4 *"unknown"*) **Fenfluramine is a controversial drug.** **At higher doses (>1.5mg/kg/day) it causes drowsiness, dizziness and anorexia.** **There are reports of possible neurotoxicity with long-term depletion of serotonin in laboratory models.** **FENFLURAMINE HAS BEEN WITHDRAWN IN THE UK DUE TO REPORTS OF LINKS WITH VALVULAR HEART DISEASE** (Fenfluramine: Health gain notation – 6 *"likely to be harmful"*)	**i.** Aman MG, Kern RA, Osborne P, *et al.* Fenfluramine and methylphenidate in children with mental retardation and borderline IQ: clinical effects. *American Journal of Mental Retardation* 1997; **101(5)**:521-34 (Type II evidence - double-blind placebo-controlled crossover study of Methylphenidate (0.4 mg/kgday) and different doses of Fenfluramine (1.0, 1.5, or 2.0 mg/g/day) in 35 children aged 5-14 years with mental retardation or borderline IQ and ADHD)

6 FORENSIC PROBLEMS AND OFFENDING

This document is a supplement to, not a substitute for, professional skills and experience. Users are advised to consult the supporting evidence for a consideration of all the implications of a recommendation.

The *statements*

6a. The relationship between behavioural disturbance and **forensic problems** in people with intellectual disability is subtle. There is no doubt that many behaviour problems in people with severe and profound intellectual disability would be construed as offences in more able individuals.

One of the determining characteristics of an 'offence' is that the perpetrator is aware of behaviour that is socially sanctioned or censured. Even when someone with mild intellectual disability may understand the nature of the offence, the criminal justice response and the response of carers is diverse across cases and situations[i,ii].

General methodological difficulties with work in this area are that offenders with intellectual disability are only mentioned as part of larger offender cohorts. Where studies are specifically directed towards offenders with intellectual disability, many studies are small in subject numbers[iii].

The *evidence*

i. Clare ICH, Murphy GH. Working with offenders or alleged offenders with intellectual disabilities. In E Emerson, C Hatton, J Bromley and A Caine (eds.) *Clinical Psychology and People with Intellectual Disabilities.* Chichester: Wiley, 1998
(Type V evidence - expert opinion and review of some important cases)

ii. Swanson CK, Garwick GB. Treatment for low functioning sex offenders: group therapy and interagency co-ordination. *Mental Retardation* 1990; **28**: 155-61
(Type V evidence - expert opinion based on a description of a group therapy treatment service)

iii. Johnston SJ, Halstead S. Forensic issues in intellectual disability. *Current Opinion in Psychiatry* 2000; (in press)
(Type V evidence - systematic review of studies over the previous year. Does not include a randomised control trial but reviews important issues and evidence relating to the current status and use of high security, medium security and community provision; issues of consent, capacity, competence, assessment and treatment effectiveness)

6b. An important practical problem encountered when considering the population of individuals who offend is one of **identifying** those people with a intellectual disability and ensuring they are offered the additional safeguard of having an Appropriate Adult present during police interviews[i].

i. Robertson G. *The Role of Surgeons.* Research Study No 6. Royal Commission on Criminal Justice. London: HMSO, 1992
(Type V evidence - expert opinion)

This document is a supplement to, not a substitute for, professional skills and experience. Users are advised to consult the supporting evidence for a consideration of all the implications of a recommendation.

The *statements*	The *evidence*
6c. It is generally considered that the **prevalence** rates for offenders with intellectual disability may be higher than those in the general population. This is especially true for sexual offences and arson[i,ii,iii,iv,v].	**i.** Walker N, McCabe S. *Crime and Insanity in England*. Edinburgh: University Press, 1973 (Type III and V evidence - review of legislation, secure hospital provision and prison services up until 1973. Detailed review of statistics from 1950-1970 relating to criminals with a psychiatric diagnosis) **ii.** Murphy WD, Coleman EM, Haynes MR. Treatment and evaluation issues with the mentally retarded sex offender. In Greer JG, Stuart IR (eds.). *The Sexual Aggressor: Current Prospectives on Treatment*. New York: Van Nostrand, Reinhold, 1983. pp. 22-41 (Type IV evidence - review of treatment work with men who have committed sex offences. Treatments included plethysmographic assessment and electrical aversion; number of participants not noted) **iii.** Hayes S. Sex offenders. *Australia and New Zealand Journal of Developmental Disabilities* 1991; **17**: 221-7 (Type V evidence - expert opinion based on an extensive review of clinical cases. 12-13% of offenders in the New South Wales prison population were assessed as having intellectual disability) **iv.** Raesaenen P, Hirvenoja R, Hakko H, Vaeisaenen E. Cognitive functioning ability of arsonists. *Journal of Forensic Psychiatry* 1994; **5**: 615-20 (Type III evidence - a study of 72 arsonists examined before trial they found that 11% fell into the range of intellectual disability) **v.** Bradford J, Dimock J. A comparative study of adolescents and adults who wilfully set fires. *Psychiatric Journal of the University of Ottawa* 1986; **11**: 228-34 (Type III evidence - out of 57 adults and 47 juvenile arsonists they found intellectual disability to be the diagnosis in just over 10% of both groups)
6d. Well controlled studies have found **prevalence** rates for individuals with intellectual disability to be slightly higher in offender populations than in the general population. There is a vast predominance of males amongst offenders with intellectual disability[i,ii].	**i.** MacEachron AE. Mentally retarded offenders: prevalence and characteristics. *American Journal of Mental Deficiency (American Journal on Mental Retardation)* 1979; **84**: 165-76 (Type III evidence - review of 3938 adult male offenders. Offending rates were only slightly higher than in the general population) **ii.** Borthwick-Duffy SA. Epidemiology and prevalence of psychopathology in people with mental retardation. *Journal of Consulting and Clinical Psychology* 1994; **62(1)**: 17-27 (Type IV evidence - review of 8 observational studies between 1975 & 1985 involving adults with intellectual disability in both the hospital and community settings)

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The *statements*	The *evidence*
6e. The way in which **intelligence** is measured and the use of different population bases leads to a wide variability in prevalence statistics across studies[i]. For these reasons there is little substantive evidence to support any link between the presence of intellectual impairment and a predisposition to criminal behaviour. Different studies report prevalence rates for intellectual disability within prison populations varying from around 2% to around 40%.	**i.** Holland AJ. Challenging and offending behaviour by adults with developmental disorders. *Australia and New Zealand Journal of Developmental Disabilities* 1991; **17**: 119-26 (Type V evidence - expert opinion based on a review of a range of relevant studies)
6f. **In-patient treatment** has been provided for individuals who have shown offending behaviours of violence, fire-setting, sexual abuse and also for individuals who have offended and have concurrent intellectual disability and psychiatric illness. Reports on the short-term outcome for individual case studies have been encouraging[i,ii,iii]. (Health gain notation – 2 "likely to be beneficial")	**i.** Murphy GH, Holland AJ, Fowler P, Reep J. MIETS: A service option for people with mild mental handicaps and challenging behaviour or psychiatric problems 1. Philosophy service and service users. *Mental Handicap Research (Journal of Applied Research in Intellectual Disabilities)* 1991; **4**: 41-66 (Type IV evidence - review of a series of cases) **ii.** Murphy GH, Clare ICH. MIETS: A service option for people with mild mental handicaps and challenging behaviour or psychiatric problems. Assessment, treatment and outcome for service users and service effectiveness. *Mental Handicap Research* 1991; **4**: 180-206 (Type IV evidence - review of a series of cases) **iii.** Day K. Male mentally handicapped sex offenders. *British Journal of Psychiatry* 1994; **165**: 630-39 (Type III evidence - review of 47 male sex offenders admitted to hospital. Detailed review of characteristics and recommendations for treatment provision)
6g. Study of **longer term** outcomes indicates that 84.2% of treated patients return to community based resources. Arsonists are over-represented in those with a poorer outcome[i].	**i.** Xenitidis KI, Henry J, Russell AJ, *et al*. An in-patient treatment model for adults with mild intellectual disability and challenging behaviour. *Journal of Intellectual Disability Research* 1999; **43**: 128-34 (Type III evidence - systematic review of cases from 1987-1998 which found that 54.7% of admissions were offenders)

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The *statements*	The *evidence*
6h. Reviews of **high security provision** indicate that offenders with intellectual disability have the longest duration of stay and are the most difficult to discharge because of the lack of availability of suitable discharge resources[i,ii].	**i.** Jamieson E, Butwell M, Taylor P, *et al.* Trends in special (high security) hospitals, 1: referrals and admissions. *British Journal of Psychiatry* 2000; **176**: 253-9 (Type III evidence - review of referrals and admissions to 3 high security hospitals) **ii.** Butwell M, Jamieson E, Leese M, *et al.* Trends in special (high security) hospitals, 2: residency and discharge episodes. *British Journal of Psychiatry* 2000; **176**: 260-5 (Type III evidence - systematic review and analysis of the case registers of 3 high security hospitals over a 10 year period from 1986-95)
6i. More recently, clinicians and researchers have begun to address the problem of **treatment in the community** for individuals who have offended. Without necessarily admitting clients for in-patient treatment, several reports have suggested the feasibility of such treatment[i,ii,iii,iv,v]. (Health gain notation – 2 *"likely to be beneficial"*)	**i.** Lindsay WR, Neilson C, Smith AHW, *et al.* The treatment of six men with a learning disability convicted of sex offences with children. *British Journal of Clinical Psychology* 1998; **37**: 83-98 (Type IV evidence - detailed process study of 6 cases. No re-offending is reported 4 years following the initial conviction although the authors did not feel confident about re-offending data in one case) **ii.** Lindsay WR, Olley S, Baillie N, Smith AHW. Treatment of adolescent sex offenders with intellectual disability. *Mental Retardation* 1999; **37**: 201-11 (Type IV evidence - review of four case studies: no re-offending reported 3 years following initial conviction) **iii.** Lindsay WR, Marshall I, Neilson CQ, Quinn K, Smith AHW. The treatment of men with learning disability convicted of exhibitionism. *Research in Developmental Disabilities* 1998; **19**: 295-316 (Type IV evidence – a detailed process study of four cases. No reoffending reported four years following initial conviction) **iv.** Clare ICH, Murphy GH, Cox D, Chaplin EH. Assessment and treatment of fire-setting: a single case investigation using a cognitive behavioural model. *Criminal Behaviour and Mental Health* 1992; **2**: 253-68 (Type IV evidence - case study review of a series of cases) **v.** O'Connor W. A problem solving intervention for sex offenders with an intellectual disability. *Journal of Intellectual and Developmental Disability* 1996; **21**: 219-35 (Type IV evidence - description of a problem solving intervention with 13 adult male sex offenders aged 17-43 years. Most subjects achieved more community access)

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The *statements*

6j. Characteristics and predisposing factors. Sex offenders with intellectual disability may have a high incidence of family psychopathology, low specificity for age and sex of the victim, psycho-social deprivation, behavioural disturbances at school, psychiatric illness, social naivety, poor ability to form normal sexual and personal relationships, poor impulse control and low self-esteem[i,ii,iii].

Experience of sexual and physical abuse in childhood is associated with offending in adulthood although it is neither a necessary or sufficient cause of adult offending including sexual offending[iv,v,vi].

Sex offenders with learning disability have a greater tendency to offend against male children and younger children[vii].

The *evidence*

i. Day K. Male mentally handicapped sex offenders. *British Journal of Psychiatry* 1994; **165**: 630-9
(Type III evidence - review of 47 male patients referred for antisocial sexual behaviour)

ii. Caparulo F. Identifying the developmentally disabled sex offenders. *Sexuality and Disability* 1991; **9**: 311-322
(Type V evidence - expert opinion based on clinical evidence and experience)

iii. Winter N, Holland AJ, Collins S. Factors predisposing to suspected offending by adults with self-reported learning disabilities. *Psychological Medicine* 1997; **27**: 595-607
(Type IV evidence - investigation into adults charged with offences and/or leaving custody. Only two subjects with a self-reported intellectual disability actually had an IQ below 70)

iv. Langevin R, Pope S. Working with learning disabled sex offenders. *Annals of Sex Research* 1993; **6**: 149-160
(Type V evidence – expert opinion based on clinical evidence)

v. Thompson D. Profiling the sexually abusive behaviour of men with intellectual disabilities. *Journal of Applied Research and Intellectual Disabilities* 1997; **10**: 125-139
(Type IV evidence – an analysis of the characteristics of 75 men who had allegedly perpetrated some form of sexual abuse)

vi. Lindsay WR, Law J, Smith AHW, *et al.* A comparison of physical and sexual abuse histories of sexual and non-sexual offenders with intellectual disability. *Child Abuse and Neglect* 2000; (In Press)
(Type IV evidence – study comparing the abuse histories of 46 sexual offenders with 48 non-sexual offenders)

vii. Blanchard R, Watson M, Choy A *et al.* Pedophiles: Mental retardation, maternal age and sexual orientation. *The Archives of Sexual Behavior* 1999; **28(2)**: 111-127
(Type IV evidence – study, by interview, clinical chart information, phallometric tests and self-administered questionnaire, of 991 male sexual offenders)

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The *statements*

6k. Studies have found **re-offending rates** of untreated offenders of between 40 and 70%[i,ii].

The risk of **recidivism** is highest during the year immediately following discharge[iii].

A range of studies have found **re-offending** rates following treatment to be between 20 and 55% depending on the type of treatment and the offence[iv].

Outcomes for individuals treated for 2 or more years would appear to be superior to outcomes for individuals treated for less than one year[v,iv].
(Health gain notation – 2 *"likely to be beneficial"*)

The *evidence*

i. Scorzelli JF, Reinke-Scorzelli M. Mentally retarded offenders: a follow-up study. *Rehabilitation Counselling Bulletin* 1979; September: 70-73
(Type III evidence - review of 135 offenders with intellectual disability found that 68% had a prior history of arrest)

ii. Klimecki MR, Jenkinson J, Wilson L. A study of recidivism amongst offenders with an intellectual disability. *Australia and New Zealand Journal of Developmental Disabilities* 1994; **19**: 209-19
(Type III evidence - detailed review of 75 incarcerated offenders with intellectual disability. Recidivism rates were 41.3% with 84% of recidivism occurring within 12 months of release from prison)

iii. Day K. Crime and mental retardation: a review. In Howells K, Hollin CR (eds.) *Clinical Approaches to the Mentally Disordered Offender.* Cambridge: John Wyllie, 1993
(Type IV evidence – expert opinion based on clinical experience and a review of the literature)

iv. Thomas DH, Singh T. Offenders referred to a learning disability service: a retrospective study from one county. *British Journal of Learning Disabilities* 1995; **23**: 24-7
(Type IV evidence - 3 year follow-up of 20 offenders treated in a community based service: 50% of subjects re-offended and appeared before a court)

v. Brier N. Targeted treatment for adjudicated youths with learning disabilities: effects on recidivism. *Journal of Learning Disabilities* 1994; **27**: 215-22
(Type III evidence - controlled group study comparing 73 offenders who completed the treatment requirements with 85 who did not and a further matched group of 34 untreated subjects. Over an average follow-up period of 20 months, the completors had a significantly lower recidivism rate (12%) relative to the non-completors (40%) and the matched controls (38%))

vi. Lindsay WR, Smith AHW. Responses to treatment for sex offenders with a learning disability: a comparison of men with one year and two year probation sentences. *Journal of Intellectual Disabilities Research* 1998; **42**: 346-53
(Type III evidence - comparison of two groups of sex offenders. significant differences were found between the groups with the greater and most durable changes occuring in the group treated for a longer duration)

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The *statements*

6l. **Representation**, **consent** and **competence**. People with an intellectual disability may be disadvantaged by the judicial process because of lack of appropriate support and appropriate legal representation from early stages in the process[i,ii,iii,iv,v].

The *evidence*

i. Cockram J, Jackson R, Underwood R. People with an intellectual disability in the criminal justice system: the family perspective. *Journal of Intellectual and Developmental Disability* 1998; **23**: 41-55
(Type IV evidence - review of cases and analysis of the responses of 20 carers involved with offenders with intellectual disability)

ii. Hayes SC. Prevalence of intellectual disability and local courts. *Journal of Intellectual and Developmental Disability* 1997; **22**: 71-85
(Type IV evidence - review of 208 individuals appearing before 6 courts. The review emphasises the need for policies safeguarding the rights of people with intellectual disability in the criminal justice system)

iii. Gudjonsson G, MacKeith J. Learning disability and the Police and Criminal Evidence Act 1984. Protection during investigative interviewing: a video recorded false confession to double murder. *Journal of Forensic Psychiatry* 1994; **5**: 35-49
(Type IV evidence - careful case study illustrating the psychological processes causing an individual to confess falsely to a double murder)

iv. Kebbell MR, Hatton C. People with mental retardation as witnesses in court: a review. *Mental Retardation* 1999; **37**: 179-87
(Type I evidence - comprehensive review which concludes that in general people with intellectual disability can provide accurate accounts of evidence. Cross-examination methods may lead to memory distortions. Resulting errors could lead to false conviction or acquittal)

v. Everington C, Fulero SM. Competence to confess: measuring understanding and suggestibility of defendants with mental retardation. *Mental Retardation* 1999; **37**: 212-20
(Type III evidence - group comparison of individuals with and without intellectual disability. Participants with intellectual disability were significantly less able to comprehend their Miranda rights. They were also more likely to respond to suggestive questioning)

7 MEDICAL CONDITIONS IN PEOPLE WITH INTELLECTUAL DISABILITY

This document is a supplement to, not a substitute for, professional skills and experience. Users are advised to consult the supporting evidence for a consideration of all the implications of a recommendation.

The *statements*	The *evidence*
7.1 Medical Conditions – General	
7.1a. The frequency of most common medical conditions is similar in adults with intellectual disability and the general population. There is however an increased frequency of **thyroid disorders, non-ischaemic heart disorders, and sensory (visual and hearing) impairment**[i,ii].	**i.** Kapell D, Nightingale B, Rodriguez A, Lee JH, Zigman WB, Schuff N. Prevalence of chronic medical conditions in adults with mental retardation: comparison with the general population. *Mental Retardation* 1998: **36(4)**: 269-79 (Type IV evidence – use of standardised mortality ratios based on the review of medical records and interviews with care-givers of 278 adults with intellectual disability, with and without Down syndrome, 45-74 years of age) **ii.** Beange H, McElduff A, Baker W. Medical disorders of adults with mental retardation: a population study. *American Journal on Mental Retardation* 1995; **99(6)**: 595-604 (Type IV evidence – comparison of rates of medical disorders among 202 adults with intellectual disability between age 20 and 50 years and a control group of 619 non-intellectually disabled adults)
7.1b. Compared with non-Down syndrome adults with intellectual disability, people with Down syndrome have a significantly **lower rate of hypertension**[i].	**i.** Kapell D, Nightingale B, Rodriguez A, *et al.* Prevalence of chronic medical conditions in adults with mental retardation: comparison with the general population. *Mental Retardation* 1998; **36(4)**: 269-79 (Type IV evidence - use of standardised mortality ratios based on the review of medical records and interview with care-givers of 278 adults with intellectual disability, with and without Down syndrome, 45-74 years of age)
7.1c. People with intellectual disability have lower levels of **arthritis** and **back pain** compared to the general population[i].	**i.** Welsh Office. *Welsh Health Survey* 1995. London: HMSO, 1996 (Type IV evidence – postal survey of a random sample of 4000 people with intellectual disability with a 56% useable response rate, N=2240)
7.1d. People with intellectual disability have higher levels of **impaired vision** compared to the general population[i].	**i.** Welsh Office. *Welsh Health Survey* 1995. London: HMSO, 1996 (Type IV evidence – postal survey of a random sample of 4000 people with intellectual disability with a 56% useable response rate, N=2240)

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The *statements*	The *evidence*
7.1e. People with intellectual disability have higher levels of **impaired hearing** (14.2%) compared to the general population (11.7%)[i].	**i.** Welsh Office. *Welsh Health Survey* 1995. London: HMSO, 1996 (Type IV evidence – postal survey of a random sample of 4000 people with intellectual disability with a 56% useable response rate, N=2240)
7.1f. People with intellectual disability have fewer natural **teeth** (less than 20 including teeth which have been capped or filled) compared to the general population[i]. One third of children with mild, moderate and severe intellectual disability have high levels of **poor oral hygiene**, but this is no higher than the general population[ii]. Children with borderline or mild intellectual disability have the poorest dental condition and worst dental care with the lowest level of **restorative care** (restorative index 43.9%). 22% do not **brush daily** and over 90% do not receive any help with **toothbrushing** from their parents or carers[ii,iii]. **Oral health care guidelines** for people with a learning disability are due for publication in February 2001[iv].	**i.** Welsh Office. *Welsh Health Survey* 1995. London: HMSO, 1996 (Type IV evidence – postal survey of a random sample of 4000 people with intellectual disability with a 56% useable response rate, N=2240) **ii.** Declerck D. Vinckier F. Gizani S, *et al.* [Status of the teeth and degree of care in handicapped in Flanders]. [French] *Revue Belge de Medecine Dentaire*. 1995: **50(3)**: 9-24 (Type IV evidence: comparison of 12-year old children with intellectual disability with age-matched children without intellectual disability in Flanders regarding general caries prevalence, caries distribution and total caries experience, Belgium) **iii.** Gizani S, Declerck D, Vinckier F, *et al.* Oral health condition of 12-year-old handicapped children in Flanders (Belgium). *Community Dentistry & Oral Epidemiology.* 1997: **25(5)**: 352-7 (Type IV evidence: observational study of 625 12-year-old children with mild, moderate and severe intellectual disability living in Flanders, Belgium) **iv.** *Oral Health Care Guidelines for People with a Learning Disability* will be available from the Royal College of Surgeons (http://www.rceng.ac.uk) or the British Society for Disability and Oral Health (http://www.bsdh.org.uk).
7.1g. People with intellectual disability are less likely to **smoke** (19.2% smokers / ex-smokers) compared to the general adult population (63.1% smokers / ex-smokers)[i].	**i.** Welsh Office. *Welsh Health Survey* 1995. London: HMSO, 1996 (Type IV evidence – postal survey of a random sample of 4000 people with intellectual disability with a 56% useable response rate, N=2240)
7.2 Hypothyroidism	
7.2a. Subclinical hypothyroidism* is present in one third of children and adults with Down syndrome. **Clinically manifested hypothyroidism** can be detected in 2.3% of children with Down syndrome[i,ii]. *(high basal level TSH, low total or free T4)	**i.** Karlsson B, Gustafsson J, Hedov G, Ivarsson S-A, Anneren G. Thyroid dysfunction in Down's syndrome: relation to age and thyroid autoimmunity. *Archives of Disease in Childhood* 1998; **79(3)**: 242-5 (Type IV evidence – longitudinal study of 85 patients with Down syndrome aged up to 25 years) **ii.** Rubello D, Pozzan GB, Casara D, *et al.* Natural course of subclinical hypothyroidism in Down's syndrome: prospective study results and therapeutic considerations. *Journal of Endocrinological Investigation* 1995; **17**: 35-40 (Type IV evidence – Two to seven year follow-up of 344 people with Down syndrome, 257 age- and sex-matched healthy subjects, and 120 parents of subjects with Down syndrome)

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The *statements*	The *evidence*
7.2b. The presence of **antithyroid antibody** is higher amongst people with Down syndrome (18%) when compared with a control group of non-Down syndrome subjects (5.8%)[i].	**i.** Rubello D, Pozzan GB, Casara D, *et al.* Natural course of subclinical hypothyroidism in Down's syndrome: prospective study results and therapeutic considerations. *Journal of Endocrinological Investigation* 1995; **17**:35-40 (Type IV evidence – two to seven-year follow-up study of 344 people with Down syndrome, 257 age- and sex-matched healthy subjects, and 120 parents of subjects with Down syndrome)
Hepatitis B and Autoimmune Thyroiditis	
7.2c. The frequency of thyroiditis in people with Down syndrome who are also **carriers of HBsAg** is three times higher than in people with Down syndrome who are non-carriers. They should be regularly monitored for the development of thyroid disease. This does not apply to non-Down syndrome people with intellectual disability[i]. (Health gain notation – 2 *"likely to be beneficial"*)	**i.** May P, Kawanishi H. Chronic hepatitis B infection and autoimmune thyroiditis in Down syndrome. *Journal of Clinical Gastroenterology* 1996; **23(3)**: 181-4 (Type IV evidence – case-controlled study of 57 adults with Down syndrome and 450 age-, sex- and environmentally matched disabled people without Down syndrome)
Screening for Thyroid Function	
7.2d. People with Down syndrome should be **screened annually** for thyroid function. Antithyroid antibodies are rare in children under 8 years of age but titres subsequently increase with age[i,ii,iii]. (Health gain notation – 2 *"likely to be beneficial"*)	**i.** Karlsson B, Gustafsson J, Hedov G, Ivarsson S-A, Anneren G. Thyroid dysfunction in Down's syndrome: relation to age and thyroid autoimmunity. *Archives of Disease in Childhood* 1998; **79(3)**: 242-5 (Type IV evidence – longitudinal study of 85 patients aged up to 25 years) **ii.** Rubello D, Pozzan GB, Casara D, *et al.* Natural course of subclinical hypothyroidism in Down's syndrome: prospective study results and therapeutic considerations. *Journal of Endocrinological Investigation* 1995; **17**: 35-40 (Type IV evidence – two to seven-year follow-up study of 344 people with Down syndrome, 257 age- and sex-matched healthy subjects, and 120 parents of subjects with Down syndrome) **iii.** Rooney S, Walsh E. Prevalence of abnormal thyroid function tests in a Down's syndrome population. *Irish Journal of Medical Science* 1997; **166(2)**: 80-2 (Type IV evidence - observational study of 36 subjects)

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The *statements* | The *evidence*

7.3 Epilepsy

7.3a. 14-24% of people with an intellectual disability are affected by **epilepsy**.

The frequency of **life-time history** of epilepsy ranges from 7-15% of people with mild to moderate intellectual disability, 45-67% of people with severe intellectual disability and 50-82% of people with profound intellectual disability. The prevalence also varies according to the age of patients and the aetiology of intellectual disability[i,ii,iii,iv,v].

The cumulative incidence of epilepsy at 22 years of age is much higher among those intellectually disabled people who also have cerebral palsy (38%) compared to those who do not (15%)[ii].

i. Rutter M, Tizand J, Yule W, *et al*. Research Report: Isle of Wight Studies 1964-1974. *Psychological Medicine* 1976; **6**: 313-32
(Type IV evidence – several epidemiological studies of children in the Isle of Wight)

ii. Goulden KJ, Shinnar S, Koller H, Katz M, Richardson SA. Epilepsy in children with mental retardation: a cohort study. *Epilepsia* 1991; **32(5)**: 690-697
(Type IV evidence - prospective cohort study of 221 children with intellectual disability born in Aberdeen between 1951 and 1955)

iii. McGrother CW, Hauck A, Bhaumik S, Thorp C, Tomb N. Community care for adults with learning disability and their carers: needs and outcomes from the Leicestershire register. *Journal of Intellectual Disability Research* 1996; **40(2)**: 183-90
(Type IV evidence - cross sectional study of 2117 adults with intellectual disability and 982 carers)

iv. Shepherd C, Hoskins G. Epilepsy in school children with intellectual impairment in Sheffield: the size and nature of the problem and its implications in service provision. *Journal of Mental Deficiency Research* 1989; **33**: 511-14
(Type IV evidence – a study of the prevalence and nature of epilepsy in all children between the ages of 5 and 16 years in Sheffield, UK)

v. Deb S. Epidemiology and treatment of epilepsy in patients who are mentally retarded. *CNS Drugs* 2000; **13(2)**: 117-28
(Type V evidence – expert opinion based on a review of observational, experimental and randomised controlled trials)

7.3b. False positive and false negative **diagnoses of epilepsy** in people with intellectual disability are possible[i].

i. Alvarez N, Besag F, Iivanainen M. Use of antiepileptic drugs in the treatment of epilepsy in people with intellectual disability. *Journal of Intellectual Disability* Research 1998; **42(S1)**: 1-15
(Type V evidence – expert opinion based on a review of the literature)

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The *statements*	The *evidence*
7.3c. For people with intellectual disability **multiple seizure types** are common and up to three-quarters of patients remain refractory to treatment. **Tonic-clonic** seizures are the most common type of epilepsy in people with an intellectual disability (60%). **Complex partial** seizures are the second most common type (20%). Compared with the general population, seizure types such as absences (typical and atypical), myoclonus, tonic and atonic are more common among adults with an intellectual disability[i,ii].	**i.** Deb S, Joyce J. Characteristics of epilepsy in a population based cohort. *Irish Journal of Psychological Medicine* 1999; **16(1)**: 5-9 (Type IV evidence - cross sectional study of 143 adults with intellectual disability and epilepsy) **ii.** Branford D. Bhaumik S. Duncan F. Epilepsy in adults with learning disabilities. *Seizure* 1998; **7(6)**: 473-7 (Type IV evidence - cross sectional study of adults with intellectual disability and epilepsy)
Assessment **7.3d. EEG** remains difficult to perform in a proportion of people with an intellectual disability. EEG abnormality is detected in a high proportion of adults with an intellectual disability and epilepsy (>90%). In most cases EEG abnormality is non-specific such as excessive background slow wave. In 50% of cases the abnormality includes epileptiform changes in the EEG[i,ii].	**i.** Deb S. Electrophysiological correlates of psychopathology in individuals with mental retardation and epilepsy. *Journal of Intellectual Disability Research* 1995; **39(2)**: 129-35 (Type IV evidence - cross sectional study of 100 adults, with intellectual disability and epilepsy, randomly selected from hospital and community settings) **ii.** Deb S, Joyce J. Characteristics of epilepsy in a population based cohort. *Irish Journal of Psychological Medicine* 1999; **16(1)**: 5-9 (Type IV evidence - cross sectional study of 143 adults with intellectual disability and epilepsy)
Treatment and Care **7.3e** Reducing **polypharmacy** use of antiepileptic drugs in institutionalised people with intellectual disability is associated with a reduced frequency of seizures and a reduced frequency of behavioural disorders and improved quality of life. *Large scale studies including community based cohorts are required to confirm this apparent benefit*[i,ii]. (Health gain notation – 2 *"likely to be beneficial"*)	**i.** Pellock JM, Hunt PA. A decade of modern epilepsy therapy in institutionalized mentally retarded patients. *Epilepsy Research* 1996; **25(3)**: 263-8 (Type IV evidence - prospective cohort study of 244 institutionalised patients) **ii.** Mirza WU, Credeur LJ, Penry JK. Results of antiepileptic drug reduction in patients with multiple handicaps and epilepsy. *Drug Investigation* 1993; **5(6)**: 320-26 (Type IV evidence – open prospective study of 44 institutionalised patients)
7.3f **Phenobarbitone** is no longer a drug of choice for people with intellectual disability. It can cause cognitive deficiency and serious behavioural disturbances[i]. (Health gain notation – 6 *"likely to be ineffective or harmful"*)	**i.** Alvarez N. Barbiturates in the treatment of epilepsy in people with intellectual disability. *Journal of Intellectual Disability Research* 1998; **42(S1)**: 16-23 (Type V evidence – expert opinion based on a review of experimental and observational studies, but no randomised controlled trials)

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The *statements*	The *evidence*
7.3g **Phenytoin** can not be recommended as a first line drug for treatment of epilepsy in people with intellectual disability due to its potentially severe adverse effects on the central nervous system[i]. (Health gain notation – 6 *"likely to be ineffective or harmful"*)	**i.** Iivanainen M. Phenytoin: effective but insidious therapy for epilepsy in people with intellectual disability. *Journal of Intellectual Disability Research* 1998; **42(S1)**: 24-31 (Type V evidence – expert opinion based on a review of experimental and observational studies)
7.3h. **Sodium Valproate** is a drug of **first choice** for a broad range of epileptic seizures in people with intellectual disability. These include: generalised tonic-clonic, tonic, clonic, atonic (drop attacks), myoclonic, absence and partial seizures with or without secondary generalisation[i]. (Health gain notation – 2 *"likely to be beneficial"*)	**i.** Friis ML. Valproate in the treatment of epilepsy in people with intellectual disability. *Journal of Intellectual Disability Research* 1998; **42(S1)**: 32-5 (Type V evidence – expert opinion based on a review of experimental and observational studies)
7.3i. **Carbamazepine** is a drug of **first choice** for a range of epileptic seizures in people with intellectual disability. These include partial seizures with or without secondary generalisation and generalised tonic-clonic seizures[i]. (Health gain notation – 3 *"trade-off between beneficial and adverse effects"*) **CARBAMAZEPINE MAY MAKE ABSENCE, MYOCLONIC AND ATONIC (DROP ATTACKS) SEIZURES WORSE**[i].	**i.** Waisburg H, Alvarez N. Carbamazepine in the treatment of epilepsy in people with intellectual disability. *Journal of Intellectual Disability Research* 1998; **42(S1)**: 36-40 (Type V evidence – expert opinion based on a review of experimental and observational studies)
7.3j. **Oxcarbazepine** is similar to Carbamazepine in its indication, but has fewer adverse effects. It is useful in the treatment of epilepsy in people with intellectual disability including partial seizures with or without secondary generalisation and generalised tonic-clonic seizures[i]. (Health gain notation – 2 *"likely to be beneficial"*)	**i.** Gaily E, Granström M-L, Liukkonen E. Oxcarbazepine in the treatment of epilepsy in children and adolescents with intellectual disability. *Journal of Intellectual Disability Research* 1998; **42(S1)**: 41-5 (Type III evidence – open-label non-controlled (non-randomised) prospective study of 40 children and adolescents with intellectual disability, with a mean follow-up of 18.8 months)
7.3k. **Lamotrigine** is an effective broad-spectrum antiepileptic treatment with minimal adverse effects in people with intellectual disability. It is effective in generalised tonic-clonic, partial seizures with or without secondary generalisation, Lennox-Gastaut and West Syndrome[i]. (Health gain notation – 2 *"likely to be beneficial"*)	**i.** Besag FMC. Lamotrigine in the treatment of epilepsy in people with intellectual disability. *Journal of Intellectual Disability Research* 1998; **42(S1)**: 50-6 (Type V evidence – expert opinion based on a review of experimental and observational studies)

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The *statements*

7.3l. Vigabatrin[i], Gabapentin[ii], Topiramate[iii] and **Tiagabine[iv]** are effective as add-on therapies in the treatment of partial seizures in people with intellectual disability.
(Health gain notation – 2 *"likely to be beneficial"*)

Vigabatrin is effective in the treatment of infantile spasms[i].
(Health gain notation – 3 *"trade off between beneficial and adverse effects"*)

THERE IS EVIDENCE OF AN ASSOCIATION BETWEEN VIGABATRIN AND VISUAL FIELD DEFECTS (BILATERAL VISUAL FIELD CONSTRICTION)[i]. IT IS SOMETIMES ASYMPTOMATIC. ONE STUDY FOUND A DEFINITE BILATERAL FIELD DEFECT IN 39% OF PATIENTS, WHICH PERSISTED AFTER TREATMENT WAS WITHDRAWN[v].

The *evidence*

i. Ylinen A. Antiepileptic efficacy of vigabatrin in people with severe epilepsy and intellectual disability. *Journal of Intellectual Disability Research* 1998; **42(S1)**: 46-9
(Type III evidence – evaluation study in a group of patients with refractory epilepsy; 36 patients with intellectual disability and 75 patients with normal intelligence)

ii. Mikati MA, Choueri R, Khurana DS, Riviello J, Helmers S, Holmes G. Gabapentin in the treatment of refractory partial epilepsy in children with intellectual disability. *Journal of Intellectual Disability Research* 1998; **42(S1)**: 57-62
(Type III evidence - non-randomised trial of 26 children and adolescents with intellectual disability and 6 with normal intelligence, all suffering from refractory partial seizures)

iii. Kerr MP. Topiramate: uses in people with an intellectual disability who have epilepsy. *Journal of Intellectual Disability Research* 1998; **42(S1)**: 74-9
(Type V evidence – expert opinion based on a review of experimental and observational studies)

iv. Kälviäinen R. Tiagabine: a new therapeutic option for people with intellectual disability and partial epilepsy. *Journal of Intellectual Disability Research* 1998; **42(S1)**: 63-7
(Type V evidence – expert opinion based on a review of experimental and observational studies)

v. Lawden MC, Eke T, Degg C, Harding GFA, Wild JM. Visual field defects associated with vigabatrin therapy. *Journal of Neurology, Neurosurgery and Psychiatry* 1999; **67**: 716-722
(Type IV evidence – prevalence study of visual defects in 33 patients with epilepsy taking vigabatrin (31 assessed) and 16 unexposed control patients with epilepsy)

7.3m. Zonisamide is effective in the treatment of partial and generalised seizures in people with intellectual disability[i].
(Health gain notation – 2 *"likely to be beneficial"*)

NOTE: ZONISAMIDE IS NOT CURRENTLY LICENSED IN THE UK

i. Iinuma K, Minami T, Cho K, Kajii N, Tachi N. Long-term effects of zonisamide in the treatment of epilepsy in children with intellectual disability. *Journal of Intellectual Disability Research* 1998; **42(S1)**: 68-73
(Type III evidence - non-randomised controlled trial of 115 children with epilepsy (66 with intellectual disability and 49 with normal intelligence))

This document is a supplement to, not a substitute for, professional skills and experience. Users are advised to consult the supporting evidence for a consideration of all the implications of a recommendation.

The *statements*	The *evidence*
7.3n. **Benzodiazepines** including clobazam, nitrazepam and clonazepam can be used as short-term adjuncts in the treatment of epilepsy in people with intellectual disability[i]. Long term use of benzodiazepines is not recommended due to the effects on tolerance and symptoms associated with withdrawal[i]. (Health gain notation – 3 *"trade off between beneficial and adverse effects"*)	**i.** Isojärvi JIT, Tokola RA. Benzodiazepines in the treatment of epilepsy in people with intellectual disability. *Journal of Intellectual Disability Research* 1998; **42(S1)**: 80-92 (Type V evidence – expert opinion based on a review of experimental and observational studies)
7.3o. Intranasal and buccal spray of **Midazolam** may have significant advantages over rectal diazepam as a rescue medication for prolonged recurrent seizures or seizures associated with hypoxia in people with intellectual disability[i,ii,iii]. **Intranasal midazolam** is as effective as **intravenous diazepam** in the treatment of prolonged febrile seizures in children[ii]. **Buccal midazolam** is at least as effective as **rectal diazepam** in the acute treatment of children and adolescents[iii]. (Health gain notation – 2 *"likely to be beneficial"*)	**i.** Scheepers M, Scheepers B, Clough P. Midazolam via the intranasal route: an effective rescue medication for severe epilepsy in adults with a learning disability. *Seizure* 1998; **7**: 509-12 (Type IV evidence – case studies of 3 patients with epilepsy) **ii.** Lahat E, Goldman M, Barr J. Bistritzer T, Berkovitch M. Comparison of intranasal midazolam with intravenous diazepam for treating febrile seizures in children: prospective randomised study. *British Medical Journal* 2000; **321**: 83-86 http://www.bmj.com/cgi/content/full/321/7253/83 [accessed 8.12.00] (Type II evidence – randomised controlled trial (intranasal midazolam or intravenous diazepam) of 47 children, aged 6 months to 5 years, with prolonged febrile seizures) **iii.** Scott RC, Besag FMC, Neville BGR. Buccal midazolam and rectal diazepam for treatment of prolonged seizures in childhood and adolescence: a randomised trial. *Lancet* 1999; **353**: 623-626 (Type II evidence – randomised controlled trial of young people, aged 5-19, treated with buccal midazolam (40 episodes in 14 patients) or rectal diazepam (39 episodes in 14 patients))
7.3p. A substantial proportion of epileptic patients with an intellectual disability improve following **neurosurgery** with some becoming totally seizure free[i]. (Health gain notation – 2 *"likely to be beneficial"*)	**i.** Henriksen O, Bjørnaes H, Røste GK. Epilepsy surgery in metal retardation: the role of surgery. In Sillanpää M, Gram L, Johannessen SI, Tomson T (eds.) *Epilepsy and Mental Retardation.* Philadelphia:Wrightson Biomedical Publishing Ltd, 1999. pp. 105-113 (Type V evidence – expert review of the literature – no randomised controlled trials reported)

8 DEMENTIA IN DOWN SYNDROME

This document is a supplement to, not a substitute for, professional skills and experience. Users are advised to consult the supporting evidence for a consideration of all the implications of a recommendation.

The *statements*	The *evidence*
8.1 Background	
8.1a. The quoted **prevalences of dementia** in people with Down syndrome are: 0-4% under 30 years of age; 2-33% for 30-39 years of age; 8-55% for 40-49 years of age; 20-55% for 50-59 years of age; 29-75% for 60-69 years of age[i].	**i.** Zigman W, Schupf N, Haveman M, *et al.* The epidemiology of Alzheimer disease in mental retardation: results and recommendations from an international conference *Journal of Intellectual Disability Research.* 1997; **41(1)**: 76-80 (Type V evidence – expert review of 14 studies)
8.1b. Between 31% and 78.5% of adults 65 years or older with intellectual disability but without Down syndrome show **Alzheimer's neuropathology**[i,ii,iii].	**i.** Barcikowska M, Silverman W, Zigman W, *et al.* Alzheimer-type neuropathology and clinical symptoms of dementia in mentally retarded people without Down syndrome. *American Journal of Mental Retardation* 1989; **93(5)**: 551-7 (Type IV evidence - post-mortem findings of 70 people aged over 65, with intellectual disability but without Down syndrome) **ii.** Cole G, Neal JW, Fraser WI, Cowie VA. Autopsy findings in patients with mental handicap. *Journal of Intellectual Disability Research* 1994; **38**: 9-26 (Type IV evidence – observational autopsy study of people with intellectual disability – 15 Down syndrome and 18 non-Down syndrome) **iii.** Popovich ER, Wisniewski HM, Barcikowska M, *et al.* Alzheimer neuropathology in non-Down's syndrome mentally retarded adults. *Acta Neuropathologica* 1990; **80**: 362-367 (Type IV evidence – observational autopsy study of 385 non-Down syndrome people with intellectual disability)
8.1c. Almost all adults over the age of 40 years with Down syndrome display **Alzheimer's neuropathology**[i].	**i.** Mann DMA. Alzheimer's disease and Down's syndrome. *Histopathology* 1988; **13**: 125-137 (Type IV evidence – review of case-reports including 398 cases altogether)

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The *statements*	The *evidence*
8.1d. Among people with intellectual disability, the only known risk factors for the development of **Alzheimer's disease** are increasing age and Down syndrome[i,ii]. It is not clear what effect, if any, possible risk factors as seen in the general population – family history, low educational level, head trauma, cardio-vascular disease, stroke, diabetes, apolipoprotein E-4, major depressive episode – have on dementia in people with Down syndrome[i,ii,iii,iv].	**i.** Zigman W, Schupf N, Haveman M, *et al*. The epidemiology of Alzheimer disease in mental retardation: results and recommendations from an international conference. *Journal of Intellectual Disability Research* 1997; **41(1)**: 76-80 (Type V evidence – expert review of 14 studies) **ii.** Tsolaki M, Fountoulakis K, Chantzi E, *et al*. Risk factors for clinically diagnosed Alzheimer's disease: a case-control study of a Greek population. *International Psychogeriatrics* 1997; **9(3)**: 327-41 (Type III evidence - case-control study of 65 patients with Alzheimer's disease and 69 age-matched controls) **iii.** Deb S, Braganza J, Norton N, *et al*. Apoliprotein E e4 allele influences the manifestation of Alzheimer's disease in adults with Down's syndrome. *British Journal of Psychiatry* 2000; **176**: 468-472 (Type IV evidence – case-control study of the ApoE genotypes among 24 adults with dementia and 33 non-demented adults with Down syndrome, aged 35 or over, and an additional group of 164 non-intellectually disabled adults. Also a meta-analysis of 9 studies) **iv.** Rubinsztein DC, Hon J, Stevens F, *et al*. ApoE genotypes and risk of dementia in Down syndrome. *American Journal of Medical Genetics* 1999; **88(14)**: 344-347 (Type IV evidence – case-control study of the ApoE genotypes among 20 demented and 25 non-demented adults with Down syndrome. Also a meta-analysis of 6 studies)

8.2 Assessment

8.2a. The **diagnosis of dementia** in people with intellectual disability, especially in the early stages, is made difficult by the lack of reliable and standardised criteria and diagnostic procedures. Neuropsychological tests[i] and informant-based questionnaires such as the Dementia Questionnaire for Persons with Mental Retardation[ii] need further evaluation before they could be accepted for day-to-day clinical assessment[iii]. (Health gain notation – 4 *"unknown"*)	**i.** Aylward EH, Burt DB, Thorpe LU, Lai F, Dalton A. Diagnosis of dementia in individuals with intellectual disability. *Journal of Intellectual Disability Research* 1997; **41(2)**: 152-64 (Type V evidence – expert opinion based on a review of observational studies) **ii.** Evenhuis HM. Further evaluation of the Dementia Questionnaire for Persons with Mental Retardation (DMR). *Journal of Intellectual Disability Research* 1996; **40(4)**: 369-73 (Type IV evidence – 5 year longitudinal follow-up of 33 elderly institutionalised persons (aged 70 and over) and 45 institutionalised persons with Down syndrome (aged 35 and over) with no dementia in the diagnosis at initial evaluation) **iii.** Deb S, Braganza J. Comparison of rating scales for the diagnosis of dementia in adults with Down's syndrome. *Journal of Intellectual Disability Research* 1999; **43(5)**: 400-7 (Type IV evidence – a study of the Clinician's diagnosis (ICD-10), the Dementia Questionnaire for Persons with Mental Retardation (DMR), the Dementia Scale for Down Syndrome (DSDS) and the Mini Mental State Examination (MMSE) in 62 adults with Down syndrome – 26 demented and 36 non-demented according to clinician's diagnosis)

9 STAFF TRAINING

This document is a supplement to, not a substitute for, professional skills and experience. Users are advised to consult the supporting evidence for a consideration of all the implications of a recommendation.

The *statements*

9a. **Staff** are supporting clients with a range of challenging behaviours, including **aggression**[i,ii,iii] and **sexually inappropriate behaviour**[iv] in community settings, and such staff are likely to be the victims of **assault**.

The *evidence*

i. Harris, P. The nature and extent of aggressive behaviour amongst people with learning difficulties (mental handicap) in a single health district. *Journal of Intellectual Disability Research* 1993; **37**: 221-42
(Type IV evidence - survey of the prevalence rates different categories of challenging behaviour including: aggression, self-injury, stereotyped and withdrawal behaviours. Study covered one health district and included 78 services. Based on base population data available, the overall prevalence rate of aggression was estimated at 17.6%)

ii. Department of Health. *Services for People with Learning Disabilities and Challenging Behaviours or Mental Health Needs. Report of the Project Group.* London: HMSO, 1993
(Type V evidence - expert committee analysis of the approaches of a number of services, service commissioners and providers to challenging behaviour, with a recommendation that models of care should centre around community based residences)

iii. McKenzie K, Simpson F, Matheson E, *et al.* Challenging experiences. *Learning Disability Practice* 2000; **2(3)**: 8-11
(Type IV evidence - survey covering three geographical areas and including 53 social care and 40 health staff working in intellectual disability services, and control group (n=30) who did not. Study found 73% of former group had experienced workplace assault, compared with 7% of the latter group)

iv. McKenzie K, Matheson E, McKaskie K, *et al.* Health and social care staff responses to working with people with a learning disability who display sexual offending type behaviours. *Journal of Sexual Aggression* 2000; (In Press)
(Type IV evidence - survey of 81 social care staff and 15 health staff. The latter group were employed to provide medium security accommodation to sex offenders. 59% of the former group supported a client who had committed a sexual offence or displayed an offending type behaviour. The range of behaviours was similar to that displayed by clients supported by the former group)

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The *statements*	The *evidence*
9b. Well **trained and skilled staff** are identified as essential in the provision of quality community services[i,ii,iii,iv,v].	**i.** Scottish Executive. *The Same as You: A Review of Services for People with Learning Disabilities.* Edinburgh: Scottish Executive, 2000 http://www.scotland.gov.uk/ldsr/docs/tsay-00.asp [accessed 8.12.00] (Type V evidence - policy document based on expert opinion, consultation exercises, workshops and commissioned research. Concluded there is a need to develop a Scottish Centre to provide and promote staff training) **ii.** Department of Health. *Services for People with Learning Disabilities and Challenging Behaviours or Mental Health Needs*. Report of the Project Group. London: HMSO, 1993 (Type V evidence - expert committee analysis of the approaches of a number of services, service commissioners and providers to challenging behaviour, identifying the factors required for good quality challenging behaviour services) **iii.** Department of Health and Social Security. *Better Services for the Mentally Handicapped.* London: HMSO, 1971 (Type V evidence - early policy document based on expert opinion, identifying staff skills and training as central to community care provision) **iv.** Social Services Inspectorate. *Training for Community Care- A Strategy.* London: Department of Health, 1990 (Type V evidence - strategy document based on expert opinion) **v.** Mittler PJ. Staff development: changing needs and service context in Britain in Hogg J, Mittler P. (eds.) *Staff Training in Mental Handicap.* London: Croom Helm, 1987 (Type V evidence - expert opinion based on overview of staff and service development issues)
9c. Both health and social care staff have been found to be **lacking knowledge** about the basic defining features of an intellectual disability[i,ii] and their duty of care to intervene if clients put themselves or others at risk[iii,iv].	**i.** McKenzie K, Murray GC, Higgon J & Matheson E. What is a learning disability? - Do people need to be reminded. *Learning Disability Practice* 1999: **2(1)**: 8-11 (Type IV evidence - survey of 163 health and social care staff which found all groups had low levels of knowledge about the criteria for a intellectual disability) **ii.** McKenzie K, Murray GC, Matheson E. Learning disability services - a survey of general practitioners opinion. *Scottish Medicine* 1999: **17(5)**: 4-6 (Type IV evidence - survey of 34 General practitioners which found they had low levels of knowledge about the criteria of a intellectual disability) **iii.** Brown H, Hunt N, Stein J. Alarming but very necessary: Working with staff groups around the sexual abuse of adults with learning disabilities. *Journal of Intellectual Disability Research* 1994: **38(4)**: 393-412 (Type IV evidence - survey of 83 staff regarding knowledge of sexual abuse issues. It was found that staff were uncertain about their roles and responsibilities and that sexual abuse was dealt with haphazardly) **iv.** Lyall I, Holland A, Collins S. Offending by adults with learning disabilities and the attitudes of staff to offending behaviour. *Journal of Intellectual Disability Research* 1995: **39(6)**: 22-31 (Type IV evidence - survey of residential and day care provision in the Cambridge Health District which found the tolerance of some dangerous and antisocial behaviour of clients was high)

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The *statements*	The *evidence*
9d. Staff have been found to be **lacking knowledge, training** and **confidence** in managing challenging behaviour and sexually inappropriate behaviour[i,ii,iii,iv,v].	**i.** Hastings RP, Remington B. Staff behaviour and its implications for people with learning disabilities and challenging behaviours. *British Journal of Clinical Psychology* 1994; **33**: 423-38 (Type III evidence - review of observational and experimental studies: staff behaviour maintains challenging behaviours by negative or positive reinforcement). **ii.** Bromley J, Emerson E. Beliefs and emotional reactions of care staff working with people with challenging behaviour. *Journal of Intellectual Disability Research* 1995; **39**: 341-52 (Type IV evidence - survey of 70 staff supporting clients with an intellectual disability. Staff reported colleagues often reacted inappropriately to displays of challenging behaviour e.g. by showing fear and disgust) **iii.** McKenzie K, McIntyre S, Matheson, Murray GC. Health and social care workers' understanding of the meaning and management of challenging behaviour in learning disability services. *Journal of Learning Disabilities for Nursing, Health And Social Care* 1999; **3(2)**: 98-105 (Type IV evidence: questionnaire examining the knowledge of 95 health and social care staff working in intellectual disability services about the factors important in managing challenging behaviour). **iv.** Murray GC, McKenzie K, Quigley A, Sinclair B. The relationship between training and the experience of aggression in the work-place in social care staff working in learning disability services. *Journal of Learning Disabilities for Nursing, Health and Social Care* 2000; **3(4)**: 214-218 (Type IV evidence - survey of 50 social care staff. The minority had received training in prevention and management and levels of confidence varied widely) **v.** McKenzie K, Matheson E, McKaskie K, *et al*. Health and social care staff responses to working with people with a learning disability who display sexual offending type behaviours. *Journal of Sexual Aggression* 2000; (In Press) (Type IV evidence - randomised controlled survey of 81 social care and 15 health staff supporting clients with a forensic or sexual offence background. Few had received formal training in dealing with prevention and management of offending type behaviour)
9e. **Staff behaviour** has been shown to effect the occurrence or non-occurrence of challenging behaviour[i,ii,iii].	**i.** Hastings RP, Remington B. Staff behaviour and its implications for people with learning disabilities and challenging behaviours. *British Journal of Clinical Psychology* 1994; **33**: 423-38 (Type III evidence - review of observational and experimental studies. Staff behaviour maintains challenging behaviours by negative or positive reinforcement and implicating the role of social interaction as a maintaining factor) **ii.** Hastings RP. Staff strategies and explanations for intervening with challenging behaviours. *Journal of Intellectual Disability Research* 1996; 40(2): 166-75 (Type IV evidence - cohort study examining staff (n=109) descriptions of their reactions to a challenging behaviour scenario) **iii.** Donnellan A, La Vigna G, Shoultz N, Fassbender L. *Progress Without Punishment.* London: Teachers College Press, 1988 (Type V evidence - expert opinion outlining constructive, non-aversive approaches to challenging behaviour based on case studies, clinical experience and the implementation of psychological principles)

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The *statements*	The *evidence*
9f. **Training** may range from time-limited formal and informal training courses[i,ii,iii] to ongoing input[iv].	**i.** Care Sector Consortium. *National Occupational Standards for Care.* London: HMSO, 1992 (Type V evidence - example of formal National Vocational Qualifications (NVQs) for staff working in intellectual disability services) **ii.** McVilly KR. Residential staff: How they view their training and professional support. *British Journal of Learning Disabilities* 1997; **25**: 18-25 (Type IV evidence - review of some formal training courses available to staff working with clients with an intellectual disability) **iii.** McKenzie K, Matheson E, Patrick S, *et al.* An evaluation of the impact of a one-day challenging behaviour course on the knowledge of health and social care staff working in learning disability services. *Journal of Intellectual Disabilities* 2000; **4(2)**: 153-165 (Type II evidence - randomised control study: the impact of a one day training course on the knowledge of 59 health and social care staff, compared to a control group of 73 untrained staff) **iv.** Taylor I, O'Reilly M, Lancioni G. An evaluation of an ongoing consultation model to train teachers to treat challenging behaviour. *International Journal of Disability, Development and Education* 1996; **43(3)**: 203-18 (Type III evidence - interventional study evaluating the impact of a psychologist providing continuing advice to staff working with a client who exhibited high rates of self-injury)
9g. A substantial number of staff have not received **training**[i,ii] or report that it is inadequate to meet the needs of their job[ii].	**i.** Smith B, Wun W-L, Cumella S. Training for staff caring for people with learning disability. *British Journal of Learning Disabilities* 1996; **24**: 20-5 (Type IV evidence - survey of 299 staff in six health districts in the West Midlands. 12% of managers and 17% of care staff had received induction training: 75% of care staff in private establishments, 32% of local authority care staff, 17% of voluntary sector care staff and 4% of health care staff had not attended any courses in the previous five years) **ii.** McVilly KR. Residential staff: How they view their training and professional support. *British Journal of Learning Disabilities* 1997; **25**: 18-25 (Type IV evidence - review of formal training courses available to staff working with clients with an intellectual disability. Both staff and managers of social care services felt that the training that they had received was inadequate in relation to that required for their job)

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The *statements*	The *evidence*
9h. Some **training** has been found to be effective in increasing staff **knowledge**[i,ii] and impacting on **practice**[iii,iv]. (Health gain notation – 2 *"likely to be beneficial"*)	**i.** McKenzie K, Matheson E, Patrick S, *et al.* An evaluation of the impact of a one-day challenging behaviour course on the knowledge of health and social care staff working in learning disability services. *Journal of Learning Disabilities* 2000; **4(2)**: 153-165 (Type II evidence - randomised control study examining the impact of a one day training course on the knowledge of 59 health and social care staff, compared with a control group of 73 untrained staff. Training was found to significantly increase knowledge for up to one year) **ii.** Berryman J, Evans IM, Kalbag A. The effects of training in non-aversive behaviour management on the attitudes & understanding of direct care staff. *Journal of Behaviour Therapy and Experimental Psychiatry* 1994; **25(3)**: 241-50 (Type III evidence - intervention study of the impact of two types of training on staff (n=83) attitudes and knowledge. Those trained in non-aversive techniques showed increased understanding of complexity of causes for challenging behaviour and skills based treatment approaches) **iii.** Allen D, McDonald L, Dunn C, Doyle T. Changing care staff approaches to the prevention and management of aggressive behaviour in a residential treatment unit for persons with mental retardation & challenging behaviour. *Research in Developmental Disabilities* 1997; **18(2)**: 101-12 (Type III evidence - intervention study over a 5 year period which found clinically significant changes in terms of reduction in use of restraint, medication and in rates of staff and client injury) **iv.** Taylor I, O'Reilly M, Lancioni G. An evaluation of an ongoing consultation model to train teachers to treat challenging behaviour. *International Journal of Disability, Development and Education* 1996; **43(3)**: 203-18 (Type III evidence - interventional study evaluating the impact of a psychologist giving ongoing consultation regarding functional assessment and adhering to behavioural principles to staff working with a client who exhibited high rates of self-injury. This led to a significant decrease in the client's behaviour.)
9i. **Training** has not always been found to be cost-effective[i] or to have long-term benefits[i,ii].	**i.** Ziarnik JP, Bernstein GS. A critical examination of the effect of inservice training on staff performance. *Mental Retardation* 1982; **20(3)**: 109-14 (Type V evidence - expert opinion based on a review of early literature in relation to effectiveness of staff training. Concludes that staff training alone is not an adequate solution to deficits in staff performance) **ii.** Cullen C. *A review of Some Important Issues in Research and Services for People with Learning Disabilities and Challenging Behaviour. 2000: Scottish Executive Review of Services for People with a Learning Disability.* Edinburgh: Scottish Executive, 2000 (Type V evidence - expert opinion based on a literature review, concluding that staff training alone is not a sufficiently powerful factor to achieve enduring change)

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The *statements*	The *evidence*
9j. **Evaluating** the effectiveness of staff training is difficult. The outcome of training can be effected by a number of factors; the social, organisational and political context that the staff work in[i] (e.g. if changes in staff attitudes, knowledge and behaviour are not supported in the work environment they are unlikely to be maintained over time); staff characteristics (e.g. experience, skills and knowledge)[ii]; the perceived quality, relevance and applicability of the training itself[ii].	**i.** Harper DJ. Evaluating a training package for staff working with people with learning disabilities prior to hospital closure. *The British Journal of Developmental Disabilities* 1994; **XL(1)**: 45-53 (Type V evidence - expert opinion based on a review of the literature) **ii.** Landesman-Dwyer S, Knowles M. Ecological analysis of staff training in residential settings. In Hogg J, Mittler P (eds.) *Staff Training in Mental Handicap.* London: Croon Helm, 1987 (Type V evidence - expert opinion, presentation of models for the relationship between staff characteristics and behaviour, and the relationship between the quality and relevance of training to the effects of that training)
9k. It is important to establish clearly the type and nature of the **training needs** of the service in question[i,ii] and to establish which goals the training is designed to meet and which outcome measures will be used to evaluate effectiveness. Five different types of outcome measures used in this field are outlined[ii]. **Subjective** i.e. what staff report about the usefulness, validity, and quality of the training; **Cognitive** i.e. knowledge gain; **Behavioural** i.e. the impact of training on behaviour; **Client centred** i.e. the impact on clients; and **Organisational** i.e. the impact on the work organisation.	**i.** Cullen C. *A review of Some Important Issues in Research and Services for People with Learning Disabilities and Challenging Behaviour. 2000: Scottish Executive Review of Services for People with a Learning Disability.* Edinburgh: Scottish Executive, 2000 (Type V evidence - expert opinion based on a literature review, presenting a model to identify staff deficits and monitor performance) **ii.** Ziarnik JP, Bernstein GS. A critical examination of the effect of inservice training on staff performance. *Mental Retardation* 1982; **20(3)**: 109-14 (Type V evidence - expert opinion based on a review of early literature)
9l. *There is currently **insufficient evidence** to unequivocally establish the effectiveness of staff training alone in improving staff practice in managing challenging behaviour.* (Health gain notation – 4 *"unknown"*)	

10 CARERS AND CARING

This document is a supplement to, not a substitute for, professional skills and experience. Users are advised to consult the supporting evidence for a consideration of all the implications of a recommendation.

The term *Carer* is taken to mean informal caregivers, rather than those providing care in the formal sector on an organised and paid basis.

The 'hard evidence' base for carers specifically in the area of intellectual disability is limited. However, it is clear that carers and the people they care for are individuals with a vast range of preferences and needs. Just as one carer may find caring a stressful experience, another may find it enriching and rewarding. It is difficult to draw conclusions concerning interventions that work. The main message from the many research publications is the need for flexibility, i.e. the service system (health, social services and voluntary) should be 'carer sensitive'. Health service providers should listen and respond to the expressed preferences of the people to whom they are providing services. A related chapter, covering the evidence for supporting carers in general, is available in the Healthy Living Bulletin (http://hebw.uwcm.ac.uk/healthyliving/chapter6.html, accessed 8.12.00).

The *statements*	The *evidence*
10.1 Epidemiology and Background	
10.1a. In the 1998 Welsh Health Survey, one in thirteen (7.5%) of adults reported that they were **carers** and one in ten of those cared for had intellectual disability[i].	**i.** *Welsh Health Survey* 1998. Cardiff: The National Assembly for Wales, 1999 http://www.wales.gov.uk/subihealth/topics-e.htm Health [accessed 8.12.00] (Type IV evidence – survey of 50,023 adults, 1 in every 45 adults in Wales, with a response rate of 63%)
10.2 Gain and Strain in Caregiving	
10.2a. Informal carers of learning disabled adults reported 40% more **limiting health disorders** than the general population, with **depression** almost four times more common among female carers (standard morbidity prevalence ratio for depression = 3.7, 95% CI, 2.4-5.7)[i].	**i.** McGrother CW, Hauck A, Bhaumik S, Thorp C, Taub N. Community care for adults with learning disability and their carers: Needs and outcomes from the Leicestershire register. *Journal of Intellectual Disability Research* 1996; **40(2)**: 183-190 (Type IV evidence – cross-sectional study, based on the Leicestershire Learning Disabilities Register, to describe the prevalence of disabilities, felt needs, and use of services for 2,117 learning disabled adults, and to compare outcomes of morbidity, stress, and satisfaction among 982 informal and residential carers)

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The *statements*	The *evidence*
10.2b. In a large Dutch study, the **significant predictors of caregiving burden** were time demands, child physical health, child adaption skills, (less) service use and parents (lower) educational level. Service needs of parents varied according to the age range of the child [i]. The major needs mentioned were: ■ Age 0-9: Information and help with developmental issues, medical/dietician/speech therapy advice, in-home respite; ■ Age 10-19: Information and help with development and future residential living, leisure activity and respite care, dental help; ■ Adults: Information and concrete help re future out-of-home placements, information and advice from physicians.	**i.** Haveman M, van Berkum G, Reijnders R, Heller T. Differences in service needs, time demands, and caregiving burden among parents of persons with mental retardation across the life cycle. *Family Relations*: *Interdisciplinary Journal of Applied Family Studies*. 1997; **46(4)**: 417-425 (Type IV evidence – population-based study in the Netherlands of 2,573 parents of children with intellectual disability living at home – A 77% response rate to the distribution of 3327 questionnaires)
10.2c. The presence of **significant behaviour problems** is more important than disability type in determining most forms of parental stress, and predicts mental health services use. Parents of children with intellectual disability worried most about providing ongoing care into adulthood. Single mothers were not more stressed but used more services than 2-parent families [i].	**i.** Floyd FJ, Gallagher EM. Parental stress, care demands, and use of support services for school-age children with disabilities and behavior problems. *Family Relations*: *Interdisciplinary Journal of Applied Family Studies.* 1997; **46(4)**: 359-371 (Type IV evidence – study, in the US, of mothers and fathers of 231 children (aged 6-18 years) with intellectual disability with (n=46) or without (n=46) behaviour problems, or chronic illness, and a nondisabled behavior-problems sample (n=66). No details were given as to how the sample was recruited)

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The *statements*	The *evidence*
10.2d. Caregivers report the existence of pervasive **rewards and gratifications,** as well as stresses, as part of the caregiving experience, and these stem from various sources[i,ii]. The collection of six **predictors of burden and satisfaction** findings indicate that greater support from the adult child to the caregiver resulted in greater satisfaction and less burden. Adaptive and maladaptive behaviours and caregiving assistance all predicted caregiving satisfaction but only maladaptive behaviours predicted caregiving burden. The study also found that increased levels of support by the caregiver to the adult with intellectual disability was associated with greater caregiving satisfaction[ii]. In contrast, another study found that neither help given, nor help received demonstrated significant effects on either positive well-being, negative well-being or subjective burden[iii].	**i.** Grant G, Ramcharan P, McGrath M, Notan M, Keady J. Rewards and gratifications among family caregivers: towards a refined model of caring and coping. *Journal of Intellectual Disability Research* 1998; **42(1)**; 58-71 (Type IV evidence – preliminary analysis of a qualitative study of 120 families supporting children and adults with intellectual disability in Wales) **ii.** Heller T, Miller AB, Factor A. Adults with mental retardation as supports to their parents: effects on parental caregiving appraisal. *Mental Retardation* 1997; **35(5)**: 338-346 (Type IV evidence – study by survey and interview of 80 primary caregivers of adult children, mean age 42 years, with intellectual disability in the United States) **iii.** Smith GC. Caregiving outcomes for older mothers of adults with mental retardation: A test of the two-factor model of psychological well-being. *Psychology & Aging* 1996; **11(2)**: 353-361 (Type IV evidence – test of a two-factor model of caregiving appraisal and psychological well-being, tested with 225 older mothers providing care at home to an offspring with intellectual disability in New York) (The above studies used volunteer rather than representative samples, and cross-sectional rather than longitudinal study designs. Studies ii and iii were based in the United States)
10.2e. The **marital status** of the caregiver, the **level of retardation**, **frequency of maladaptive behaviours**, and **health status** of the **adult** family member with mental retardation; and the number and level of **services** needed were factors in the stress experienced by families[i].	**i.** Hayden MF, Goldman J. Families of adults with mental retardation: Stress levels and need for services. *Social Work* 1996; **41(6)**: 657-667 (Type IV evidence – interview data from a convenience sample of 105 families of adults (aged 20+) with intellectual disability living in Minnesota, US)
10.2f. Parental responses indicate that caretakers of adult children with intellectual disability are worried and feel responsible for their care regardless of **residential placement.** There were no statistically significant differences between carers of adult children living in-home and out-of-home in terms of social burdens, gratifications (eg intimacy), emotional burdens or objective burdens[i].	**i.** McDermott S, Valentine D, Anderson D, Gallup D, Thompson S. Parents of adults with mental retardation living in-home and out-of-home: caregiving burdens and gratifications. *American Journal of Orthopsychiatry* 1997; **67(2)**: 323-329 (Type IV evidence – interviews with 95 volunteer families of adult children living at home (n=55) or out-of-home (n=44) in the US. The authors acknowledged that, due to the study's cross-sectional design, it was not possible to determine if the individuals in out-of-home placements had been more burdensome to their parents prior to placement compared to those in the in-home group)

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The *statements*	The *evidence*
10.3 Support and Respite Care **10.3a.** The leading **unmet needs** reported by informal carers were for financial help, long-term social support, respite care and housing adaptations[i].	**i.** McGrother CW, Hauck A, Bhaumik S, *et al*. Community care for adults with learning disability and their carers: Needs and outcomes from the Leicestershire register. *Journal of Intellectual Disability Research* 1996; **40(2)**: 183-190 (Type IV evidence – cross-sectional study based on the Leicestershire Learning Disabilities Register to describe the prevalence of disabilities, felt needs, and use of services for 2,117 learning disabled adults, and to compare outcomes of morbidity, stress, and satisfaction among 982 informal and residential carers)
10.3b. **Younger caregivers** are more predisposed toward seeking outside help and have higher expectations of the service system than older caregivers. Overall there were no differences in the number of support services received. However, younger caregivers reported significantly more unmet service needs and rated significantly more of them as a critical or an emergency need. Older caregivers were more likely to seek spiritual support and the younger caregivers more apt to mobilize their families to acquire and accept help[i].	**i.** Hayden MF, Heller T. Support, problem-solving/coping ability, and personal burden of younger and older caregivers of adults with mental retardation. *Mental Retardation* 1997; **35(5)**: 364-372 (Type IV evidence – interview data from a convenience sample of 105 families of adults (aged 20+) with intellectual disability living in Minnesota, US)
10.3c. From a longitudinal study of **older mothers caring** for an adult with intellectual disability, the authors made the following conclusions[i]: ■ support groups were not beneficial although some groups may provide a forum for social contact and information exchange ■ mothers whose friendship networks were composed largely of close friends who were also coping with a relative with disabilities, reported greater increases in burden than those with more diverse networks ■ mothers who were pessimistic about their son's or daughter's future had increasing levels of burden and depressive symptoms over time. Service providers could encourage these parents to make arrangements to help them reduce their fears and pessimism	**i.** Greenberg JS, Seltzer MM, Krauss MW, Kim H-W. The differential effects of social support on the psychological well-being of aging mothers of adults with mental illness or mental retardation. *Family Relations: Interdisciplinary Journal of Applied Family Studies*. 1997; **46(4)**: 383-394 (Type IV evidence – longitudinal study, over three years, of volunteer mothers (aged 55 years and older) of adults with mental illness (n=73) or intellectual disability (n=288) living in the US)

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The *statements*	The *evidence*
10.3d. Interview data showed that **support services** for adult offspring were positively received by parents in the way they interrupted, what would otherwise be, a continuous cycle of care. However, for some parents the nature of the provision was such that support services heightened rather than moderated their sense of living a restricted lifestyle. The authors noted that the challenge for service providers and planners is to find innovative responses to these parents by allowing a greater flexibility of provision. The paradox is that, greater support could lead to an increased demand for residential provision, as parents sought to emulate their non-carer peers[i,ii].	**i.** Todd S, Shearn J. Time and the person: The impact of support services on the lives of parents of adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* 1996; **9(1)**: 40-60 (Type IV evidence – data from qualitative, in-depth interviews of 33 parents (aged 43-75 years) of co-resident adult offspring with intellectual disability. Of 40 randomly selected families in South Wales, 28 agreed to participate) **ii.** Todd S, Shearn J. Struggles with time: The careers of parents with adult sons and daughters with learning disabilities. *Disability & Society* 1996; **11(3)**: 379-401 (Type IV evidence – as above)
10.3e. From a systematic review of the literature, the major recommendations to **support** informal carers of people with **intellectual disability and challenging behaviour** were that[i]: ■ stress management techniques were effective for use both routinely and at times of high arousal ■ respite care services which genuinely provide respite and are able to offer support both on a planned and crisis basis are valuable ■ information should be provided (eg regarding the child's disability, challenging behaviour, support services and welfare benefits) (Health gain notation – 2 *"likely to be beneficial"*)	**i.** Allen, D. Mediator analysis: An overview of recent research on carers supporting people with intellectual disability and challenging behaviour. *Journal of Intellectual Disability Research* 1999; **43(4)**: 325-339 (Type IV evidence – descriptive systematic review (using PsychLIT, Medline and reference list follow-up))

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The *statements*	The *evidence*
10.3f. Community Support Teams (CST) for people with **intellectual disability and challenging behaviour** report that they serve the majority of their clients (at least two thirds) with some degree of success. However, from an analysis of recent cases, the majority of cases successfully closed were closed due to such factors as the acceptance of recommendations or the person being referred on to another service after the completion of assessment rather than reduction in challenging behaviour (which accounted for only 36% of closures)[i]. *It was recommended that, due to the potential bias of positive reporting from Teams, the actual rather than reported outcomes of CST cases should also be examined*[i]. One small study in the UK suggested that carers were satisfied with the **Adult Learning Disability Community Support Team (CST)**. The most popular response was that a mild improvement in the referred problem (38%) or in life-quality (48%) had resulted from the referral. Areas of improvement suggested by carers included the provision of more information regarding the team's role and more written information for referred cases[ii]. (Health gain notation – 4 *"unknown"*)	**i.** Emerson E, Forrest J, Cambridge P, Mansell J. Community support teams for people with learning disabilities and challenging behaviours: Results of a national survey. *Journal of Mental Health* 1996; **5(4)**: 395-406 (Type IV evidence – A survey of 65 community support teams in England and Wales, 71% useable responses) **ii.** Witts P, Gibson KB. Satisfaction with an Adult Learning Disability Community Support Team. *Journal of Applied Research in Intellectual Disabilities* 1997; **10(1)**: 41-47 (Type IV evidence – questionnaire study including 48 carers in an urban industrial community in the UK, 73% response rate)
10.3g. A three year study found that **adults with intellectual disability** were more likely to **move away** from the parental home if their mothers were older and in poorer health. Following the move to out-of-home, 93.6% of the sample had a least weekly contact with the mother and 48.4% of mothers continued to provide help with at least one caregiving task[i].	**i.** Seltzer MM, Greenberg JS, Krauss MW, Hong J. Predictors and outcomes of the end of co-resident caregiving in aging families of adults with mental retardation or mental illness. *Family Relations: Interdisciplinary Journal of Applied Family Studies*. 1997; **46(1)**: 13-22 (Type IV evidence – prospective study of aging mothers living with an adult child with either intellectual disabilites (n=308) or mental illness (n=73) to determine the antecedents and consequences of the end of co-residence. This was a US study using a volunteer rather than a representative sample)

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The *statements*	The *evidence*
10.3h. A review of **respite services** for people with intellectual disability concluded that, although quantifiable results from research studies are limited, expressed satisfaction with respite and felt relief are sufficient criteria to justify the need. However it is generally considered that respite can influence the quality of life of carers (and users of the services) in both negative and positive ways. To provide a benefit, services must be flexible and responsive to users so that they feel confidence in the care provided[i]. (Health gain notation – 4 *"unknown"*)	**i.** Cotterill L, Hayes L, Flynn M, Sloper P. Reviewing respite services: some lessons from the literature. *Disability and Society* 1997; **12(5)**: 775-88 (Type V evidence - expert summary from a non-systematic review of the literature)
10.3i. In a questionnaire study of families of children with an intellectual disability, **respite care** was generally preceived as an inadequate service, although 88% of respondents had no knowledge of the existence of respite-care services[i]. Mothers found a **pilot summer respite scheme** for children with intellectual disability (aged 6-18 years) very useful and expressed felt needs for substantially more such provision both during the summer and at other times[ii]. (Health gain notation – 4 *"unknown"*)	**i.** Treneman M, Corkery A, Dowdney L, Hammond J. Respite-care needs – met and unmet: assessment of needs for children with disability. *Developmental Medicine and Child Neurology* 1997; **39(8)**: 548-553 (Type IV evidence – questionnaire study of 634 families of children with a learning and/or physical disability in South London, UK. 49% response rate) **ii.** McGill P. Summer holiday respite provision for the families of children and young people with learning disabilities. *Child: Care, Health & Development* 1996; **22(3)**: 203-212 (Type IV evidence – results of interviews with mothers of 18 children who attended the scheme in the Medway, UK)

This document is a supplement to, not a substitute for, professional skills and experience. Users are advised to consult the supporting evidence for a consideration of all the implications of a recommendation.

The *statements*

10.3j. *A **review of research approaches and service design** for people with intellectual disability and their carers noted the following research gaps in the literature[i]:*

- *A dearth of longitudinal studies and therefore deficits in evidence about caring and adaptation over the life course, over the course of disability, and how carers manage service transitions*
- *A failure to fully involve carers and families in setting the research agenda*
- *A concentration on the perspectives of mothers and caregiving dyads (eg mother-child, carer-professional) to the exclusion of the broader family relationships*
- *The lack of a balanced examination of stress, uplift and effective coping in families (ie considering both the strain and gain of caregiving)*
- *A failure to include both user and carer views in research. The chances of obtaining the views of people with intellectual disability (including profound disability) should be maximised, for example via generation of research questions by users and differing communication techniques. Improved outcomes for carers should be accompanied by gains for their dependents.*

The *evidence*

i. Grant G, Ramcharan P. *Views and Experiences of Users and Carers:* A Research Review. University of Sheffield: Department of Health Learning Disability Research Initiative, 1999
(Type IV evidence – descriptive systematic review of the literature)

This document is a supplement to, not a substitute for, professional skills and experience. Users are advised to consult the supporting evidence for a consideration of all the implications of a recommendation.

The *statements*

The *evidence*

10.4 Carers Entitlements

10.4a. The **Carers (Recognition and Services) Act 1995** gives people who provide or intend to provide "a substantial amount of care on a regular basis" the right to request an assessment from social services[i]. The implementation of this Act is patchy [ii,iii]. Carers are not always informed of their rights (53% in one survey) [ii] and many Social Services staff are unclear about entitlement and lack relevant training [iii]. Assessments are not always carried out. Some carers are offered very sensitive and practical support, others almost nothing. However, when assessments are undertaken, carers report satisfaction both with the process and the results [ii,iii]. Carers should be entitled to expect at least an annual discussion of what they need, what is available, the help they are receiving and the care provided [iv].

i. *Carers (Recognition and Services Act)* 1995 (c.12)
(Type V evidence – influential report)

ii. Carers National Association. *Still battling? The Carers Act One Year On.* London: CNA, 1997
(Type IV evidence – a questionnaire survey (1655 replies) from 12,000 members of the Carers National Association) and 50 follow-up interviews)

iii. Fruin D. Social Services Inspectorate. *A Matter of Chance for Carers? Inspection of Local Authority Support for Carers.* London: Department of Health Social Care Group, 1998. CI(98)19
http://www.doh.gov.uk/scg/chance.htm [accessed 8.12.00]
(Type IV evidence – report of an inspection of 7 social services departments in England during 1997/8 using interviews & focus group techniques with users/staff and case file reviews)

iv. *"The National Strategy for Carers"* London: Department of Health, 1999
http://www.doh.gov.uk/carers.htm [accessed 8.12.00]
(Type V evidence – influential report)

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