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Systematic Reviews of the Health or Healthcare of People with Intellectual Disabilities:

A Systematic Review to Identify Gaps in the Evidence Base

Abstract

Background. Systematic reviews are important in evaluating evidence concerning the health of people with intellectual disabilities. This paper conducts a systematic review of systematic reviews to identify strengths and gaps in this evidence.

Method. Electronic literature searches and email requests identified systematic reviews published in English from 2008 to 2013 on the health or healthcare of people with intellectual disabilities. Reviews were categorised using ICD-10 chapter headings and information extracted regarding methods, number of studies reviewed and findings.

Results. Ninety-four reviews were identified. Fifty-two related to ICD-10 Chapter V: Mental or behavioural disorders, 28 to Chapter XXI: Factors influencing health status and contact with services, and 14 related to other chapters or encompassed multiple chapters. Nine reviews were 'empty'. No reviews were found for many ICD-10 chapter headings.

Conclusions. Systematic reviews are heavily weighted towards mental health, with little coverage of several areas important to the health and mortality of people with intellectual disabilities.

Introduction

People with intellectual disabilities have poorer health than their non-disabled peers, differences in health status that are, to a significant extent, avoidable (Emerson and Hatton, 2014, Ouellette-Kuntz, 2005, NHS Health Scotland, 2004, Krahn et al., 2006, US Department Health & Human Services., 2002, Van Schrojenstein Lantman-de Valk, 2005, O'Hara et al., 2010). Responding to these health inequalities is a critically important issue for primary and secondary healthcare services (US Department of Health & Human Services, 2002, Emerson *et al.*, 2012, Emerson and Hatton, 2014, Disability Rights Commission, 2006, Michael, 2008) and demands action on several fronts. This includes building a more robust evidence-base of the scale and determinants of health inequalities and the effectiveness of interventions to reduce the health inequalities experienced by people with intellectual disabilities. For example, existing clinical guidelines relating to areas of health inequality for people with intellectual disabilities rarely contain content relevant to people with intellectual disabilities (Mizen et al., 2012), an omission at least in part due to under-investment in high quality research on the health of people with intellectual disabilities.

Systematic reviews are becoming increasingly important in evaluating evidence concerning the health of people with intellectual disabilities. The aim of this paper is to provide an overview of systematic reviews published from 2008 to 2013 on the health or healthcare of people with intellectual disabilities and to identify gaps and strengths in the coverage of these reviews. Reviews are categorised using Chapter Headings from the International Statistical Classification of Diseases and Related Health Problems Tenth Revision (ICD-10) (World Health Organization, 2010) as this is an internationally recognised system for classifying health related conditions and has been used recently to categorise the main causes of death of people with intellectual disabilities in England (Heslop *et al.*, 2013). The paper aims to identify ICD-10 categories where systematic reviews have good coverage and to identify categories where there are currently gaps in the evidence base. This review also aims to provide information on the extent of the underlying research evidence base on topics addressed by identified reviews, by summarising specific aspects of reviews (this information is presented via tables). The paper also aims to compare the ICD-10 categories which have been the focus of the reviews identified with those categories which have been found to be important in relation to mortality in people with intellectual disabilities to determine the degree of congruence between the published evidence base and the major causes of death of people with intellectual disabilities. For example, the Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) reviewed 247 deaths of people with intellectual disabilities that occurred over a two year period in five areas of South West England (Heslop *et al.*, 2013). Underlying causes and immediate causes of death were grouped by ICD-10 categories. The most common underlying causes of death were: heart and circulatory disorders (21%); cancer (20%); nervous system (16%); respiratory disorders (15%); congenital and chromosomal (7%); digestive system (5%); external causes (4%); endocrine, nutritional and metabolic (3%); and mental and behavioural disorders (2%).

The review has been done to help inform future research on the health or healthcare of people with intellectual disabilities. With limited resources available, it is important that future work is directed towards priority areas and that attempts are made to avoid duplication of effort in relation to both primary research and systematic reviews (Chalmers *et al.*, 2014).

Method

Electronic literature searches were performed by the first author in July 2013 using the following databases: Cochrane Library, Database of Abstracts of Reviews of Effects (DARE), Medline, Cumulative Index to Nursing and Allied Health Literature (Cinahl), Embase, PsycINFO, and Web of Science. Searches used word terms (and MeSH/index headings where possible) for 'intellectual disability' including terms identified in a study using 'Pearl-Harvesting' methodology to identify a list of search keywords for intellectual disabilities (Sandieson et al., 2010). These were combined with terms for systematic reviews using 'and'. Searches were also conducted in specialist intellectual disability journals using systematic review terms only. Search terms are summarised below. Full details of the search strategy can be obtained from the first author.

Summary of Search Terms	
Intellectual disability word search terms	retard* OR "mental* disab*" OR "mild disab*" OR "moderate* disab*" OR "severe* disab*" OR "profound* disab*" OR "multipl* disab*" OR "intellectual* disab*" OR "developmental* disab*" OR "substantial* disab*" OR "cognitive disab*" OR "mild* handicap*" OR "moderate* handicap*" OR "severe* handicap*" OR "mental* handicap*" OR "multi* handicap*" OR "profound handicap*" OR "developmental* handicap*" OR "developmental* delay*" OR "delay* development" OR "mental* delay*" OR "intellectual* delay*" OR "mental* impair*" OR "intellectual* impair*" OR "cognitive impair*" OR “learning disab*” OR “intellectual development disorder”
MeSH/index headings	Cochrane/DARE: intellectual disability; mentally disabled persons; developmental disabilities. Cinahl/Medline: mental retardation; intellectual disability; developmental disabilities; mentally disabled persons. PsycINFO: intellectual development disorder
Systematic review word search terms	“systematic* review*” OR “meta*analys*”

Searches were designed to identify any systematic reviews relating to people with intellectual disabilities and reviews related to health or healthcare selected from these. This approach was taken in preference to attempting to employ specific 'health' search terms as this would have involved a vast number of search terms. In addition to database searches, email requests for information on relevant reviews were sent in July 2013 to the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) Health Special Interest Research Group and the Intellectual Disability Research United Kingdom (UK) Network. These sources identified an initial pool of 205 references. The full list of 205 references can be obtained from the first author. The following inclusion and exclusion criteria were then applied to the 205 candidate references by two independent reviewers (the first and second author) based on abstracts, or from full text if insufficient information was available in the abstract. The two reviewers discussed any uncertainty regarding inclusion or exclusion of articles until consensus was reached.

Inclusion and Exclusion Criteria

The inclusion criteria were: published in English Language; peer reviewed; publication date (or assessed as up to date for Cochrane reviews) from 2008 to 2013; systematic review or review adopting rigorous method for identification of literature including multiple search terms and the use of more than one electronic literature database; population of interest people with intellectual disabilities; and relates directly to health or health care. If reviews included people without intellectual disabilities, reviews were included if: results for people with intellectual disabilities were presented separately; people with intellectual disabilities constituted 50% or more of the overall sample; or the review identified no eligible studies. As the intention was to provide a broad overview of systematic reviews relating to health or healthcare, the exclusion criteria were brief: studies focusing on autism or relatively rare conditions associated with intellectual disabilities; and studies focusing on measurement instruments related to health.

Data Extraction & Analysis

For those articles meeting the inclusion and exclusion criteria, data were extracted and entered into an Excel spreadsheet by the first author in relation to the following: authors, year of publication, ICD-10 chapter heading, specific topic (e.g. dementia), focus (e.g. prevalence, pharmacological treatment, assessment or diagnosis), date range covered by searches, language limits for searches (e.g. only covering articles in English language), geographical coverage of included articles, databases and other sources used for searches, inclusion and exclusion criteria, quality assessment method, review process in relation to independent reviewers, method of analysis, number of studies included, total (range and median) number of participants in included studies (calculated using IBM SPSS 20 software), main findings, conclusion, and type of review (Cochrane, DARE, or other). ICD-10 Chapter Headings were ascertained by entering the main topic of each review into the search facility for the ICD-10 Online (see http://apps.who.int/classifications/icd10/browse/2010/en).

Review Process Assessment

The following review process measure was devised based on the Cochrane Handbook definition of systematic review and a systematic review quality assessment tool (Shea et al., 2007). Reviews were scored '1' for each of the following giving a possible score range of 0-3:

1. Searches include one supplementary strategy in addition to electronic searches and reference searching (i.e. contact with experts, contact with pharmaceutical companies).
2. Study selection and/or data extraction performed by two or more independent reviewers.
3. Assessment of quality of included studies was performed and a quality rating allocated, and reported, for each study (i.e. not an overall summary of quality).

The process score does not constitute a thorough assessment of review quality (for example it does not account for use of appropriate meta-analysis versus narrative review) but gives an indication in relation to specific elements of the review procedure. It should be noted that this is based on information reported in papers and where information has not been identified in the methodology section this is scored as ‘0’ with no attempt being made to clarify processes with review authors. No studies were excluded on the basis of these scores, with all exclusions taking place during the initial application of the inclusion and exclusion criteria. Process scores are included in the tabulation of studies in Tables 2, 3 and 4. Cochrane reviews are indicated by an asterix (‘*’) after the process score.

Results

Overview of Reviews Identified

Following application of the inclusion and exclusion criteria by two independent reviewers, a total of 94 reviews remained of which 19 were Cochrane reviews. Of these, over half (52) related to ICD-10 Chapter V: Mental and Behavioural Disorders, 28 to Chapter XXI: Factors Influencing Health Status and Contact with Services, and 14 related to other chapters or covered multiple chapter headings.

Languages Covered

The vast majority of reviews were restricted to studies published in the English language. Reviews which specifically mentioned methodologies for the potential inclusion of additional languages included the following: translation into English if required (Beavis et al., 2007a, Beavis et al., 2007b); inclusion criteria of English abstract but any language full text (Unwin and Deb, 2011, Deb et al., 2008, Einfeld et al., 2011); searches of Latin American and Caribbean Health Science Literature (LI-LACS) carried out in Spanish and Portugese, and Scandinavian databases searched using appropriate languages (Montgomery et al., 2008, Mayo-Wilson et al., 2008b, Mayo-Wilson et al., 2008a); potential inclusion of studies in Dutch and German (Courtenay et al., 2010, de Winter et al., 2011, Haveman et al., 2010, Strydom, 2010); Dutch (van de Wouw et al., 2012); Chinese (Chan et al., 2010); French (Cleaver et al., 2009); and Portugese, Spanish, French or German (Molina et al., 2011). However, it is not possible to comment on the extent to which reviews actually included studies published in languages other than English.

Geographical Coverage

In relation to geographical coverage, over half of the reviews did not present information on the countries in which included studies were undertaken. Where information on countries was given, the studies most commonly came from Europe (particularly the UK), North America or Australia.

Less commonly, studies were found in high income countries in Asia such as Hong Kong and Japan. Only seven reviews clearly identified studies relating to low- or middle-income countries. A small number of reviews identified studies from South Africa (Ali et al., 2012, Einfeld et al., 2011, Humphries et al., 2009, Oeseburg et al., 2011). Other low- and middle-income countries included were: India, Pakistan and Vietnam (Ali et al., 2012); China, Mexico and Nigeria (Anders and Davis, 2010); Chile and China (McGillivray et al., 2013); and Brazil (Willis et al., 2008a). As noted in a review of health risks associated with age, there was almost a total lack of information about persons with intellectual disability in low- and middle-income countries (Haveman et al., 2010). This lack of information on low- and middle-income countries appears to be apparent across almost the entire range of reviews on the health or healthcare of people with intellectual disabilities.

‘Empty’ Reviews

Nine reviews, all of which were Cochrane reviews, found no eligible studies for inclusion. These are summarised in Table 1. Of these nine ‘empty reviews’, five were concerned with pharmacological interventions in relation to mental and behavioural disorders (Duggan and Brylewski, 2004, Mohan et al., 2009c, Mohan et al., 2009a, Mohan et al., 2009b, Thomson et al., 2009b). One was concerned with RCTs of both pharmacological and non-pharmacological interventions for sex offenders with intellectual disability (Ashman and Duggan, 2008). Two were related to ICD-10 Chapter XXI: Factors influencing health status and contact with health services. One looked at studies on the effectiveness of smart home technologies as an intervention for people with physical disability, cognitive impairment or intellectual disability, who are living at home (Martin et al., 2008) and one the effectiveness of personal assistance for children and adolescents (age 0 to 18 years) with both physical and intellectual impairments (Mayo-Wilson et al., 2008b). One review was related to Chapter VI: Diseases of the nervous system which found one ongoing randomised controlled trial (RCT) in relation to non-pharmacological interventions for epilepsy (Beavis et al., 2007a).

Table One Here:

Summary of reviews identifying no eligible studies (all are Cochrane reviews)

Non-Empty Reviews

The remaining 85 reviews are summarised in Table 2 (ICD-10 Chapter V: Mental and Behavioural Disorders), Table 3 (Chap XXI: Factors influencing health status and contact with health services) and Table 4 (Other ICD-10 chapter headings). These tables present information on authors, date of publication, topic, date range covered, inclusion criteria in relation to study designs, number of studies included, total number (range and median) of participants in samples (presented separately for control groups or comparison groups where these exist), process score, and main findings and conclusions (see end of Table 4 for a list of all acronyms used). It is important to note that no attempt has been made to critically appraise the reviews with a view to commenting on or altering the reported main findings and conclusions.

Due to the high number of reviews identified for Chapter V: Mental and Behavioural Disorders, these have been tabulated in three sections in Table 2. Section I includes reviews relating to pharmacological interventions; Section II non-pharmacological interventions; and Section III ‘other’ reviews. Similarly, due to the large number of reviews identified for Chapter XXI: Factors influencing health status and contact with health services, these have been presented in two broad sections: Section I includes reviews relating to health or related services, and Section II reviews related to health status or factors influencing health status (see Table 3). Reviews are listed in each section in chronological order from the most recent.

ICD-10 Chapter V: Mental & Behavioural Disorders

In total, 46 reviews with sufficient data covered topics within ICD-10 Chapter V: Mental & Behavioural Disorders: 10 reviews concerning pharmacological interventions (Table 2 Section I), 23 reviews concerning non-pharmacological interventions (Table 2 Section II) and 13 reviews concerning mixed interventions or other issues related to mental & behavioural disorders (Table 2 Section III).

Chapter V Mental & Behavioural Disorders Section I: Pharmacological interventions

Ten reviews were concerned with the efficacy of pharmacological interventions in relation to mental and behavioural disorders in people with intellectual disability. These include three Cochrane reviews: pharmacological interventions for self-injurious behaviour (Rana et al., 2013); donepezil for Alzheimer's dementia (AD) in people with Down's syndrome (Mohan et al., 2009d); and amphetamine for attention-deficit hyperactivity disorder (ADHD) (Thomson et al., 2009a). Other reviews considered: atypical antipsychotics for behaviour problems in children with intellectual disability or borderline intelligence (Unwin and Deb, 2011); clozapine for behaviour problems (Singh et al., 2010); melatonin for sleep problems (Braam et al., 2009); mood stabilizers and antiepileptic medication for behaviour problems in adults (Deb et al., 2008); pharmacological treatment of bipolar disorder in children and adolescents (Gutkovich and Carlson, 2008); pharmacological management of inappropriate sexual behaviours (Sajith et al., 2008); and somatic treatment of psychiatric and behavioural problems, including psychotropic medication and electroconvulsive therapy (Ulzen and Powers, 2008). These reviews are summarised in Table 2 Section I.

The majority of these reviews conclude that there is insufficient or poor quality evidence on effectiveness on which to base practice, and therefore a need for further trials. It has been noted that prescribing is based on extrapolation from research in people without intellectual disability (Thomson et al., 2009a). The two exceptions to this were: 'some evidence' for the use of ri~~e~~speridone to manage behaviour problems in children and adolescents with the caveat that these should be used with caution due to possible adverse events (Unwin and Deb, 2011); and results of a meta-analysis indicating that melatonin is effective and safe for treating sleep problems with the caveat that long term effects are not known and the drug is non-licensed in most countries (Braam et al., 2009).

Table 2 Section I Here:

ICD-10 Chapter V Mental and Behavioural Disorders: Pharmacological interventions

Chapter V Mental & Behavioural Disorders Section II: Non-pharmacological interventions

Twenty three reviews considered non-pharmacological interventions for mental and behavioural disorders which are categorised here as psychological, behavioural, or 'other' (see Table 2 Section II). However, these categories are not entirely mutually exclusive, for example one review notes that there is some evidence that psychological interventions can reduce challenging behaviour and that they are most effective when linked to functional behaviour analysis (Campbell et al., 2014). Only one Cochrane review was identified in this section and this looked at behavioural and cognitive-behavioural interventions for aggression (Hassiotis and Hall, 2009).

Eight reviews considered psychological interventions for people with intellectual disability: any psychological interventions for challenging behaviour (Campbell et al., 2014); psychologically based anger management for adults living in the community (Borsay, 2013); mindfulness training for people with intellectual disability or family/paid carers (Chapman et al., 2013); anger management in adults (Hamelin et al., 2013); mindfulness for behaviour problems (Harper et al., 2013); mindfulness for behavioural or psychological problems (Hwang and Kearney, 2013); cognitive behavioural therapy (CBT) for anger (Nicoll et al., 2013); and any psychological therapies (Vereenooghe and Langdon, 2013).

The majority of these reviews present some positive study findings for the interventions but overall conclusions are limited by methodological weaknesses in the included studies. However, one review and meta-analysis of CBT for anger concludes that the findings indicate at least a medium treatment effect (Nicoll et al., 2013) and a review and meta-analysis of psychological therapies indicated that it was efficacious with a moderate effect size (Vereenooghe and Langdon, 2013). Finally, one review notes that, whilst there is limited research meeting stringent standards of empirical evidence, there is some evidence that psychological interventions can reduce challenging behaviour and that they are most effective when linked to functional behaviour analysis (Campbell et al., 2014).

Eight reviews consider behavioural interventions. These reviews tend to be based predominantly on single-participant research using designs such as multiple baseline, alternating treatments and reversal. These reviews have looked at: types of motivating operations in interventions for problem behaviour with school age children (Simó-Pinatella et al., 2013); behavioural interventions for aggression (Brosnan and Healy, 2011); differential reinforcement to manage problem behaviour in adults (Chowdhury and Benson, 2011); behavioural interventions for rumination and operant vomiting (Lang et al., 2011); behavioural treatment of chronic skin picking (Lang et al., 2010); non-contingent reinforcement for problem behaviour (Carr et al., 2009); behavioural treatment of elopement (Lang et al., 2009a); and behavioural treatment for self-injurious behaviour (Prangnell, 2010).

In all but one of these reviews, all or the majority of the studies included reported positive improvements following behavioural interventions, with for example 80% of studies reporting positive outcomes (Lang et al., 2009a) or improvements in behaviour being reported in all studies (Lang et al., 2010) although in some cases, as noted in the latter study, evidence is limited due to a paucity of studies. The one exception was a review on behavioural interventions for self-injurious behaviour which found that efficacy was highly variable (Prangnell, 2010).

Finally, there were seven ‘other’ reviews of non-pharmacological interventions, of which one was the Cochrane review investigating both behavioural and cognitive-behavioural interventions for aggression (Hassiotis and Hall, 2009). In addition, reviews considered: the role of engagement in meaningful occupation in reducing challenging behaviour (Ball and Fazil, 2013); varied intervention programs to treat behavioural problems in children (Petrenko, 2013); effectiveness of augmentative and alternative communication (AAC) on challenging behaviour (Walker and Snell, 2013); effectiveness of massage therapy on relaxation and challenging behaviour (Chan and Tse, 2011); effect of multisensory therapy on challenging, stereotypic and positive behaviour (Chan et al., 2010); and effectiveness of multisensory therapy (Snoezelen) in relation to behaviour (Lotan and Gold, 2009).

For these reviews, whilst some positive outcomes were noted, most of the reviews were inconclusive due to a paucity of studies and small numbers of participants, or due to methodological weaknesses of the included studies. The one exception is the review of AAC which suggests that whilst the quality of studies is somewhat limited, AAC intervention has positive effects in decreasing challenging behaviour for people with varying disabilities (predominantly intellectual disability). Overall, there is a call for more rigorous research to evaluate these interventions.

Table 2 Section II Here:

Chapter V Mental & Behavioural Disorders: Non-pharmacological interventions

Chapter V Mental & Behavioural Disorders Section III: Other & Mixed Pharmacological/Non-pharmacological intervention reviews

Thirteen reviews either included a mixture of non-pharmacological and pharmacological interventions or addressed other issues relevant to mental and behavioural disorders such as prevalence (see Table 2 Section III). Those focussing on varied interventions were: a meta-analysis of single-case and small-n research on interventions for reducing challenging behaviour (Heyvaert et al., 2012); non-pharmacological (social-psychological) and pharmacological interventions for people with intellectual disability affected by dementia and their carers (Courtenay et al., 2010); a meta-analysis of biological, psychotherapeutic and contextual interventions for challenging behaviour (Heyvaert et al., 2010); and interventions for bruxism (teeth clenching or teeth grinding) (Lang et al., 2009b).

Other reviews considered interventions within the context of wider scope reviews including information on, for example, prevalence. These included: prevalence, factors associated with and treatment of sleep problems in adults (van de Wouw et al., 2012); assessment, prevalence and treatment of post-traumatic stress disorder (PTSD) (Mevissen and de Jongh, 2010); and assessment, diagnosis and management of personality disorder (Pridding and Procter, 2008).

For reviews considering interventions, some reviews concluded that there was insufficient research evidence available relating to interventions including: interventions related to dementia (Courtenay et al., 2010); bruxism, although it is noted that some treatments are promising (Lang et al., 2009b); and personality disorder (Pridding and Procter, 2008). Other reviews suggest that there is some evidence for interventions although not necessarily based on RCTs. Case reports suggest positive treatment effects for various treatments for PTSD although studies on pharmacological treatments are lacking (Mevissen and de Jongh, 2010). Whilst there is some evidence that interventions (mainly based on behavioural or environmental improvement) are beneficial in treating sleep problems, research has mainly focused on subjectively derived data (van de Wouw et al., 2012). One meta-analysis of various interventions for challenging behaviour found an overall large to medium positive effect size with no significant difference for mean effects of biological (most commonly atypical antipsychotics), psychotherapeutic and contextual interventions (Heyvaert et al., 2010). However, a meta-analysis of single case and small-n research found evidence endorsing the positive effects of psychotherapeutic and contextual intervention components, but no evidence for an overall positive effect of pharmacological interventions (Heyvaert et al., 2012).

A number of reviews looked at issues related to mental and behavioural disorders without consideration of interventions. These included: the relationship between anxiety and challenging behaviour (Pruijssers et al., 2014); the prevalence of psychiatric disorders in adults (Buckles et al., 2013); determining physical conditions that may be associated with challenging behaviour (de Winter et al., 2011); the prevalence of mental disorders in children or adolescents and factors associated with prevalence (Einfeld et al., 2011); the clinical presentation of schizophrenia in people with mild or borderline intellectual disability compared to those with average or high IQ (Welch et al., 2011); and the epidemiology, presentation and diagnosis of dementia (Strydom, 2010).

Table 2 Section III Here:

Chapter V Mental & Behavioural Disorders: Other & Mixed Pharmacological/Non-pharmacological intervention reviews

ICD-10 Chapter XXI; Factors influencing health status or contact with health services

In total, 23 reviews with sufficient data covered topics within ICD-10 Chapter XXI; Factors influencing health status or contact with health services: 10 reviews concerning contact with services (Table 3 Section I) and 16 reviews concerning factors influencing health status (Table 3 Section II).

Chapter XXI Factors Influencing Health Status or Contact with Health Services Section I: Contact with Services

Ten reviews considered contact with health or related services. Of these, three were Cochrane reviews which addressed: organisational interventions aimed at improving the care of mental and physical health problems of adults with intellectual disability (Balogh et al., 2008); the effectiveness of personal assistance for adults with both physical and intellectual impairments (Mayo-Wilson et al., 2008a); and the effectiveness of personal assistance for children and adolescents with intellectual impairments (Montgomery et al., 2008). Of the remaining reviews, three considered aspects of hospital care: influences on the health, safety and welfare of adults with intellectual disabilities in acute hospitals (Bradbury-Jones et al., 2013); factors influencing and interventions improving general hospital care (Phillips, 2012); and experiences of secondary healthcare for people with intellectual disability (Backer et al., 2009). Other topics addressed were: ethnic variation in uptake of mental health services by people with intellectual disability in high income countries (Durà-Vilà and Hodes, 2012); the impact of health checks for people with intellectual disability (Robertson et al., 2011); outcomes (including health and related risk factors, mortality, mental health, and behaviour) in different residential settings for people with intellectual disability (Kozma et al., 2009); and evidence relating to informed consent and assessment of mental capacity to healthcare interventions for people with intellectual disability (Goldsmith et al., 2008).

With the exception of the Cochrane reviews, which as would be expected focus on RCT-type studies of a specific intervention, the reviews in this section cover a wide range of studies including both quantitative and qualitative studies. Even though broad inclusion criteria were used in the reviews, only two reviews reported on a substantial number of studies. Firstly, in relation to the international evidence on the impact of checking the health of people with intellectual disabilities, 38 studies were identified and overall it was concluded that health checks are effective in identifying unrecognised health needs, including life threatening conditions (Robertson et al., 2011). Secondly, 68 studies were identified relating to outcomes in different residential settings for people with intellectual disability and it was concluded that small-scale residential settings are superior to large, congregate options in most domains studied (Kozma et al., 2009).

Table 3 Section I Here:

Chapter XXI Factors Influencing Health Status and Contact with Health Services: Contact with Health Services

Chapter XXI Factors Influencing Health Status and Contact with Services Section II: Factors Influencing Health Status

Sixteen reviews were included in this section (see Table 3 Section II). Of these, two were Cochrane reviews, one looking at the effectiveness of treadmill interventions on locomotor development in children and infants under 6 years of age at risk of neuromotor delay (Valentin-Gudiol et al., 2011), and one on aerobic exercise training programmes for physiological and psychosocial outcomes in adults with Down's syndrome (Andriolo et al., 2010). A number of other reviews also considered physical therapy or exercise interventions, with specific topics being: effects of exercise training interventions on percent body fat (Casey and Rasmussen, 2013); benefits of exercise intervention on the fitness of people with Down's syndrome (Li et al., 2013); meta-analysis of the effects of exercise programs (Shin and Park, 2012); effectiveness of physical activity interventions (Bartlo and Klein, 2011); motivational correlates that contribute to and may be effects of participation in sport, recreation, or health-related physical activity (Hutzler and Korsensky, 2010); and the effectiveness of treadmill training and body weight support in pediatric rehabilitation including studies based on samples of children with Down's syndrome (Damiano and DeJong, 2009).

These reviews suggest that physical exercise interventions can improve muscular strength and balance (Li et al., 2013, Bartlo and Klein, 2011) and may also have some benefit in relation to psychosocial outcomes such as self-esteem (Hutzler and Korsensky, 2010) or quality of life (Bartlo and Klein, 2011). Evidence of an effect in reducing body fat composition is inconclusive (Casey and Rasmussen, 2013, Li et al., 2013, Shin and Park, 2012). Two reviews looking at treadmill training in pediatric rehabilitation support its efficacy in promoting independent walking (Valentin-Gudiol et al., 2011, Damiano and DeJong, 2009).

A number of reviews looked at health promotion interventions more broadly. Topics addressed were: main characteristics of health promotion intervention studies (Naaldenberg et al., 2013); feasibility, appropriateness, meaningfulness and effectiveness (FAME) of interventions for tobacco or alcohol use in people with mild or moderate intellectual disability (Kerr et al., 2013); evidence for physical activity and nutrition health promotion interventions (Heller et al., 2011); and non-surgical and non-pharmacological interventions to promote weight loss (Jinks et al., 2011). Generally, the evidence base is reported to be insufficient or lacking rigorous studies, with a call for theoretically driven health promotion studies (Naaldenberg et al., 2013, Kerr et al., 2013).

Finally, reviews in this section have covered: incidence and prevalence of mobility limitations in adults (Cleaver et al., 2009); nutritional status of adults with intellectual or developmental disabilities (Humphries et al., 2009); parental and parenting risk factors associated with obesity in children and adolescents (McGillivray et al., 2013); and experiences of and impact of self-stigma in people with intellectual disability and courtesy stigma in family carers (Ali et al., 2012). Overall, conclusions were noted to be limited due to a lack of methodological quality of research, although it is concluded that significant nutrition related risks exist for adults with intellectual or developmental disabilities including poor diet, elevated rates of over- or underweight, significant CVD risk factors and multiple limiting secondary conditions (Humphries et al., 2009).

Table 3 Section II Here:

Chapter XXI Factors influencing health status & contact with health services: Factors Influencing Health Status

Other ICD Chapter Heading & Multiple Chapter Heading Topics

Finally, 13 reviews were identified in relation either to other ICD-10 Chapters than V or XXI or included information relevant to multiple ICD-10 chapters (see Table 4). These are outlined below by ICD-10 chapter.

Chapter II Neoplasms

Two reviews were found, one looking at cervical cancer risks, frequency and screening (Sullivan et al., 2010) and one review, reported across two articles, looking at breast cancer screening and awareness (Willis et al., 2008a, Willis et al., 2008b). In both reviews, although evidence is limited, it is concluded that women with intellectual disability should be encouraged to attend screening.

Chapter VI Diseases of the Nervous System

Two reviews were found. A Cochrane review on pharmacological interventions for epilepsy broadly supports the use of antiepileptic drugs to reduce seizure frequency but was unable to comment of the relative efficacy of different medications (Beavis et al., 2007b). A review on the prevalence, reasons and implications of misdiagnosis of epilepsy and improving diagnosis highlighted a lack of research and the need to make families and those in services aware of the possibility of misdiagnosis (Chapman et al., 2011).

Chaper VII Diseases of the Eye & Adnexa

One review on the prevalence of ophthalmic abnormalities in children with Down’s syndrome was found (Creavin and Brown, 2009). This review found that conditions that are potentially detrimental to vision, such as cataract and glaucoma, are found in a significant minority reinforcing the need for early assessment and treatment of people with Down’s syndrome.

Chapter XI Diseases of the Digestive System

Three reviews were found. One looked at preventative and restorative treatment programmes for managing dental caries in disabled people (Molina et al., 2011). This review was unable to produce guidance on strategies for the prevention and treatment of dental caries in people with disabilities (including intellectual disability) and a call is made for more and higher quality research. On a related topic, one review compared the oral health status of people with intellectual disability to those without intellectual disability (Anders and Davis, 2010). It was concluded that people with intellectual disability are more likely to have poor oral hygiene and periodontal disease, and possibly more likely to have caries. Finally, one review looked at the symptoms of gastroesophageal reflux disease (GORD) in people with severe intellectual disability (de Veer et al., 2008). It is concluded that no single symptom is clearly related to GORD and carers should be alert to a wide range of symptoms.

Chapter XIII: Diseases of the Musculoskeletal System & Connective Tissue

One review was identified which investigated the prevalence of osteoporosis and osteopenia in people with intellectual disability (Srikanth et al., 2011). The majority of studies identified increased prevalence of osteoporosis & osteopenia with associated low bone mass density (BMD) and in most studies individuals with intellectual disability presented with more than two risk factors (e.g. reduced physical activity, increased exposure to antiepileptic or antipsychotic medication).

Chapter XX: External Causes of Morbidity & Mortality

One review on risk factors and preventive strategies for fall-related injuries was found (Willgoss et al., 2010). Whilst up to 57% of people with intellectual disabilities experienced a fall and falling was the cause of 50–62% of all recorded injuries, there was a paucity of evidence for intervention strategies identified.

Reviews Covering Multiple Chapter Headings

Three reviews covered topics which spanned multiple ICD-10 chapter headings. One investigated the prevalence of chronic health conditions in children with intellectual disability and found prevalence rates to be higher than those reported in studies of children without intellectual disability, although the number of studies and conditions covered by these studies were limited (Oeseburg et al., 2011). Two reviews considered age-related morbidity. One looked at age-associated health risk factors in aging persons with intellectual disability (Haveman et al., 2010). This review found cardiovascular disease (CVD) to be as prevalent and as common a cause of death as in the general population, a high occurrence of digestive problems such as GORD, and a growing body of research on health risk factors such as overweight and obesity. Finally, one review covered causes of mortality and age-related morbidity in people with Down's syndrome aged over 40 (Torr et al., 2010). This review concludes that functional decline in older adults with Down's syndrome cannot automatically be assumed to be due to dementia of the Alzheimer type, which is not inevitable, as there are very high rates of early onset-age related disorders, especially sensory impairments and musculoskeletal disorders.

Table 4 Here:

Other ICD Chapter Headings & Multiple Chapter Heading Reviews

Discussion

The primary aim of this review was to provide an overview of recent systematic reviews on the health or healthcare of people with intellectual disabilities and to identify gaps and strengths in the coverage of these reviews. The results indicate that the predominant focus of attention in the research literature regarding the health or healthcare of people with intellectual disabilities has been mental and behavioural disorders. There has also been some attention focussed on factors influencing health status and contact with health services. In relation to a number of physical conditions, very little or no systematic reviews were identified. No reviews were identified that specifically covered the following ICD-10 Chapters: I Certain infectious diseases and parasitic diseases; III Diseases of the blood and blood forming organs and certain disorders involving the immune mechanism; IV Endocrine, nutritional and metabolic diseases (although it could be argued that interventions related to body fat could be categorised here instead of under factors influencing health status); VIII Diseases of the ear and mastoid process; IX Diseases of the circulatory system; X Diseases of the respiratory system; XII diseases of the skin and subcutaneous tissue; XIV Diseases of the genitourinary system; XV Pregnancy birth and the puerperium; XVI Certain conditions originating in the perinatal period; XVII Congenital malformations, deformations and chromosomal abnormalities; XVIII Symptoms, signs and abnormal clinical and laboratory finding not elsewhere classified; and XIX Injury, poisoning and certain other consequences of external causes.

The paper also aimed to compare the ICD-10 categories which have been the focus of reviews with those found to be important in relation to mortality in people with intellectual disabilities. The balance of topics covered in the reviews does not reflect the most prevalent causes of death for people with intellectual disabilities (Glover and Ayub, 2010, Heslop *et al.*, 2013). The most common ICD-10 categories for underlying cause of death are poorly covered by existing systematic reviews, if at all. This mismatch between research and causes of death may partly reflect the professional dominance of psychiatry and psychology within specialist services for people with intellectual disabilities.

This review also aimed to provide an insight into the extent and quality of the underlying research evidence base on topics addressed by identified reviews. Most systematic reviews reported serious issues with the methodology of the studies they were reviewing, such that clear conclusions could not be drawn. The review also identified nine ‘empty’ reviews, all of which were Cochrane reviews. Generally regarded as the ‘gold standard’ for systematic reviews, Cochrane reviews tend to include only RCTs or other robust research designs and when using the stringent criteria for inclusion in Cochrane reviews, research relating to intellectual disabilities is lacking.

There are a number of potential reasons for this lack of robust research evidence concerning the health and healthcare of people with intellectual disabilities. First, people with intellectual disabilities are largely excluded from mainstream health and medical research. In a study of the inclusion of people with intellectual disabilities in medical research trials, only 6 (2%) of 300 randomly chosen studies clearly included people with intellectual disabilities (Feldman *et al.*, 2013). Over 90% of the studies were designed in ways that would automatically exclude people with intellectual disabilities from participating, whereas in at least 70% of the studies people with intellectual disabilities could have been included if simple accommodations or procedural modifications were made.

Second, there are challenging ethical and logistical problems when conducting RCTs with people with intellectual disabilities (Oliver-Africano *et al.*, 2010), for example when considering informed consent and when conducting intervention research with a distributed population across multiple sites where professional expertise and willingness to engage with people with intellectual disabilities is lacking.

Third, administrative datasets within mainstream health services often used for large-scale research rarely identify intellectual disability with the reliability and validity required. Similarly, general population health surveys rarely include people with intellectual disabilities in sufficient numbers to allow meaningful comparisons to be made (Emerson & Hatton, 2014).

Careful prioritisation of both research areas and accompanying research designs is required. For many health interventions (for example management of blood pressure or the effectiveness of chemotherapy for a particular type of cancer) it is likely that the research evidence for the general population will apply equally to people with intellectual disabilities. For these types of question, the research that is likely to be required concerns how these health interventions can be effectively delivered to people with intellectual disabilities, in terms of the adjustments required by health services to increase the chances of people with intellectual disabilities adhering to medication, diet and/or physical activity regimes, for example. Effective identification of people with intellectual disabilities within health service datasets will help to identify areas of inequality, and evaluative research to investigate the impact of adjustments on the health of people with intellectual disabilities will be required.

Limitations

This review presents a ‘snapshot’ of a specific time period and it may be possible to identify reviews on these topics that were published prior to 2008. There is also an inevitable time lag between conducting searches and publishing the results of this review so additional reviews are likely to have now been published, and indeed additional examples have been identified (Roy *et al.*, 2014, Hellenbach *et al.*, 2014). Further, there are also ongoing reviews which may address some of these gaps in evidence. A number of relevant Cochrane review protocols were identified: non-pharmaceutical management of respiratory morbidity in children with severe global developmental delay (Winfield *et al.*, 2013); clozapine for psychotic disorders in adults with intellectual disabilities (Paul and Ayub, 2013); and risperidone for disruptive behaviour disorders in children with intellectual disabilities (Bezuidenhout et al., 2012). A series of National Institute for Health Research (NIHR) rapid systematic reviews are also being carried out, including reviews on: diabetes in adults with intellectual disability; Ischaemic cardiovascular disease including hypercholesterolemia in adults with intellectual disability; sexual health in adults with intellectual disability; cancer screening in people with intellectual disabilities; and thyroid disorders (Strydom and Buszewicz, 2014). However, initial results suggest that for most conditions data on prevalence and associated factors are lacking.

Further, lack of an existing systematic review does not mean that there is therefore no research on a topic and indeed for some topics narrative reviews may exist which did not fulfil the criteria for inclusion in this review. For example, key contextual issues in cancer and intellectual disability have been covered in one review which did not meet the inclusion criteria (Hogg and Tuffrey-Wijne, 2008). Similarly, a report by the IASSIDD Special Interest Group on Aging (Haveman et al., 2009) includes information relating to pain and sensory impairment which is not included in the peer reviewed article included in this review (Haveman et al., 2010). A further source of information is a book which provides a review of physical and mental health co-morbidities in people with intellectual disability using the ICD-10 as a framework (O'Hara et al., 2010). Each of the 20 chapters consist of a review of evidence on ill health with searches including dates up to 2008, including topics such as respiratory diseases, obstetric and gynaecological disorders, eye diseases and visual impairment, mental illness, and three chapters related to diseases of the nervous system.

The findings of this review also have to be considered in light of two layers of quality. Firstly, there are few high quality studies included within the reviews, with most reviews pointing to a lack of credible research on the topic area reviewed. Secondly the quality of the reviews themselves varies, with some falling short of the methodological quality demonstrated by Cochrane reviews and indeed some do not purport to be 'systematic' reviews. As such, the findings reported here should be considered in relation to the identification of gaps in the research base regarding the health and healthcare of people with intellectual disabilities. The findings are not intended as a statement of, for example, the established efficacy of specific interventions. Such conclusions are beyond the scope of this paper, although the overall picture presented helps to identify directions and gaps of the research base.

One limitation of the review is that all data were extracted by one reviewer and extraction by two independent reviewers would reduce the possibility of error and bias. Summarising findings from reviews, particularly those with a wide scope, necessitates focusing on specific aspects of the findings and thus the information presented may represent bias on the part of the reviewer. Further, the conclusions and findings are as reported by the authors of the original reviews and there has been no attempt to critically appraise these. What authors consider acceptable evidence for the effectiveness of an intervention may differ markedly between reviews. Finally, it was not possible to scrutinise all studies included in reviews when extracting data and there is a possibility of double counting in the total number of participants if included studies have used the same samples.

Conclusions

The conclusions and recommendations arising from this review fall into two areas: the production of systematic reviews; and enhancing the evidence-base on the health and healthcare of people with intellectual disabilities.

The production of systematic reviews. The current imbalance in the topics addressed by reviews has led to important gaps and also duplication or near-duplication of effort, with multiple reviews addressing similar topics. Whilst it is important for further systematic reviews to be carried out, there is a case for greater co-ordination of efforts in order to redress this imbalance. There is also a lack of consistency in the methodological quality of existing systematic reviews. International identification of priorities for systematic reviews, with larger (and international) teams involved would help to increase the quality of reviews, reduce bias and create a clearer programme of work on systematic reviews. The co-ordination of reviews could also consider setting a minimum standard for the number and quality of studies that are likely to be included before undertaking them to avoid using scarce resources to create ‘empty’ reviews (Chalmers *et al.*, 2014).

Enhancing the evidence-base. In many areas, the methodological quality of studies included in the reviews is mainly not of sufficient methodological quality or quantity to allow clear conclusions to be drawn. Better targeting of research funding is needed to support research to enhance the underlying evidence-base regarding the health and healthcare of people with intellectual disabilities. Specifically, there is a need for a greater quantity and quality of research on making reasonable adjustments to make health interventions effective for people with intellectual disabilities across conditions. Greater clarity is also needed regarding when health research is needed in a topic that is specific to people with intellectual disabilities and how people with intellectual disabilities can be included and identified within general population health research. The identification of priorities should primarily be guided by general research priorities for intellectual disability. In relation to this, the World Health Organisation has addressed setting global research priorities for developmental disabilities, including intellectual disabilities and autism (Tomlinson *et al.*, 2014). Finally, from a public health perspective, there is a need to increase the volume and quality of research both on the health of adults with mild/moderate intellectual disabilities who are unlikely to be identified within administrative populations, and on populations of people with intellectual disabilities in low and middle income countries (Emerson & Hatton, 2014).

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Tables

Table 1: Summary of reviews identifying no eligible studies (all are Cochrane reviews)

Chapter V: Mental & Behavioural Disorders			
Author & Date	**Topic**	**Dates covered**	**Key inclusion & exclusion criteria**
Ashman & Duggan (2008)	Efficacy of interventions for sex offenders with intellectual disabilities (ID)	Varied start dates from 1887 to 2006	Inclusion: randomised controlled trials (RCTs); adult males or females with ID or borderline ID, either convicted of a sexual offence or with sexually offensive behaviour. Treated within the community, hospital or prison. Interventions to include cognitive behavioural therapy (CBT), behaviour therapy or pharmacological treatment.
Duggan & Brylewski (2004; updated 2012)	Antipsychotic medication for people with a dual diagnosis of ID & schizophrenia	Any start date to July 2012	Inclusion: RCTs, over 18 years of age with both ID & schizophrenia, any antipsychotic medication, regardless of dosage, but of one month’s duration, compared to placebo of at least one month's duration. Exclusion: diagnosis of 'psychosis'.
Mohan, Bennett & Carpenter (2009c)	Rivastigmine for Alzheimer’s dementia (AD) in people with Down’s syndrome (DS)	Start dates from 1872 to October 2008	Inclusion: RCTs (including cross-over studies) of participants with AD in DS in which treatment with rivastigmine was administered for more than a day & compared with a placebo group; any age, diagnosed with dementia using standardised instruments.
Mohan, Bennett & Carpenter (2009a)	Galantamine for AD in people with DS	Start dates from 1872 to October 2008	Inclusion: RCTs (including cross-over studies) of participants with AD in DS in which treatment with galantamine was administered for more than a day & compared with a placebo group; any age, diagnosed with dementia using standardised instruments.
Mohan, Bennett & Carpenter (2009b)	Memantine for AD in people with DS	Start dates from 1872 to October 2008	Inclusion: RCTs (including cross-over studies) of participants with AD in DS in which treatment with memantine was administered for more than a day & compared with a placebo group; any age, diagnosed with dementia using standardised instruments.
Thomson, Maltezos, Paliokosta et al (2009)	Risperidone for attention-deficit hyperactivity disorder (ADHD) in people with ID	Any start date to February 2009	All RCTs including cluster randomisation or a cross-over design, both published & unpublished, in any language, in which children or adults with ADHD & ID were treated with risperidone compared to placebo. Exclusion: participants with uncontrolled epilepsy, comorbid psychotic illness or a history of head injury.
Chapter VI Diseases of the nervous system			
Beavis, Kerr, Marson et al (2007a; updated 2011)	Non-pharmacological interventions for epilepsy in people with ID	1806 to 2010	Inclusion: RCTs; Quasi-RCTs with inadequate method of allocation concealment; blinded or unblinded; age 12 years & over with epilepsy & ID. Non-pharmacological interventions, including: surgical; specific diets; psychological interventions; yoga; acupuncture; types of relaxation therapy. Seizure related, behavioural, cognitive, quality of life (QOL), or adverse effects outcomes. Exclusion: studies specifically recruiting children under 12 years of age; infantile spasms; West syndrome.
Chapter XXI Factors influencing health status & contact with health services			
Martin, Kelly, Kernohan et al (2008)	Effectiveness of smart home technologies for people with physical disability, cognitive impairment or ID, who are living at home	Start dates from 1966 to March 2007	Inclusion: RCTs, quasi-experimental studies, controlled before & after studies (CBAs) & interrupted time series analyses (ITS); adults living in their home in a community setting; studies that included participants with a physical disability, dementia or ID; interventions - social alarms, electronic assistive devices, telecare social alert platforms, environmental control systems, automated home environments & ’ubiquitous’ homes. Exclusion: studies solely evaluating telemedicine applications.

Mayo-Wilson, Montgomery & Dennis (2008b)	Effectiveness of personal assistance for children & adolescents with both physical & intellectual impairments	1980 to June 2005	Inclusion: published or unpublished, RCTs, quasi-RCTs & nonrandomised controlled studies of personal assistance compared to other forms of support or to 'no-intervention' (which may include unpaid care); children & adolescents (0-18) living in the community who require assistance to perform tasks of daily living & to participate in normal activities due to permanent physical & intellectual impairments; defined personal assistance as individualised support for people living in the community by a paid assistant other than a healthcare professional for at least 20 hours per week, which is provided for an indefinite period of time. Exclusion: rehabilitation or respite care; young people living in institutions; physical impairments only & intellectual impairments only.

Table 2 Section I: ICD-10 Chapter V Mental and Behavioural Disorders: Pharmacological interventions

Author & date	Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	Number participants (range; Mdn)	Process Score	Main findings & Conclusions
Rana, Gormez & Varghese (2013)	Effectiveness of pharmacological interventions in management of self-injurious behaviour (SIB) in adults with ID	Any to 2011	RCTs, including individually randomised, cluster-randomised & cross-over trials	5	57 (4-33; 8), 50 excluding 7 participants in one study who did not exhibit SIB. Controls: n/a all cross over design	1/1/1=3*	All studies had a cross-over design. Four trials compared the effects of naltrexone versus placebo & one trial compared clomipramine versus placebo. One of the naltrexone versus placebo trials reported that naltrexone had clinically significant effects (≥ 33% reduction) on the daily rates of three of the four participants' most severe form of SIB & modest to substantial reductions in SIB for all participants; however, this study did not report on statistical significance. Another trial reported that naltrexone attenuated SIB in all four participants, with 25 mg & 50 mg doses producing a statistically significant decrease in SIB (P value < 0.05). Another trial (eight people) indicated that naltrexone administration was associated with significantly fewer days of high frequency self injury & significantly more days with low frequency self injury. Naltrexone had different effects depending on the form & location of self injury. Another trial with only 26 participants found that neither single-dose (100 mg) nor long-term (50 & 150 mg) naltrexone treatment had any therapeutic effect on SIB. Comparison of clomipramine versus placebo found no statistically significant benefit for any outcome measure, which included SIB rate & intensity, stereotypy & adverse events. However, it showed clinically significant improvement in the rate & intensity of SIB & stereotypy. There were very few noteworthy adverse events. There was insufficient evidence to support the use of drugs for participants with SIB, although some of the trials found clinically significant benefits of using naltrexone & in one trial, clomipramine, compared with placebo. No RCTs that examined the efficacy of newer & more commonly used medications, for example, SSRIs, & newer antipsychotics were found. Given their widespread use, this is a significant evidence gap.
Unwin & Deb (2011)	Efficacy of atypical antipsychotic medication for behaviour problems in children with ID & borderline intelligence	Any to 2010	RCTs	6 (plus three open-label trial extensions of three of these RCTs)	222 (6-55; 44.5). Controls: 237 (7-63; 45.5)	0/1/1=2	All of the studies found the risperidone group to show a greater degree of positive change from baseline compared with the placebo group on all or some of the outcome measures. The most commonly reported adverse events across the studies were somnolence, tiredness/drowsiness/fatigue, weight gain (including increased appetite), & headache. Five of the studies reported rates of any adverse events. The overall rates of any adverse event were common in both risperidone (66.7–100%) & placebo (28.6–79.5%) treated children but the risperidone group always showed a higher rate of adverse events according to the individual studies. The effectiveness of risperidone shown in the double-blind phase was maintained throughout the open label phase for all three extension studies. Somnolence, weight gain & headache were commonly reported adverse events in these extension studies. There was some evidence in favour of the

Author & date	Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	Number participants (range; Mdn)	Process Score	Main findings & Conclusions
							use of risperidone. However, because of possible adverse events, these medications have to be used with caution.
Singh, Matson, Hill et al (2010)	Effectiveness of clozapine for behavioural purposes among people with ID	ns	At least quasi-experimental	13	180 (1-51; 5) including controls (not stated (ns) separately)	0/0/0=0	None of the studies used placebo control, controlled and/or cross-over procedures, double blind procedures, standardized dosages & evaluations, & appropriate statistical analyses. Information regarding the social & behavioural effects of clozapine on social & behavioural functioning was vague as all of the reviewed studies relied primarily on measures of global functioning. No studies reviewed employed any measure to specifically assess the cognitive effects of clozapine. The most commonly reported side effects were sedation & hypersalivation, while other reported side effects included weight gain, extrapyramidal symptoms, & tachycardia. Research on the use of clozapine to manage behaviour among individuals with ID is inconclusive at best. Based on the quantity & quality of the available research, it was not possible to draw any definitive conclusions about Clozapine's cognitive or behavioural effects among this population.
Braam, Smits, Didden et al (2009)	Exogenous melatonin for sleep problems in people with ID	1990 to 2008	RCTs	9 (3 further studies found but excluded from meta-analysis)	183 (6-51; 9) including controls (ns separately & 7 studies were cross-over design)	0/1/1=2	Melatonin decreased sleep latency by a mean of 34 minutes ($p<0.001$), significantly decreased mean number of wakes per night ($p=0.024$), & increased total sleep time by 50 minutes ($p<0.001$). Reports on adverse effects were given in four studies. Adverse effects were minor & their incidence in both melatonin & placebo phases were the same. Results of meta-analysis indicated that melatonin was effective & safe in the treatment of sleep problems in individuals with ID, at least in short-term treatment. Although melatonin can be prescribed safely in individuals with sleep problems & ID, prescribers should realize that melatonin is a non-licensed drug in most countries, & that its long term treatment effects are still unknown.
Mohan, Bennett & Carpenter (2009d)	Efffectiveness & safety of donepezil for Alzheimer's dementia (AD) in people with Down's syndrome (DS)	1872 to 2008	RCTs (including cross-over studies)	1	30 in one study; 16 in intervention group. Controls 14.	1/1/1=3*	One small RCT on the effect of donepezil was found. No significant differences were found on any four validated outcomes including global functioning & three measures of cognitive abilities & behavioural problems. 6 out of 16 carers (37%) of participants on donepezil & 2 out of 15 (13%) on placebo reported improvement. No data were available for day to day skills, institutionalisation, reduction in carers' stress or economic outcomes. Half the intervention group & 20% of the placebo group reported adverse events; 2 participants left because of adverse events. The one study shows, at best, a modest, non statistically significant trend in favour of people with DS & AD who are able to tolerate donepezil (this drug is currently only dispensed in relatively large doses & is contraindicated for those with cardiac & respiratory problems).This study does not provide good evidence on which to base practice. Findings in an open-label follow up to this study suggest possible benefit in some individuals. Further, larger RCTs with longer-term follow up are required.
Thomson,	Effectiveness of	Any to	RCTs	1	15. Controls:	1/1/1=3*	One study identified with double-blind, randomised cross-over design with one week

Author & date	Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	Number participants (range; Mdn)	Process Score	Main findings & Conclusions
Maltezos, Paliokosta et al (2009)	amfetamine for attention-deficit hyperactivity disorder (ADHD) in people with ID	2007	(including cross-over studies)		n/a cross-over design		each of treatment with amfetamine, methylphenidate, & placebo. The one included study only presented graphs of results. Although positive trends were identified, no significant differences (using t-tests) were reported between amfetamine & placebo for any measures of ADHD symptoms. Ten out of 15 participants (all 15 children with Fragile X/ID/ADHD) were considered clinical responders to either methylphenidate or amfetamine, according to teacher & parent reports. The number who responded to amfetamine is not reported, though two participants were continued on amfetamine after the end of the study. Mean side effects scores were significantly higher for amfetamine compared to placebo (28.5 & 17.5 respectively; p=0.05). The most frequent complaints were mood lability & irritability. There was very little evidence for the effectiveness of amfetamine for ADHD in people with ID. Prescribing in this population is based on extrapolation of research in people without ID. More research into effectiveness & tolerability is urgently needed.
Deb, Chaplin, Sohanpal et al (2008)	Effectiveness of mood stabilizers & antiepileptic medication for behaviour problems in adults with ID	Pre-1990 to 2006	All types of trials including RCTs & case series	7	228 (10-66; 28). Controls: 20 in one study that used control group	1/1/1=3	One RCT relating to lithium & two non-RCTs, one on lithium & the other on carbamazepine, were identified. One prospective noncontrolled trial on sodium valproate & three retrospective case series studies were identified, of which one considered the efficacy of lithium, one valproate & one topiramate. Between 40% & 74% of participants in the reviewed studies were noted to have 'improved' (although it should be noted that in the former study 40% also 'improved' in a placebo condition, & one further study reported 30% 'improved' in placebo). Evidence lends some support for the use of lithium & some antiepileptic mood stabilizer medication for the management of behaviour problems in adults with ID but findings should be interpreted with caution due to methodological limitations of the studies reviewed. More methodologically sound trials are needed.
Gutkovich & Carlson (2008)	Medication treatment of bipolar disorder in developmentally disabled children & adolescents	1950 to 2007	Inclusion criteria not stated. Trials, case series & case reports included.	17	40 (1-18; 1). Controls: n/a mainly case series or case reports or ns separately	0/0/0=0	Lithium: total 18 participants in case/case series, including 14 with ID. Carbamazepine: total 2 cases both with ID; lithium carbonate valporate: total 8 case/case series, 5 with ID. Valproic acid: 2 open label trials, total 28, of which 19 with ID. Largely anecdotal accounts showed some effectiveness of mood-stabilizing agents & atypical antipsychotics in people with all degrees of ID including profound ID. Weakness of the data prohibits definitive conclusions. Clinical trials are needed to accumulate data for evidence-based treatment.
Sajith, Morgan & Clarke (2008)	Evidence, rationale & scope of pharmacological	1950 to 2008	Any trials (majority were open trials and	11 in tabulation	152 (1-95; 3) in study tabulation. Controls: n/a	1/0/0=1	5 studies of cyproterone acetate (CPA) were identified that included participants with ID, 3 of medroxyprogesterone acetate (MPA), & 3 of luteinising hormone releasing hormone (LHRH) agonists. CPA trials were conducted in 1970s & suffered from poor methodology or did not give adequate information on their participants & assessments.

Author & date	Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	Number participants (range; Mdn)	Process Score	Main findings & Conclusions
	management of inappropriate sexual behaviours (ISBs) in ID		most relied on self-report measures)		no control groups noted		For MPA, 3 case reports were identified, with all 3 patients showing marked improvement in their ISBs but relapse on discontinuation or reduction in dose of MPA. For LHRH agonists, 2 uncontrolled trials & 1 case report with numbers of people with ID included ranging 1 to 3 were identified; remarkable improvement in ISBs were noted which were maintained over many years while on treatment but two patients relapsed on discontinuation of treatment. The quality of evidence base for the use of pharmacological agents in the treatment of ISBs was inadequate to justify their use in routine clinical practice. If used, they should only be a part of a comprehensive treatment programme & closely monitored.
Ulzen & Powers (2008)	Evidence on psychotropic and other somatic treatments (inc. electro-convulisve therapy (ECT)) for psychiatric & behavioural problems	1998 to 2008	Placebo controlled trials (other studies latterly included due to paucity of placebo controlled trials)	ns	ns	0/0/0=0	The review revealed few RCTs on the medications frequently prescribed for patients with ID. Three RCTs of risperidone in children, one combining adults & children, & one with adults only are discussed. There was one RCT involving quetiapine & one on citalopram. The few RCTs involving the use of risperidone in managing aggression showed some promise but were limited by numerous methodological issues including very small sample sizes which reduced the power of the statistical analyses. Other than the few studies involving risperidone, the overall quality of studies was poor. There was little evidence to support the scope of psychotropic medication use in the ID population. The contribution of psychiatric illness to challenging behaviours was not systematically addressed in the literature.

Table 2 Section II. Chapter V Mental & Behavioural Disorders: Non-pharmacological interventions

Author & date	Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	Number participants (range; Mdn)	Process Score	Main findings
Campbell, Robertson & Jahoda (2014)	Evidence for psychological interventions used with people who have ID & challenging behaviour (CB)	1980 to 2010	Any research design	20; 8 of these were reviews or meta-analyses	194 (1-63; 15) includes controls for 1 study (ns separately, n=63). Controls: 2 studies n=17 & 30.	1/1/1=3	Of the 20 papers, eight were at level of evidence 'A'; four at level 'B'; & eight at evidence level 'C'. The findings & recommendations from papers included offer some evidence that psychological interventions can effectively reduce CB. Interventions were most effective when linked to functional behaviour analysis. Constructional approaches were also effective; specialist behaviour therapy teams were more clinically effective than standard multi-disciplinary teams working alone; & active support training for staff worked well with people who present the most difficult CB. There was a limited amount of efficacy research that met the most stringent standards of empirical evidence. There was no one intervention or combination of interventions associated with highly effective results for all categories of behaviour. Consideration is needed of who the interventions work for, when, where & how.
Ball & Fazil (2013)	Role of engagement in meaningful occupation in reducing CB	ns	Any intervention research study	13	316 (2-89; 20) including controls (ns separately)	1/0/1=2	Authors note it is very hard to draw definitive conclusions from this review due to the limited number & variable quality of the research identified. There is a suggestion that when a well organised, skilled approach is taken to engage people in activity, it may be effective in reducing CB, although this was not supported in all the literature. The limited evidence identified in this review suggests that there is a need for further, more robust research on the use of occupation as a tool to reduce CB.
Borsay (2013)	Effectiveness of psychologically based anger management interventions for adults with ID living in the community	2000 to 2010	Case studies, case series, quasi-RCTs or RCTs	14	Authors note difficulty calculating no. of participants, conservatively estimate 132 receiving anger management & 88 wait list controls	0/0/0=0	The majority of studies (11) adopted a Cognitive Behavioural Therapy (CBT) approach to intervention; 10 of these made use of a group format. Evidence for the effectiveness of CBT interventions for anger management in adults with ID was mixed. The majority of studies showed evidence of statistically significant improvement on questionnaire measures for active vs. control participants, & gains were typically maintained at follow-up periods of up to 12 months. However, clinically significant change, where calculated, was seen in less than a third of participants. Two studies (one single case, one case series) with a total of 4 participants used a mindfulness-based approach to anger management. One case study discussed the impact of individual psychodynamic psychotherapy. Methodological weaknesses made it difficult to draw any firm conclusions about the effectiveness of the different approaches. There are examples in the literature of people who have benefitted from CBT, mindfulness & psychodynamic psychotherapy approaches. However, there are also examples of people who do not appear to have shown sufficient improvement, particularly when the more stringent calculation of clinical change is applied.
Chapman,	Effectiveness of	1980 to	Any study	11 (7 ID, 2	ID 34 (1-15;	1/1/1=3	All of the studies were rated as 'weak' using the Evaluative Method for evidence-based

Author & date	Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	Number participants (range; Mdn)	Process Score	Main findings
Hare, Caton et al (2013)	mindfulness training & practice in relation to people with ID, or family/paid carers	2012	evaluating an intervention based on mindfulness	paid carers, 2 family carers)	3). Family carers: n=4 & n=3. Paid carers: n=6 & n=23. Controls: n/a all studies uncontrolled		practice (EBP). The studies found improvements in aggression & sexual arousal for people with ID after mindfulness training. Training staff led to benefits for people with ID, decreased use of physical restraint for aggressive behaviour & increased job satisfaction. Training parents led to improved parental satisfaction & well-being & improved parent–child interactions. Serious methodological limitations mean that the positive findings should be treated with caution, & it is debateable whether the evidence is strong enough to recommend the use of mindfulness.
Hamelin, Travis & Sturmey (2013)	Evidence for anger management in adults with ID	ns	Wait-list control or alternate treatment control group (initial random assignment to groups criterion dropped)	8	192 (7-50; 18). Controls: 144 (7-34; 17.5)	0/0/0=0	Two RCTs & 6 pretest-posttest nonequivalent control group studies identified. The unweighted mean Cohen's d for the between-group effect size of RCT studies was 1.52 (range 1.49–1.54) & would be considered large. The unweighted mean Cohen's d for the between-group effect size of pretest posttest nonequivalent control group studies was 0.89 (range 0.16–1.32). One study also found a large effect size (d = 1.21) for an anger intervention that was administered individually rather than in a group. Tabulation of studies indicates that most effect sizes were medium to large. Methodological limitations mean it was not possible to conclude that anger management is effective (e.g. all studies used a wait-list comparison group which may introduce confounds, no studies demonstrated treatment integrity, all studies used self & staff reports of behaviour but did not validate these reports against actual behaviour). Given these extensive methodological limitations, it cannot be concluded that anger management is an EBP with people with ID.
Harper, Webb & Rayner (2013)	Evidence for mindfulness-based interventions for behaviour for people with ID	ns to 2012	Multiple baseline, RCTs, pre-post, single case studies	18	118 (1-34; 3). Controls: n/a no controlled studies	0/0/0=1	Eleven studies used multiple baseline designs, 7 used pre-post designs, 5 were single case studies. No RCTs. Consistently positive outcomes were reported across all 18 studies e.g. all 10 studies that recorded aggression as the dependent variable found a reduction in aggression. Other studies found positive outcomes including reduced: stress, obsessive thoughts, self injury, injury to staff, depression & anxiety, & staff use of medication & restraints. More rigorous research with improved designs & greater statistical power is necessary to ensure that the findings are not affected by confounding variables.
Hwang & Kearney (2013)	Effectiveness of mindfulness for behavioural or psychological problems in people with developmental	Any to 2012	Any (all except one were single subject designs)	12; 9 with ID sample	22 (1-6; 3) in ID studies. Controls: n/a no controlled studies	0/0/0=0	9 studies had ID sample, 7 of which used 'meditation on soles of feet' as all or part of the intervention where attention directed to a neutral part of the body. All except one study (which used a pre-post no-control group design) employed a single subject design (seven multiple-subject & four single-subject studies). Of these, 10 studies, conducted by the same research group, adopted a multiple baseline design. All studies reported positive effects for individuals with DD from mindfulness practice. In seven studies where the objectives were to reduce aggression in people with ID or autistic spectrum

Author & date	Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	Number participants (range; Mdn)	Process Score	Main findings
	disabilities (DD)						disorder (ASD), aggressive behaviour decreased to zero or near zero. Single subject studies with people with ID demonstrated weight loss, smoking cessation, & reduction of anxiety. The use of mindfulness to control deviant sexual arousal in one study of offenders with ID appeared less clinically successful than its use to reduce aggressive behaviour, where reported levels of sexual arousal reduced from 12 (a maximum level) for all three participants to 2.95, 3.03 & 1.51. Despite methodological problems including absence of both a clear definition of mindfulness & assessment of intervention fidelity, the intervention studies demonstrated the possible usefulness of mindfulness for individuals with DD, including ID.
Nicoll, Beail & Saxon (2013)	Effectiveness of CBT for anger in adults with ID	1999 to 2011	Randomized or non-randomized controlled trials or case series	12; 9 included in meta-analysis	237 (5-50; 14) may include controls for 4 studies. Controls where stated: 81 (9-36; 18)	0/1/1=2	The meta-analysis yielded an overall uncontrolled effect size of 0.88 (95% CI = 0.65–1.12, N = 168). Analysis of group treatment alone yielded an uncontrolled effect size of 0.84 (95% CI = 0.57–1.12, N = 123), & analysis of individual treatment formats yielded an uncontrolled effect size of 1.01 (95% CI = 0.54–1.48, N = 45). These are considered to be large effect sizes. However, confidence intervals were wide, & the anger literature was restricted by the small study sample sizes. It was advised that the effect sizes should be interpreted cautiously & that particular attention be given to the lower ranges of the effect sizes reported. Despite these issues & limitations, the findings indicate at least a medium treatment effect.
Petrenko (2013)	Intervention programs to prevent & treat behavioural problems in young children with DD	1990 to 2011	RCT or quasi-experimental controlled	17; 3 focused on ID	251 in 3 ID studies n= 15; 78; 88. Controls: 15; 28; 27 respectively	0/0/0=0	Three studies focused on interventions specifically for children with ID. One RCT of parent child interaction therapy found a reduction in behaviour problems; a quasi-experimental controlled trial found no difference in child behaviour for a 'Signposts for Building Better Behaviour Programme'; and a quasi-experimental controlled trial of a multi-component intervention found improved parent reported severity of behaviour but no change in frequency. Results from studies targeting children with ID were more varied than those in the review generally due to wide differences in the nature of the samples (e.g., severity of ID, whether excluded autism), length of intervention, mode of delivery, & program uptake across studies.
Simó-Pinatella, Font-Roura, Planella-Morató et al (2013)	Types of motivating operations (MO) in interventions for problem behaviour with school age ID	2000 to 2010	Any intervention study (all were single case designs)	31	55 (1-4; 1). Controls: n/a single case designs	0/1/0=1	All of the designs evaluated were for single-participant research. The designs most frequently used were reversal design (n = 17), multielement (n = 16), multiple baseline (n = 3), alternating treatments (n = 3), & multiprobe design (n = 2). Nine studies used more than one design. Across participants, problem behaviour was maintained by automatic reinforcement (n = 19, 34.54%), escape (n = 12, 21.81%), attention (n = 9, 16.36%), & tangible reinforcement (n = 6, 0.9%). Problem behaviour was maintained by multiple functions for six participants (10.9%), & the behavioural function was not specified for three participants (5.45%). The studies included many different MOs. Most of the interventions involved an alteration of the social context or characteristics of the

Author & date	Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	Number participants (range; Mdn)	Process Score	Main findings
							environment MOs. A small number of interventions took place involving a MO of the participant's personal context, & very few interventions considered the activity or nature of the task. The majority of the MOs had a clear effect (establishing or abolishing) on the problem behaviour in the predicted direction. The review suggests that antecedent interventions involving MOs have a clear effect on problem behaviour. That is, when an antecedent event that serves as a MO is changed or modified, the problem behaviour that arises in individuals with ID can be reduced or increased.
Vereen-ooghe & Langdon (2013)	Efficacy of psychological therapies for people with ID	ns to 2012	Intervention studies with two or more independent groups	22; 14 in meta-analysis	552 (7-91; 20). Controls (where stated): 81 (9-36; 18).	0/0/1=1	The results of the meta-analysis indicated that psychological therapy with people who have ID is efficacious with a moderate effect size of g = .682 when calculated using all the studies included within the current review. However, this effect size varied depending on whether the studies made use of randomisation, individual or group based interventions, & also varied according to the type of problem being treated. Studies evaluating CBT for depression generated a moderate to large effect size, g = .742 (95% CI =.116-1.599, N = 126). CBT for anger & aggression had an average estimated effect size of g = .827 (95% CI =.508- 1.146, N = 494). Randomised studies were associated with a lower, but moderate effect size, g = .555, compared to non-randomised studies which had a large effect size, g = .846. Individual therapy, g = .778, appeared superior to group-based interventions, g = .558; & there was no evidence that therapy had an effect on interpersonal functioning, g = .342. Psychological therapy has a moderate effect in treating symptoms of mental health problems amongst people with IDs. The results further suggest CBT to be at least moderately effective in the treatment of anger & depression. Individual therapy may be more effective than group psychotherapy, but this conclusion must remain tentative until further research is completed.
Walker & Snell (2013)	Effectiveness of augmentative & alternative communication (AAC) on CB in people with disabilities	Any to ns	Experimental single case research	54 (all disabilities)	111 (1-8; 2); of these 75% ID. Controls: n/a single case designs	0/1/1=2	Meta-analysis with effect size calculated using Nonoverlap of All Pairs (NAP).The mean effect size across all participants was .88 (moderate). For those with ID (n=83) NAP effect size was .87 (moderate). Across all participants, one participant characteristic & two intervention characteristics were found to moderate intervention effects. Age: effect sizes were weaker for those aged 18+ (.74) than for those aged 5 or less (.86) or 5 to 12 (.89). There were stronger effects for those who received functional communication training (FCT) intervention (.87) than those who received picture exchange communication system (PECS) intervention (.74). There were stronger effects for interventions that applied a functional behaviour assessment (FBA) to determine the function of behaviour (.88) than for interventions that did not (.72). AAC intervention has positive effects in decreasing CB for individuals with varying disabilities (predominantly ID). AAC intervention may be more effective for younger persons, where a FBA is conducted to inform the intervention, & FCT with AAC is used to address CB. However,

Author & date	Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	Number participants (range; Mdn)	Process Score	Main findings
							the quality of the reviewed studies is somewhat limited.
Brosnan & Healy (2011)	Behavioural interventions for the treatment of aggression in individuals with DD	1980 to 2009	Single subject design	18	30 (1-4; 1); at least 15 of whom had ID or ASD & ID. Controls: n/a single case designs	0/0/0=0	The designs most utilized were: multiple baseline (6); multi-element (6); reversal design (4); alternating treatments design (1); ABCD design (1). Of the interventions employed the most common were extinction (7), & functional communication training (5). A number of studies incorporated visual cue prompts (5), differential reinforcement procedures (5); & environmental enrichment (3). All studies reported decreases in CB attributed to the intervention. Seven reported total or near elimination of aggression of at least one individual during intervention in at least one condition. Overall, the single subject design studies reviewed suggest that the treatments implemented have effectively decreased or eliminated aggression in individuals with developmental disabilities (ASD, ID & ASD & ID) aged 3–18 years.
Chan & Tse (2011)	Effectiveness of massage therapy on relaxation & reduction of CB in ID	1806 to 2010	Any research design	7; 2 of these based on same sample of 8	20 (1-8; 3); sample of 8 counted once only. Controls: n/a no controlled studies	0/0/0=0	Five studies used a case study design & two used cross-over designs, no study employed an experimental design or RCT. All studies used behaviour observations as part of their outcome measures. Subjects with severe CB showed a decreased frequency of such behaviours after the interventions in 4 studies. Based on narrative data from caregivers & behaviour observations, positive behaviours generally increased following massage therapy. The effectiveness of massage therapy is inconclusive because of the paucity of studies & the small number of participants. More rigorous research designs, e.g. experimental or randomized clinical trials, are needed to evaluate accurately the therapeutic effects of massage therapy.
Chowdhury & Benson (2011)	Differential reinforcement (DR) procedures to manage problem behaviours in adults with ID.	1980 to 2009	Any DR-based intervention (most single case)	31; 22 with sample size of 1	48 (1-4; 1). Controls: n/a no controlled studies	0/0/1=1	15 studies reported DR to be an effective intervention when used independently. Of the remaining, 10 studies found DR to be useful as part of a treatment package, & six found a DR contingency used independently to be ineffective, & only observed treatment effects when an aversive component was added. Very few studies assessed the use of DR in older adults & in individuals with mild ID. The overall positive findings about the effectiveness of DR were considered encouraging but more methodologically robust studies are required.
Lang, Mulloy, Giesbers et al (2011)	Behavioural interventions for rumination & operant vomiting in individuals with ID	1987 to 2011	No specific exclusions. All identified were single-case	21	32 (1-5; 1); 29 with severe or profound ID. Controls: n/a single case designs	0/1/1=2	Intervention outcomes were summarized by calculating the Nonoverlap of All Pairs (NAP). NAP scores between 0 & 65% can be classified as ‘‘weak effects’’, 66–92% as ‘‘medium effects’’, & 92–100% as ‘‘strong effects’. Found 3 general approaches to intervention: (a) diet manipulations that involved either increasing the amount of food or calories consumed or withholding certain foods or liquids (across these studies the mean NAP was 90.9%); (b) sensory-based interventions in which the participant was either provided with an alternative means to obtain automatic reinforcement or access to the automatic reinforcement was blocked (mean NAP 82.6%); & (c) interventions based on

Author & date	Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	Number participants (range; Mdn)	Process Score	Main findings
							socially mediated reinforcers in which the participants' access to attention from staff or escape from demands was manipulated (mean NAP 86.3%). Combined, the results suggest that behavioural interventions for rumination & operant vomiting can produce sustained positive effects across time and settings. However, although reductions in rumination & operant vomiting were reported in all 21 of the included studies, caution is warranted in the interpretation of these results. Specifically, only three of the included studies could be classified as providing a conclusive level of certainty. A comparison of the studies included in this current review to the studies included in previous reviews reveals a shift away from punishment & towards function-based interventions & diet manipulations. Preliminary guidelines for practitioners faced with assessing & treating these behaviours are offered & directions for future research are discussed.
Chan, Thompson, Chau et al (2010)	Evidence on the effect of multisensory therapy in adults with DD on challenging, stereotypic & positive behaviour	1861 to 2008	Observational studies, experimental studies mixed method studies & case studies	17	304 (1-96; 8). Controls: 3 studies n=1, 30 & 41	0/1/1=2	Developmental disability defined as 'Mental retardation' as in DSM-IV in this review. All studies adopted a repeated measures design. Thirteen studies had a single treatment group but some adopted cross-over design or reversal design with two or more treatments. One had two comparison groups, i.e. experimental & controlled. One also had two comparison groups & adopted a cross-over design. One had three groups using a counterbalanced design. One had three comparison groups; control, placebo-control & treatment. The evidence suggests that participants displayed more positive behaviour after multisensory therapy sessions. Lack of trial-derived evidence makes it difficult to arrive at a conclusion on the effectiveness of the multisensory therapy & there is insufficient evidence for multisensory therapy as a way to reduce challenging or stereotypic behaviour. Future study should use well-designed RCTs to evaluate the short & long term effectiveness of multisensory therapy.
Lang, Didden, Machalicek et al (2010)	Behavioural treatment of chronic skin-picking in people with DD	Any to 2009	Any behavioural treatment study	16	19 (1-2; 1); of these 13 ID & 2 borderline ID. Controls: n/a single case designs	0/1/1=2	Main findings were summarized for the single-case experimental designs by calculating the percentage of non-overlapping data (PND). Treatment approaches included combinations of differential reinforcement, providing preferred items & activities stimuli (e.g., toys), wearing protective clothing (e.g., helmets or gloves), response interruption & redirection, punishment, & extinction. In terms of reducing skin-picking, outcomes across studies were judged to be positive. The mean PND across studies was 97% (range, 75–100%) although PND could not be calculated for one study due to a zero quantity in baseline. Nine studies collected maintenance data & demonstrated persistent treatment effects following intervention from 2 to 35 months. Improvements in behaviour were reported in all of the reviewed studies. However, none of the reviewed treatments would qualify as ''well established'. The evidence is limited because of the sheer paucity of studies & the small number of participants.
Carr,	Evidence for	ns	Any NCR	59; 24	58 (mainly	0/1/0=1	Forty-nine participants out of 58 (84.5%) who engaged in problem behaviour were

Author & date	Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	Number participants (range; Mdn)	Process Score	Main findings
Severtson & Lepper (2009)	noncontingent reinforcement (NCR) for problem behaviour in people with DD		treatment studies (mainly single case)	included in analysis	n=1); 49 treated using NCR of whom 81.6% diagnosed with ID. Controls: n/a single case designs		successfully treated with at least one of the NCR treatments. The other nine participants (15.5%) who engaged in problem behaviour were treated with a treatment other than NCR. The most commonly treated topographies of problem behaviour were SIB (55.1% of participants) & aggression (51.0%), followed by disruptive behaviour (20.4%), property destruction (10.2%), & inappropriate vocalizations (6.2%). Analysis of efficacy conducted using 24 studies of appropriate quality. Two measures of effect size calculated, percentage of non-overlapping data (PND) & mean baseline reduction (MBLR). The fixed time + extinction with schedule thinning (FTST + EXT) treatment was deemed well established, with 11 studies demonstrating its efficacy with 25 participants. The mean PND & MBLR values for FTST + EXT treatments were 70.7 (S.D. = 38.1) & 85.1 (S.D. = 16.2), respectively. No studies were identified that employed variable time + extinction with schedule thinning (VTST + EXT) treatments although it is noted to be similar to FTST + EXT treatment. The fixed time + extinction (FT + EXT) treatment was deemed probably efficacious, with 8 studies demonstrating its efficacy with 15 participants. The mean PND & MBLR values for FT + EXT treatments were 66.7 (S.D. = 39.3) & 78.6 (S.D. = 20.9), respectively. The variable time + extinction (VT + EXT) treatment was deemed probably efficacious, with three studies demonstrating its efficacy with seven participants. The mean PND & MBLR values for VT + EXT treatments were 80.9 (S.D. = 35.8) & 81.5 (S.D. = 14.8), respectively. The fixed time (FT) treatment was classified as experimental because only two supporting studies were identified in which FT was implemented for five participants. The mean PND & MBLR values for FT treatments were 83.7 (S.D. = 32.4) & 82.3 (S.D. = 25.3), respectively. Fixed-time reinforcer delivery (plus extinction & schedule thinning) was classified as well established, while fixed time reinforcer delivery (plus extinction) & variable-time reinforcer delivery (plus extinction) were deemed probably efficacious.
Hassiotis & Hall (2009)	Evidence for behavioural & cognitive-behavioural interventions for outwardly-directed aggressive behaviour in people with ID	1872 to 2007	Randomised or quasi-randomised controlled clinical trials	4	50 (6-18; 13). Controls: 44 (6-20; 9)	1/1/1=3*	Only four heterogeneous small studies identified so the results should be treated with caution. Direct interventions based on cognitive-behavioural methods (modified relaxation, assertiveness training with problem solving, & anger management) appear to have some impact on reduction of aggressive behaviour at the end of treatment & in some studies also at follow up (up to six months). Caregiver & individual ratings post treatment (assertiveness, problem solving interventions & CBT) showed improvement in measures of emotional distress, anger management & adaptive functioning compared with the control group in all but one study. There is some evidence that behavioural & cognitive behavioural treatments are efficacious on their own in the long term management of outwardly-directed aggression. All four of the included studies report significant improvement immediately after treatment is completed but the confidence

Author & date	Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	Number participants (range; Mdn)	Process Score	Main findings
							intervals given are quite wide. There is a paucity of methodologically sound clinical trials. RCTs of sufficient power, using primary outcomes of reduction in outward directed aggression, improvement in quality of life & cost efficacy as measured by standardised scales are needed.
Lang, Rispoli, Machalicek et al (2009)	Treatment of elopement (leaving an area without supervision or permission) in individuals with DD	Any to 2008	Any intervention research study	10	53 (1-39; 1); 47 with ID. Controls: n/a no control groups	0/1/1=2	Combinations of the following intervention components were utilised: (a) differential reinforcement, (b) extinction, (c) time out procedure, (d) token economy, (e) response cost, (f) functional communication training, (g) response blocking, & (h) non-contingent reinforcement. One study evaluated a single component intervention (scheduled periods of exercise). Overall, 80% of the studies reported positive outcomes & 20% reported mixed outcomes. The evidence base suggests that function-based assessment (e.g. functional analysis procedures) & function-based treatments (e.g. functional communication training) may be most effective in the treatment of elopement in this population. However, evidence must be considered limited because of the sheer paucity of studies & the relatively few number of participants. None of the reviewed treatments would qualify as 'well established' evidence based practice.
Lotan & Gold (2009)	Effectiveness of individual intervention in the controlled multisensory environment (Snoezelen) in relation to behaviour for individuals with ID	Any to ns	Any research based individual intervention suitable for meta-analysis	10 reported in 13 articles	121 (2-54; 12) including any controls (ns separately)	1/0/0=1	No RCTs were found. Comparisons between groups were only available in 4 of the 13 included studies & for most studies only a pre-post comparison was available. The 'best' results were found when inspecting the fourth planned meta-analysis which concerned generalised behaviour outside the Snoezelen in a pre-post comparison. This included seven studies & no heterogeneity was found. The effect size was large (0.76) & highly significant ($p < .001$), indicating that participants receiving Snoezelen developed more adaptive behaviour than they presented prior to the intervention. Weaknesses in the examined research methodologies, the heterogeneity between research designs, the small number of available research projects, & the small number of participants in each research project, prevent a confirmation of this method as a valid therapeutic intervention at this time.
Pragnall (2009)	Evidence for behavioural interventions for SIB	1998 to 2008	Single case studies, case series, quasi-randomised trials, RCTs, meta-analyses & literature reviews	34 (includes 4 reviews, 2 guidelines)	121 (1-45; 2) mainly single case design. Controls: 8 for 1 study with matched control design	0/0/0=0	The 34 articles include 4 reviews & 2 professional guidelines. Over the past 10 years research into behavioural interventions for SIB has yielded mixed results. These studies are primarily single case studies, & rarely include follow-up data. The efficacy of behavioural interventions for SIB was highly variable. For some people, when delivered in specialist settings, behavioural interventions can reduce the frequency with which they engage in SIB for the duration of the intervention. It is not possible to conclude as to the long term efficacy of these treatments, due to the lack of follow-up data. There is a dearth of research considering how these techniques may be applied in clinical or 'real life' settings, & despite a growing emphasis on positive behavioural support there has been little empirical evaluation of this in the treatment of SIB.

Table 2 Section III. Chapter V Mental & Behavioural Disorders: Other & Mixed Pharmacological/Non-pharmacological intervention reviews

Author & date	Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	No. participants (range; Mdn)	Process Score	Main findings
Pruijssers, van Meijel, Maaskant et al (2014)	Examination of the relationship between anxiety & CB in persons with ID.	2000 to 2012	Any empirical study	7	5,214 (26-4,069; 180) including comparison groups (ns separately)	0/1/1=2	Most of the studies found a relationship between anxiety disorders/anxiety symptoms & CB. However, the associations between anxiety & CB must be interpreted within the context of associations found between other psychiatric disorders & CB. In three of the studies, anxiety had the strongest association with CB; in the other four studies, depression, bipolar disorder, psychosis or impulse control disorder had stronger associations with CB than anxiety. Two of the seven studies did not identify any statistically significant relationships between anxiety & CB, but they did notice signs of such relationships. The study points toward the existence of a moderate association between anxiety & CB. The relationship is complex in nature, probably bidirectional, & therefore no causal relationships can be inferred. Further research is needed to clarify the complex nature of the association between anxiety & CB.
Buckles, Luckasson & Keefe (2013)	Prevalence of psychiatric disorders in adults with ID	2003 to 2010	Any research with data on prevalence	16	ns	0/0/1=1	Of the 16 reviewed studies 10 utilized population-based sampling of which 6 were from one Scottish research team. Estimates of prevalence varied greatly & much of this variation was due to differences in the diagnostic criteria utilized & the specific samples examined. Reported rates of diagnostic co-occurrence in population-based studies ranged from 14% to 74%. The high end of these rates was based upon psychiatric symptoms in a population sample of persons over 65 which do not equate to diagnosis. Consistently higher overall prevalence rate was found in studies that used administrative sampling, with estimates of prevalence of a mental disorder ranging from 29% to 75%. It can be concluded with reasonable confidence that mental disorders & psychiatric symptoms occur with significant frequency in persons with ID.
Heyvaert, Maes, Van den Noortgate et al (2012)	Meta-analysis of single-case & small-n (SCSn) research on interventions for reducing CB in persons with ID	2000 to 2011	Single-case or small-n study measuring CB under baseline & treatment conditions, with each containing at least two data points	285 studies (155 single case, 130 small-n (>1))	598; all SCSn. Controls: n/a all SCSn	0/1/0=1	Quality rating for each study used in meta-analysis but not reported for each study. Overall intervention effect was high (-2.96) & statistically significant ($Z = 13.16$, $p <$ .0001), suggesting that on average the interventions for CB in people with ID reported in the SCSn studies were highly effective. In the final three level meta-analysis model, interventions on average were less effective for persons with aggression as CB-type, & more effective for persons with a diagnosis of ASD, for older participants, & where the intervention included the component 'Manipulating antecedent factors'. After controlling for six extreme outliers, significant evidence was only found for the moderator effect of the CB topography aggression, & the intervention component manipulating antecedent factors. The overall effect of different contextual, behavioural, & pharmacological interventions for CB among persons with ID was large & statistically significant. However, this effect varied significantly over the included studies & participants & there

Author & date	Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	No. participants (range; Mdn)	Process Score	Main findings
							was evidence of publication bias (i.e. research reporting significant results more likely to be reported). Evidence was found endorsing the positive effects of psychotherapeutic and contextual intervention components, but no evidence for an overall positive effect of pharmacological interventions. The results of the multilevel meta-analysis of SCSn research to a large extent correspond with the conclusions of meta-analyses & reviews focusing on group-studies in this research domain.
van de Wouw, Evenhuis & Echteld (2012)	Prevalence, associated factors & treatment of sleep problems in adults with ID	1990 to 2011	Empirical or observational studies with at least 10 participants, case reports & case-series	50	Prevalence 2,810 (19-1,023; 79); associated factors 4,320 (20-1,023; 70); treatment 60 (1-34; 1). Controls: n/a no controlled studies (including no comparison groups for non-intervention studies)	0/1/1=2	Of the 50 studies, 17 were on prevalence, 28 associated factors, & 13 treatment. The results take into account levels of evidence. Based on the most reliable studies, the prevalence of sleep problems in adults with ID ranges from 9% to 27% for settling problems, & from 11% to 34% for night waking problems. The prevalence of significant sleep problems is 9%. Sleep problems were associated with the following factors: CB; respiratory disease; visual impairment; psychiatric conditions; & using psychotropic, antiepileptic and/or antidepressant medication. There is no clear evidence for an association with age, gender or level of ID, conflicting evidence concerning the association of ASD & sleep problems, evidence of insufficient quality to confirm an association between dementia & sleep problems, no clear association with sleep problems & caffeine intake, evidence of an association with DS & sleep problems is conflicting. There is limited evidence of an association with communicative ability, living environment & grief. There is some evidence that interventions (mainly based on behavioural/environmental improvement) are beneficial to treat sleep problems in adults with ID. Research on the prevalence, associated factors & treatment of sleep problems in adults & older people with ID has mainly focused on subjectively derived data. The definitions used to describe a sleep problem are not uniform, & associations are mainly described as correlations. In order to give recommendations for clinical practice further research is needed, involving objective measurements & multivariate analysis.
de Winter, Jansen & Evenhuis (2011)	Determining physical conditions that may be associated with CB	1990 to 2008	Empirical or observational study with minimum sample size of five	45	16,164 (9-3,065; 168). Three studies with same sample of 1023 counted once only. Controls: 2 case control studies, control group	0/1/1=2	Most articles addressed the review topic as a secondary issue. There were many categories about which no articles were found, e.g. menopause, cardiac & pulmonary disease, infectious disease & malignancies. The review identified 11 well-conducted studies that found significant & independent associations with urinary incontinence, pain related to cerebral palsy & chronic sleep problems. Visual impairment was significantly associated with SIB. No association was found with hearing impairment, bowel incontinence, mobility impairment or epilepsy. Twenty-one analytical studies of unsatisfactory quality & 13 non-analytical studies or case series, usually based on file data, suggest associations with gastroesophageal reflux disease (GORD), dysphagia, dementia, menstrual cycle phases & specific sub-types of epilepsy. However, so far, these are insufficiently substantiated. Medical conditions can play a role in CB & this

Author & date	Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	No. participants (range; Mdn)	Process Score	Main findings
					n=88 & 150		should be evaluated in the clinical setting. Because of the cross-sectional design of all the studies, no firm conclusions can be drawn about the causative character of the physical conditions discussed. The level of evidence is low with no longitudinal studies.
Einfeld, Ellis & Emerson (2011)	Prevalence of mental disorders in children and/or adolescents with ID & key factors associated with prevalence	ns to 2008	Any prevalence study with representative sample of ID of 100 or more using rigorous method	9	3,396 (59-1041; 355). Controls: 4 studies with non-ID comparison groups 27,677 (1,855 – 17,774; 4,024)	0/0/0=0	Of the 9 studies, 4 had a comparison group without ID and 5 had no comparison group. Studies with comparison group: 30% to 50% of children & adolescents with ID were identified as having a mental disorder compared with 8% to 18% of children & adolescents without ID. The relative risk of mental disorder associated with ID ranged from 2.8 to 4.5. Studies without comparison group: reported prevalence estimates for mental disorder ranged from 30% to 41%. The literature reviewed is limited with regard to the identification of risk factors associated with mental disorder among people with ID. Only three risk factors (age, gender, severity of ID) have been investigated with any degree of regularity, & results of these analyses are inconclusive. The results do suggest markedly increased rates of mental disorder among children & adolescents with ID. Appreciation of this comorbidity needs to be a fundamental component of both mental health & ID services
Welch, Lawrie, Muir et al (2011)	Compares the clinical presentation of schizophrenia in people with mild/borderline ID to that in people with average/high IQ.	1950 to 2008	Any primary research	5	280 (25-104; 53). Non-ID comparison groups: 908 (26-482; 53).	0/0/0=0	The 5 studies compared a total of 280 individuals with schizophrenia & mild ID/borderline intellectual functioning (BIF) to 908 individuals with schizophrenia & average/high IQ. The mild ID/BIF group scored higher on scales measuring negative symptoms in four of the five studies reviewed, higher on scales measuring positive symptoms in two, & higher on scales measuring general symptoms in two. Meta-analysis was only possible for negative symptoms (3 studies). The meta-analysis of ratings on scales measuring negative symptoms produced an effect size of 1.72 (95% CI= 0.99-2.46). This is an extremely large effect size, indicating that ID individuals with schizophrenia experience substantially greater negative symptoms than patients with average/high IQ. The available evidence supports the proposal that the clinical presentation of schizophrenia in an ID population differs from that in a population with normal IQ.
Courtenay, Jokinen & Strydom (2010)	Social-psychological & pharmacological caregiving for adults with ID affected by dementia	1997 to 2008	Any research study	25	Medication studies only: n=6, 14 & 17. Controls: n=9, 13 & 13. Not calculated for other studies due to wide variety of samples inc.	0/0/0=0	Of the 25 studies, 3 were medication trials & one an open label continuation of one of the trials. Review identified one study of a nonpharmacological intervention in adults with ID & dementia using structured psychotherapeutic groups for persons with ID & dementia. Research & evidence for nonpharmacological therapeutic strategies for dementia in the ID population is rare. The research evidence on antidementia drugs in people with ID is sparse at present & consists of small trials & case reports on side effects. The evidence base of both nonpharmacological & pharmacological interventions that can help people with ID & dementia & their carers is insufficient because of the absence of systematic & robust studies. Service organizations often have to extrapolate from the evidence base of dementia care practices in the general population.

Author & date	Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	No. participants (range; Mdn)	Process Score	Main findings
					organisations, staff, carers.		
Heyvaert, Maes & Onghena (2010)	Review of biological, psycho-therapeutic & contextual interventions for CB among persons with ID, & analysis of intervention effects & moderating variables (meta analysis).	2000 to 2008	Any empirical study suitable for meta-analysis	30	1,444 (7-118; 39) including controls (ns separately)	0/0/1=1	18 described a biological, 13 a psychotherapeutic & 9 a contextual intervention, with sometimes more than one implemented treatment discussed in a single article. Effect sizes (standardised mean differences) ranged from 0.223 to 1.411 i.e. varying between a small & a very large effect, all indicating positive treatment effects. The combined effect size over all studies is 0.671 (95% CI= .570 - 0.771), which is a medium to large effect. The implemented sensitivity analysis revealed that this effect is robust. Analyses of variance showed no significantly different treatment effects for biological, psychotherapeutic & contextual interventions. Interventions for CB among persons with ID described in the 30 articles were effective, with only small differences between the mean effects for biological, psychotherapeutic & contextual treatments, & for unimodal & multimodal interventions. The effects in the meta-analysis were considered robust & convincing.
Mevissen & de Jong (2010)	Overview of the available literature on the assessment, prevalence, & treatment of post-traumatic stress disorder (PTSD) in people with ID	1992 to 2008	Any literature on the assessment, prevalence, & treatment	18	Prevalence: 358 (6-310; 43); treatment where stated: 25 (1-19; 2). Controls: n/a no studies with controls (including no comparison groups in prevalence studies)	0/0/0=0	Assessment: no diagnostic instrument is available specifically aimed at assessing PTSD in ID. Caregivers often do not possess information concerning the person's trauma history or do not recognize events typically associated with PTSD. Certain events, for example a move arranged by others, is in general not considered as potentially traumatic but such events may have a negative or traumatizing effect on individuals with ID. Prevalence: 4 articles were found reporting on incidence rates of PTSD in samples (with a total number of 359 persons) with ID who were referred for treatment, & had a history of one or more traumatic experiences. Prevalence rates of PTSD varied substantially, from 3% to 60%; prevalence studies using large heterogeneous populations entirely lacking. Treatment: 9 articles involve treatment of PTSD in people with ID. Interventions reported involve those aimed to establish environmental change, the use of medication & psychological treatments (i.e., CBT, Eye Movement Desensitization & Reprocessing (EMDR) & psychodynamic based treatments). Case reports suggest positive treatment effects for various treatment methods. Empirical studies of the pharmacological treatment of PTSD in people with ID are lacking. Development of diagnostic instruments for the assessment of PTSD & its symptomatology among people with ID is warranted, which could facilitate further research on prevalence. Evidence based methods have to be developed to treat people with various levels of ID who suffer from PTSD. A first step might be to systematically evaluate the use of already established methods such as trauma-focused CBT & EMDR.

Author & date	Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	No. participants (range; Mdn)	Process Score	Main findings
Strydom, Shooshtari, Lee et al (2010)	Epidemiology, presentation & diagnosis of dementia in older adults with ID	1997 to 2008	Primary research on epidemiology & presentation	17 tabulated on prevalence & incidence	Prevalence & incidence: 5,622 (68-1041; 144). Controls: n/a no comparison groups noted in tabulated studies	0/0/0=0	Due to varied methodologies & challenges in diagnosis there is a wide range of reported prevalence, particularly in the results obtained from the small number of studies in adults with ID who do not have DS. Rates of dementia in the population with ID not because of DS are comparable with or higher than the general population. Alzheimer's disease onset in DS appears earlier & the prevalence increases from under 10% in the 40s to more than 30% in the 50s, with varying prevalence reported for those 60 & older. Incidence rates increase with age. Few studies of dementia in other genetic syndromes were identified. Presentation differs in the ID population compared with the general population; those with DS present with prominent behavioural changes believed to be because of frontal lobe deficits. In the future, larger studies with representative samples using comparable ascertainment & diagnostic methods, & a good description of participants, could clarify these findings.
Lang, White, Machalicek et al (2009)	Treatment of bruxism (teeth clenching or teeth grinding) in individuals with DD	Any to 2008	Any empirical intervention study	11	19 (1-6; 1); 14 of these profound ID. Controls: n/a no controlled studies	0/1/1=2	Assessment procedures included dental screening under sedation & interviews with caregivers. Intervention approaches included prosthodontics, dental surgery, injection of botulinum toxin-a, behaviour modification, music therapy, & contingent massage. Overall, 82% (n = 9) of the studies reported positive outcomes & 18% (n = 2) reported negative outcomes. Overall, the evidence base is extremely limited & no definitive statements regarding treatment efficacy can be made. None of the reviewed treatments would qualify as 'well established' evidence-based practice. However, behaviour modification & dental or medical treatment options (e.g prosthodontics) seem to be promising treatment approaches. At present, a two-step assessment process, consisting of dental screening followed by behavioural assessment, can be recommended.
Pridding & Procter (2008)	Assessment, diagnosis & management of personality disorder (PD) in people with ID	Any to 2007	All literature that referred to personality disorder in people with ID	ns	ns	0/1/0=1	A previous review of diagnosis of PD in ID found reported prevalence rates from 1% to 91% in community settings & 22% to 92% in hospital with previous authors concluding that no accurate prevalence figures for PD in ID are available. However, there is a consensus that PD is more common in this population & that its distribution mirrors that found in the general population with significantly higher rates amongst inpatient psychiatric & prison populations. In more recent studies, a prevalence of 22% was found amongst referrals to a specialist dual diagnosis service, & 39% of forensic ID clients had at least one PD. No validated PD diagnostic scale exists for use in people with ID. Assessment & diagnosis is complex & often overshadowed by ID. Few papers address treatment, there are no trial-based studies. The literature on PD in ID is notable for its paucity. There is a lack of either research or guidance on the treatment or management of PD in this population & it has not been established if evidence on treatment in the general population can be extrapolated.

Table 3 Section I. Chapter XXI Factors Influencing Health Status and Contact with Health Services: Contact with Health Services

Author & date	Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	No. participants (range; Mdn)	Process Score	Main findings
Bradbury-Jones (2013)	Influences on the health, safety & welfare of adults with ID in acute hospitals.	2000 to 2011	Empirical data whether quantitative or qualitative	7	119 in survey. Qualitative studies mixed samples of ID, paid & unpaid carers, other professionals, conference attendees: 228 (9-80; 25). Controls: n/a no controlled studies	0/1/1=2	Seven qualitative studies were identified, one of which also included a survey. A range of stakeholder perspectives were reported (healthcare professionals, ID, parents, carers & supporters). Six studies highlighted the issue of care provision, with significant emphasis on inadequate care (e.g. continent adults with ID being given continence pads, rather than taken to the toilet, people who needed special eating utensils not having access to them). Communication was highlighted as a core issue in all but one of the articles, with people with ID frequently having difficulty communicating their needs. In relation to staff attitudes, discrimination towards people with ID was noted to be 'endemic'. One study found a lack of knowledge among many nurses regarding the issue of ID. Carers may chose to spend up to 24 hours a day at the hospital & their presence was valued by nurses. In relation to the physical environment, simple strategies can promote safety, e.g. preadmission assesement, provision of symbols or pictures. Six areas of influence on the health, safety & welfare of adults with ID in acute hospitals were identified: care provision (meeting health & personal needs); communication; staff attitudes; staff knowledge; supporters; & carers (valuing their role); physical environment. These six areas are represented diagrammatically, as concentric rings. These influences on health, safety & welfare form an inner (direct) layer & an outer (indirect) layer consisting of liaison services & education/training. This conceptualisation of influences as being multi-layered assists in the identification of similarly multi-layered improvement strategies.
Durà-Vilà & Hodes (2012)	Ethnic variation in uptake of mental health services by people with ID across the lifespan in high income countries	1950 to 2009	Qualitative or quantitative research excluding case studies	9	15,103 (24-6,535; 271). Controls: n/a no controlled studies	0/1/1=2	The nine studies included in the review offered a direct comparison among two or more ethnic groups in their level of mental health utilisation in people with ID. Six studies found a difference or an association between cultural & ethnic factors, & mental health utilisation. Differences found by these studies among ethnic groups ranged from small differences limited to a particular area to very significant & broad differences in psychiatric service use. Three studies found no statistically significant ethnic/cultural variation. The most consistent finding was that South Asian children, adolescents & adults with ID in the UK had lower use of mental health services than White British comparison groups. The extent of ethnic variation in mental health service utilisation among people with ID in high income countries remains largely unexplored as this review only includes studies from two countries.
Phillips	Factors	1990 to	Any primary	14	ns	0/0/0=0	Several factors can lead to people with ID becoming bored, distressed, fearful, angry or

Author & date	Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	No. participants (range; Mdn)	Process Score	Main findings
(2012)	influencing & interventions improving general hospital care for people with ID	2010	research				frustrated. These factors include anxiety about going into hospital, long waiting times, lack of age-appropriate activities, feeling ignored by hospital staff, poor communication about investigations & treatments, fear of procedures & not having needs met. People with ID & their carers perceived that staff tended to lack experience & knowledge of caring for people with ID. Staff had negative attitudes towards & were less confident in working with patients who had ID than those with physical disabilities. Recurrent themes of difficulties in hospital emerged from the literature (e.g. confusing signage, given incontinence aids rather than being given assistance to get to a toilet, one person going without food because he was unable to open a packet of sandwiches). Credible research in this area is lacking. The review identified a variety of ways to improve the care people with ID receive in hospital (pre-admission visits, education & training for hospital staff, recognising & valuing the role of carers & meeting the needs of carers, improving the hospital environment & implementing the learning disability liaison role). Areas of good practice need to be evaluated & disseminated so that people with ID receive the best possible health care.
Robertson, Roberts, Emerson et al (2011)	Impact of health checks for people with ID	1989 to 2010	Any quantitative or qualitative	38	>5,000 (1-1,311; ns). Controls: ns.	1/1/0=2	Of the 38 publications identified, three were based on RCTs. The majority of studies were based on clinical interventions where a sample of people with ID received a single episode of a health check & information was presented on the outcome(s) of the health check. Studies consistently suggest that health checks are effective in identifying a wide range of previously unidentified conditions, including serious & life-threatening conditions such as cancer, heart disease & dementia. The evidence also suggests that health checks consistently lead to targeted actions to address health needs. However, few studies have investigated the extent to which the provision of health checks leads to short-, medium- or long-term changes in health status. Overall, studies suggest that health checks are acceptable to the majority of people with ID & family carers who support them. Health checks are effective in identifying previously unrecognised health needs, including life-threatening conditions. Future research should consider strategies for optimising the cost effectiveness or efficiency of health checks.
Backer, Chapman & Mitchell (2009)	Experiences of secondary healthcare for people with ID	1990 to 2008	Any research on factors related to access or interventions to improve access	13	ns	0/0/0=0	People with ID experience a range of barriers to secondary health care & that their needs are not being adequately met when they go to hospital. The main barriers impacting on the experiences of people with ID & carers are related to the process of hospital care (for example, appointment systems & waiting times), the knowledge, attitudes & communicative style of health staff & the physical environment. A range of recommendations & initiatives have been developed to improve hospital care. More research is needed, given that so few studies are published in this area. Initiatives to improve access to secondary healthcare need to be evaluated to inform the

Author & date	Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	No. participants (range; Mdn)	Process Score	Main findings
							development of services.
Kozma, Mansell & Beadle-Brown (2009)	Outcomes in Different Residential Settings for People With ID	1997 to 2007	Qualitative or quantitative research	68	Not calculated due to high likelihood of double counting. 42 of 68 studies had a sample size of 100 or more; 11 studies sample less than 50. Controls: n/a no controlled studies	0/0/0=0	Twenty-seven studies had a cross-sectional design with matched samples & 23 had a longitudinal design. In 18 studies investigators combined both & either compared ‘movers’’ & ‘stayers’ or people moving to different types of residential arrangements. People in small scale community-based residences or in semi-independent or supported living arrangements had a better objective quality of life than did people in large, congregate settings. Particularly, they had more choice-making opportunities; larger social networks & more friends; accessed more mainstream activities & participated more in community life; had more chances to acquire new skills & develop or maintain existing skills; & were more satisfied with their living arrangements. Five main conclusions emerge from this literature: the overall picture is comparable to previous reviews, namely, small-scale arrangements are superior to large, congregate options in most domains; there is considerable variability in individual outcomes based on individual & service characteristics; there are three areas where community-based services might not provide better outcomes (CB, psychotropic medication, & mortality); experiences are similar in different countries; & despite significant improvements, people with ID are still one of the most disadvantaged groups of society.
Balogh, Ouellette-Kuntz, Lunsky et al (2008)	Organisational interventions aimed at improving care of mental & physical health problems of adults with ID	1990 to 2006	RCTs, CBA studies, & ITS	8	148 (10-50; 15). Controls: 162 (10-54; 23). Unknown for one study.	1/1/1=3*	Only interventions dealing with mental health problems of persons with ID were included, none focused on physical health problems. Three of the studies identified effective organisational interventions & five showed no evidence of effect. By decreasing caseloads & increasing the frequency of direct care of participants in their natural environment one study found a significant increase in adaptive behaviour & a decrease in maladaptive behaviour in the intervention group; improvements in behaviour were found among control group participants who received bereavement counselling from bereavement counsellors with little experience working with people with ID; & services delivered by mainstream intensive case management teams with small case-loads significantly decreased the number of days in hospital for psychiatric reasons among persons with mild & borderline ID. Only two studies were similar enough to analyse using a meta-analysis. In the pooled analyses 25 participants received assertive community treatment & 25 received standard community treatment. Results from measures of function, caregiver burden & quality of life were non-significant. There are currently no well designed studies focusing on organising the health services of persons with an ID & concurrent physical problems. There are a small number of studies of organisational interventions targeting mental health needs but the results of these require corroboration. There is an urgent need for high quality health services research to identify optimal health services for persons with ID & concurrent physical problems.

Author & date	Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	No. participants (range; Mdn)	Process Score	Main findings
Goldsmith, Skirton & Webb (2008)	Empirical evidence relating to informed consent (to include assessment of mental capacity) to healthcare interventions for people with ID	1990 to 2007	Quantitative or qualitative research (primary or secondary) & review articles	22; includes 2 review articles	933 (1-171; 33.5) including non-ID comparison groups of n=142 (ns for one study)	0/1/0=1	Identified 10 quantitative studies, eight qualitative, one mixed methods, one with unclear methodology & two literature reviews. One RCT was identified. The main themes identified were: life experience, interaction between healthcare professionals & participants, ability to consent, & psychometric variables. A consensus seemed to emerge that capacity to consent is greater in people with higher cognitive ability & verbal skills, but that the attitudes & behaviour of healthcare professionals was also a crucial factor. Some researchers investigated consent to research; others consent to treatment or (indirectly) consent to taking medication, while some used hypothetical vignettes & some 'real life' situations. Limitations noted in applying finding of the studies to clinical practice. The findings support use of the functional approach to assessing mental capacity for the purpose of obtaining informed consent. The complexity & nature of the decision need to be taken into account. Whether or not capacity to consent is achieved may depend on the effort made to 'tailor' the relevant information to the abilities & needs of the individual concerned.
Mayo-Wilson, Montgomery & Dennis (2008a)	Effectiveness of personal assistance for adults (age 19 to 64 years) with both physical & intellectual impairments	1980 to 2005	RCTs, quasi-randomised controlled trials & non-randomised controlled studies	2	500 (44 & 456). Controls: n=44 & 458 respectively.	1/1/1=3*	Only two studies identified, both compared personal assistance with usual care, one of which was randomised. There was some evidence that personal assistance recipients may express greater satisfaction & fewer unmet needs than participants receiving other services. For physical health, though not a goal of the intervention, data suggest that that personal assistance had no comparative impact on mortality. Data on other health outcomes were mixed, with some trends in favour of personal assistance. There was no evidence of detrimental impacts. Further data would be required to draw conclusions about impacts on health & cost. This review did not find evidence that personal assistance reduces long-term institutional care. One trial found mixed effects on caregivers. Personal assistance may have some benefits for some recipients, their friends & families; however, the relative total costs to recipients & society are unknown. This review does not indicate that personal assistance would be superior to other services for people who are already satisfied with the assistance they receive. Further data would be required to draw conclusions about impacts on health.
Montgomery, Mayo-Wilson & Dennis (2008)	Effectiveness of personal assistance for children & adolescents (age 0 to 18 years) with intellectual	1980 to 2005	RCTs, quasi-randomised controlled trials & non-randomised controlled studies	1	501 intervention, 501 usual care	1/1/1=3*	This review identifies some evidence that personal assistance may benefit children with intellectual impairments. Impacts on carers appear somewhat mixed. Further data would be required to draw conclusions about cost. Data suggest that that personal assistance had no comparative impact on mortality. Data on other health outcomes suggest personal assistance might have some beneficial impacts on health. There was no evidence of detrimental impacts. No studies looked at the impact of personal assistance on mental health outcomes. Research in this field is limited. While advocates may support personal assistance for myriad reasons, this review demonstrates that further

Author & date	Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	No. participants (range; Mdn)	Process Score	Main findings
	impairments						studies are required to determine which models of personal assistance are most effective & efficient for particular people.

Table 3 Section II. Chapter XXI Factors influencing health status & contact with health services: Factors Influencing Health Status

Author & date	Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	No. participants (range; Mdn)	Process score	Main findings
Casey & Rasmussen (2013)	Effects of exercise training interventions on percent body fat in individuals with ID (scoping review)	1975 to 2011	Any	11	219 (3-41; 16). Controls: 94 (12-23; 15)	0/1/1=2	Six studies used randomized control designs, the remainder pre-post quasi-experimental designs. Ten studies used exercise training alone, one combined exercise & caloric restriction. Aerobic training was incorporated into all interventions, & four studies also included a strength training component. Three studies produced a loss of body fat amongst participants following an exercise training period. One study produced a significant increase in body fat following the intervention. Seven studies saw no change in body fat levels from pre to post tests. The vast majority of studies reporting no change in outcome measures did not take into account the dietary intake or nutritional status of individuals with ID. Methodological limitations make it difficult to evaluate effectiveness of reduction measures used to date. The existing literature contains too few well-conducted studies to conclusively determine the efficacy of exercise training on body fat for individuals with ID.
Kerr, Lawrence, Darbyshire et al (2013)	Interventions designed to address the use of tobacco and/or alcohol in people with mild or moderate ID	1996 to 2011	RCTs, quasi-experiments, before & after studies, cohort studies, feasibility studies, exploratory trials, qualitative studies	9	213 (1-79; 7). Controls:128 (n=55 & 73)	0/1/1=2	Review considers Feasibility, Appropriateness, Meaningfulness & Effectiveness (FAME) of tobacco and/or alcohol interventions. 4 papers focused on tobacco-related interventions, 3 on alcohol-related interventions & 2 on interventions designed to address both tobacco & alcohol. There was one RCT, one quasi-experiment,3 case study approaches, 3 before & after studies, & one audit. No qualitative studies were identified. Only two studies appeared to have appropriate theoretical underpinnings. Methodological limitations mean results should be treated with caution & little can be deduced regarding effectiveness. Only one study (RCT) is informative in terms of effectiveness & this appeared to be effective in terms of raising the knowledge levels of people with ID in relation to tobacco & alcohol. However, there were methodological limitations that may impact on the validity of the results. There is a dearth of evidence & little to guide health & social care professionals. There is an urgent need to develop theoretically driven tobacco & alcohol-related health promotion interventions & to ensure that the effectiveness of these interventions is tested in large-scale well designed trials.
Li, Chen, How et al (2013)	Benefits of physical exercise intervention on fitness of people with DS	Any to 2013	RCTs	10	176 (8-46; 12.5). Controls: 173 (8-46; 12.5)	0/1/1=2	Four fitness outcomes evaluated: balance, muscle strength & endurance, cardiovascular fitness, & body composition. Exercise interventions led to moderate to high effects of improving muscular strength & balance (Cohen's d 0.74-1.10). Other outcomes showed less conclusive or limited positive evidence. There were no reported instances of injury sustained by any participants. People with DS can benefit from physical exercise programs such as weight-bearing exercises, balance exercise, which show a trend of improving muscular strength & balance. There is less evidence for muscle endurance,

Author & date	Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	No. participants (range; Mdn)	Process score	Main findings
							cardiovascular fitness & body composition.
McGillivray, McVilly, Skouteris et al (2013)	Parental & parenting risk factors associated with obesity in children & adolescents with disability	Any to ns	Any research design	Total 11; of these 7 had ID samples	All studies: 3,812 (54-808; 261). ID only studies 2,341 (88-808; 261). Two ID secondary analyses with large non-ID samples	0/1/1=2	In this review the term 'disability' is used to refer to any type of intellectual and/or developmental disability, Six of the 11 studies included in the review reported statistically significant relationships between increased body mass index (BMI) in the children & parental/parenting factors (all included children with ID). Socio-economic status, parents' BMI, parents' perception & attitude towards their children's weight & level of physical activity, & actual levels of physical activity in parents & their children might be associated with overweight & obesity in children & adolescents with disability. However, findings were not consistent across studies. Firm conclusions remain elusive due to the small amount of research, the methodological limitations of the available research & the lack of consensus in findings between identified studies.
Naaldenberg, Kuijken, van Dooren et al (2013)	Main characteristics of published health promotion intervention studies for people with ID	2002 to 2012	Any empirical studies including process evaluations & case studies	25	2,223 (1-361; 68) approx prior to drop outs, includes comparison & control groups. Also 2 group homes & 2 support staff	0/1/1=2	Nine papers reported using a pretest/posttest single group design, making this the most prevalent research design. Seven used a pre/post control group design & three a pre/post comparative group design. Other designs used were single group descriptive designs, process evaluations & one case study. The majority of the included papers focused on exercise or healthy nutrition. To improve the health of people with ID these topics are pertinent; however, there are several other key issues that must be addressed through health promotion including: healthy aging; osteoporosis, fractures & the prevention of falling incidents; constipation; mental health & well being, stress reduction & social well being. Findings suggest that the field of health promotion research is underdeveloped for this group, with a need for theoretically driven studies. Given the health inequities they experience, it is critically important that public health & health promotion researchers ensure their study designs are inclusive of people with ID. Only three studies used interventions adapted from general population interventions, demonstrating the urgent need for collaboration between mainstream & ID related health promotion research.
Ali, Hassiotis, Strydom et al (2012)	Experiences of & impact of self stigma in ID & courtesy stigma in family carers	1990 to 2012	Qualitative or quantitative primary research with sample size of 10 or more	37 (17 self stigma ID; 20 courtesy stigma family carers)	ID: 618 (13-94; 32). One non-ID comparison group (n=20). Carers: 1,415 (12-350; 38) approx. 2 comparison	0/1/1=2	Both ID & family carers experience stigma & it may have a negative impact on psychological wellbeing. Awareness of stigma in people with ID appears to be related to the extent to which individuals accept & internalise the label of ID. Most studies were qualitative or small descriptive studies. There is a lack of large prevalence studies & longitudinal studies examining the impact of stigma, in both individuals with ID & their family carers.

Author & date	Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	No. participants (range; Mdn)	Process score	Main findings
					groups carers of people with mental illness (n=66 & 108)		
Shin & Park (2012)	Effects of physical exercise programs on individuals with ID	ns to 2010	Any using group design suitable for meta-analysis	14	ns	0/1/0=1	In a meta-analysis of the 14 studies, the overall effect size was 0.41, a small to medium effect. The effect sizes of professional/scholastic measures (0.91) & exercise physiological data (0.84) were large, & the measures of performance were small (0.33), but the effect size of biometric & body composition data was trivial (0.03). Short-duration exercise had a better effect than long-duration exercise, & the effect of exercising 4 times per week was better than the effect of exercising 3 times per week (other frequencies were not reported). The most effective duration of exercise was 31–60 min, & exercise was more effective for older people than for younger people. Further studies must be performed with more specific outcome variables & moderating variables, such as age, exercise time, duration, frequency, & type of exercise program. A more comprehensive examination of moderating & mediating variables should be implemented to understand & promote exercise programs in individuals with ID.
Bartlo & Klein (2011)	Effectiveness of physical activity interventions for people with ID	1990 to 2010	Experimental or quasi-experimental clinical trial or systematic review	11	299 (12-53; 25) including controls (ns separately)	1/0/1=2	Nine studies were RCTs. One was a cohort-group study design, & the remaining study was a one-group pre–post-test design. Reported results included: strength increases from baseline, ranging from 10% to 29%; a 4% decrease in heart rate after a walking test in intervention participants; balance improvements of between 9% & 25% for intervention groups compared with control groups; overall life satisfaction score increase of 4% for an intervention group compared with a 7% decrease for the control group; and an improvement in self-efficacy scores of 16% compared with a 4% improvement for the control group. The authors report that there was strong evidence that physical activity positively affects balance & muscle strength in individuals with ID. There was moderate evidence that benefits in physical activity, function, & QOL could be experienced.
Heller, McCubbin, Drum et al (2011)	Evidence for physical activity & nutrition health promotion interventions for ID	1986 to 2006	Any primary research (excluding case studies, descriptive studies, or clinical interventions) & review articles	12	566 (1-192; 25) approx including control groups (ns separately)	1/1/0=2	Of the 12 studies, 11 had a component related to exercise/physical activity, & 5 related to nutrition. Some included both. Only 3 of the 11 physical activity studies had a control or comparison group in the study design, limiting the validity of the findings in most of the studies. The most common research design for the nutrition studies was a repeated measures design, without any comparison groups. Two used a randomized control group. Most of the studies included no longer term follow-up. Outcomes of physical activity programs included improved fitness, weight reduction, fewer maladaptive behaviours & improved adaptive behaviours, better attitudes toward exercise, & improved life satisfaction. Nutrition studies show some weight reduction for those who are overweight. However, when both exercise & nutrition interventions are combined

Author & date	Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	No. participants (range; Mdn)	Process score	Main findings
							with a more comprehensive health behaviour education program that incorporates exercise & nutrition information, stronger evidence exists for reductions in weight. Health promotion interventions incorporating physical activity, better nutrition, & health behaviour education can have some positive impacts on the health & function of adults with ID. However, the interventions need more rigorous testing because the evidence to date lacks a strong empirically tested evidence base.
Jinks, Cotton & Rylance (2011)	Effectiveness of non-surgical, non-pharmaceutical interventions designed to promote weight loss in ID	1998 to 2009	RCTs, primary quantitative studies such as those with quasi-experimental or similar design, any qualitative research design	12	669 (1-201; 23.5) includes control group for 1 study (ns separately). Also 1 study non-input group of 50, 1 study group of 97 non-ID	0/1/0=1	Most frequent design was a quasi-experimental pretest & post-test design (9). Only one study had a clinical trial approach & there was one predominantly qualitative interview study. Interventions included focus on nutrition, physical activity, health promotion including use of behavioural relapse prevention strategies, behavioural approaches concentrating on teaching self-control techniques & self-monitoring of food intake, a mindfulness programme, & educational programmes designed to increase understanding of the importance of maintaining a healthy lifestyle. A number of studies reported a reduction in participants' BMIs, & some identified the weight loss achieved as being statistically significant. Other positive outcomes reported included decreases in health risks, increased consumption of fruit & vegetables, & improvements in self-reported exercise levels & cardiovascular fitness. Many of the studies reviewed are encouraging, but the general weakness of the evidence base is reflected in the quality assessment scoring & by the fact that only one study achieved a maximum score (scores are summarised and not available for individual studies). There is a lack of RCTs & an absence of randomization in sample selection.
Valentin-Gudiol, Mattern-Baxter, Girabent-Farrés et al (2011)	Effectiveness of treadmill interventions on locomotor motor development in pre-ambulatory infants & children under six years of age at risk of neuromotor delay	1997 to 2011	RCTs and quasi-RCTs	5.	77 (8-25; 16). Controls: 62 (12-18; 16). 139 (8-41; 32). Total of 139 includes 90 children with DS in three studies (n=22; 32; & 36)	1/1/1=3*	Evidence suggested that treadmill intervention could lead to earlier onset of independent walking when compared to no treadmill intervention (two studies; effect estimate -1.47 (95% CI= -2.97- 0.03)), though these trials studied two different populations & children with DS seemed to benefit while it was not clear if this was the case for children at high risk of neuromotor disabilities. Another two studies, both in children with DS, compared different types of treadmill intervention: one compared treadmill intervention with & without orthotics, while the other compared high versus low intensity treadmill intervention. Both were inconclusive regarding the impact of these different protocols on the age at which children started to walk. The available evidence indicates that treadmill intervention may accelerate the development of independent walking in children with DS. Further research is needed to confirm this.
Andriolo, El Dib, Ramos, et	Effectiveness & safety of aerobic exercise	1996 to 2009	Randomised or quasi-randomised	3	56 (n=14, 16 & 26) assumed	1/1/1=3*	In meta-analyses, only maximal treadmill grade was improved after aerobic exercise training programmes (4.26 grades (%) (95% CI= 2.06 - 6.45)). Other variables relative to work performance that could not be combined in a meta-analysis were also improved in

Author & date	Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	No. participants (range; Mdn)	Process score	Main findings
al (2010)	training programmes for physiological & psychosocial outcomes in adults with DS		controlled trials		including controls (ns separately)		the intervention group: maximal test time (p=0.0003), total turns of fan wheel (p=0.02), resistance of ergometer (p=0.003), power knee extension & flexion (p<0.00001), & timed up & go test (p=0.008). Thirty other outcomes including, oxidative stress & body composition, could not be combined in the meta-analysis. Apart from work performance, trials reported no statistically significant improvements. There is insufficient evidence to demonstrate that aerobic exercise in adults with DS improves physical or psychosocial outcomes. Although evidence exists to support improvements in physiological & psychological aspects from strategies using mixed physical activity programmes, well-conducted research examining long-term physical outcomes, adverse effects, psychosocial outcomes & costs is required before informed practice decisions can be made.
Hutzler & Korsensky (2010)	Motivational correlates that both contribute to, & can be assumed to be effects of, participation in sport, recreation, or health-related physical activities in persons with ID	1980 to 2008	Any research including qualitative	23	Intervention studies only: 223 (16-50; 24.5). Controls (sedentary): 142 (8-31; 24) & 1 study non-ID group of 34. Total sample for <u>all</u> studies noted to be 1,596 in article	0/1/1=2	Twelve (52%) of the 23 studies recruited participants from Special Olympics (SO). Of 8 intervention studies, 2 were randomised trials. Positive psychosocial outcomes of physical activity were reported, particularly with regard to self competence, self-esteem & self-concept. Several outcomes commonly reported in non-ID populations were missing in the studies retrieved in this review, including increased self-determination or empowerment & reduced depression & anxiety. The improved physical fitness & elevated skill levels gained during exercise & sport activities were found to serve as mediators for increased perceptions of self-efficacy, as well as for personal & social competence. These factors, together with social support mechanisms, such as peer, attendant & family support, are important determinants of initiation & maintenance of physical activity. The specific contribution of segregated compared with integrated activity in this regard could not be ascertained. Both exercise & sport-related activities seem to contribute to well-being. Improved physical fitness & elevated skill level gained during exercise & sport activities appear to serve as mediators for increased perceptions of self-efficacy & social competence. Peer modelling, as well as video & audio reinforcement, appear to be important modalities in maintaining compliance to exercise programmes.
Cleaver, Hunter & Ouellette-Kuntz (2009)	Incidence & prevalence of mobility limitations in adults with ID	1980 to 2007	Any research related to prevalence	32	21,943 (15-6,401; 214). Controls: n/a no controlled studies	1/1/1=3	The pooled prevalence of mobility limitations varied between 3% & 63% (excluding one study considered an outlier). This variation can be partly explained by differences in the study populations & samples, including the prevalence of other disabilities, the distribution of age, gender or level of ID. However, the biggest cause for variation among studies is likely related to measurement. Mobility limitations were loosely defined in studies & the measurement approach was rarely justified. Studies addressing the epidemiology of mobility limitations in adults with ID, although reasonable in number, are predominantly cross-sectional in design & of insufficient quality to draw conclusions upon

Author & date	Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	No. participants (range; Mdn)	Process score	Main findings
							the frequency or rate of development of mobility limitations.
Damiano & De Jong (2009)	Effectiveness of treadmill training & body weight support in pediatric rehabilitation	1980 to 2008	Any research design	6 on DS from total of 29; based on 2 RCTs	45 in 2 RCTs by single lab, controls: 15	0/1/1=2	Of 29 articles identified, 6 related to 2 RCTs involving infants with DS involving a total of 60 infants with DS, 45 of whom participated in a treadmill intervention. One of the 2 RCTs (level of evidence II) was the first to demonstrate that locomotor development, as measured by milestone achievement, in children with a known motor disability (DS) could be accelerated by as much as several months by practicing stepping on a treadmill while being supported by a parent for eight minutes per day. It also demonstrates the efficacy of treadmill training in children with a motor disability compared to a control intervention. A second RCT evaluated whether development could be further accelerated by increasing intensity in terms of greater treatment time, speed & resistance. The more intense group showed several beneficial short or longer term effects (up to 15 months after training ceased) including a more mature gait pattern as revealed through principal component analysis of multiple gait parameters, & through significant differences on several, but not all, measured temporal-spatial & kinematic gait parameters. The group that received more intense training also showed more advanced obstacle avoidance strategies & more time spent at moderate-high activity level at 15 months post training, suggesting a possible longer term effect on levels of physical activity. Reports on adverse events consistently found that none of the possible risks that were anticipated & monitored were found to have occurred. Studies support the efficacy of treadmill training for promoting the development of independent walking & for advancing other quantitative & qualitative aspects of gait performance in DS. Some evidence suggests that a higher intensity of training may be more effective than a less intense protocol. The intervention has not yet been compared to other possible methods of stepping practice or other intense training regimens which may offer similar benefits.
Humphries, Traci & Seekins (2009)	Nutritional status of adults with ID or DD	1985 to 2007	Descriptive studies & reports of empirical research using either a comparison group or pre–post measures of behaviour	71	(a) 2,689 (8-739; 118). Non-ID comparisons: n=40 & 49 plus 2 studies compared to general population surveys (b) 12,274 (13-1,963;	0/0/0=0	Tabulation & description of studies organised under headings: (a) dietary intake analysis, (b) anthropometric testing, (c) biochemical assessments, & (d) clinical examinations. (a) current dietary intake methods are not adequate to gather valid food intake data in the population of adults with ID or DD living independently or semi-independently. Despite these data collection limitations, the trends indicate that adults with ID or DD who live in the community subsist on nutritionally poor diets planned & prepared by poorly trained support staff, are lacking guidance in making food selections, & have diets that may be inadequate in some essential nutrients & recommended food groups (e.g., fruits & vegetables & dairy) & excessive in other food groups (e.g., fats, sweets, & junk food). (b) the population has a high proportion of overweight & underweight people outside the normal weight range. (c) Lipid biochemistry testing had the most consistent results & showed significant cardiovascular disease (CVD) risk

Author & date	Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	No. participants (range; Mdn)	Process score	Main findings
					229). 1 non-ID comparison group n=49. 10 studies comparison to national surveys or local census data. (c) 676 (7-150; 19). Controls: 370 (10-235; 30). (d) 2,765 (11-553; 108). Controls: 243 (12-78; 37) & 3 studies comparison to large scale survey or study		factors present in adults with ID or DD. (d) Clinical assessments of adults with ID or DD have shown significant problems in the areas of CVD, bone health, gastrointestinal dysfunction, & eating difficulties. The prevalence of these clinical conditions has not been determined precisely. Significant nutrition-related risks exist for adults with ID or DD, including poor diet, elevated rates of over- & underweight, significant CVD risk factors, & multiple, limiting secondary conditions.

Table 4: Other ICD Chapter Headings & Multiple Chapter Heading Reviews

Author & date	ICD Chapter & Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	No. participants (range; Mdn)	Process Score	Main findings
Sullivan, Satgé & Willis (2010)	Chapter II Neoplasms. Cervical cancer risks, frequency, & screening uptake in ID	ns	ns	ns	ns	0/0/0=0	Two large studies linked records of ID to cancer registries. In Finland, no cervical cancer cases were observed in 1,693 women (30,042 person-years) when 2.9 expected. In Australia, of 3,919 women (66,068 person-years), 2 cases were found where 5.68 were expected. However, expected estimates are extremely unstable & should be treated with caution. In conjunction with other smaller studies, this suggests that there is a lower incidence of cervical cancer in women with ID but some do get cervical cancer. There are no known genetic conditions that enhance or decrease the risk of cervical cancer. Uptake of screening is low, with British studies suggesting rates between 7% & 28%. Whilst women with ID are at lower risk of cervical cancer, probably due to lower exposure to key risk factors such as human papilloma virus infection, there is a subgroup of women who are sexually active who should be actively recruited into screening programmes.
Willis, Kennedy & Kilbride (2008) plus Willis, Kennedy, Kilbride, Satge & Sullivan (2008)	Chapter II Neoplasms. Breast cancer, breast cancer screening & breast awareness in women with ID	1997 to 2007	All studies; includes e.g. discussion papers, letters to editors	35	ns	1/0/0=1	Work on incidence of breast cancer in people with ID is limited & weakened by comparing different populations, aetiologies & data collection methods. Few studies specifically concentrate on breast cancer & those that have produce different conclusions about incidence. Some studies suggest a low incidence in women with DS. The consensus from the literature was that up-take of breast cancer screening was lower in women with ID than women in the general population. Barriers to uptake of screening include method of referral, physical disability, ID level, ill health of either women with ID or carers, moving area/into a nursing home, transport & fear of the procedure. Three British studies have looked at improving uptake. More research is needed into the incidence & prevalence of breast cancer & a better understanding of what knowledge, information & understanding, women with ID have & need in order to participate in breast screening. With increased risk factors such as nulliparity, limited exercise & obesity it is essential that women with ID are encouraged to attend breast screening.
Beavis, Kerr, Marson et al (2007b; updated 2011)	Chapter VI Diseases of the nervous system. Pharma-cological interventions for epilepsy in ID	1806 to 2011	RCTs & quasi-RCTs with inadequate method of allocation concealment; blinded or	13	872 (14-169; 73) including controls (numbers presented are total randomised)	1/1/1=3*	In the majority of cases where antiepileptic drugs (AEDs) were trialled in this population, moderate reductions in seizure frequency & occasional seizure freedom were obtained. The quality of the studies does not aid clinicians greatly with respect to side effects. In general, in trial settings patients continued on treatment in the majority of cases, & placebo groups often experienced fewer side effects. Where side effects were experienced they appeared similar to those seen in non-ID studies. The majority of studies had a lack of or used non-reliable measures of behavioural exacerbation. Where measured, little obvious impact on behaviour was seen in terms of behaviour disorder.

Author & date	ICD Chapter & Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	No. participants (range; Mdn)	Process Score	Main findings
			unblinded				The review broadly supports the use of AEDs to reduce seizure frequency in people with refractory epilepsy & ID. The evidence suggests that side effects are similar to those in the general population & that behavioural side effects leading to discontinuation are rare, but that other effects are under-researched. It is not possible to comment on relative efficacy between medications, making clinical decisions difficult.
Chapman, Iddon, Atkinson et al (2011)	Chapter VI Diseases of the nervous system. Misdiagnosis of epilepsy in people with ID: prevalence; reasons; implications; & improving diagnosis	1998 to 2008	Any primary research & systematic reviews	8	1,362 (1-666; 134) number of total with ID not known. Controls: n/a cohort studies & cases studies	1/1/0=2	Six cohort studies & two case studies identified. Majority of participants were children or adolescents with only one cohort study & two case studies focusing on adults. Where data was provided in the cohort studies between 32% & 38% of people with ID were diagnosed as not having epilepsy or as having non-epileptic events. The main reason for misdiagnosis was the misinterpretation of behavioural, physiological, syndrome related, medication related or psychological events by parents, paid carers & health professionals. People may receive the incorrect treatment due to misdiagnosis e.g. if non-epileptic events are misdiagnosed as epileptic events people may be prescribed unnecessary antiepileptic medication. There is a lack of research focusing on the diagnosis & misdiagnosis of epilepsy amongst people with ID. Families & those working in ID service should be made more aware of the possibility of misdiagnosis.
Creavin & Brown (2009)	Chapter VII diseases of the eye & adnexa. Prevalence of ophthalmic abnormalities in children with DS	ns to 2008	Any study related to prevalence	23	ns but noted that sample size ranged from 18 to 524	0/0/0=0	The most common disorders affecting vision in children with DS were poor visual acuity (30% to 62%) & strabismus (3% to 57%). Hyperopia, found in 4% to 59% & astigmatism, found in 6% to 60% were also common. Less common were myopia (8% to 41%), blepharitis (3% to 47%), & nystagmus (3% to 33%). Two studies found glaucoma affected more than 5% of patients. Early treatment of cataract can prevent amblyopia & this condition was found in more than 20% of patients by 2 studies. Of the ocular findings not affecting vision, the most common were slanting fissures & epicanthic folds. The high prevalence of ophthalmic disorders in children with DS demonstrated by all studies highlights the need for these children to have ophthalmic assessment by a trained professional. A number of studies found conditions that are potentially detrimental to vision, such as cataract and glaucoma, in a significant minority of patients, reinforcing the need for early assessment & treatment of individuals with DS.
Molina, Leal & Frencken (2011)	Chapter XI Diseases of the digestive system. Preventative & restorative treatment programmes for	1991 to 2011	RCTs (clinical), cohort studies, case control studies, systematic reviews	8 (4 clearly ID)	145 (10-90, 23) for studies where sample clearly ID. Includes all groups (ns separately)	1/1/1=3	Of the 8 studies, 4 clearly used ID samples, 1 mixed ID/physically disabled, 1 unspecified 'special needs', & 2 physically disabled. For preventive programmes, quality of (all) studies was rated from level II to level III-3 with one RCT. For restorative programmes, quality rated as level II to level III-2 with one RCT. Due to heterogeneity, quality, number, types & outcomes of studies the review did not discover strategies for preventive & restorative care of caries in people with disabilities. Clinical guidance could not be produced. It was not possible to extract a common strategy for prevention & treatment of caries in people with disabilities. More & high quality research is required.

Author & date	ICD Chapter & Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	No. participants (range; Mdn)	Process Score	Main findings
	managing dental caries in disabled people						
Anders & Davis (2010)	Chapter XI Diseases of the digestive system. Oral health status of ID compared to those without ID	1975 to 2008	Any with quantitative measure of oral health & non-ID comparison group	27	17,026 (12-9,620; 166). Controls or comparisons: 547 (23-191; 43) & for 20 studies comparison from sources such as National Surveys	0/1/1=2	People with ID are more likely to have poor oral hygiene & periodontal disease & possibly more likely to have caries than people without ID. Levels of untreated caries were consistently higher in people with ID (% prevalence not given). Elimination of this health disparity & its implications on quality of life should become a public health priority.
de Veer, Bos, Niezen-de Boer et al (2008)	Chapter XI Diseases of the digestive system. Symptoms of gastro-esophageal reflux disease (GORD) in people with severe ID	1990 to 2006	Empirical studies with a minimal sample size of five	19	1,050 (12-186; 34). Controls: 3,351 (6-2,580; 38)	1/1/1=3	Many studies focus on people with neurological disorders without mentioning whether they have ID. Most studies do not give exact definitions of the symptoms, making clustering of results difficult. For example vomiting is defined as daily vomiting, including regurgitating; as persistent vomiting & regurgitation being two separate symptoms; or as repeated regurgitation (without mentioning vomiting as another symptom). There is no single symptom that is clearly related to GORD. For example, vomiting was examined in eight studies. For five studies 2 × 2 tables could be reconstructed. Three of them revealed a significant difference in vomiting between the GORD & non-GORD group. Two studies did not find a statistically significant relationship between vomiting & the diagnosis of GORD. Sensitivity in the eight studies ranged from 22% to 100% (median 57%). Vomiting in the non-GORD group was less frequent (5 studies, range 13%–31%, median 14%). Vomiting, rumination & hematemesis are associated with a higher risk of the presence of GORD. There is no clear evidence that particular behavioural symptoms are indicative for GORD. Patients with cerebral palsy, patients using anticonvulsive drugs, & those with an IQ lower than 35 more frequently have GORD. Nearly 50% of those with IQ < 50 have GORD.There is no single symptom that is clearly related to GORD, those giving care to people with severe ID should be alert to a broad range of symptoms.
Srikanth, Cassidy, Joiner et al	Chapter XIII Diseases of the musculoskeletal	1950 to 2008	Any on prevalence	13	2,646 (22-994; 133). Controls: 225	0/0/0=0	The majority of studies identified increased prevalence of osteoporosis & osteopenia with associated low bone mass density. In most studies individuals with ID presented with more than two risk factors. Risk factors are discussed (e.g. reduced physical

Author & date	ICD Chapter & Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	No. participants (range; Mdn)	Process Score	Main findings
(2011)	system & connective tissue. Prevalence of osteoporosis & osteopenia in ID				(23-108; 47)		activity, early menopause in women, increased exposure to antiepileptics or antipsychotic medications). Further research is needed to identify the prevalence of risk factors in people with ID. Monitoring for risk factors associated with osteoporosis should be included in Health Action Plans & education regarding bone health offered to all the patients & their carers.
Willgoss, Yohannes & Mitchell (2010)	Chapter XX External causes of morbidity & mortality. Risk factors & preventative strategies for fall-related injuries in people with ID	2000 to 2009	Any including literature reviews	7	1,942 (18-1,014; 257). Controls: n/a no studies with controls	0/1/0=1	Identified four epidemiological studies, two non-controlled trials, & one pilot study. Up to 57% of people with ID experienced a fall. Falling was the cause of 50–62% of all recorded injuries. Risk factors for falls in people with ID may include older age, impaired mobility, epilepsy & behavioural problems. There was a paucity of evidence for intervention strategies identified. There is a lack of evidence for falls management in people with ID. Findings suggest that falls are a common cause of injury, institutionalisation & impaired quality of life in people with ID. Environmental safety, careful medical management & exercise interventions may play an important role in minimising fall-related injuries. Further research is needed to explore risk factors for falls & falls management in this group.
Oeseburg, Dijkstra, Groothoff et al (2011)	Multiple chapters. Prevalence of chronic health conditions in children with ID	1996 to 2008	Cohort, patient-control, or cross-sectional design	31	30,070 (64-11,892; 310) not available for one study. Controls: n/a no studies with controls	0/1/1=2	The 6 most prevalent chronic health conditions in children with ID were epilepsy (weighted mean prevalence 22.0/100; 95% CI=20.8–23.2), cerebral palsy (19.8/100; 95% CI=18.6–21.1), any anxiety disorder (17.1/100; 95% CI=15.1–19.4), oppositional defiant disorder (12.4/100; 95% CI=10.7–14.4), DS (11.0/100; 95% CI= 10.5–11.4), & autistic disorder (10.1/100; 95% CI=8.8–11.6). For visual problems, prevalence rates ranged from 2.2% to 26.8% (not possible to calculate weighted mean prevalence); hearing problems 0.0% to 7.1% (4.5/100; 95% CI=3.4–5.7). Researchers in 7 studies reported prevalence rates of miscellaneous somatic chronic health conditions, such as chronic obstructive pulmonary disease (8.9%), gastric & esophageal diseases (6.9%), back & neck disorders (6.9%), osteoarthropathia (2.5%), cerebrovascular accident (range: 0.3% to 2.5%), Reye syndrome (0.3%), HIV (0.0%), & other chronic health conditions (4%). The weighted mean prevalence rate for cerebrovascular accident was 2.0/100 (95% CI=1.8–2.3). It was not possible to calculate a weighted mean prevalence rate for the other somatic chronic health conditions. Prevalence rates of chronic health conditions in children with ID are higher than the prevalence rates reported in studies of children without ID. However, the number of studies that were included & the number of chronic health conditions they reported about were limited.
Haveman, Heller, Lee et al (2010)	Multiple chapters. Age-associated	1999 to 2009	Any	ns	ns	0/0/0=0	The prevalence rates of health conditions for adults with ID were inconsistent among the studies. Only for some conditions (i.e., constipation) were the rates quite similar. There was almost a total lack of information about the aging process & its consequences for

Author & date	ICD Chapter & Topic	Dates covered by searches	Inclusion criteria (study designs)	Number of studies	No. participants (range; Mdn)	Process Score	Main findings
	health risk factors in aging persons with ID						persons with ID in low- & middle-income countries. Significant evidence is emerging that CVD is as prevalent among people with ID & is as common a cause of death as in the general population. Digestive system problems were evident with high occurrence rates of helicobacter pylori, GORD, & constipation. The review revealed a growing body of work on health risk factors, such as overweight & obesity, which are often linked to the onset of a variety of diseases & impairing conditions. Healthier lifestyles, better nutrition & more exercise, & greater surveillance of health risks were seen as ways to improve the health status of aging adults with ID.
Torr, Strydom, Patti et al (2010)	Multiple chapters. Causes of mortality & age-related morbidity in people with DS aged 40 years & over	1993 to 2008	Epidemiological & clinical studies	25 tabulated	DS: 2,794 (6-420; 49). Comparison Groups Non DS ID: 5,040 (8-1,178; 141.5). Non-ID: 3 studies n=10, 67 & 78; 1 study age matched controls (n=ns)	0/0/0=0	Findings are described by study in relation to psychiatric disorders, dementia of the Alzheimer type, pulmonary disorders, menopause, sensory impairments, & musculoskeletal disorders. Dementia of the Alzheimer type among adults with DS is associated with high levels of morbidity. However, this overshadows very high rates of early onset age-related disorders, especially sensory impairments & musculoskeletal disorders. These are important disorders because of the associated functional disability, pain, & distress, as well as the increased risk of mortality associated with vision & mobility impairments. Functional decline in older adults with DS cannot be automatically assumed to be due to dementia of the Alzheimer type, which is not inevitable in all adults with DS. Functional decline may be the result from a range of disorders, especially sensory & musculoskeletal impairments. Given the high rates of early-onset age-related disorders among adults with DS, programmatic screening, monitoring, & preventive interventions are required to limit secondary disabilities & premature mortality.

Acronyms: AAC: augmentative & alternative communication; AD: Alzheimer's disease; ADHD: attention-deficit hyperactivity disorder; AED: antiepileptic drug; ASD: autistic spectrum disorder; BIF: borderline intellectual functioning; BMI: body mass index; CB: challenging behaviour; CBA: controlled before and after study; CBT: cognitive behavioural therapy; CPA: cyproterone acetate; CVD: cardiovascular disease; DD: developmental disabilities; DR: differential reinforcement; DS: Down's syndrome; EBP: evidence-based practice; ECT: electroconvulsive therapy; EMDR: Eye Movement Desensitization & Reprocessing; FBA: functional behaviour assessment; FCT: functional communication training; FT + EXT: fixed time + extinction; FTST + EXT: fixed time + extinction with schedule thinning; GORD: gastroesophageal reflux disease; ID: intellectual disabilities; ITS: interrupted time series analysis; LHRH: luteinising hormone releasing hormone agonists; MBLR: mean baseline reduction; MO: motivating operations; MPA: medroxyprogesterone acetate; NAP: non-overlap of all pairs; NCR: non-contingent reinforcement; ns: not stated; PD: personality disorder; PECS: picture exchange communication system; PND: percentage of non-overlapping data; PTSD: post-traumatic stress disorder; QOL: quality of life; RCT: randomized controlled trial; SCSn : single-case & small-n; SIB: self-injurious behaviour; VT + EXT: variable time + extinction; VTST + EXT: variable time + extinction with schedule thinning