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Organising health care services for persons with an intellectual disability

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ABSTRACT

Background

When compared to the general population, persons with an intellectual disability have lower life expectancy, higher morbidity, higher rates of unmet health needs, and more difficulty finding and getting health care. Organisational interventions are used to reconfigure the structure or delivery of health care services and may prove useful to decrease the noted disparities.

Objectives

To assess the effects of organisational interventions for the mental and physical health problems of persons with an intellectual disability.

Search methods

We searched the Cochrane Effective Practice and Organisation of Care Group specialised register (no year restriction), MEDLINE, EMBASE, CINAHL, other databases from January 1990 to April 2006 reference lists of included studies, and we consulted experts in the field.

Selection criteria

Randomised controlled trials, controlled clinical trials, controlled before and after studies and interrupted time series of organisational interventions aimed at improving care of mental and physical health problems of adult persons with an intellectual disability.

Data collection and analysis

Two review authors independently extracted data and assessed study quality. Missing data were requested from authors of included studies.

Main results

Eight studies met the selection criteria: six were randomised controlled trials, one was a controlled before and after study, and one was an interrupted time series. In general the studies were of acceptable methodological quality. The included studies investigated interventions dealing with the mental health problems of persons with an intellectual disability, none focused on physical health problems. Three of the studies identified effective organisational interventions and five showed no evidence of effect. Only two studies were similar enough to analyse using a meta-analysis. In the pooled analyses 25 participants received assertive community treatment and 25 received standard community treatment. Results from measures of function, caregiver burden and quality of life were non-significant.

Authors' conclusions

There are currently no well designed studies focusing on organising the health services of persons with an intellectual disability and concurrent physical problems. There are very few studies of organisational interventions targeting mental health needs and the results of those that were found need corroboration. There is an urgent need for high quality health services research to identify optimal health services for persons with an intellectual disability and concurrent physical problem.

PLAIN LANGUAGE SUMMARY

Health care services for adults with an intellectual disability

Adults with an intellectual disability often have difficulty meeting their health care needs. Compared to the general population, they have poorer health and have more difficulty finding, getting to, and paying for health care. This difficulty is true for both physical and mental health care needs.

Efforts in the community have been made to reduce these problems for people with intellectually disabilities. In the past, people with intellectually disabilities were taken care of in special institutions. Now there is a shift towards moving people out of institutions and into the community. But with this shift, it is necessary to ensure that there are appropriate community services available. Many ways to organise the community health care services have been developed.

To determine what are the effects of different ways to organise services, a review of the literature was conducted. After searching for all relevant studies, eight studies were found. These studies were done in a variety of countries which have different health care systems overall. Therefore it is difficult to say whether a specific service works the same way in a different country.

In England, community services which provide more contact to people with intellectual disabilities and mental health problems, may provide the same benefits as a standard service.

In the United States, community services which provide more intense services to people with intellectually disabilities and mental health problems, may provide more benefits than standard services. This may be true in England for people with mild or borderline intellectual disabilities.

Overall, more research is needed to determine the effects of different ways to organise services for people with intellectual disabilities. Most studies focused on people who had intellectual disabilities and mental health problems. But there were no studies on people who had intellectual disabilities and physical problems.

BACKGROUND

Intellectual disability originates before age 18 and is characterised by significant limitations in intellectual functioning and adaptive behaviour as expressed in conceptual, social, and practical adaptive skills (American Association on Mental Retardation ([AAMR](#)

[2002](#))). An intelligence quotient (IQ) score of 70 or below is generally used as the diagnosis criterion. The term 'intellectual disability' is gaining acceptance worldwide, but 'mental retardation', 'developmental disability' and 'learning disability' are still used synonymously. Between 1 to 3% of the world's population has an in-

tellectual disability (World Health Organization (WHO 2001)). It is more common in developing countries due to more frequent injuries at birth, childhood brain infections, and iodine deficiency. Other common causes include genetic factors (e.g. Down syndrome, Fragile X syndrome, Prader-Willi syndrome), prenatal exposure to alcohol, and environmental hazards.

In developed countries, the disparity between life expectancy and morbidity in persons with an intellectual disability and the general population have decreased in recent years; however, a real difference still exists (Frid 1999; Patja 2001; United Nations 2006; Van Schrojen 1997; Yang 2002). Studies consistently find that the most common causes of mortality for persons with an intellectual disability are respiratory, cardiovascular, and gastrointestinal diseases, neoplasms, and external causes such as accidents and poisonings (Durvasula 2002; Patja 2001). Although results vary according to methodology, a recent study found that 41% of adult persons with an intellectual disability also experience mental ill-health of some type (Cooper 2007). This co-occurrence of intellectual disability and mental illness is sometimes referred to as a 'dual diagnosis'. A broad definition of dual diagnosis includes people with an intellectual disability exhibiting changes, challenges or problems in normal behaviour as well as people with a formal psychiatric diagnosis (Morris 2003). This review uses specific categories to describe clinical problems in most instances; when it uses the term dual diagnosis it is consistent with the preceding definition.

The best way to organize health care services for persons with an intellectual disability has been debated since the deinstitutionalization of services for this population started in developed countries (Alexander 2002; Aspray 1999; Hassiotis 2000; O'Hara 2000). Deinstitutionalization has been credited with improving the lives of persons with an intellectual disability; however, in doing so it has shifted the responsibility of the many specialised health care needs to the community without sufficient preparation or financial support. Different countries have developed various models of care to deal with this shift in responsibility. In England for example, Community Learning Disability Teams were created to provide a diverse range of clinical services to meet the comprehensive mental and physical health needs of persons with an intellectual disability (O'Hara 2000). This model of care has been criticised for frequently bypassing mainstream primary care services. This review uses the term mainstream to describe health care that could potentially be used by any person in the general population including persons with an intellectual disability. Jurisdictions like the United States have relied more on the mainstream health care system; however, this model of care has been criticised for its insufficient capacity to effectively manage the specialised needs of this population (Bouras 2004; Lennox 2002). Well designed research on organisational interventions may provide insight to resolve such dilemmas and may prove useful to decrease the disparities in health outcomes that exist between persons with an intellectual disability and the general population.

There is general agreement among review articles that the mainstream health system has lagged in providing adequate health care to this population (Alborz 2005; Durvasula 2001; Fisher 2004; Havercamp 2006; Krahn 2006; Lennox 1997; Ouellette Kuntz 2005). Using unmet needs to measure health disparity, the National Health Interview Survey in the United States showed that persons with an intellectual disability were 1.89 times more likely to report unmet health care needs than persons with no functional limitations (Anderson 2003). Larson 2005 conducted a review of access to health care among persons with an intellectual disability. It summarised that for persons with an intellectual disability, between 3.2% and 50% experience an unmet medical need and between 1.2% and 27% experience an unmet mental health need. In addition, people living on their own or with family members were less likely to get routine health care than those in community or institutional residential settings. Unmet health care need is a serious issue among persons with an intellectual disability and effective interventions and models of care need to be identified in order to decrease health disparities in this population.

The situation for persons with an intellectual disability in developed countries is summarised well in a report by the U.S Secretary of Health and Human Services: compared with other populations, adults with an intellectual disability experience poorer health and more difficulty in finding, getting to, and paying for appropriate health care (United States. Public Health Service. Office of the Surgeon General (US PHS 2002)). The lifetime direct and indirect economic costs for intellectual disability have been estimated at \$1,014,000 per person in the United States (Centers for Disease Control and Prevention CDCP 2004). These costs will surely increase over the years as more persons with an intellectual disability acquire age related health problems and if their health needs continue to go unmet.

A number of options for organising health care services for persons with an intellectual disability have been proposed. Models of care range from enhancements to already existing mainstream health care to specialty care programs which specifically target the health needs of this population. The purpose of this systematic review was to evaluate recent and high quality research on health services interventions for persons with an intellectual disability in order to provide the highest evidence on how to effectively care for this population.

OBJECTIVES

The objectives of the systematic review were to:

1. Identify effective methods of organising health care services to improve the health outcomes of persons with an intellectual disability
2. Interpret the results of the review in context of ongoing debates in the area of health care services for persons with an intellectual

disability

METHODS

Criteria for considering studies for this review

Types of studies

Randomised controlled trials (RCT), controlled trials, controlled before and after (CBA) studies, and interrupted time series (ITS) were included (Cochrane 2006b).

Types of participants

Persons with an intellectual disability and concurrent physical, mental, or behavioural problems (16 years and older).

Types of interventions

Researchers have identified components of health care services that can be targeted to improve outcomes in disease management (Gilbody 2003; Wagner 1996; Wagner 1998). These include:

- 1) developing and implementing evidence based guidelines or protocols;
- 2) supporting guidelines or protocols through health provider education and reminders and increased interaction between generalists and specialists;
- 3) supporting self management for the patient; and
- 4) reorganising the health service such that it meets the needs of the target population.

This last item is the focus of this review.

The Cochrane EPOC Review Group categorizes interventions in further detail and using an adapted version of its taxonomy, the following organisational interventions were included (Cochrane 2006b):

- a) Revision of professional roles: Shifting roles among health professionals or expanding roles to include new tasks; also known as 'professional substitution', 'boundary encroachment'.
- b) Clinical multidisciplinary teams: Creating a new team of health professionals of different disciplines or adding new members to the team who work together to care for patients; includes changing the caseload of the team or members of the team, or changing the frequency of episodes of care by the team or members of the team.
- c) Formal integration of services: Bringing together services across sectors or teams, or organising services to bring all services together at one time; also called 'seamless care'.
- d) Continuity of care: Arranging for follow up or case management; includes co-ordination of assessment, treatment and arrangement for referrals.

e) Changes to the setting/site of service delivery: Includes home-based, hospital-based (inpatient and outpatient), and peripartetic interventions; excludes comparisons to institution based residential settings.

f) Changes in scope and nature of services.

In countries where deinstitutionalization has taken place, researchers commonly examined the effect of change from institution based residential settings to community based residential settings. These were considered out of scope for this study and are considered elsewhere (Lynch 1997; Young 1998). Financial interventions were also excluded.

Types of outcome measures

Type of outcome measure was not used as an inclusion or exclusion criteria. Possible outcomes included (but were not restricted to) measures of the following: physical health, psychological health, behavioural problems, carer burden, quality of life, and health system issues.

Search methods for identification of studies

See: Effective Practice and Organisation of Care (EPOC) Group methods used in reviews.

The following electronic databases were searched for primary studies between the years of January 1990 and April 2006 with the assistance of a professional librarian:

- a) The EPOC Register (and the database of studies awaiting assessment) was reviewed
- b) Bibliographic databases, including MEDLINE, CINAHL, EMBASE, Evidence Based Medicine Reviews Multifile (EBMZ), Applied Social Sciences Index and Abstracts (ASSIA), Education Resources Information Center (ERIC), Health Sciences, PAIS International, Physical Education Index, Political Science, Proquest Education Journals, PsycARTICLES, Psychology, PsycINFO, Social Science Abstracts, Social Services Abstracts, Sociological Abstracts.

Electronic databases were searched using a strategy developed incorporating the methodological component of the EPOC search strategy combined with selected MeSH terms and free text terms relating to intellectual disability. The MEDLINE search strategy was translated into the other databases using the appropriate controlled vocabulary as applicable.

The MEDLINE search used the term mental retardation** (exploded) and any of the following exploded terms: case management, primary health care, continuity of patient care, "delivery of health care, integrated", care coordination, health promotion, health services, health planning, organisational models, patient care management, comprehensive health care, delivery of health care, disease management, patient care team, health services research, critical pathways, dentist's practice patterns, patient-centered care, outcome and process assessment (health care), program

evaluation, quality assurance, health care reform, health services accessibility, and community mental health services. The CINAHL search was based on mental retardation (exploded), intellectual disability or developmental disability and any of the following exploded search terms: multidisciplinary care team, home health care, managed care programs, case management, care coordination, primary care, health care delivery, integrated health care delivery, health care reform, health resource allocation, health resource utilization, health services accessibility, managed care programs, primary health care, organizational change, organizational structure, quality management, shared services, continuity of patient care, disease management, family centered care, patient centered care, protocols, and community mental health services.

The EMBASE search was based on mental deficiency (exploded), intellectual impairment (exploded), mental retardation malformation syndrome (exploded), learning disorder (exploded), or learning disability and any of the following exploded search terms: community mental health center, health center, mental health center, health care delivery, periodic medical examination, mental health care, patient monitoring, health care management, health care system, group practice, care coordination, primary medical care.

The EBMZ database search was based on mental retardation, developmental disability, intellectual disability, mental handicap, learning disability, or mental deficiency with any of the following search terms: primary care, care coordination, care management, community mental health, team, health planning, health management, and health care.

The remaining databases were searched with mental retardation, intellectual disability, developmental disability, mental handicap, Angelman syndrome, Bardet-Biedl syndrome, Cockayne syndrome, congenital syndrome, cri-du-chat syndrome, de Lange syndrome, Down syndrome, fragile X syndrome, Laurence-Moon syndrome, Prader-Willi syndrome, Rett syndrome, Rubinstein-Taybi syndrome, or Williams syndrome with any of the following terms: health service, medical care, medical service, health care, health policy, or primary care.

Detailed search strategies are included in [Appendix 1](#).

Other sources:

- a) Handsearching of those high-yield journals and conference proceedings which have not already been handsearched on behalf of the Cochrane Collaboration.
- b) Reference lists of all papers and relevant reviews identified.
- c) Authors of relevant papers were contacted regarding any further published or unpublished work.
- d) Authors of other reviews in the field of effective professional practice were contacted regarding relevant studies of which they may be aware.

**The MEDLINE mental retardation terms include the following: Cri-du-Chat syndrome, De Lange syndrome, Down Syndrome, Fragile X syndrome, Prader-Willi syndrome, Rett syndrome and Williams syndrome.

Data collection and analysis

Selection of studies

We compiled a list of potential studies for inclusion from the database searches. The inclusion criteria were applied to this list in stages by two review authors in the following manner: the review authors independently read the titles and abstracts of each study and excluded those that were not related to the study population or to the research question; full articles of studies that could not conclusively be rejected were obtained; based on the full text, the two review authors independently decided whether to include or exclude the study; and information was fully extracted from studies that could not be excluded at this stage. Disagreements on the eligibility of a study were generally resolved by discussion; in cases where consensus could not be achieved, a third review author acted as an arbitrator.

Data extraction and management

The Cochrane EPOC Review Group ([Cochrane 2006a](#)) data collection form was modified and piloted to fit the needs of the review. The data collection form includes sections on inclusion criteria, interventions, study participants, setting, methods, outcome measures, results, and quality criteria. The two review authors independently extracted data from studies and disagreements were resolved as previously described.

For time series analyses, methods suggested by [Grilli 2002](#) were used to manage the data. When the original paper provided only a graph of results, data were digitised with a computer scanner and results were derived by electronically measuring each observation. Researchers sometimes inappropriately analyze data from interrupted time series by comparing means before and after the introduction of an intervention. Statisticians consider this inappropriate and have proposed using time series regression techniques, a double bootstrap method or autoregressive integrated moving average models (ARIMA) instead ([Huitema 2004](#); [Ramsay 2003](#)). This is to control for the influence of time trend and autocorrelation between observations. The double bootstrap method described by McKnight et al. were used here since it is a preferred method for research with small numbers of data points ([Huitema 2004](#); [McKnight 2000](#)). Using McKnight et al's methodology, we calculated two regression coefficients corresponding to two standardised effect sizes for each interrupted time series ([Grilli 2002](#)).

Assessment of methodological quality of included studies

For the RCTs included in the review, a protection against bias score was assigned based on criteria developed by EPOC ([Cochrane 2006a](#); [Cochrane 2006b](#)).

The criteria were: 1) concealment of allocation, 2) completeness of follow up of study participants, 3) blinded or objective assessment of primary outcome(s), 4) no important concerns in relation to baseline measures, 5) reliable primary outcomes, and 6) protection against contamination. The protection against bias rating was assigned in the following manner: “not clear” if no relevant information was reported in the study; “not done” if the study authors specifically describe the item and it does not meet EPOC criteria; “done” if the study authors specifically describe the item and it meets EPOC criteria. For non-RCT studies a detailed quality evaluation was performed using EPOC criteria relevant to the study design and results were presented in the text (Cochrane 2006a; Cochrane 2006b).

Assessment of heterogeneity

Clinical heterogeneity -defined as between study variability in the participants, interventions, and outcomes- was evaluated among the included studies (Higgins 2005). Only studies with similar study populations, interventions and outcome measures were considered to have low clinical heterogeneity and were considered for a meta-analysis.

Statistical heterogeneity was evaluated for studies where pooling was deemed appropriate. Statistical heterogeneity is variability in the treatment effects being evaluated among the different trials (Higgins 2005). It was evaluated using a χ^2 test and I^2 . A P-value of 0.10 rather than the usual 0.05 was used to determine statistical significance for the χ^2 test due to the small sample sizes and low number of included studies. This increases the power of the test to detect heterogeneity. A value of I^2 greater than 50% was considered to represent significant heterogeneity. Due to the low number of studies in the current review, an in depth investigation of statistical heterogeneity was of limited value; when warranted, however, strategies described in the Cochrane handbook to address heterogeneity were applied (Higgins 2005).

Data synthesis

In most instances, it was not possible to pool study results due to the substantial heterogeneity. Instead results and characteristics of all included studies were summarised in tables.

The complexity of health service interventions mean that they may not fit precisely into single a priori defined categories. Campbell et al. have suggested a framework for evaluating interventions that are complex or made up of interconnected parts (Campbell 2000). Consistent with this framework an attempt was made to specify the “active ingredients” of the interventions of included studies. If possible, we presented the results from the following outcomes: the primary outcome, quality of life, and carer burden. The primary outcome was either identified by the original study author(s) or identified by the review authors as best reflecting the intervention (Grilli 2002). Including quality of life and carer burden in health service research acknowledges the importance of evaluating the individual as a whole and the impact on support persons.

Meta-analysis

RevMan 4.2 was used for all statistical analyses (Nordic 2003). In the absence of heterogeneity, we used a pooled effect estimate from a fixed-effect meta-analysis. A random-effects model was considered for studies showing statistical heterogeneity. The mean difference (MD) was used to calculate a summary statistic of final values from studies reporting an outcome using the same measure (Higgins 2005). When results came from different outcome measures, the standardised mean difference (SMD) was used. This standardizes the results of the trials to a uniform scale before being combined.

RESULTS

Description of studies

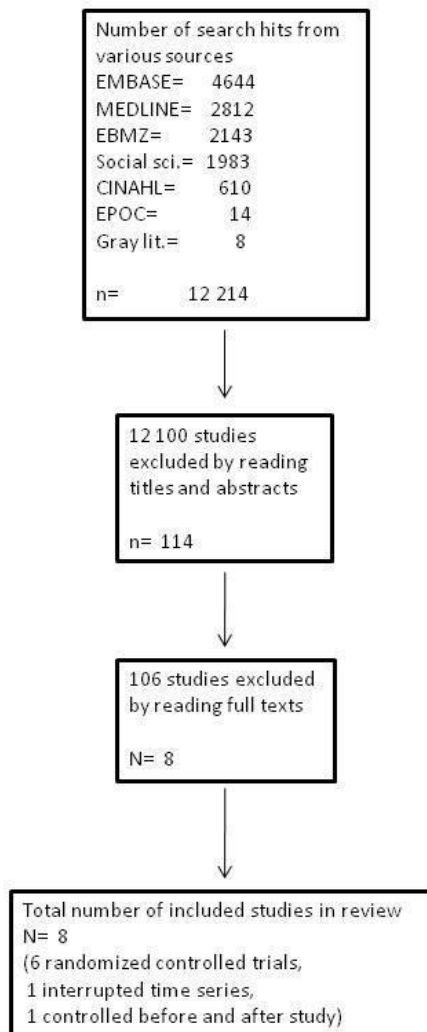
See: [Characteristics of included studies](#); [Characteristics of excluded studies](#).

Results of the search

A total of 12,214 potentially relevant studies were identified and of these 114 full texts were examined. [Figure 1](#) shows a flowchart of search results.

Figure 1. EMBASE = Excerpta Medica Database MEDLINE = United States National Library of Medicine's bibliographic database EBMZ = Evidence Based Medicine Reviews Multifile Social Sci.= Social sciences database CINAHL = Cumulative Index to Nursing & Allied Health Literature EPOC = Effective Practice and Organisation of Care registry

Figure 1: Search results from all sources



Included studies

The eight included studies are described in [Characteristics of included studies](#). One of the studies ([Hassiotis 2001](#)) was identified through the reference list of included studies and the remainder came from electronic databases. Six of the studies were randomised controlled trials ([Coelho 1993](#); [Dowling 2006](#); [Hassiotis 2001](#); [Martin 2005](#); [Oliver 2005](#); [Van Minnen 1997](#)), one was a controlled before and after study ([Lowe 1996](#)), and one was an interrupted time series analysis ([Allen 1998](#)).

The study [Allen 1998](#) did not report information on the sample and demographics. Among studies for which the information was available, the average age of study participants was 34.6 ([Coelho 1993](#); [Lowe 1996](#); [Martin 2005](#); [Oliver 2005](#); [Van Minnen 1997](#)) and 59% were male ([Coelho 1993](#); [Dowling 2006](#); [Hassiotis 2001](#); [Lowe 1996](#); [Martin 2005](#); [Oliver 2005](#); [Van Minnen 1997](#)). The sample size for included studies was small (range 20 to 50) ([Coelho 1993](#); [Dowling 2006](#); [Lowe 1996](#); [Martin 2005](#); [Oliver 2005](#); [Van Minnen 1997](#)) with the exception of the study by [Hassiotis 2001](#) (sample size = 104). The studies used population samples from Wales ([Allen 1998](#); [Lowe 1996](#)), England ([Hassiotis 2001](#); [Martin 2005](#); [Oliver 2005](#)), the United States ([Coelho 1993](#)), the Netherlands ([Van Minnen 1997](#)) and from across the United Kingdom ([Dowling 2006](#)). All the studies included persons with an intellectual disability who had psychological or behavioural problems ranging in seriousness from bereavement ([Dowling 2006](#)) to severe psychotic illness ([Hassiotis 2001](#)). [Hassiotis 2001](#) included participants with mild intellectual disability and borderline IQ, identified as such using the National Adult Reading Test. Physical health problems were included in the search strategy but none of the studies identified physical health problems among participants.

Interventions

All of the studies were complex interventions and several fit into more than one of the EPOC taxonomy of interventions. Some studies stated which components of the intervention were thought to be most responsible for expected outcomes. None of the studies used an intervention focusing on formal integration of services. [Characteristics of included studies](#) provides more detail on the nature of the intervention and control groups.

The study by [Allen](#) included several service interventions introduced at different time periods, making it difficult to identify which was responsible for changes in outcome ([Allen 1998](#)). The baseline period (1975 to 1982) included the services primarily provided by an inpatient specialty hospital for persons with an intellectual disability. The second time period (1983 to 1989) introduced community support teams for persons with an intellectual

disability. The third time period (1990 to 1995) included specialist services for persons with an intellectual disability in addition to the already existing community support teams. There is no control group since the study design is an interrupted time series.

[Coelho et al.](#) described an intervention with “differences in the frequency and intensity of participant involvement” when compared to the control treatment and where the intervention emphasized contact with participants in their natural environment ([Coelho 1993](#)). The degree of specialization in intellectual disability was similar in both groups.

The intervention in ([Dowling 2006](#)) changed the role of carers of persons with an intellectual disability to include bereavement work. Control conditions consisted of mainstream bereavement counselling provided by trained bereavement counsellors with no experience working with persons with an intellectual disability.

[Hassiotis et al.](#) used intensive case management as an intervention and specified smaller case-load size to differentiate from the control treatment ([Hassiotis 2001](#)). The intervention and control were mainstream management strategies meant for the general population.

In the study by ([Lowe 1996](#)), both the intervention and control groups had access to standard care which includes services provided Community Learning Disability Teams in the United Kingdom. The authors identified components of the intervention which were in addition to standard care: 1) Intensive individually tailored support to people with an intellectual disability and their carers, 2) taking place in the participant’s natural setting, and 3) provided by a multidisciplinary team ([Lowe 1996](#)). It was not possible to distinguish which was the most active factor.

[Martin et al.](#) identified frequency of contact as the main criterion for assertive community treatment ([Martin 2005](#)). In their study on assertive community treatment, [Oliver et al.](#) stated that the intervention was best measured in terms of frequency and types of contact ([Oliver 2005](#)). Like the study [Lowe 1996](#), the control conditions for [Martin 2005](#) and [Oliver 2005](#) were standard care which included services provided by Community Learning Disability Teams.

[Van Minnen et al.](#) studied an intervention provided by a multidisciplinary team which included a care coordinator: they identified the setting as the most important difference between the hospital-treated controls versus the participants in the intervention group who were seen in their home environment ([Van Minnen 1997](#)).

Excluded studies

We obtained the full texts of 114 studies of which 33 were clearly not eligible. Upon further screening, another 73 were excluded ([Characteristics of excluded studies](#)). The most common reasons were lack of control group in before and after studies and study

designs incompatible with inclusion criteria.

Risk of bias in included studies

The [Table 1](#) shows results from methodology quality evaluations for RCTs. The criteria that were most consistently given low ratings were 'Protection against contamination' and 'blinded assessment of outcome'. All the studies ensured that a 'baseline measurement' of patient outcome was done prior to the introduction of the intervention. Three of the studies clearly described adequate methods to conceal allocation to the control or intervention groups ([Dowling 2006](#); [Martin 2005](#); [Oliver 2005](#)).

One of the included studies was a controlled before and after study which used a non-random method to assign intervention and control groups ([Lowe 1996](#)). The study included a pre and post intervention period of assessment for the outcome and ensured comparability of intervention and control groups. Participants receiving the intervention were a subset of all individuals accepted on the caseload of specialist services between October 1990 and March 1992. The control group constituted a subset of individuals that presented challenging behaviour but who were not referred for specialist services in the summer 1991. The intervention and control subsets were formed in order to control for differences found in baseline measures between initial study groups. The study met three out of five quality criteria developed by EPOC for controlled before and after studies ([Cochrane 2006b](#)). One study used an interrupted time series design measuring changes in trend over 20 years for short and long term admissions to a hospital for people with an intellectual disability ([Allen 1998](#)). The study clearly defined when the interventions occurred and included more than three data points before and after intervention periods. It met four out of seven quality criteria provided by EPOC for interrupted time series ([Cochrane 2006a](#); [Cochrane 2006b](#)). This study used a t-test to compare pre and post intervention means. Its results were therefore reanalysed to account for auto-correlation and time trend. None of the included studies conducted a formal power calculation to identify the number of participants required to identify a statistically significant clinically important difference.

Effects of interventions

[Table 2](#) describes the results of the eight included studies. Five of the studies measured aspects of behaviour ([Coelho 1993](#); [Dowling 2006](#); [Lowe 1996](#); [Martin 2005](#); [Van Minnen 1997](#)), two evaluated overall psychological and psychiatric function ([Martin 2005](#); [Oliver 2005](#)), one focused on number of annual admissions ([Allen 1998](#)), and one on mean number of days in hospital ([Hassiotis 2001](#)). Only four studies included measures of quality of life ([Hassiotis 2001](#); [Lowe 1996](#); [Martin 2005](#); [Oliver 2005](#)) and only three reported using carer burden as an outcome ([Lowe 1996](#); [Martin 2005](#); [Oliver 2005](#)).

Three of the included studies identified beneficial interventions ([Coelho 1993](#); [Dowling 2006](#); [Hassiotis 2001](#)). By decreasing caseloads and increasing the frequency of direct care of participants in their natural environment, Coelho et al. found a significant increase in adaptive behaviour and a decrease in maladaptive behaviour in the intervention group ([Coelho 1993](#)). Dowling et al. consistently found improvements in behaviour among control group participants who received bereavement counselling from bereavement counsellors with little experience working with people with an intellectual disability ([Dowling 2006](#)). Hassiotis et al. found that 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 and borderline intellectual disability ([Hassiotis 2001](#)). This study's results were taken from a larger study which included persons without an intellectual disability ([Burns 1999](#)).

Five of the included studies did not find any difference between the intervention and comparison groups ([Allen 1998](#); [Lowe 1996](#); [Martin 2005](#); [Oliver 2005](#); [Van Minnen 1997](#)). The reanalysed data from the interrupted time series by Allen showed no evidence of effect for a multifaceted intervention, including community support teams alone and in combination with specialist services ([Allen 1998](#)). Although the results were compatible with a decreased mean number of long and short-term hospitalizations per year, they did not reach statistical significance. In a controlled before and after study of persons with an intellectual disability and challenging behaviour, Lowe et al. found only minor differences comparing participants referred with those non-referred to specialist services ([Lowe 1996](#)). This study, however, also found that the effect of the intervention changed depending on which of two multidisciplinary teams provided the specialist support. The authors concluded that professional training and relevant experience are important factors in providing effective specialist support. In their study comparing standard versus assertive community teams specializing in intellectual disability, Martin et al. showed quality of life outcomes favoured the control group: all other results were non-significant ([Martin 2005](#)). In a similar study, [Oliver 2005](#) found no significant difference for any of the outcomes measured. Van Minnen et al. found no difference in psychiatric symptoms when comparing outcomes of a 48-bed hospital specializing in the treatment of persons with a dual diagnosis with an intervention group that was seen by a multidisciplinary team in their home environment ([Van Minnen 1997](#)). Quality of life and carer burden were not used for comparisons in this study; nevertheless, based on its lower costs, the outreach treatment team was encouraged as a better choice by the study authors.

Meta-analysis

Only two of the studies ([Oliver 2005](#); [Martin 2005](#)) were similar enough in terms of participants, intervention and outcomes to warrant pooling of results. The combined results for these stud-

ies are shown in [Analysis 1.1](#); [Analysis 1.1](#); [Analysis 1.3](#); [Analysis 1.4](#). A total of 25 participants received assertive treatment and 25 received standard community treatment. [Analysis 1.1](#) combines the results according to the Global Assessment of Function-Symptomatology. The common effect was not significant in favour of the standard treatment (MD -0.76; 90% confidence interval (CI) -6.07 to 4.55). [Analysis 1.2](#) shows the results when the data from Global Assessment of Function-Disability are pooled. The common effect was not significant in favour of the assertive community treatment (1.05; 90% CI -4.05 to 6.16). The pooled results for carer uplift/burden are found in [Analysis 1.3](#). For this outcome it was necessary to obtain unpublished data from [Oliver 2005](#) in order to combine the results from the 'uplift' and 'burden' dimensions into a single uplift/burden score to match the methods used by [Martin 2005](#). The common effect was non-significant and favoured neither of the treatment options (MD 0.03; 90% CI -3.48 to 3.54). [Analysis 1.4](#) shows the pooled results for quality of life. The standardised mean difference is used as a summary statistic since the trials used different outcome measures to evaluate quality of life. The common effect was not significant in favour of the standard community treatment (SMD -0.20; 90% CI -0.75 to 0.36) in units of standard deviation.

The results for the statistical heterogeneity tests were very low for all the comparisons except when examining the pooled results for carer uplift/burden. To decrease the level of heterogeneity, change from baseline scores were used instead of final values for the study by [Oliver 2005](#). This eliminated the influence of the differences in baseline scores for this outcome (assertive community treatment = 35.4 (SD 4.7); standard community treatment = 42.5 (SD 6.6)) and decreased the impact of heterogeneity on the results of the meta-analysis from $I^2 = 76\%$ to $I^2 = 36\%$.

DISCUSSION

We found eight studies that met the inclusion criteria: six were randomised controlled trials, one was a controlled before and after study, and one was an interrupted time series. In general the studies were of acceptable methodological quality. Three of the studies identified effective organisational interventions and five showed no evidence of effect. Only two studies were similar enough to analyse using a meta-analysis.

Systematic reviews allow healthcare providers, consumers, researchers, and policy makers to make decisions that are based on the totality of available evidence ([Higgins 2005](#)). By allowing for quasi-experimental study designs, the Cochrane Effective Practice and Organisation of Care Review Group provided useful guidance to conduct a systematic review of organisational interventions.

This systematic review evaluated the organisation of health services for persons with an intellectual disability. There was insufficient evidence to provide clear guidelines on how best to organise health

services for persons with an intellectual disability across all settings. The interpretation of the review depends on the jurisdiction in which it is being applied and therefore the following discussion avoids making generalizations about local and national resources and values with one caveat: the included studies were conducted in countries where the process of deinstitutionalization has been ongoing for many years and the results are applicable mostly to countries in the same situation.

Even among countries where deinstitutionalization has taken place, there are considerable differences in how health services for persons with an intellectual disability have been organised. It is useful to briefly describe the situation in the United Kingdom since most of the included studies originate from there ([Allen 1998](#); [Dowling 2006](#); [Hassiotis 2001](#); [Martin 2005](#); [Lowe 1996](#); [Oliver 2005](#)) and its 'standard' for health care for persons with an intellectual disability is unlike most other places in the world. Although many persons with an intellectual disability living in the United Kingdom use general practitioners or primary health care teams to meet their health care needs, Community Learning Disability Teams are widespread with up to 350 identified in England alone and the vast majority of persons with moderate to profound intellectual disability use their services ([Moss 2000](#); [Slevin 2008](#)). One of the functions of the Community Learning Disability Team is to provide high quality health care services for persons with an intellectual disability ([Slevin 2008](#)). In their recent review, [Slevin 2008](#) described key objectives of Community Learning Disability Teams including:

- 1) To provide specialist treatment where primary and secondary health services are unable to meet the client's needs,
- 2) To support general practitioners and primary health care teams to identify and meet the health needs of people with learning disabilities
- 3) To work with local health trusts and social services to provide coordinated services
- 4) To facilitate access to primary and secondary healthcare services
- 5) To provide education and advice to clients, their families, carers and other professionals.

The composition of Community Learning Disability Teams has evolved over the years with key positions frequently held by psychiatrists, clinical psychologists and specially trained nurses to service the needs of persons with an intellectual disability and concurrent mental health illness and/or challenging behaviour. This is in contrast to the situation in countries like Australia and the United States where specialist services for persons with an intellectual disability are not well developed ([Chaplin 2004](#); [Fletcher 1993](#); [Lennox 1995](#)). In these countries persons with an intellectual disability have had to rely much more heavily on the same primary and specialist health services that are accessed by the general population. These examples stress the importance of interpreting

study results within the context of jurisdictions with similar levels of standard care.

The following discusses the review in the context of two ongoing debates on effective health care delivery for persons with a dual diagnosis. The debates regard the merits and drawbacks of in-patient admissions versus out-patient/outreach treatment and health service delivery by specialised health care professionals versus the mainstream health care system (Xenitidis 2004).

Summary of main results (merits and drawbacks)

The Dutch study by van Minnen et al. addressed the first debate on whether in-patient admissions or out-patient/outreach treatment are more effective for this population (Van Minnen 1997). In a randomised controlled trial, they found no difference in outcomes between in-hospital treatment and an outreach team for participants with mild or borderline intellectual disability and serious mental illness. On the basis of this study's results and the substantially higher costs for hospital admissions, the Dutch government supported a non-hospitalization policy (Van Minnen 1997).

Only one study addressed the second debate on whether mental health services provided by specialised health professional or the mainstream health care system are more effective. Dowling 2006 found that bereavement counselling provided by mainstream counsellors led to better outcomes than grief work provided by carers of persons with an intellectual disability. According to the authors this supports the United Kingdom's department of health policy direction towards inclusion of persons with an intellectual disability within mainstream service provision. In reality, this would only be the case if the comparison was between services provided by mainstream bereavement counsellors and similarly trained counsellors with specialised experience dealing with persons with an intellectual disability.

The controlled before and after study by (Lowe 1996) studied a component of the specialty services described by Allen (Allen 1998). Lowe et al. included a control group that was not referred for specialist input. The control group received standard care only, which in Wales, includes access to Community Learning Disability Teams. In a personal communication with Lowe 2008 the author clarified that the control conditions included very limited access to psychology and little to no community-based psychiatry; nevertheless, most readers would not consider contact with a Community Learning Disability Team as an example of a mainstream health service. A systematic review comparing specialist to mainstream psychiatric services for persons with an intellectual disability found 27 studies on the subject (Chaplin 2004). Consistent with the current review, Chaplin found the evidence inadequate to give clinicians and managers guidance as to the most suitable services to use or design.

The deliberations regarding the best way to organise health care services for persons with an intellectual disability are similar to dilemmas for patients in the general population with a chronic illness. In the review by Wagner et al. on care for patients with chronic illnesses, they summarised that health professionals "feel unprepared or are too rushed to meet the educational, behavioural, and psychosocial needs of chronically ill patients and their caregivers" (Wagner 1996). There is evidence that specialised care is better suited to deal with the needs of persons from the general population with time consuming problems (Rich 1995). Condition specific specialised programs may prove effective for the general population and persons with an intellectual disability but this may be at the detriment of coordinated care. Integrated care where services are provided across sectors or teams, or organised to bring all services together at one time provides one possible solution (Cochrane 2006b). This review, however, found no suitable studies that tested interventions of this nature, a result consistent with the findings of a recent systematic literature search by Jansen 2006.

Overall completeness and applicability of evidence

Care should be taken when generalizing the results of this review due to differences in inclusion criteria and jurisdictions among the included studies. The English study by Hassiotis 2001 showed that intensive case management improved outcomes for persons with unrecognised mild or borderline intellectual disability and a concurrent psychotic illness. Martin 2005 and Oliver 2005, also in England, were not able to reproduce these findings in a population that had more significant cognitive impairments and a broader range of psychiatric and behavioural issues. The differences in study population may explain the different results and lack of generalizability of intervention effectiveness. Hassiotis 2001 identified a subset of persons not eligible for intellectual disability services at higher risk of experiencing adverse outcomes in the absence of intervention (Chaplin 2006; Higgins 2005). The control and intervention groups from the Hassiotis 2001 study received only standard or intensive case management from mainstream health services: they did not benefit from the services provided by local Community Learning Disability Teams as did the study groups from Oliver 2002 and Martin 2005. This suggests a need for targeted and well coordinated services with clear descriptions of responsibilities so that the mental health and behaviour needs of persons with mild or borderline intellectual disability do not fall through service gaps (Hassiotis 2002; Moss 2000; Oliver 2002). Another example of the lack of generalizability of effect is seen when comparing the Michigan state based study by Coelho et al. with the studies by Oliver et al. and Martin et al. (Coelho 1993; Martin 2005; Oliver 2005). In this case the study populations were similar but the jurisdictions were different. The different results may be because the investigations were carried out in jurisdictions

with different health service structures. Michigan had no system of Community Learning Disability Teams like England's in place at the time of the study (Kelley 2006). As stated by Oliver 2005 the different results in England and Michigan depend substantially on the quality of the standard care. If Community Learning Disability Teams are providing services similar to the intervention being tested, then the effect shown in other jurisdictions may not be detected.

Quality of the evidence

The similarities between the studies by Martin 2005 and Oliver 2005 made a meta-analysis possible. Pooling resulted in very little statistical heterogeneity for the measures of function and quality of life. Assertive community treatment did not show the expected improvements in function and quality of life over standard community treatment; further research, though, is required before stating categorically that there is no evidence of effect since the meta-analysis was based on only two studies contributing 50 participants. Uneven baseline scores for carer uplift/burden in the study by Oliver 2005 suggested that insufficient numbers were recruited to achieve truly randomised groups. For this reason change from baseline scores were used for this outcome. Caution should be taken when interpreting the pooled results for this outcome due to the continued presence of unexplained heterogeneity ($I^2 = 35.7\%$).

Three of the studies (Martin 2005; Oliver 2005; Van Minnen 1997) discussed lack of power as a limitation of study methods. Oliver 2005 stated that though it was possible that a statistical difference between the treatment groups existed in their study, it was unlikely that a type II error was occurring since the differences in outcome between groups were so small. Though this may be true, one of the guidelines for assessing causation is consistency of effect across trials (Higgins 2005). The results of the included studies all require corroboration from research conducted in the same context and adequately powered to find clinically important a priori defined differences of the primary outcomes.

This systematic review used strict inclusion criteria advocated by the Cochrane EPOC Review Group. As such, many intervention studies were excluded if they lacked an appropriate comparison group. By virtue of being included, the eight studies in this review should be seen as methodologically sound despite the range in methodology quality. There may be concern that we included two non-RCT studies with relatively low quality ratings (Allen 1998; Lowe 1996); these studies were retained since they met the a-priori defined EPOC inclusion criteria for non-RCT studies.

Potential biases in the review process

Some challenges and limitations of the current review are summarised. The review did not search for studies published before 1990. It is therefore possible that some appropriate studies were

missed; this is unlikely, however, since concern over the quality of health care services provided in the community for persons with an intellectual disability is a relatively new development. The subtleties of complex interventions and lack of agreed upon taxonomy made it hard to properly categorize the included studies. The taxonomy of interventions provided by the Cochrane EPOC Review Group was useful for identifying studies during the literature search but was not detailed enough to properly describe organisation of care interventions. This was especially true when trying to differentiate between 'assertive community treatment' and 'intensive case management'. For this purpose the framework developed by Campbell 2000 describing how complex interventions should be designed and evaluated was useful. The framework describes sequential phases for developing trials of complex interventions and recommends starting with a theoretical basis for an intervention and specifying its possible active ingredients.

AUTHORS' CONCLUSIONS

Implications for practice

Organisational interventions have the potential to improve health outcomes of persons with a dual diagnosis; however, this review found insufficient evidence to guide policy decisions about how to optimise services in different jurisdictions. The results of the meta-analysis suggest that there is no evidence assertive community treatment is superior to standard community treatment as practiced in England: this should not be taken as evidence that assertive community treatment is not effective, only that, to date, there is insufficient evidence to support it over standard treatment. Intensive case management should be considered when providing mental health services for persons with a dual diagnosis in the United States and for persons with a mild or borderline intellectual disability living in England. On the basis of cost, countries with health and social systems similar to the Netherlands should consider delivering mental health services in the home environment rather than in hospitals.

Implications for research

The included studies of this review were of acceptable methodological quality, albeit their small sample size. They require replication before firm conclusions can be made. Well designed appropriately powered studies focusing on organising the health services of persons with an intellectual disability and concurrent physical problems were conspicuously absent. Also missing were studies on integration of care interventions which may prove useful to resolve ongoing health care service debates. The debate over the effectiveness of mainstream versus specialised health services for persons with an intellectual disability remains unanswered and requires rigorous study. The objective of the current review was to

identify effective methods of organising health care services for persons with an intellectual disability; decision makers, however, also need information on the efficient use of resources. Researchers should address economic issues more thoroughly. The authors of the current review will consider including a formal evaluation of financial issues in future updates.

Although researchers have identified challenges when conducting randomised controlled trials using persons with an intellectual disability as subjects, six out of the eight included studies in the current review were randomised trials (Lennox 2005; Oliver 2002). Intervention trials using randomization procedures are therefore feasible in this population and should be the first choice to test the effectiveness of organisational interventions. When a randomised trial is not possible, researchers could consider conducting a controlled clinical trial, controlled before and after study or an interrupted time series. To be rigorous, before and after studies require comparable control groups and interrupted time series require at least three observation points before and three observation points after the intervention. Future research should include sample size

calculations to ensure adequate study power and measures of clinical, carer burden, and quality of life outcomes. High quality health services research aimed at improving the lives of persons with an intellectual disability is possible and long overdue.

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* Indicates the major publication for the study

CHARACTERISTICS OF STUDIES

Characteristics of included studies *[ordered by study ID]*

Allen 1998

Methods	Study Design: ITS Types of interventions : Multidisciplinary team + Change to site of service delivery + Change in scope and nature of services
Participants	Clinical Problem: Focus is on persons with ID and any of the following alone or in combination: challenging behaviour, psychiatric needs, offending against the law) Setting: Wales Sample size and demographics not reported
Interventions	No C group. Compares results from three intervention time periods: I ₁ : Baseline (1975 - 1982). Specialty hospital for persons with an ID I ₂ : Community support teams (1983 - 1989). Multiple agencies (health, social services, and volunteer sectors) provide care from broad range of professions (e.g. social work, occupational therapy, physiotherapy, psychology) specific to persons with ID I ₃ : Intervention includes I ₂ plus additional specialist services specific to with an ID including Intensive Support Services, Emergency Intervention Service and weekly outpatient clinics (1990 - 1995). I ₃ differs from I ₂ in three ways: 1) The specialist services focuses on the needs of persons with an intellectual disability and complex behavioural and/or psychiatric needs, 2) with a less broad complement of professions consisting primarily of psychologists and nurses, and 3) the services are more intensive and practical (as opposed to consultative) (D. Allen, personal communication, April 21, 2008: Allen 2008). (Neither caseload nor frequency of intervention reported)
Outcomes	Mean number of annual admissions at hospital for persons with an intellectual disability for short-term and long term (i.e. > 6 months) stays Quality of life and burden measures NR
Notes	Presence of co-interventions may bias results Lacks control group for comparison Mann-Whitney U test used to compare mean results from different time periods: does not account for time trend and auto-correlation

Coelho 1993

Methods	Study Design: RCT Types of interventions : Multidisciplinary team + Continuity of care + Change to setting/site of service
Participants	Clinical Problem: Persons with moderate to mild ID with a DSM-III-R diagnosis of mental illness or behavioral complications concerning mental illness; residing in community Setting: Michigan, USA Sample Size: N = 23 I; 23 C Gender: 61% male Average age: Intervention 34, Control 33

Coelho 1993 (Continued)

Interventions	C: Standard case management specializing in ID. Community mental health agency administers range of multidisciplinary mental health services coordinated by case manager specializing in ID. (Caseload average 35 participants per case manager. Approximately 0.5 episodes of direct care per week) I: Intensive case management specializing in ID. Intervention provides services described in C as well as greater direct contact services with participants in their natural environment. Team members specialised in ID (Caseload between 7-10 participants per professional. Approximately 2 episodes of direct care per week)
Outcomes	Behaviour: Adaptive behaviour: Relevant section of American Association of Mental Deficiency Adaptive Behaviour Scale (AAMD-ABS) Maladaptive behaviour: Relevant section of AAMD-ABS Michigan Maladaptive Behaviour Scale (MMBS) Quality of life and burden measures NR
Notes	Stratified by level of maladaptive behaviour before randomised ensuring similarity between groups Used repeated measures analysis of variance to identify significant interaction term

Dowling 2006

Methods	Study Design: RCT Types of interventions : Revision of professional roles
Participants	Clinical Problem: Adults with ID who experienced significant bereavement (death of sibling or parent); excluded persons with dementia or psychosis Setting: United Kingdom Sample Size: N = 11 I; 23 C Gender: 41% male Only age range reported: Intervention < 30 - >60 Control 30-60
Interventions	C: Standard mainstream control group. Trained bereavement counselors with no experience working with persons with ID deliver counseling in fixed setting of client's choice. (Initially 1 episode of direct care per week, then every other week: Average of 15 episodes of care per client) I: Bereavement work provided by carers (family or paid worker) who know client well but have no bereavement counseling experience. (Frequency of care not reported)
Outcomes	Behaviour: Aberrant Behaviour Checklist-Community (ABC-C) comprising scales for 1) irritability, 2) lethargy, 3) stereotypy, 4) hyperactivity, 5) inappropriate speech Health of the Nation Outcome Scales for People with Learning Disabilities (HoNOS-LD) Quality of life and burden measures NR
Notes	t-test used to compare magnitude of change between pre and post intervention scores

Hassiotis 2001

Methods	Study Design: RCT Types of interventions : Multidisciplinary team + Continuity of care
Participants	Clinical Problem: Patients with severe psychotic illness with mild intellectual disability (IQ range 51-70) or borderline IQ (IQ range 71-85) Setting: London and Manchester, England Sample size: N = 50 I; 54 C Gender: 65% male Median age: 36.5
Interventions	C: Standard mainstream case management: Case manager is trained mental health professional responsible for direct care and coordinating health and social inputs outside of hospital; member of multidisciplinary team (1 case manager: 30-35 clients) I: Intensive mainstream case management. Same as C but smaller case load (1 case manager: 10-15 clients).
Outcomes	Mean number of days in hospital for psychiatric reasons Quality of life: Lancashire quality of life profile Burden measures NR
Notes	Results are from larger study including persons without low IQ score 95% confidence intervals show effect of intervention in persons with lower IQ

Lowe 1996

Methods	Study Design: CBA Types of interventions : Multidisciplinary team + Change in setting/site of service
Participants	Clinical Problem: Persons with intellectual disability and challenging behaviour Setting: Wales Sample size: N = 14 I; 12 C Gender: 50% male Average age: Intervention 29, Control 33
Interventions	C: Standard community treatment team specializing in ID. Persons with ID exhibit challenging behaviour, but are not referred for specialist input. Persons with ID had very little behavioural support, no written plans, and their carers had no specific training in challenging behaviour (K. Lowe, personal communication, April 16, 2008) (Neither caseload nor frequency of intervention reported) I: In addition to C, multidisciplinary specialist support team for persons with ID. Provides intensive, individually tailored support to people with ID and their carers in natural setting over short to medium term. (Neither caseload nor frequency of intervention reported)
Outcomes	Problem behaviour: Disability Assessment Schedule (DAS) Aberrant Behavior Checklist (ABC) Quality of life: Index of Community Involvement (ICI) average score

Lowe 1996 (Continued)

	Carer burden: Maslach Burnout Inventory (MBI)
Notes	Mann-Whitney U test used to compare distributions of I vs. C

Martin 2005

Methods	Study Design: RCT Types of interventions : Multidisciplinary team + continuity of care
Participants	Clinical Problem: Persons with mild to moderate intellectual disability and psychiatric disorder Setting: South-east London, England Sample size: N = 10 I, 10 C Gender: 50% male Average age: 45
Interventions	C: Standard community treatment team specializing in ID. (One member of team has direct contact no more than once per week) I: Assertive community treatment team specializing in ID. Same as C but, with as many contacts as needed from two professionals, one of whom acts as case-coordinator. Author note: Frequency of contact was main criterion for identifying assertive community treatment (Frequency of contact not reported)
Outcomes	Function and problem behaviour: Global Assessment of Function (GAF) Symptomatology; Disability Aberrant Behaviour Checklist (ABC) Quality of Life: Quality of Life Questionnaire (QOLQ) Carer burden: Uplift/Burden scale
Notes	Differences in baseline measurement between groups adjusted using ANCOVA

Oliver 2005

Methods	Study Design: RCT Types of interventions : Multidisciplinary team
Participants	Clinical Problem: Persons with mild to moderate intellectual disability and a (1) serious mental health disorder or (2) challenging behaviour, or both (1) and (2) Setting: England Average age: N = 15 I; 15 C Gender: 43% Male Average age: 40.53

Interventions	C: Standard community treatment team specializing in ID. Author note: standard= no more than one visit per week from any one professional (Average 9.87 intervention events from a professional over 3 weeks) I: Assertive community treatment team specializing in ID. Same as C, but more frequent contact. Author note: assertive = more than one visit per week from one or more professionals (Average 16.8 intervention events from a professional over 3 weeks)
Outcomes	Function: Global Assessment of Function (GAF) Symptomatology; Disability Quality of Life: World Health Organisation Quality of Life-Bref (WHOQOL-Bref) Carer burden: Uplift/Burden scale
Notes	Authors used two way ANOVA. Differences in outcome were compared using time x intervention type interaction term in model

Van Minnen 1997

Methods	Study Design: RCT Types of interventions : Multidisciplinary team + Changes to the setting/site of service delivery + Continuity of care
Participants	Clinical Problem: Persons with mild or borderline intellectual disability and serious mental illness (i.e. require in-patient hospitalization) Setting: Netherlands Sample size: N = 25 I; 25 C Gender: 76% Male Average age: Intervention: mean 31.4, SD 12.6 Control: mean 31.0, SD 10.8
Interventions	C: Standard hospital treatment: 48-bed facility specializing in treatment of people with dual diagnosis. Interventions include: psychopharmacological medication, behavioral therapy, social skills training, education, structured daily activities. (Patient contact 24 hours/day) I: Outreach treatment team: One member of team visits patient in home environment; works with care givers involved in daily life. Other interventions similar to C. (Interventions average 1 hour per week per patient)
Outcomes	Psychiatric symptoms: Psychopathology Inventory for Mentally Retarded Adults Subject Response (PIMRA-SR) Psychopathology Inventory for Mentally Retarded Adults Informant response (PIMRA-I) Reiss Screen for Maladaptive Behaviour Quality of life measure NR Carer burden: Nijmegen Child-Rearing Situation Questionnaire (NCSQ)

Notes	Differences in baseline measurement between groups adjusted using ANCOVA Authors also conducted equivalence testing
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Characteristics of findings tables:

C: Control group conditions.

I: Intervention group conditions.

ID: intellectual disability.

ITS: interrupted time series.

RCT: randomised controlled trial.

CBA: controlled before and after study.

NR: not reported.

NS: not significant.

SD: standard deviation.

CI 95% confidence interval.

* primary outcome was either identified by original study author or identified by review authors as best reflecting intervention

Characteristics of excluded studies [ordered by study ID]

Study	Reason for exclusion
Alexander 2001	After only design with a control group No pre and post intervention comparison of data
Arana 1991	Before and after study with no control group for comparison Only 3 patients with intellectual disability out of 39 in study
Aronow 2005	Pilot for upcoming RCT study Outcome measure is being tested No data available comparing intervention to control group
Arya 2002	Study participants are children
Barr 1999	After only design with no control group for comparison
Baxter 2006	After only design with no control group for comparison
Bhaumik 2005	Descriptive study
Bollard 1999	Before and after study with no control group Qualitative responses before and after health checks
Calkins 1994	Persons with intellectual disability not identified in study Participants must speak and read English

(Continued)

Camfield 2004	Before and after study with no baseline for comparison
Carlsen 1994	Before and after study with no control group
Cassidy 2002	Before and after study with non-comparable controls (persons without intellectual disability)
Chicoine 1994	Descriptive study of health problems and diagnoses
Chubb 1995	Before and after study with not control group
Codling 2005	Descriptive study
Cooray 1998	Before and after study with no control group
Criscione 1993	After only study comparing care coordination to a control group. Adjusted length of stay results using diagnosis-related standard. Did not compare outcomes at baseline
Criscione 1994	Describes costs and review of Criscione 1993
Criscione 1995	Same methods as Criscione 1993 using updated data
Davidson 1995	Descriptive study of individuals with dual diagnosis
Feldman 2002	Interrupted time series with insufficient data points for adults
Fernando 2001	Descriptive study of physical health needs
Findholt 1990	Interrupted time series Insufficient number of pre-intervention data points
Galligan 1990	Before and after study with no control group
Gaskell 1995	Interrupted time series Insufficient number of pre-admission data points
Goldsmith 2000	Impact of intervention not studied
Greenswag 1990	Study of Children with Prader-Willi syndrome
Guo 2001	Does not evaluate effect of intervention on persons with intellectual disability alone Evaluation of mobile services on hospitalization outcomes
Hahn 2005	Before and after study with no control group
Halstead 2000	'Naturalistic' study (i.e. no attempt to influence interventions) with no baseline comparison
Hassiotis 2003	Review article on assertive community treatment

(Continued)

Hatton 1995	Descriptive study of residential models
Holmes 2004	Persons with intellectual disability not identified in study Comparisons of community mental health centres
Jones 1997	Randomised controlled trial of opportunistic health screening tool Published study is missing relevant and interpretable data Study authors contacted to obtain unpublished analysis
Jurek 1994	Cross sectional study of oral health needs at Texas state facilities
Kaufman 1995	Before and after study with no control group or Interrupted time series with insufficient pre-intervention data points
Kerr 2003	Descriptive study Profile of medical needs
Kwok 2001	Descriptive study of specialised hospital psychiatric unit
Lennox 2001	Descriptive study of educational intervention to improve communication between stakeholders
Lepler 1993	Before and after study with no control group
Litzinger 1993	Before and after study with no control group Compares cohort moving from institution to community based residences at different times
Lowe 1993	Study of impact of multidimensional service provision Does not focus on impact of health care service
Luiselli 2001	Before and after study with no control group
MacPherson 2002	Study sample does not include persons with intellectual disability
Madianos 1999	Cross sectional study of impact of Community Mental Health Centre on contact with inpatient psychiatric services Only ~ 2% of sample has intellectual disability
Martin 1997	Descriptive study using comprehensive health check in primary care
Martin 2003	Descriptive study with no control group Health checks used to highlight treatable conditions
Martin 2004a	Qualitative description of general practice using annual health review
Martin 2004b	Before and after study with no control group

(Continued)

McCabe 2006	Randomised controlled trial of cognitive behavioural programme Outside scope of review
McKee 1994	Pharmacy intervention in institution based residential setting. Controlled before and after with no control group and interrupted time series
Melville 2006	Before and after study with control group Nurse training intervention outside scope of current review
Merrick 2000	Study participants are children
Michael 2004	Descriptive and retrospective evaluation of referrals and referral letters evaluated for appropriateness
Moss 1993	Descriptive study of persons with intellectual disability with and without support from community intellectual disability team
Nesbitt 1998	Descriptive study of residential setting options
Patterson 1995	After only study with no control group Evaluation of collaborative system of care for persons with dual diagnosis
Paxton 1998	Descriptive study of health and health education needs
Radler 1996	Before and after study with no control group
Roy 1997	Descriptive study of unmet needs in persons with dual diagnosis
Rudolph 1998	Follow up study with no control group
Singh 1991	Descriptive retrospective study of out-patient clinic for persons with intellectual disability
Singh 2002	Interrupted time series Teaching and training of professionals outside scope of current review
Tajuddin 2004	Descriptive study of acute specialist inpatient unit for persons with dual diagnosis
Trower 1998	Descriptive study of admissions to specialist inpatient unit for persons with dual diagnosis
Van Loon 2005	Descriptive study of general practitioners views on specialist physician support
Van Minnen 1993	Case studies of outreach treatment for persons with dual diagnosis
Van Minnen 1994	Descriptive study of patients with dual diagnosis in outreach and inpatient setting
Webb 1999	Follow up study with no control group
Wells 1997	Follow up study using general population as control

(Continued)

Xenitidis 1999	Follow up study with no control group Evaluates inpatient model for persons with intellectual disability and challenging behaviour
Xenitidis 2004	Before and after study with no control group Evaluates specialist inpatient unit for dual diagnosis Missing baseline information when comparing specialist to mainstream service using length of stay
Zhang 1994	Evaluation of sheltered workshop Outside scope of current review

DATA AND ANALYSES

Comparison 1. Assertive community treatment versus standard community treatment

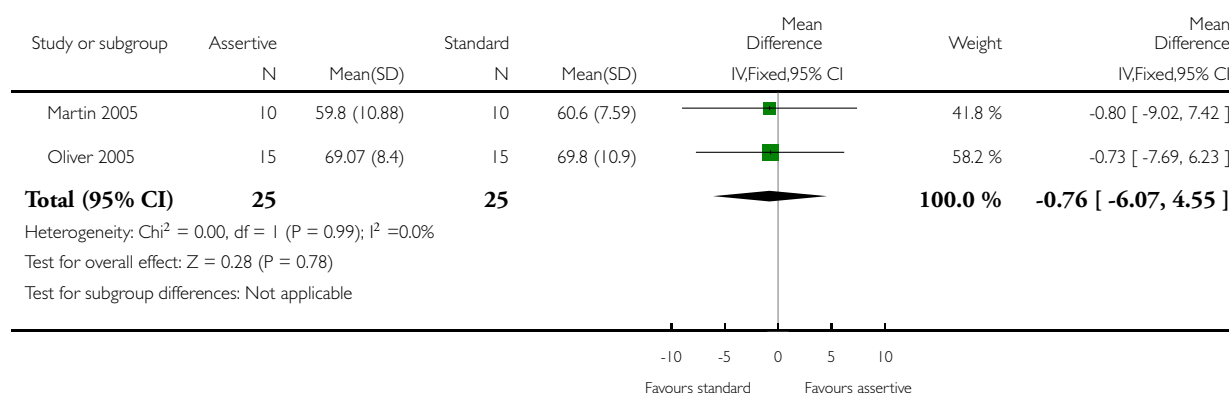
Outcome or subgroup title	No. of studies	No. of participants	Statistical method	Effect size
1 Global assessment of function (symptomatology)	2	50	Mean Difference (IV, Fixed, 95% CI)	-0.76 [-6.07, 4.55]
2 Global assessment of function (Disability)	2	50	Mean Difference (IV, Fixed, 95% CI)	1.05 [-4.05, 6.16]
3 Carer uplift/burden	2	50	Mean Difference (IV, Fixed, 95% CI)	0.03 [-3.48, 3.54]
4 Quality of life	2	50	Std. Mean Difference (IV, Fixed, 95% CI)	-0.20 [-0.75, 0.36]

Analysis 1.1. Comparison 1 Assertive community treatment versus standard community treatment, Outcome 1 Global assessment of function (symptomatology).

Review: Organising health care services for persons with an intellectual disability

Comparison: 1 Assertive community treatment versus standard community treatment

Outcome: 1 Global assessment of function (symptomatology)

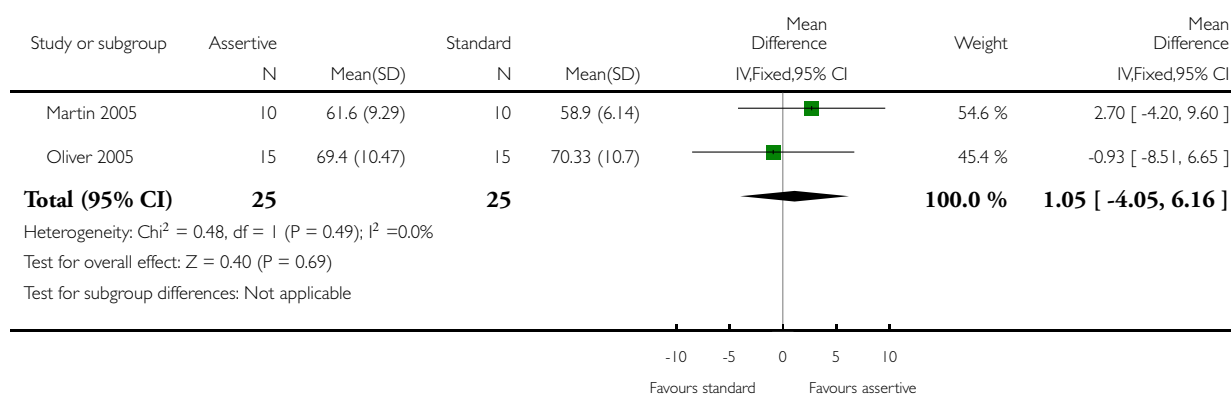


Analysis 1.2. Comparison 1 Assertive community treatment versus standard community treatment, Outcome 2 Global assessment of function (Disability).

Review: Organising health care services for persons with an intellectual disability

Comparison: 1 Assertive community treatment versus standard community treatment

Outcome: 2 Global assessment of function (Disability)

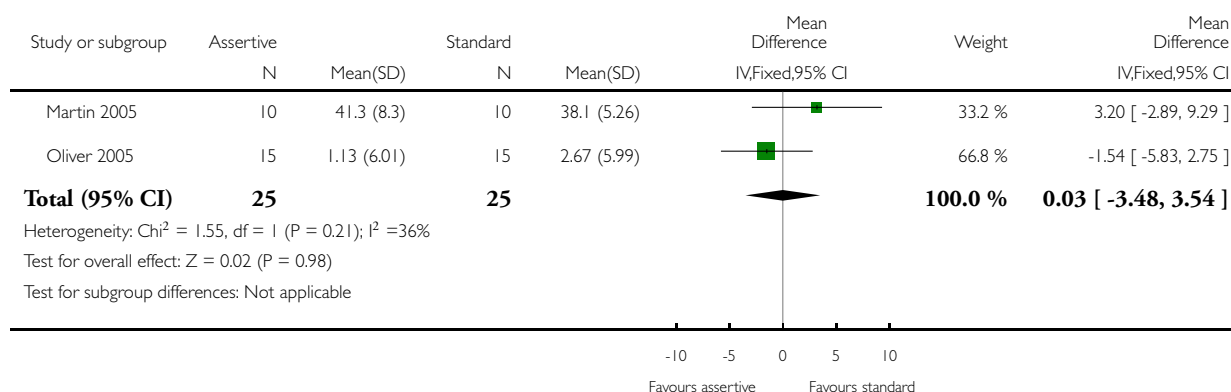


Analysis 1.3. Comparison 1 Assertive community treatment versus standard community treatment, Outcome 3 Carer uplift/burden.

Review: Organising health care services for persons with an intellectual disability

Comparison: 1 Assertive community treatment versus standard community treatment

Outcome: 3 Carer uplift/burden

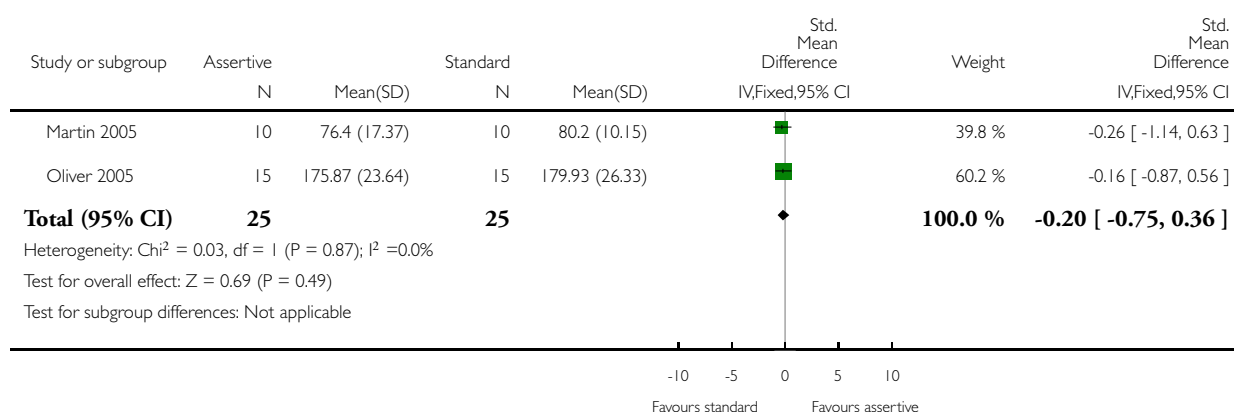


Analysis 1.4. Comparison 1 Assertive community treatment versus standard community treatment, Outcome 4 Quality of life.

Review: Organising health care services for persons with an intellectual disability

Comparison: 1 Assertive community treatment versus standard community treatment

Outcome: 4 Quality of life



ADDITIONAL TABLES

Table 1. Quality criteria results of protection against bias for randomised clinical trials

Author, year	Concealment of allocation	Fol- low up of study participants	Blinded assess- ment of out- come	Baseline measurement	Reliable pri- mary outcome	Protection against contam- ination
Coelho, 1993	Not clear	Done	Not done	Done	Not clear	Not clear
Dowling, 2006	Done	Not done	Not done	Done	Done	Not done
Hassiotis, 2001	Not clear	Not clear	Not done	Done	Not Done	Done
Martin, 2005	Done	Done	Not clear	Done	Done	Not done

Table 1. Quality criteria results of protection against bias for randomised clinical trials (Continued)

Oliver, 2005	Done	Done	Done	Done	Done	Not done
VanMinnen, 1997	Not clear	Done	Not clear	Done	Done	Done

Not clear: not reported in study

Not done: study authors specifically describe item and does not meet EPOC criteria

Done: study authors specifically describe item and it meets EPOC criteria

Scoring criteria provided by EPOC ([Cochrane 2006b](#); [Cochrane 2006a](#))

Table 2. Results and Summary of Included Studies

Author, Year	Main results	Summary
Allen, 1998	<p>I₁ vs I₂ Short term stays: mean (SD): pre = 142.5 (42.0); post = 124.7 (20.7) change: 17.8 less admission/year for I₂ change in level: -3.3 (P = 0.94) change in slope: -14.6 (P 0.49) Long term stays: mean (SD): pre = 16 (4.5); post = 9.0 (2.1) change: 7 less admissions/year for I₂ change in level: -43.5 (P = 0.07) change in slope: 11.7 (P = 0.26)</p> <p>I₂ vs I₃ Short term stays: mean (SD): pre = 124.7 (20.7); post = 30.7 (30.7) change: 94.0 less admissions/year for I₃ change in level : -6.1 (P = 0.21) change in slope: -0.6 (P = 0.57) Long term stays: mean (SD): pre = 9 (2.1); post = 3.5 (2.4) change: 5.5 less admissions/year for I₃ change in level: 2.5 (P = 0.62) change in slope: -0.3 (P = 0.90)</p>	<p>Reanalysis of results showed no evidence that community support teams alone or in combination with specialist services decreases short stay admissions</p> <p>Reanalysis of results showed no evidence that community support teams alone or in combination with specialist services decreases long term stay admissions</p>
Coelho, 1993	<p>Intervention with time shows significantly better results in all behaviour measures: AMD-ABS: mean (SD) for I: pre = 199.4 (28.5); post = 211.9 (30.9) mean (SD) for C: pre = 206.0 (30.0); post = 201.3 (29.0) Adaptive behaviour increases more for I (P = 0.001) AAMD-ABS: mean (SD) for I: pre = 53.7 (22.5); post = 40.1 (20.3) mean (SD) for C: pre = 53.4 (27.5); post = 53.0 (29.0)</p>	<p>Supports the use of decreased caseloads by professionals in a team and greater frequency of episodes of direct care with persons with dual diagnosis in their natural environment</p>

Table 2. Results and Summary of Included Studies (Continued)

	<p>0)</p> <p>Maladaptive behaviour decreases more for I ($P = 0.001$)</p> <p>MMBS:</p> <p>mean (SD) for I: pre = 12.7 (7.0); post = 6.5 (4.6)</p> <p>mean (SD) for C: pre = 12.0 (7.6); post = 11.5 (6.4)</p> <p>Maladaptive behaviour decreases more for I ($P = 0.001$)</p>	
Dowling, 2006	<p>Improvements in behaviour for standard practice control group ONLY. Significant difference in change in all measures except speech:</p> <p>1) ABC irritability: mean change (SD) for I = -0.9 (5.8); for C = 6.1 (4.4); Greater improvement for C ($P > 0.001$)</p> <p>2) ABC lethargy: mean change (SD) for I = -1.8 (4.5); for C = 5.7 (6.4); Greater improvement for C ($P = 0.001$)</p> <p>3) ABC stereotypy: mean change (SD) for I = -0.8 (3.4); for C = 1.5 (2.0); Greater improvement for C ($P = 0.020$)</p> <p>4) ABC hyperactivity: mean change (SD) for I = -0.3 (4.5); for C = 6.2 (6.5); Greater improvement for C ($P = 0.005$)</p> <p>5) ABC inappropriate speech: mean change (SD) for I = 0.4 (2.1); for C = -0.1 (5.5); NS difference ($P = 0.781$)</p> <p>HoNOS-LD: mean change (SD) for I = 0.4 (6.7); for C = 7.4 (7.0); Greater improvement for C ($P = 0.009$)</p>	Supports mainstream bereavement counselling over grief work provided by carers at home and during day activities
Hassiotis, 2001	<p>Persons with IQ of 85 or lower in intervention group were hospitalised for shorter lengths than those in control:</p> <p>mean days in hospital (SD): I = 47.2 (98.0); C = 104.8 (159.5)</p> <p>difference = 57.5 days; CI 110.9 to 4.2</p> <p>Study reports no significant difference for quality of life scores for persons with IQ of 85 or less (results NR)</p>	Supports intensive case management to decrease hospital length of stays for persons with a borderline or mild intellectual disability and psychotic illness
Lowe, 1996	<p>DAS shows I group has significantly more behaviour problems ($P < 0.05$), but shows no difference in percentage rated severe + frequent (SD and P-value NR)</p> <p>ABC shows no difference in average score and no difference for number of problem behaviours (SD and P-values NR)</p> <p>No difference in ICI score (SD and P-value NR)</p> <p>MBI not used for this comparison</p>	No evidence that specialist support services team is better than standard community treatment alone for persons with intellectual disability and challenging behaviour

Table 2. Results and Summary of Included Studies (Continued)

Martin, 2005	No difference in GAF scores: Symptoms (P = 0.263) Disability (P = 0.209) No difference in ABC score (P = 0.447) Difference in QOLQ score favours C (P < 0.023) No difference in Uplift/Burden score (P = 0.151) (See figures 2-5 for details)	No evidence that assertive community treatment is better than standard community treatment for persons with ID and mental health disorders
Oliver, 2005	No difference in GAF scores: Symptomatology (P = 0.080), Social function and performance (P = 0.79) No difference in any dimension of WHOQOL-Bref or of Uplift/Burden Scale (See figures 2-5 for details)	No evidence that assertive community treatment is better than standard community treatment for persons with ID and mental health disorders
VanMinnen, 1997	No difference in psychiatric symptoms at endpoint: PIMRA-I mean: I = 15.6 (SD NR); C = 14.4 (SD NR) difference = -1.2 (CI -4.9 to 2.6) (P = 0.53) PIMRA-SR mean: I = 16.7 (SD NR); C = 16.8 (SD NR); difference = 0.1 (CI -3.7 to 3.9) (P = 0.96) Reiss mean: I = 12.7 (SD NR); C = 13.7 (SD NR) difference = 1.0 (CI -4.4 to 6.4) (P = 0.71) Carer burden not measured at endpoint for C group	Home based treatment of patients with dual diagnosis is as effective as hospital based treatment

* primary outcome was either identified by original study author or identified by review authors as best reflecting intervention

NR: not reported.

NS: not significant.

I: intervention.

C: control.

ID: intellectual disability.

SD: standard deviation.

CI 95% confidence interval.

APPENDICES

Appendix I. Search terms for electronic databases

United States National Library of Medicine's bibliographic database (MEDLINE) search terms April 2006

1. exp mental retardation/*
2. exp case management/
3. exp primary health care/
4. exp "continuity of patient care"/
5. exp "delivery of health care, integrated"/
6. care coordination.mp.
7. exp health promotion/
8. exp health services/
9. exp health planning/
10. exp models, organisational/
11. patient care management/
12. exp comprehensive health care/
13. exp "delivery of health care"/
14. exp disease management/
15. exp patient care team/
16. exp health services research/
17. exp critical pathways/
18. exp dentist's practice patterns/
19. exp patient-centered care/
20. exp "outcome and process assessment (health care)"/
21. exp program evaluation/
22. exp quality assurance, health care/
23. exp health care reform/
24. exp health services accessibility/
25. exp community mental health services/
26. or/2-25
27. 1 and 26
28. limit 27 to yr= "1990-2006"

*By selecting 'exp' or explode, the search term and all its more specific terms are used during the electronic database search. For mental retardation this includes terms such as Cri-du-Chat syndrome, De Lange syndrome, Down syndrome, Fragile X syndrome, Prader-Willi syndrome, Rett syndrome, Williams syndrome etc.

Cumulative Index to Nursing & Allied Health Literature (CINAHL) search terms, April 2006

1. exp mental retardation/
2. intellectual disability.mp.
3. developmental disabilities/
4. exp Multidisciplinary Care Team/
5. exp Home Health Care/
6. exp Managed Care Programs/
7. exp Case Management/
8. care coordination.mp.
9. primary care .mp.
10. exp health care delivery/
11. exp health care delivery, integrated/
12. exp health care reform/
13. exp health resource allocation/
14. exp health resource utilization/
15. exp health services accessibility/
16. exp managed care programs/

17. exp national health programs/
18. exp primary health care/
19. exp organizational change/
20. exp organizational structure/
21. exp quality management, organizational/
22. exp shared services, health care/
23. exp "continuity of patient care"/
24. exp disease management/
25. exp family centered care/
26. exp patient centered care/
- 27.. exp protocols/
28. exp community mental health services/
29. 1 or 2 or 3
30. or/ 4-28
- 31 29 and 30
32. limit 31 to yr= "1990 ? 2006"

Excerpta Medica Database (EMBASE) search terms, April 2006

1. exp mental deficiency/
2. exp intellectual impairment/
3. exp Mental Deficiency/
4. exp mental retardation malformation syndrome/
5. exp Learning Disorder/
6. learning disability.mp.
7. exp community mental health center/
8. exp health center/
9. exp mental health center/
10. exp health care delivery/
11. exp periodic medical examination/
12. exp mental health care/
13. exp patient monitoring/
14. exp health care management/
15. exp health care system/
16. exp group practice/
17. care coordination.mp.
18. exp primary medical care/
19. or/1-6
20. or/7-18
21. 19 and 20
22. prenatal screening/
23. 21 not 22
24. limit 23 to yr="1990 - 2006"

Evidence Based Medicine Reviews Multifile (EBMZ) search terms, April 2006

1. mental\$ retard\$.mp.
2. development\$ disabilit\$.mp.
3. intellectual disabilit\$.mp.
4. mental\$ handicap\$.mp.
5. learning disabilit\$.mp.
6. mental defeciency.mp.
7. primary care.mp.
8. care coordination.mp.
9. care management.mp.
10. case coordination.mp.
11. community mental health.mp.

12. team.mp.
13. health planning.mp.
14. health management.mp.
15. health care.mp.
16. or/1-6
17. or/7-15
18. 16 and 17

Applied Social Sciences Index and Abstracts (ASSIA), ERIC, Health Sciences, International, Physical Education Index (PAIS), Political Science, Proquest Education Journals, PsycARTICLES, Psychology, PsycINFO, Social Science Abstracts, Social Services Abstracts, Sociological Abstracts: search terms, April 2006

KW=(mental* retard*) or (intellectual disabilit*) or (development* disabilit*) or (mental* handicap*) or (angelman syndrome) or (bardet-biedl syndrome) or (cockayne syndrome) or (congenital hypothyroidism) or (cri-du-chat syndrome) or (delange syndrome) or (down syndrome) or (fragile X syndrome) or (Laurence-moon syndrome) or (prader-willi syndrome) or (rett syndrome) or (rubinstein-taybi syndrome) or (Williams syndrome)

and

(health service*) or (medical care) or (medical service*) or (health care) or (health policy) or (primary care)

Effective Practice and Organisation of Care register search terms, April 2006

intellectual disability, mental retardation, development disability, learning disorders

WHAT'S NEW

Last assessed as up-to-date: 16 January 2008.

Date	Event	Description
12 November 2008	Amended	Minor changes

HISTORY

Review first published: Issue 4, 2008

Date	Event	Description
9 November 2008	Amended	Formatting changed slightly
25 June 2008	Amended	Converted to new review format.

CONTRIBUTIONS OF AUTHORS

R Balogh conceived and designed the review with the supervision of A Colantonio and H Ouellette-Kuntz. R Balogh, H Ouellette-Kuntz, and A Colantonio prepared the protocol. The search strategy, search result screening, retrieval of papers, screening of retrieved papers against inclusion criteria, appraisal of quality and extraction of data from papers was conducted by R Balogh and L Bourne. A Colantonio acted as a third referee on decisions for inclusion of papers. Y Lunsky provided clinical and policy perspective and, wrote to authors of papers for additional information. H Ouellette-Kuntz edited the review with A Colantonio, Y Lunsky, and L Bourne. R Balogh acts as guarantor of the review.

DECLARATIONS OF INTEREST

None known

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Internal sources

- The Toronto Rehabilitation Institute Foundation, Canada.

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- Department of Occupational Science and Occupational Therapy, University of Toronto, Canada.

External sources

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- Health Care Technology and Place, Canada.

A strategic training initiative funded by the Canadian Institutes of Health Research.

INDEX TERMS

Medical Subject Headings (MeSH)

*Health Services Administration; *Mentally Disabled Persons; Mental Health Services [*organization & administration]; Randomized Controlled Trials as Topic

MeSH check words

Humans