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# **Parent training support for intellectually disabled parents**

Esther Coren, Jemeela Hutchfield, Manuela Thomae,  
Carina Gustafsson



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# Plain language summary

## **Parent training support for intellectually disabled parents**

Parents with intellectual or learning disabilities may need support to provide adequate care for their children and prevent problems that can arise in children's welfare or development. Parent training programmes may help them to learn the parenting skills they need. This review found three randomised controlled trials that met the inclusion criteria. The quality of the evidence in the studies is moderate to low. One study found improvement in mother-child interaction compared with the control group, whilst the second found improvement in safe home practices, recognition of child illness and safe use of medicines. The third study found improvement in child care and safety. More research is needed to assess the effects of these interventions before conclusions can be drawn.

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# Abstract

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## BACKGROUND

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Intellectual disability may impact on an individual's capacity to parent a child effectively. Research suggests that the number of intellectually disabled people with children is increasing. Children of parents with intellectual disabilities may be at increased risk of neglectful care which could lead to health, developmental and behavioural problems, or increased risk of intellectual disability.

However, there is some indication that some parents with intellectual disabilities are able to provide adequate child care if they are given appropriate training and support to do so.

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## OBJECTIVES

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To assess the effectiveness of parent training interventions to support the parenting of parents with intellectual disabilities.

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## SEARCH STRATEGY

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We searched the following databases: Cochrane Central Register of Controlled Trials (CENTRAL, The Cochrane Library), MEDLINE, EMBASE, CINAHL, PsycINFO, ASSIA, Sociological Abstracts, Dissertation Abstracts International, MetaRegister of Controlled Trials, and ZETOC.

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## SELECTION CRITERIA

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Randomised controlled trials comparing parent training interventions for parents with intellectual disabilities with usual care or with a control group. Outcomes of interest were: the attainment of parenting skills specific to the intervention, safe home practices and the understanding of child health.

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## **DATA COLLECTION AND ANALYSIS**

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Two review authors independently assessed risk of bias and undertook data extraction.

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## **MAIN RESULTS**

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Three trials met the inclusion criteria for this review but no meta-analysis was possible. One study reported improved maternal-child interaction following group parent training compared with the control group. The second study reported some improvements in parents knowledge of life threatening emergencies, ability to recognise dangers and identify precautions and smaller improvements in their ability to implement precautions, use medicines safely and recognise child illness and symptoms. The third study reported improvement in child care and safety skills following the intervention.

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## **AUTHORS' CONCLUSIONS**

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There is some risk of bias in the included studies, with limited information available to assess possible bias and to fully assess the findings of one included study. Whilst the evidence presented here does seem promising with regard to the ability of such interventions to improve parenting knowledge and skill in this population, there is a need for larger RCTs of interventions before conclusions can be drawn about the effectiveness of parent training for this group of parents.

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# 1 Background

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## 1.1 DESCRIPTION OF THE CONDITION

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Intellectual disability has been defined as significant limitations in both intellectual functioning and adaptive behaviour, originating before the age of 18. Limitations in adaptive skills, which are likely to include social and communicative functions, may have some impact on an individual's capacity to parent a child effectively. Historical definitions of intellectual disability were centred around those with an IQ of below 70, although this is no longer sufficient grounds for a diagnosis. The American Association of Intellectual and Developmental Disabilities suggest that assessments should recognise that people with such limitations may also have strengths and that, with appropriate and sustained support, their level of overall functioning may improve (Luckasson 2002). Whilst a wide range of levels of functioning are encompassed by the term 'intellectual disabilities', the International Association for the Scientific Study of Intellectual Disabilities (IASSID) suggests that most parents with the label of intellectual disabilities are actually those with mild or borderline impairments (IASSID 2008). However, since 'intellectual disability' comprises a large spectrum of cognitive and adaptive skills (British Psychological Society 2000), the likelihood of developing parenting skills to a significant level in an individual may depend on the severity of their disability, as well as social and environmental factors (IASSID 2008; Reinders 2008). The fact that many parents have mild to moderate impairments may mean that they have not had any previous contact with intellectual disability services and that the diagnosis of intellectual disability may be new to them at this stage in their life.

Research from various countries suggests that the number of people with intellectual disabilities with children is increasing (e.g., Department of Health 2000; Pixa-Kettner 2008), although it is not clear whether this reflects an increase in actual numbers or in reporting levels (IASSID 2008). Accurate figures are not available and estimates of the number of parents with intellectual disabilities vary widely. In the UK, estimates range from 60,000 to 250,000, whilst in Australia it is estimated that 1% to 2% of families with a child under 18 has at least one parent with an intellectual disability (Mildon 2003). Reasons for the lack of reliable data include: fragmented services, poor records, lack of common definitions of intellectual

disability, missing assessments, the invisibility of many parents to official agencies and the fact that many cases are 'borderline' and therefore may be included in some instances and not in others (Booth 2002; IASSID 2008).

In addition to the lack of a single definition of intellectual disability, it is important to note that internationally there is a variety of terms used. These include 'learning disabilities' and 'learning difficulties', which predominate in the UK, 'intellectual disability', which has replaced 'mental retardation' in the USA (the latter may still be found in older publications) and various others including 'mental disability', 'mental handicap' and 'cognitive impairment'.

What is known about parents with intellectual disabilities comes from social care or disability agencies where parents are known to service providers (Booth 2002; Llewellyn 2005). Very little is known about intellectually disabled parents who have not been identified or referred to the service system (Tarleton 2006), which may also be true of intellectual disability figures more generally (Kelly 2007).

Low social economic status, unemployment and social isolation/exclusion are all factors known to have adverse effects on parenting within the general population (Tarleton 2006). Mothers and fathers with intellectual disabilities may be at greater risk of experiencing these disadvantages than other parents (Tarleton 2006).

Children of parents with intellectual disabilities may be at increased risk of neglectful care which could lead to health, developmental and behavioural problems (Feldman 2002a), or increased risk of intellectual disability (James 2004). The first national survey of adults with learning difficulties in England suggested that 48% of parents interviewed were not looking after their own children (Emerson 2005). International studies suggest that 40% to 60% of children of parents with intellectual disabilities are taken into alternative care either temporarily or permanently (McConnell 2002). A recent study in the Netherlands found that of the study sample of approximately 1500 Dutch families where one or both parents had an intellectual disability, 33% functioned in a way that qualified as 'good enough' parenting according to the terms of the study (Reinders 2008).

Parents with intellectual disabilities are able to learn parenting skills and provide adequate child care if they are given appropriate training and support to do so (Tymchuck 1991; Murphy 2002). Research suggests that those problems experienced by parents with intellectual disabilities, that may affect their ability to parent effectively, can be alleviated through a number of interventions including parent training programmes (e.g., Feldman 1994), self-directed learning (e.g., Feldman 1999), home based safety interventions (Llewellyn 2003) and developing supportive peer relationships (McGaw 2002).

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## **1.2 DESCRIPTION OF THE INTERVENTION**

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Parent training interventions for parents with intellectual disabilities can take a number of forms and can be governed by a variety of approaches. The common aim of these interventions is to teach parents with intellectual disabilities essential parenting skills to enable them to parent more effectively, protect their children from harm and neglect and ultimately prevent children from being taken into alternative care. Interventions can be delivered individually or in groups and may be instructor led or self taught (Feldman 1999; Llewellyn 2003; Llewellyn 2005). They may involve the use of pictorial manuals to demonstrate essential parenting tasks such that parents with intellectual disabilities may find easy to understand (e.g., Feldman 1997).

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## **1.3 HOW THE INTERVENTION MIGHT WORK**

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Parent training interventions, particularly those based at home, can and do help some intellectually disabled parents to learn a range of parenting skills which they might not otherwise master. Research suggests, however, that it is primarily in relation to parents with an IQ of 60 or below that parenting skills deficits are more likely to arise (IASSID 2008). Parent training interventions may work by being skill-focused and using behavioural teaching strategies e.g., modelling, practice, feedback, praise, tangible reinforcement. Interventions are likely to be more successful if the skills to be learned are broken down into smaller steps which are taught individually (Feldman 1994). Interventions may also improve acquisition of parenting skills if they are based on social learning theory and therefore use methods of learning through observation, rehearsal and reinforcement (Bandura 1977). Providing that learning materials are provided in a form which parents with intellectual disabilities can readily understand, there is evidence that both instructor-led and self-taught interventions can be successful at achieving this aim (McGaw 2000).

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## **1.4 WHY IT IS IMPORTANT TO DO THIS REVIEW**

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A lack of support services for parents with intellectual disabilities is a key factor in influencing court decisions regarding placement of children (Tarleton 2006). Furthermore, the IASSID 2008 draws evidence from a range of international studies in different jurisdictions that highlight the significant proportion of cases before family courts involving families where a parent has an intellectual disability (9% to 22.1% in the studies cited). Whilst children of parents with intellectual disabilities may be at increased risk of developmental delay, where families do not get enough support, any genetic vulnerability may be compounded by a lack of environmental stimulation (McGaw 2005). In addition, other vulnerability factors may arise for parents with intellectual disabilities and their children, in single-parent families and

in families where one or both parents have an intellectual disability. Taking into account the link between social deprivation and poor parenting, it seems extremely important to establish best practice in interventions with parents with intellectual disabilities, given their increased risk of social deprivation.

A special interest group set up as part of the IASSID on 'Parents and Parenting with Intellectual Disability' "strongly emphasizes the need for a concerted international effort to mobilize knowledge from research on parenting with intellectual disabilities, for policy and practice" (IASSID 2008) A review of the different forms of parent training interventions is therefore needed to inform practice development in this field.

A recent published review (Wade 2008) assessed the effectiveness of parent training interventions for parents with intellectual disabilities; however, there are a number of reasons why it is important to undertake a Cochrane review of the topic. Firstly, Wade 2008 included different study designs as well as randomised controlled trials (RCTs), included only peer-reviewed research rather than including grey literature, and limited the search to post-1994 literature, so a more comprehensive review is needed to reinforce the evidence base in this important area (Wade 2008). Given that this is a review of effectiveness, we consider an RCT-only review to be appropriate so as to incorporate the best available evidence to answer the review question.

Although we maintain that RCTs are both feasible and ethical in this area, we are nevertheless aware that in this area single case experimental designs (SCED) are often used for evaluative purposes, for a number of clinical and practical reasons. However, there are currently no recognised ways of synthesizing data collected in studies utilising SCEDs. If this situation changes, we will amend the methods section of the protocol and update the review.

---

## 2 Objectives

To assess the effectiveness of parent training interventions for mothers and fathers with intellectual disabilities designed to support parenting, parent-child relations, safe parenting or family environments or to develop parenting skills.

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## 3 Methods

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### 3.1 CRITERIA FOR CONSIDERING STUDIES FOR THIS REVIEW

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#### **Types of studies**

Randomised controlled trials and quasi randomised studies. We included studies that compared parent training with usual care or with a control group.

#### **Types of participants**

Parents or primary caregivers with independent or shared care of one or more children aged 0 to 18 years, where the parent or caregiver has an intellectual disability, defined as above.

As per the protocol, we would have excluded studies if they had included participants whose intellectual disabilities were caused by head injury or substance misuse problems, unless results for intellectual disability were presented separately. However, we found no such studies.

#### **Types of interventions**

Parent training interventions with any theoretical background designed to improve parenting skills and knowledge, whether individual or group based, and whether instructor led or using a self-taught structured format.

#### **Types of outcome measures**

We included studies if they included one or more of the following outcomes.

##### *Primary outcomes*

Measures used at pre- and post-intervention time points related to:

- Attainment of specific parenting skill targets which were the focus of intervention. Given the nature of interventions for intellectually disabled parents, some outcome measures were based explicitly on the skills taught in a particular intervention rather than a standardised scale (Llewellyn 2003)
- Safe-home practices. Awareness of safety and danger in the home e.g., as measured by the Home Inventory of Dangers and Safety Precautions 2 (Tymchuck 1999);\*

- Understanding of child health i.e., understanding of issues related to child health, development and illness e.g., symptoms, emergencies, use of medication and healthcare. Scales were based on a validated scale e.g., those derived from the UCLA Parent-Child Health and Wellness Project (Tymchuk 2003).\*

\*These measures were developed in the context of work with intellectually disabled parents and so were appropriate for inclusion in this review.

#### *Secondary outcomes*

- Parent-child interaction
- Parents retention of child/return to independent care of the child. None of the included studies measured this.
- Lifting of any child-related court order (although this depended on the jurisdiction). None of the included studies measured this.

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### **3.2 SEARCH METHODS FOR IDENTIFICATION OF STUDIES**

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Jo Abbott, Trials Search Coordinator of the Developmental, Psychosocial and Learning Problems Group, conducted the searches in consultation with EC and JH.

#### **Electronic searches**

We searched the following databases to April 2009:

Cochrane Central Register of Controlled Trials (CENTRAL) 2009 Issue 2  
 MEDLINE (OVID) 1950present  
 EMBASE (OVID) 1980-2009 Week18  
 CINAHL  
 PsycINFO 1806 to May Week 1 2009  
 ASSIA  
 Sociological Abstracts  
 Dissertation Abstracts International  
 MetaRegister of Controlled Trials  
 ZETOC

Detailed search strategies for these databases are in appendices one to five.

We applied no language or date restriction. We did not use RCT filters as it was felt that they would restrict the search too much and could have resulted in potentially relevant records being missed.

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### 3.3 DATA COLLECTION AND ANALYSIS

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#### **Selection of studies**

EC, JH and CB independently identified, read and reviewed titles and abstracts against the inclusion criteria. EC and JH/MT obtained full copies of studies which appeared to meet the inclusion criteria and assessed them independently. We resolved uncertainties concerning the appropriateness of studies for inclusion in the review through consultation with the editorial base or a third review author. Review authors were not blinded to the name(s) of the study author(s), their institution(s) or publication sources at any stage of the review.

#### **Data extraction and management**

We developed data extraction forms a priori that included information regarding:

- methods including concealment of allocation, blinding of outcome assessors, extent of dropouts;
- participant details including severity of intellectual disability, whether participants were living independently with their child(ren), date of diagnosis of intellectual disability;
- intervention details including intensity and frequency, who the intervention was delivered by, whether the intervention was individual or group based, where it was delivered;
- other concurrent interventions and/or health problems;
- outcomes.

EC and JH/MT extracted data independently and organised them using Review Manager 5.

Where data were not available in the published trial reports, we contacted the study authors and asked them to supply the missing information. This was reported in the review.

#### **Assessment of risk of bias in included studies**

For each included study, two review authors independently completed the Cochrane Collaboration's tool for assessing risk of bias (Higgins 2008a). Review authors assessed the degree to which:

- the allocation sequence was adequately generated ('sequence generation');
- the allocation was adequately concealed ('allocation concealment');
- knowledge of the allocated interventions was adequately prevented during the study ('blinding'), whilst acknowledging that it is generally not possible to blind participants in trials of this nature;
- incomplete outcome data were adequately addressed;
- study reports were free of suggestion of selective outcome reporting;

- the study was apparently free of other problems that could put it at high risk of bias.

Each domain was allocated to one of three possible categories for each of the included studies: 'Yes' for low risk of bias, 'No' for high risk of bias, and 'Unclear' where the risk of bias was uncertain or unknown.

### **Measures of treatment effect**

For dichotomous (binary) data, we would have reported risk ratios with a 95% confidence interval to summarise results within each study. We chose the relative risk over the odds ratio because it is more accessible to understanding and interpretation by non research/statistically trained stakeholders. However, the included studies had no binary data.

For continuous data, including measurements on scales, we calculated the mean score for each outcome using a standardised tool and compared this between the two groups to give a mean difference (MD), again with a 95% confidence interval (CI).

### **Unit of analysis issues**

In order to avoid double counting where a study presented results for several periods of follow-up, we planned to undertake separate meta-analyses for the various time points: immediate post-test, six month follow-ups, and 12 month follow-up. Where a study presented data from a different time point to the other studies, we planned to present those data separately.

Where multiple treatment/control group types were presented in study reports, we have sought to present the data from each study as consistently as possible with the primary comparison of treatment compared with control group. Data from studies comparing different types of treatment/control groups would have been presented or analysed separately.

We did not anticipate that cluster designs were likely within this topic area and this did not arise. However, if this had arisen, we would have hoped that study investigators had presented their results in the units in which participants were analysed. Where it was unclear whether this had taken place, we would have contacted the study authors for further information. Had we been unable to obtain further information, we would have sought statistical guidance from the review group as to which method to apply to the published results in order to manage data errors arising from clustering, for example by identifying an intra-class correlation coefficient to utilise in adjusting the data.

Llewellyn 2003 utilised a form of cross-over design where each group received the intervention in a sequence. To avoid possible bleed-out from comparison groups

having received the intervention, only the first time point has been included in the review, incorporating the first group to receive the intervention compared with the treatment as usual group at that time point.

### **Dealing with missing data**

No dichotomous data were included in the review.

In the one instance of missing continuous data (Keltner 1995), we contacted the study author as the sample sizes for the two groups were also not provided. The study author has not responded and it is therefore not possible to impute standard deviations using relevant data (for example, using standard errors or P values).

There was no loss to follow up in the included studies at time 2, although Feldman 1992 presents follow-up data subsequent to the intervention on 8 of the 11 intervention group mothers, indicating that 3 mothers at this point were lost to follow-up.

### **Assessment of heterogeneity**

There were only three studies included in the review and it was not possible to combine their results. As such, heterogeneity was not formally assessed.

### **Assessment of reporting biases**

See Characteristics of included studies.

### **Data synthesis**

We performed no statistical meta-analysis as there were insufficient data in two of the three studies (Feldman 1992; Keltner 1995).

### **Subgroup analysis and investigation of heterogeneity**

We found insufficient studies to undertake subgroup analyses.

### **Sensitivity analysis**

We found insufficient studies to undertake sensitivity analyses.

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## 4 Results

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### 4.1 DESCRIPTION OF STUDIES

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See Characteristics of included studies; Characteristics of excluded studies.  
See Figure 1 for the flow of literature through the review process.

#### **Results of the search**

A total of 1257 studies were retrieved in the searches of electronic databases. We examined the studies and initially judged three to have met the inclusion criteria (Thompson 1984; Keltner 1995; Llewellyn 2003). On closer examination we determined that Thompson 1984, an unpublished PhD thesis, was not fully randomised and we therefore excluded it from the review. At the editorial stage, a further study was identified for inclusion that had not been identified in the original search (Feldman 1992) and one further (Feldman 1993) that we excluded on closer inspection as it did not measure outcomes included in this review.

#### **Included studies**

Three studies met the criteria for inclusion in this review (Feldman 1992; Keltner 1995; Llewellyn 2003).

#### *Participants*

Feldman 1992 included 22 mothers, described as mentally retarded, of children aged 1 to 23 months at the start of the programme. All lived in Canada and the sample included 21 Caucasian Canadians and one Japanese Canadian. The diagnoses of 'mental retardation' in this sample was made when participants were at school and then confirmed as adults with the WAIS-R IQ test. No information was given about dual diagnoses or concurrent treatments but the paper stated that study involvement did not preclude access to other services. The mean maternal age in the intervention group was 25.2 and in the control group 26.6. All mothers were primary care givers for their children, two mothers lived with their parents.

Keltner 1995 included 40 mothers of children aged 12 to 36 months at the start of the programme, who were living in rural communities in the southern USA, with an IQ of less than 85. IQ tests were administered after referral and before recruitment into the study to ensure current status. Two mothers had a dual diagnosis of intellectual disability and mental illness, both received regular therapy in relation to

the mental illness. All women lived in small communities where their extended families also lived. Maternal age range was 16 to 43 years, with a mean of 25.4 years in the intervention group. The mean age in the control group was 22.6 years.

Llewellyn 2003 recruited 63 parents of whom 45 completed the study. All parents lived in Sydney, Australia and had a diagnosed intellectual disability (ID), or history of special education for students with ID, or were identified by the referrer as having cognitive limitations and showing no benefit from the usual intervention. Parents were aged 22 to 45 years with a mean age of 32 years. Forty participants were women and five were men (partners of women included in the study). The first language of all included parents was English.

### *Interventions*

Feldman et al. (1992) developed a home based individual training program focused on teaching infant and child care skills to 'mentally retarded' mothers identified by service providers as at risk of child neglect. Trained parent trainers with undergraduate degrees in psychology or early childhood education provided the intervention by visiting the mothers on a weekly basis. The intervention included verbal instructions, specially designed picture books and modeling of skills by the trainer, as well as feedback to the mother during and after the session. Mothers received coupons when they achieved a score of 80% correct answers. Across skills, the mean training duration was 7.7 weeks ranging from two to 29 weeks. The home visits lasted as long as it took for the mother to reach the criterion on the target skills for the visit.

The control group were on a waiting list and 10 of the mothers in this group (one mother became unavailable) eventually received the intervention in the areas in which they needed support.

Keltner 1995 developed an intervention called Support to Access Rural Services (STARS) to support mothers with intellectual disabilities. Small groups of three or four mothers met weekly in the community in spaces provided by local churches, with a family service worker (qualifications etc not defined). The training focused on interpersonal skills, information about disability, recognition of health and social disorders, crisis intervention, cultural sensitivity, community liaison skills, and realistic expectations. Family service workers were available by phone out of hours. Some field trips included in programme e.g., tours of common service settings to build familiarity including health clinics, welfare benefits offices.

The control group received a support intervention - monthly contact by telephone for 12 months, in person assessments every six months and appropriate referrals as need identified.

Llewellyn 2003 used the Home Learning Program (HLP), adapted for the Australian population. The programme is designed to equip parents of under 5s with knowledge and skills to manage home dangers, accidents and childhood illness. The intervention involved ten one-to-one sessions delivered by a trained parent educator at the parent's home. During each visit the parent educator worked through a set of illustrated, plain English lesson booklets designed to help parents with special educational needs. Each visit typically addressed one issue related to home safety e.g., fire, cooking dangers and home safety precautions. Visits took place weekly over 10 to 12 weeks and each visit lasted between 60 and 90 minutes. Parents received on average 11.5 visits to complete 10 lessons as weekly visits were not always possible.

There were three concurrent groups in this study that included the intervention group, a treatment as usual group with no intervention from the project team, and a group receiving lesson booklets by mail only. Parent educators maintained weekly telephone contact with the booklets group to check progress. This latter group is not included in the analysis for this review.

#### *Outcomes*

Feldman 1992 assessed by observation (by the parent trainers) daily child care routines in the home using child care and safety skills checklists which were chosen in consultation with a range of professionals. Listed skills included diapering, feeding, bathing, sleep safety, cleaning bottles, toilet training and others. Outcomes presented in the study represented a mean percentage of correct performance across the list of skills for each mother.

Keltner 1995 assessed maternal-child interaction using NCATS (Nursing Child Assessment Teaching Scale) mean scores at baseline, six months and 12 months for each group. A higher score on this scale indicates improvement. NCATS measures mother's: sensitivity to child's cues, responsiveness to distress, socio-emotional and cognitive growth fostering and child's: clarity of cues and responsiveness to parent.

Llewellyn 2003 included five measures of child health and three measures of home safety derived from the UCLA Parent-Child Health and Wellenss Project (Tymchuk 2003) administered at baseline, post intervention and three months post intervention. Due to the cross-over design of this study, we included only baseline and post-intervention data in this review.

Five measures of child health:

- **Health comprehension:** health related vocabulary and knowledge of body parts. Scores potentially ranging from 0 to 6 comprised two subscales scored 0 to 3 (where 0 = less than 20% of answers correct and 3 = more than 80% of answers correct).

- ***Illness and symptom recognition***: knowledge about symptoms of illness and common child health problems and practical tasks such as taking a child's temperature. Scores range from 0 to 21 comprised seven subscales relating to symptom recognition scored 0 to 3 as above.
- ***Life threatening emergencies***: knowledge about life threatening emergencies including causes, prevention and response. Scores range from 0 to 12 comprised four subscales scored 0 to 3 as above.
- ***Going to the doctor***: knowledge about when to go to the doctor including what to tell/ask them and following directions. Scores range from 0 to 9 comprised three subscales scored 0 to 3 as above.
- ***Using medicines safely***: knowledge of how to use medicines including prescription medicines including reading and following information on labels. Scores range from 0 to 6 comprised two subscales scored 0 to 3 as above.

Three measures of home safety (designed to assess parental knowledge of dangers and the safety of the home environment):

- ***Home illustrations - Dangers***: Parents asked to identify dangers in pictures of six areas of the home. Scores represent total number of dangers correctly identified out of a possible 104.
- ***Home illustrations - Precautions***: Parents asked to identify precautions for dangers depicted in series of six pictures. Scores represent total number of precautions identified.
- ***Home precautions***: Home observation checklist completed by assessor with parent identifying dangers in parents home and precautions taken by parent. Scores represent total number of precautions taken to deal with total of 114 possible dangers e.g., edibles, suffocation, sharp objects etc.

### **Excluded studies**

We excluded seventeen studies from the review, all of which evaluated parenting interventions for intellectually disabled parents. Fifteen of these studies were excluded due to not being randomised and two studies due to not assessing outcomes included in the review. See Characteristics of excluded studies.

A further study, Feldman 1993, was considered for eligibility for inclusion at the editorial stage. We excluded it because the study control group received an alternative safety and emergency skills training programme. Furthermore, this study's aim was to measure child speech development, not included as an outcome in the review, and also maternal-child interaction. Whilst this latter outcome is included in the review as a secondary outcome, alongside the other exclusion criteria listed above and after deliberation, this study remained excluded.

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## 4.2 RISK OF BIAS IN INCLUDED STUDIES

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See Characteristics of included studies for risk of bias tables.

EC and JH/MT independently assessed bias in the included studies using The Cochrane Collaboration's tool for assessing risk of bias (Higgins 2008a). There was no disagreement between the review authors.

### **Sequence generation**

Feldman 1992 and Keltner 1995 provided no information about sequence generation. Llewellyn 2003 stated that a random number table was used to allocate referrals to one of three groups.

### **Allocation**

Feldman 1992 provided no information about allocation or allocation concealment. For that reason we assessed this condition as unclear. Keltner 1995 stated that random assignment was performed by a person not associated with the project so this condition was assessed as met for this review. Llewellyn 2003 stated that a project manager performed the allocation but the role this manager had in delivery of the intervention was not explained so we assessed this condition as unclear.

### **Blinding**

It is not clear in Feldman 1992 whether participants and trainers were aware of group allocation. The study did state that observers and reliability checkers were unaware of group allocation but this condition is assessed as unclear due to the absence of further information. In Keltner 1995 and Llewellyn 2003, the outcome assessors were blind to treatment allocation. However, for the purpose of this review this condition was assessed as not met as it is not possible in interventions such as this to blind either participants or personnel delivering the intervention.

### **Incomplete outcome data**

All participants from Feldman 1992 included in the review completed the study and missing data only occurred after the outcomes of the intervention were assessed. Therefore, this condition was assessed as met. In Keltner 1995 it was unclear whether all participants completed the study and therefore this condition was assessed as unclear. In Llewellyn 2003 there was no evidence of incomplete outcome data so this condition was assessed as met.

### **Selective reporting**

In none of the studies was there suggestion of selective outcome reporting from the published reports so this condition was assessed as met in all cases.

### **Other potential sources of bias**

For the purposes of this review two studies (Keltner 1995; Llewellyn 2003) were assessed as being free from other sources of bias. However, reporting standards in Keltner 1995 were poor (the sample sizes of the groups and the standard deviations were not reported) and Llewellyn 2003 included a non randomised group but this group was not included within the review. Feldman 1992 was assessed as unclear regarding other sources of bias. Firstly the programme was developed by Maurice Feldman, so he cannot be stated as free from bias. Secondly, there is significant information missing on which to base assessment of key sources of bias such as allocation concealment. Thirdly, the mothers were not given enough information to inform their consent as the study states that mothers were told that the study was 'looking at ways mothers interact with their young children' (P. 20).

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### **4.3 EFFECTS OF INTERVENTIONS**

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As indicated above, it was not possible to perform meta-analysis in this review as the three included studies measured different outcomes with Keltner 1995 measuring maternal-child interaction and Llewellyn 2003 and Feldman 1992 measuring child health and home safety skills.

Keltner 1995 assessed maternal-child interaction using NCATS mean scores at baseline, six months and 12 months for each group. A higher score on this scale indicates improvement. NCATS measures mother's: sensitivity to child's cues, responsiveness to distress, socio-emotional and cognitive growth fostering and child's: clarity of cues and responsiveness to parent.

Group sample sizes were not available for this study so data are presented narratively. We have contacted study authors but no reply has been received at the time of writing. The only outcome presented in this study was maternal-child interaction using NCATS . For the STARS group the study reports a mean at 12 months post-interventions of 51.7 and for the control group a mean of 50.3. The increase in mean NCATS score 12 months from baseline for the STARS group is 8.3 (reported as significant with  $P < .05$ ) and for the control group is 0.4.

Llewellyn 2003 included five measures of child health and three measures of home safety derived from the UCLA Parent-Child Health and Wellness Project, (Tymchuk 2003) administered at baseline, postintervention and three months postintervention. Due to the cross-over design of this study, we included only baseline and post-intervention data in this review.

We entered data from this study into Revman analyses to compute mean differences which appear as differences measured on the original measurement scales in the comparative statistic.

The results from this study were as follows:

### **Child health measures**

#### *Health comprehension*

The results for the health comprehension subscale were MD -0.7 (95% CI -1.29 to -0.11), indicating very little difference between the two groups with a small non-significant difference in favour of the control group.

#### *Illness and symptom recognition*

The results for the illness and symptom recognition subscale were MD 2.15 (95% CI -0.17 to 4.47). This result again indicates very little difference between the two groups with a small non-significant difference in favour of the HLP group.

#### *Life threatening emergencies*

The results for the life-threatening emergencies subscale were MD 1.95 (95% CI 0.46 to 3.44), suggesting a small but positive and significant difference in favour of the HLP group.

#### *Going to the doctor*

The results for the going to the doctor subscale were MD 0.65 (95% CI -0.06 to 1.36), indicating very little difference between the two groups with a small non-significant difference in favour of the HLP group.

#### *Using medicines safely*

The results for the using medicines subscale were MD 1.15 (95% CI 0.51 to 1.79). This result again shows very little difference between the two groups with a small non-significant difference in favour of the HLP group.

### **Home safety measures**

#### *Home illustrations - recognising dangers*

The results for the home illustrations: recognising dangers subscale were MD 20.55 (95% CI 13.72 to 27.38). This is a significant effect in favour of the HLP group.

#### *Home illustrations - identifying precautions*

The results for the home illustrations: identifying precautions subscale were MD 31.75 (95% CI 20.36 to 43.14). This is a significant effect in favour of the HLP group.

#### *Home precautions*

The results for the home precautions subscale were MD 7.05 (95% CI -5.45 to 19.55). This is a small non-significant difference in favour of the HLP group.

Feldman 1992 presented group mean pre- and post-test percentage scores on child care and safety checklists for the intervention and the control groups. For the intervention group the mean pre-test percentage was 62.5% and the mean post-test

percentage was 88.1%. For the control group the mean pre-test percentage was 65.2% and the mean post-test percentage was 60.6%. Repeated measures ANOVAs were calculated to determine the significance of these differences. The results of these tests present the main effect of group as ( $F(1,20) = 18.22$ ), tests as ( $F(1,20) = 24.79$ ) and significant interaction ( $F(1,20) = 50.94$ ) all significant with  $P < .001$ . The study states that the training group scored significantly higher than the control group on post-test. All eleven training group mothers were reported to show increases in the mean percentage correct performance across all skills observed as compared with control group mothers. There was no reported overlap between the groups on the post-test means as the lowest post-test mean in the training group was 79% and the highest mean score in the control group was 75%.

Feldman 1992 also presented follow-up data for a period of between 2 and 76 weeks post-test (mean 28 weeks) on eight of the eleven mothers in the original training group. The reported results show that skills were maintained with a mean of 90.2%. The difference between pre-test and follow-up scores of the training group were significant ( $t(7) = 8.86$ ,  $P < .001$ ) but the replication difference was not significant.

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## 5 Discussion

Intellectual disability has been defined as significant limitations in both intellectual functioning and adaptive behaviour, originating before the age of 18. Such disabilities may impact on an individual's capacity to parent a child effectively. Research from various countries suggests that the number of people with intellectual disabilities with children is increasing (e.g., Department of Health 2000; Pixa-Kettner 2008) although accurate figures are not available.

Children of parents with intellectual disabilities may be at increased risk of neglectful care which could lead to health, developmental and behavioural problems (Feldman 2002a), or increased risk of intellectual disability (James 2004).

However, there is evidence that some parents with intellectual disabilities are able to learn parenting skills and provide adequate child care if they are given appropriate training and support to do so (Tymchuck 1991, Murphy 2002). The common aim of parenting interventions is to teach parents with intellectual disabilities essential parenting skills to enable them to parent more effectively, and protect their children from harm and neglect. Parent training interventions, particularly those based at home, can and do help intellectually disabled parents to learn a range of parenting skills which they might not otherwise master.

The objective of this review was to assess the effectiveness of parent training interventions for parents with intellectual disabilities to support parenting.

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### 5.1 SUMMARY OF MAIN RESULTS

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A comprehensive search of the literature revealed a number of studies on parent training interventions for parents with intellectual disabilities. The majority of these were not randomised controlled trials and some addressed outcomes that were not relevant to this review, leaving only three studies that met the inclusion criteria.

The Feldman 1992 study suggests some significant benefit of the intervention on the small sample recruited to the study, although the only data available were mean percentage scores for each group, so it was not possible to examine the data in more detail.

From the information available in Keltner 1995 it appears that the STARS programme may have conferred some benefit on maternal-child interaction measures compared with the control group. It was not possible to assess this in more depth as some essential data were missing from the published text.

The largest effects within the Llewellyn 2003 study were obtained for home safety measures with recognising dangers and identifying precautions comprising the largest difference between the two groups. There were small positive results for the home precautions subscale of the home safety measures and for the illness and symptom recognition subscale, the life threatening emergencies and the using medicines safely subscales of the health measures used.

Confidence intervals were uniformly wide, which may have been the result of the small sample sizes reducing the confidence in the overall results. The study authors report that these results were statistically significant, although caution should always be applied in the interpretation of results from studies with small sample sizes.

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## **5.2 OVERALL COMPLETENESS AND APPLICABILITY OF EVIDENCE**

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The three studies included in this review were conducted in different countries; one (Keltner 1995) in a rural US location another (Llewellyn 2003) in a urban Australian location and Feldman 1992 in Canada. All three were small, so applicability is inevitably limited. Two studies, (Feldman 1992; Keltner 1995) included only women whilst the other included both men and women, although there were only five men included who were in fact partners of included women. Diagnostic criteria for intellectual disability in the included studies were broad and therefore increase the applicability of the evidence to this population, although the small overall numbers included in the review might compromise this.

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## **5.3 QUALITY OF THE EVIDENCE**

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The quality of the evidence in the included studies is moderate to low with limited information available for assessment of some domains of bias, as well as incomplete data for the computation of effect sizes in Keltner 1995 and Feldman 1992 as described above. The small sample size further compromises the confidence in the available data.

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#### **5.4 POTENTIAL BIASES IN THE REVIEW PROCESS**

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We believe that all of the published randomised controlled trials of parenting interventions for parents with intellectual disabilities published up to the cut-off date were identified by the review process. These included an unpublished PhD thesis that was excluded at data extraction stage on the grounds of incomplete randomisation. Contact to the authors of Keltner 1995 for supply of incomplete data was not successful. We contacted M Feldman who confirmed that he had not conducted further RCTs beyond those we found. No other contact to authors was attempted so it is possible that some studies were missed, although the Table of Excluded Studies demonstrates that many studies in this field have not attempted randomisation and therefore the numbers of studies eligible for inclusion was always likely to be low. A further concern is that, aside from the one ineligible PhD thesis, no unpublished studies were found in the search, so all the studies ultimately included were published studies. The review authors have no vested interests in the field. All eligibility, data extraction and assessment of bias decisions were made by two review authors independently.

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#### **5.5 AGREEMENTS AND DISAGREEMENTS WITH OTHER STUDIES OR REVIEWS**

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We are aware of one recent review of parent training interventions for parents with intellectual disabilities (Wade 2008). The conclusions of that review are similar to this review in supporting the use of behavioural parent training with some learning disabled parents and the benefits of this to the acquisition of knowledge and skills relevant to parenting. That review included wider study designs than randomised controlled trials only and based on the evidence included, the authors conclusions are made more firmly than those made within this review. The findings of that review also support the retrieval in this review of only two randomised controlled trials for the time period they included in their search, which was post 1994. The same trials were included as the only RCTs available by Wade 2008 excluding of course the additional studies included here which predated that review.

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## 6 Authors' Conclusions

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### 6.1 IMPLICATIONS FOR PRACTICE

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The results of this review offer some encouraging evidence in relation to the potential of parenting interventions designed for parents with intellectual disabilities to support and improve parenting knowledge and skills in some such parents. However, the studies included are small with risk of bias, and some of the results equivocal, so relevance to local populations should always be assessed before implementing interventions based on this review with the included data as it stands.

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### 6.2 IMPLICATIONS FOR RESEARCH

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Much more evidence of effectiveness is needed in this area. The evidence base would benefit from larger possibly multi-centre randomised controlled trials with more detailed inclusion information with which to assess generalisability. From the evidence at hand it is not clear what elements of the interventions produce the effect e.g., the manner of delivery, whether home or centre based, whether group or individual, and what frequency or duration might be optimal. As such, the evidence base would benefit from the conduct of process evaluations in order to unpack the different elements of effectiveness more specifically.

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## 7 Acknowledgements

The authors of the protocol would like to thank Cathy Bernal (Senior Lecturer in Learning Disability) and Gill Cross (Senior Practitioner Nurse in Learning Disability) for their valuable support on and input into deciding the content and scope of the review and Stevie Mortensen and Katy Russ for administrative support including the organisation of references. Cathy Bernal also assisted with first stage screening against the inclusion criteria. We would also like to thank Jane Dennis, Chris Champion and Geraldine Macdonald for their invaluable support.

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## 8 Contributions of authors

Conceiving the review: Esther Coren and Carina Gustafsson

Designing the review: Esther Coren

Coordinating the review: Esther Coren

Writing the protocol and conducting and writing the review: Esther Coren, Jemeela Hutchfield and Manuela Thomae

Providing general advice on the review: Jane Dennis and Chris Champion

Securing funding for the review: Esther Coren and Carina Gustafsson

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## 9 Declarations of interest

None known.

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## 10 Differences between protocol and review

One study (Keltner 1995) included two mothers who had comorbid mental illness. We originally intended to exclude such comorbidity but in this instance this was a small minority of included participants who were receiving treatment for their mental illness so we decided to include the study.

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## 11 Published notes

This review is co-registered with the Campbell Collaboration and will be published simultaneously on the Cochrane Library and the Campbell Library.

## 12 Characteristics of studies

### 12.1 CHARACTERISTICS OF INCLUDED STUDIES

*Feldman 1992*

|                      |  |
|----------------------|--|
| <b>Methods</b>       | Randomised controlled trial  |
| <b>Participants</b>  | 22 mothers assessed as having learning disability in school days, and with IQ tests to determine eligibility for services in adulthood |
| <b>Interventions</b> | Weekly home visits by trainer focused on improving parenting skills assessed as deficient  |
| <b>Outcomes</b>      | Child care and home safety checklists devised in consultation with relevant professionals  |
| <b>Notes</b>         |  |

*Risk of bias table*

| <b>Item</b>                               | <b>Judgement</b> | <b>Description</b>   |
|---|------------------|--|
| <b>Adequate sequence generation?</b>      | Unclear          | Not stated   |
| <b>Allocation concealment?</b>            | Unclear          | Not stated   |
| <b>Blinding?</b>                          | Unclear          | Only reliability checkers and observers stated as unaware of group allocation. No further information. |
| <b>Incomplete outcome data addressed?</b> | Yes              | No incomplete data   |
| <b>Free of selective reporting?</b>       | Yes              | It appears that all included outcomes were reported  |
| <b>Free of other bias?</b>                | Unclear          | See text of review   |

|                      |  |
|----------------------|--|
| <b>Methods</b>       | Randomised controlled trial  |
| <b>Participants</b>  | 40 mothers with IQ of less than 85   |
| <b>Interventions</b> | Support to Access Rural Services (STARS). Small groups met weekly in the community. Training on interpersonal skills, information about disability, recognition of health and social disorders, crisis intervention, cultural sensitivity, community liaison skills, realistic expectations. Control group received monthly telephone contact, 6 monthly assessments and appropriate onward referrals. |
| <b>Outcomes</b>      | Maternal-child interaction (NCATS means scores) - baseline, 6 months, 12 months  |
| <b>Notes</b>         |  |

*Risk of bias table*

| <b>Item</b>                               | <b>Judgement</b> | <b>Description</b>   |
|---|------------------|--|
| <b>Adequate sequence generation?</b>      | Unclear          | No information.  |
| <b>Allocation concealment?</b>            | Yes              | Random assignment performed by a person not associated with the project.   |
| <b>Blinding?</b>                          | No               | Assessors blind. Not possible to blind participants or those delivering the intervention.                            |
| <b>Incomplete outcome data addressed?</b> | Unclear          | Unclear whether all participants completed the study.  |
| <b>Free of selective reporting?</b>       | Yes              | From published report no suggestion of selective outcome reporting.  |
| <b>Free of other bias?</b>                | Yes              | Although poor reporting standards i.e., no sample sizes for each group provided or standard deviations for outcomes. |

*Llewellyn 2003*

|                |  |
|----------------|--|
| <b>Methods</b> | Randomised controlled trial. Design similar to cross-over in that all participants get the intervention in sequence over a period of time. To compensate for possible effects, first period only for intervention and treatment as usual only groups included. |
|----------------|--|

|                      |   |
|----------------------|---|
| <b>Participants</b>  | 63 parents recruited, 45 completed study. Diagnosed intellectual disability (ID), or history of special education for students with ID, or identified by referrer as having cognitive limitations and showing no benefit from usual intervention.                                 |
| <b>Interventions</b> | Home Learning Program (HLP) designed to equip parents of under 5s with knowledge and skills to manage home dangers, accidents and childhood illness. Ten one-to-one sessions using booklets designed to meet parents' needs. Weekly visits, 60 to 90 minutes over 10 to 12 weeks. |
| <b>Outcomes</b>      | Child health (health comprehension, illness and symptom recognition, life threatening emergencies, going to the doctor, using medicines safely) and home safety (home illustrations-dangers and precautions) and home precautions).   |
| <b>Notes</b>         |   |

*Risk of bias table*

| <b>Item</b>                               | <b>Judgement</b> | <b>Description</b>   |
|---|------------------|--|
| <b>Adequate sequence generation?</b>      | Yes              | Project manager used random number table to allocate referrals to one of three groups. A fourth group was created for late referrals but this group is not included in the analysis for this review.   |
| <b>Allocation concealment?</b>            | Unclear          | Unclear what the role of the person performing the allocation was in service delivery or evaluation.   |
| <b>Blinding?</b>                          | No               | Assessors blinded to group allocation but not clear about personnel or participants. Not really possible to blind in such interventions.   |
| <b>Incomplete outcome data addressed?</b> | Yes              | No missing data for outcomes of interest.  |
| <b>Free of selective reporting?</b>       | Yes              | From published report no suggestion of selective outcome reporting.  |
| <b>Free of other bias?</b>                | No               | Fourth group recruitment and allocation not fully random but not included in the data we extracted or included. This review only including first time point data for HLP and treatment as usual group so review not affected by possible bleed out from groups all receiving intervention in a different sequence. |

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## 12.2 CHARACTERISTICS OF EXCLUDED STUDIES

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*Aanes 1975*

|                             |         |
|-----------------------------|---------|
| <b>Reason for exclusion</b> | Not RCT |
|-----------------------------|---------|

*Bakken 1993*

|                             |         |
|-----------------------------|---------|
| <b>Reason for exclusion</b> | Not RCT |
|-----------------------------|---------|

*Fantuzzo 1986*

|                             |         |
|-----------------------------|---------|
| <b>Reason for exclusion</b> | Not RCT |
|-----------------------------|---------|

*Feldman 1989*

|                             |         |
|-----------------------------|---------|
| <b>Reason for exclusion</b> | Not RCT |
|-----------------------------|---------|

*Feldman 1993*

|                             |   |
|-----------------------------|---|
| <b>Reason for exclusion</b> | Control group also given an intervention. |
|-----------------------------|---|

*Feldman 1997*

|                             |         |
|-----------------------------|---------|
| <b>Reason for exclusion</b> | Not RCT |
|-----------------------------|---------|

*Feldman 1998*

|                             |         |
|-----------------------------|---------|
| <b>Reason for exclusion</b> | Not RCT |
|-----------------------------|---------|

*Feldman 1999*

|                             |         |
|-----------------------------|---------|
| <b>Reason for exclusion</b> | Not RCT |
|-----------------------------|---------|

*Feldman 1999b*

|                             |         |
|-----------------------------|---------|
| <b>Reason for exclusion</b> | Not RCT |
|-----------------------------|---------|

*Feldman 2004*

|                             |         |
|-----------------------------|---------|
| <b>Reason for exclusion</b> | Not RCT |
|-----------------------------|---------|

*Heinz 2003*

|                             |         |
|-----------------------------|---------|
| <b>Reason for exclusion</b> | Not RCT |
|-----------------------------|---------|

*McConnell 2008*

|                             |         |
|-----------------------------|---------|
| <b>Reason for exclusion</b> | Not RCT |
|-----------------------------|---------|

*McConnell 2008b*

|                             |         |
|-----------------------------|---------|
| <b>Reason for exclusion</b> | Not RCT |
|-----------------------------|---------|

*McGaw 2002*

|                             |                               |
|-----------------------------|-------------------------------|
| <b>Reason for exclusion</b> | No relevant outcomes included |
|-----------------------------|-------------------------------|

*Peterson 1983*

|                             |         |
|-----------------------------|---------|
| <b>Reason for exclusion</b> | Not RCT |
|-----------------------------|---------|

*Thompson 1984*

|                             |         |
|-----------------------------|---------|
| <b>Reason for exclusion</b> | Not RCT |
|-----------------------------|---------|

*Tymchuk 1991*

|                             |         |
|-----------------------------|---------|
| <b>Reason for exclusion</b> | Not RCT |
|-----------------------------|---------|

*Whitman 1989*

|                             |         |
|-----------------------------|---------|
| <b>Reason for exclusion</b> | Not RCT |
|-----------------------------|---------|

## 13 Summary of findings tables

### 13.1 PARENT TRAINING SUPPORT FOR INTELLECTUALLY DISABLED PARENTS

*Patient or population: Patients with Intellectual Disability*

*Settings:*

*Intervention: Parenting Training*

| Outcomes   | Illustrative comparative risks* (95% CI)                            |  | Relative effect (95% CI) | No of Participants (studies) | Quality of the evidence (GRADE)             | Comments |
|--|---|--|--------------------------|------------------------------|---|----------|
|  | Assumed risk  | Corresponding risk   |                          |                              |   |          |
|  | Control   | Parenting Training   |                          |                              |   |          |
| <b>Health Comprehension</b><br>Health Knowledge. Scale from: 0 to 6.<br>Follow-up: mean 12 weeks       | The mean health comprehension in the control groups was <b>5.8</b>  | The mean Health Comprehension in the intervention groups was <b>0.7 lower</b> (1.29 to 0.11 lower)         |                          | 30 (1 study)                 | + - - -<br><b>very low</b> <sup>1,2</sup>   |          |
| <b>Symptom Recognition</b><br>Child Health Knowledge. Scale from: 0 to 21.<br>Follow-up: mean 12 weeks | The mean symptom recognition in the control groups was <b>10.8</b>  | The mean Symptom Recognition in the intervention groups was <b>2.15 higher</b> (0.17 lower to 4.47 higher) |                          | 30 (1 study)                 | + - - -<br><b>very low</b> <sup>1,2</sup>   |          |
| <b>Recognising Dangers</b><br>Recognising Dangers. Scale from: 0 to 104.<br>Follow-up: mean 12 weeks   | The mean recognising dangers in the control groups was <b>55.70</b> | The mean Recognising Dangers in the intervention groups was <b>20.55 higher</b> (13.72 to 27.38 higher)    |                          | 30 (1 study)                 | + - - -<br><b>very low</b> <sup>1,2,3</sup> |          |

|  |  |   |                 |   |
|--|--|---|-----------------|---|
| <b>Home Precautions</b><br>Home observation checklist which identified dangers in the parent's home and precautions which parent has taken. Scale from: 0 to 114. Follow-up: mean 12 weeks | The mean home precautions in the control groups was <b>53.3</b>          | The mean Home Precautions in the intervention groups was <b>7.05 higher</b> (5.45 lower to 19.55 higher)          | 30<br>(1 study) | + - - -<br><b>very low</b> <sup>1,2</sup>     |
| <b>Identifying Precautions</b><br>Home illustrations for participants to identify recognised precautions in illustrations. Scale from: 0 to 6. Follow-up: mean 12 weeks                    | The mean identifying precautions in the control groups was <b>47.10</b>  | The mean Identifying Precautions in the intervention groups was <b>31.75 higher</b> (20.36 to 43.14 higher)       | 30<br>(1 study) | + - - -<br><b>very low</b> <sup>1,2,3</sup>   |
| <b>Child Care Routines</b><br>Follow-up: mean 7.7 weeks  | The mean child care routines in the control groups was <b>-4.6</b>       | The mean Child Care Routines in the intervention groups was <b>30.2 higher</b> (0 to 0 higher) <sup>4</sup>       | 22<br>(1 study) | + - - -<br><b>very low</b> <sup>1,2,3,5</sup> |
| <b>Maternal Child Interaction NCATS</b><br>Follow-up: mean 1 years   | The mean maternal child interaction in the control groups was <b>0.4</b> | The mean Maternal Child Interaction in the intervention groups was <b>7.9 higher</b> (0 to 0 higher) <sup>4</sup> | 40<br>(1 study) | + - - -<br><b>very low</b> <sup>1,2,3,5</sup> |

\*The basis for the **assumed risk** (e.g. the median control group risk across studies) is provided in footnotes. The **corresponding risk** (and its 95% confidence interval) is based on the assumed risk in the comparison group and the **relative effect** of the intervention (and its 95% CI).

**CI:** Confidence interval;

GRADE Working Group grades of evidence

**High quality:** Further research is very unlikely to change our confidence in the estimate of effect.

**Moderate quality:** Further research is likely to have an important impact on our confidence in the estimate of effect and may change the estimate.

**Low quality:** Further research is very likely to have an important impact on our confidence in the estimate of effect and is likely to change the estimate.

**Very low quality:** We are very uncertain about the estimate.

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<sup>1</sup>Very small sample size

<sup>2</sup>Published evidence is limited to a small number of trials, all of which are showing benefits of the studied intervention.

<sup>3</sup>Allocation concealment unclear and no blinding in study. Also, 4th intervention group were not randomised. Although they are not included in the data in this review, it remains a threat to validity.

<sup>4</sup>not applicable

<sup>5</sup>Very strong possibility that all studies in this review affected by publication bias as all found some positive results and no other RCTs exist that we know of in this field.

## 14 Additional tables

### 14.1 METHODS NOT REQUIRED IN CURRENT VERSION OF REVIEW

| Issue                                 | Proposed approach   |
|---------------------------------------|---|
| <b>Missing dichotomous data</b>       | If dichotomous data are included in the review we will report missing data and dropouts for each included study and report the number of participants included in the final analysis as a proportion of all participants in each study. We will provide reasons for the missing data in the narrative summary and assess the extent to which the results of the review could be altered by the missing data by, for example, a sensitivity analysis based on consideration of 'best-case' and 'worst-case' scenarios (Gamble 2005). Here, the 'best-case' scenario is that where all participants with missing outcomes in the experimental condition had good outcomes, and all those with missing outcomes in the control condition had poor outcomes; the 'worst-case' scenario is the converse (Higgins 2008b).   |
| <b>Missing continuous data</b>        | If there are missing continuous data, we will provide a narrative summary. The standard deviations of the outcome measures will be reported for each group in each trial. Higgins, Deeks and Altman (Higgins 2008b) suggest that it is plausible to assume a fixed difference for the missing data e.g., averaging 2 units more or less than the intervention or control arms. Where possible we will assess studies with missing continuous data in this way for the intervention and control groups, seeking advice from the statistical editor about specific details.   |
| <b>Assessment of heterogeneity</b>    | We will assess the extent of between-trial differences and the consistency of results of any meta-analysis in three ways: by visual inspection of the forest plots, by performing the Chi <sup>2</sup> test of heterogeneity (where a significance level less than 0.10 is interpreted as evidence of heterogeneity), and by examining the I <sup>2</sup> statistic (Deeks 2008)). The I <sup>2</sup> statistic describes approximately the proportion of variation in point estimates that is due to heterogeneity. We will consider I <sup>2</sup> values less than 30% as indicating low levels of heterogeneity, values in the range 31% to 69% as indicating moderate heterogeneity, and values greater than 70% as indicating high levels of heterogeneity. We will also attempt to identify any significant determinants of heterogeneity categorised at moderate or high by examining any clinical heterogeneity in the sample. |
| <b>Assessment of reporting biases</b> | Funnel plots (plotting of sample size against effect) will be drawn to assess publication and related biases if sufficient studies are found.   |

|   |   |
|---|---|
| <b>Data synthesis</b>                                       | <p>As referenced in the Cochrane Handbook (Higgins, 2008, section 9.1.3), statistical meta-analysis can be a useful tool in the synthesis of studies, although where studies are clinically diverse, or at risk of bias, it can be inappropriate and can obscure genuine effects (Higgins, 2008, section 9.1.4).</p> <p>If a statistical meta-analysis is possible, in the likely event that the studies found are small and heterogenous, as in the case of the three studies included in this review, we will undertake synthesis of the data using a random-effects model of meta-analysis, which accounts for the fact that included studies may be estimating similar but different treatment effects (Higgins, 2008, section 9.4.4.3; 9.5.4). Statistical heterogeneity will be assessed as described in the section above.</p> <p>In undertaking meta-analysis, the weight given to each study will be the inverse of the variance so that the more precise estimates (from larger studies with more events) are given more weight.</p>  |
| <b>Subgroup analysis and investigation of heterogeneity</b> | <p>If enough studies are found, we plan the following subgroup analyses to examine the effect on primary outcomes of:</p> <ol style="list-style-type: none"> <li>(1) severity of intellectual disability</li> <li>(2) participants living independently with children or in a supervised care situation</li> <li>(3) date of diagnosis of intellectual disability: within last 10 years/10-20 years ago/more than 30 years ago. These subgroups are of clinical relevance given that the process of assessing intellectual disability has changed over the last 30 years from a sometimes perfunctory assessment using loose criteria to the use of standardised diagnostic tools (e.g., DSM-IV). Depending on when the patient was last assessed, their diagnosis may be more or less concurrent with current knowledge on intellectual disabilities. Early diagnoses may have been less sensitive to diagnostic nuances so that service users with mild intellectual impairments may have been grouped with others whose impairments were much more severe. As a result of this, studies that include participants with older diagnoses may potentially be significantly different to studies which include only participants diagnosed more recently.</li> <li>(4) instructor-led or self-taught intervention</li> <li>(5) individual or group based intervention</li> <li>(6) length of intervention</li> <li>(7) whether delivered at home or at a centre</li> </ol> |
| <b>Sensitivity analysis</b>                                 | <p>If there are sufficient data, we will undertake sensitivity analyses to investigate the robustness of the overall findings in relation to aspects of methodological quality. A priori sensitivity analyses are planned for:</p> <ol style="list-style-type: none"> <li>(1) concealment of allocation</li> <li>(2) blinding of outcome assessors</li> <li>(3) extent of dropouts</li> </ol>   |

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## 15 References to studies

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### 15.1 INCLUDED STUDIES

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## 17 Data and analyses

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### 17.1 COMPARISON 1: CHILD HEALTH

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| Outcome or Subgroup            | Studies | Participants | Statistical Method                       | Effect Estimate      |
|--------------------------------|---------|--------------|--|----------------------|
| 1.1 Health comprehension       | 1       | 30           | Mean Difference ( IV , Random , 95% CI ) | -0.70 [-1.29, -0.11] |
| 1.2 Symptom recognition        | 1       | 30           | Mean Difference ( IV , Random , 95% CI ) | 2.15 [-0.17, 4.47]   |
| 1.3 Life threatening emergency | 1       | 30           | Mean Difference ( IV , Random , 95% CI ) | 1.95 [0.46, 3.44]    |
| 1.4 Visiting the doctor        | 1       | 30           | Mean Difference ( IV , Random , 95% CI ) | 0.65 [-0.06, 1.36]   |
| 1.5 Using medicines            | 1       | 30           | Mean Difference ( IV , Random , 95% CI ) | 1.15 [0.51, 1.79]    |

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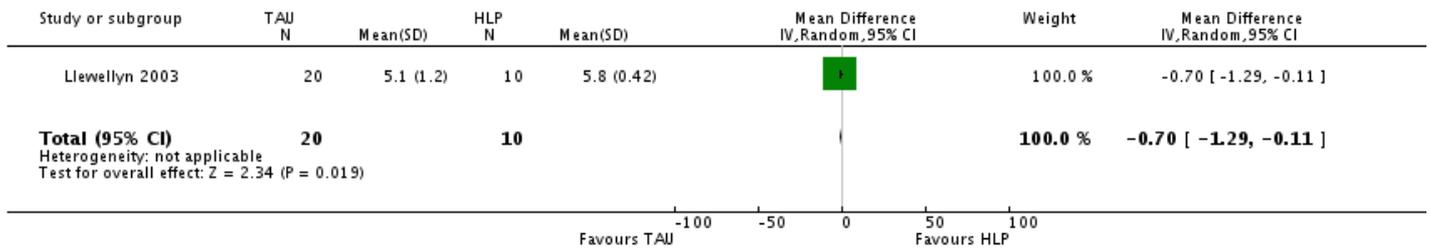
### 17.2 COMPARISON 2: HOME SAFETY

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| Outcome or Subgroup         | Studies | Participants | Statistical Method                       | Effect Estimate      |
|-----------------------------|---------|--------------|--|----------------------|
| 2.1 Recognising dangers     | 1       | 30           | Mean Difference ( IV , Random , 95% CI ) | 20.55 [13.72, 27.38] |
| 2.2 Identifying precautions | 1       | 30           | Mean Difference ( IV , Random , 95% CI ) | 31.75 [20.36, 43.14] |
| 2.3 Home precautions        | 1       | 30           | Mean Difference ( IV , Random , 95% CI ) | 7.05 [-5.45, 19.55]  |

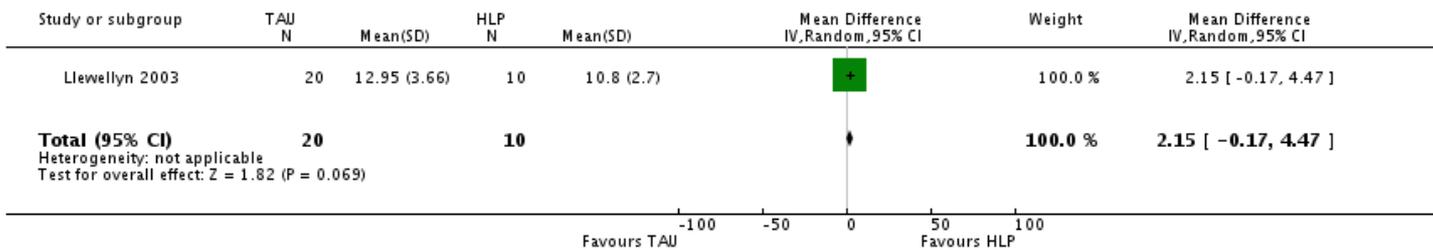
### 17.3 ANALYSIS 1.1: COMPARISON 1 CHILD HEALTH, OUTCOME 1 HEALTH COMPREHENSION.

Review: Parent training support for intellectually disabled parents  
 Comparison: 1 Child health  
 Outcome: 1 Health comprehension



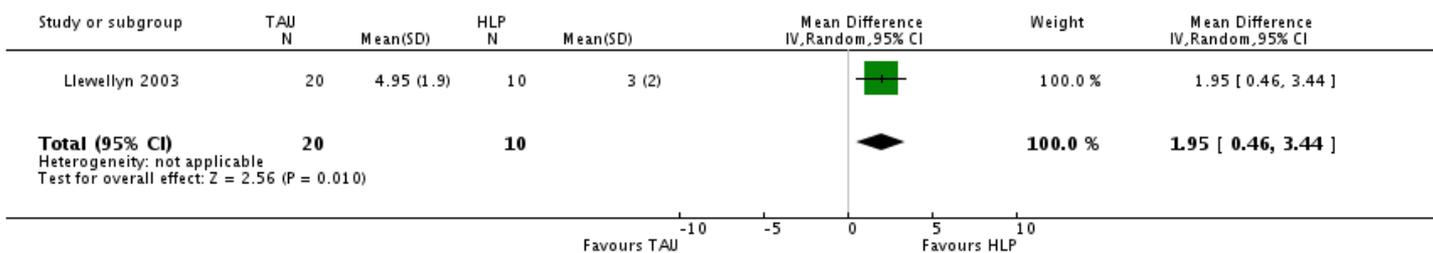
### 17.4 ANALYSIS 1.2: COMPARISON 1 CHILD HEALTH, OUTCOME 2 SYMPTOM RECOGNITION.

Review: Parent training support for intellectually disabled parents  
 Comparison: 1 Child health  
 Outcome: 2 Symptom recognition



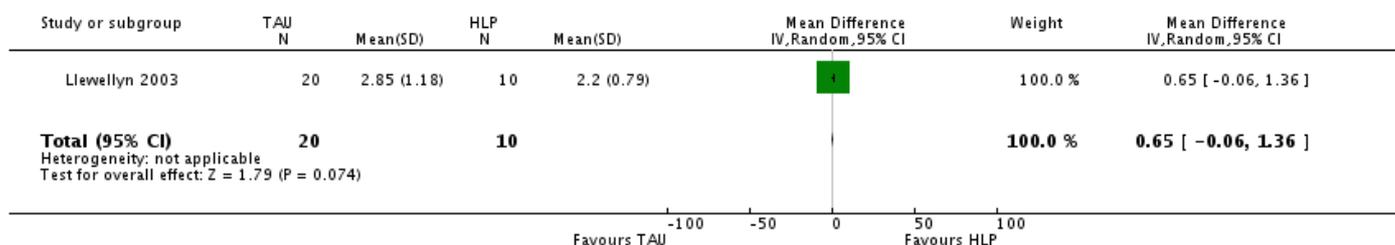
### 17.5 ANALYSIS 1.3: COMPARISON 1 CHILD HEALTH, OUTCOME 3 LIFE THREATENING EMERGENCY.

Review: Parent training support for intellectually disabled parents  
 Comparison: 1 Child health  
 Outcome: 3 Life threatening emergency



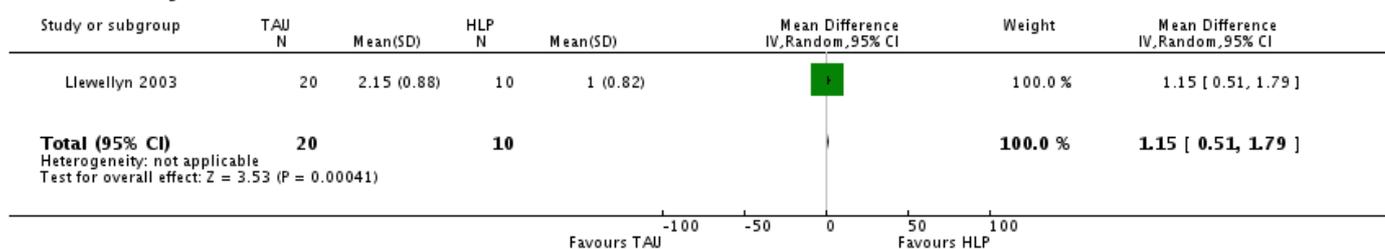
## 17.6 ANALYSIS 1.4: COMPARISON 1 CHILD HEALTH, OUTCOME 4 VISITING THE DOCTOR.

Review: Parent training support for intellectually disabled parents  
 Comparison: 1 Child health  
 Outcome: 4 Visiting the doctor



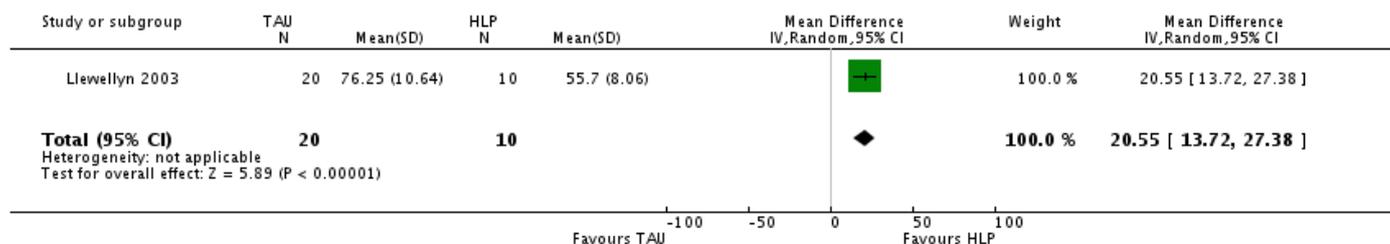
## 17.7 ANALYSIS 1.5: COMPARISON 1 CHILD HEALTH, OUTCOME 5 USING MEDICINES.

Review: Parent training support for intellectually disabled parents  
 Comparison: 1 Child health  
 Outcome: 5 Using medicines



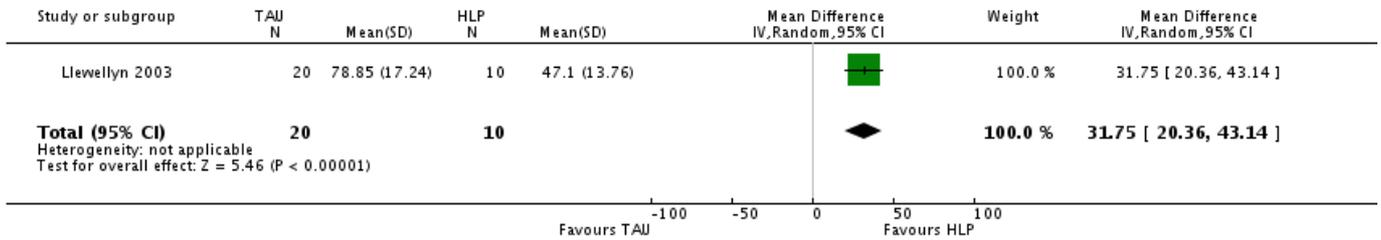
## 17.8 ANALYSIS 2.1: COMPARISON 2 HOME SAFETY, OUTCOME 1 RECOGNISING DANGERS.

Review: Parent training support for intellectually disabled parents  
 Comparison: 2 Home safety  
 Outcome: 1 Recognising dangers



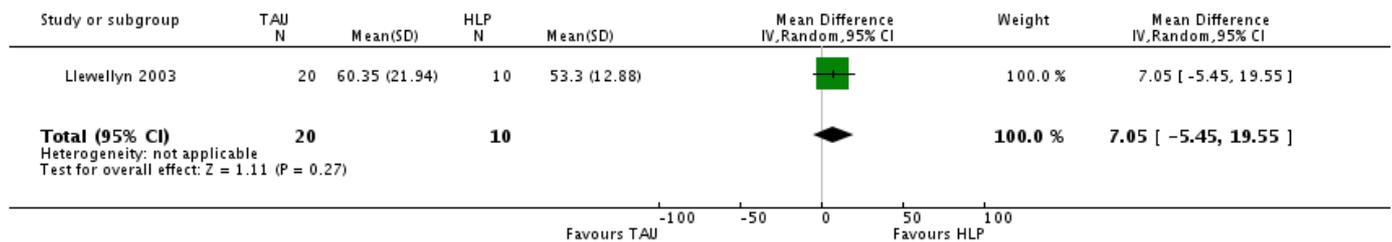
## 17.9 ANALYSIS 2.2: COMPARISON 2 HOME SAFETY, OUTCOME 2 IDENTIFYING PRECAUTIONS.

Review: Parent training support for intellectually disabled parents  
 Comparison: 2 Home safety  
 Outcome: 2 Identifying precautions



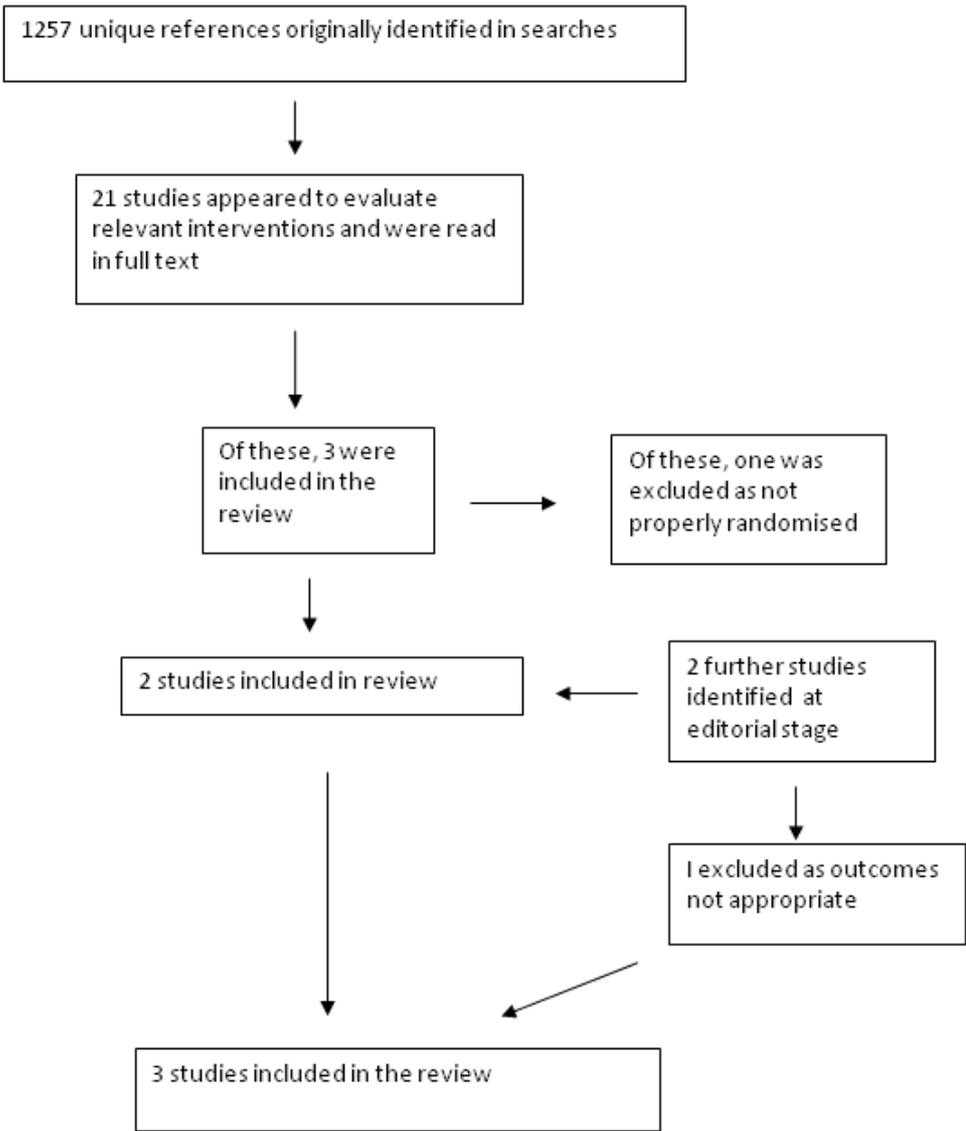
## 17.10 ANALYSIS 2.3: COMPARISON 2 HOME SAFETY, OUTCOME 3 HOME PRECAUTIONS.

Review: Parent training support for intellectually disabled parents  
 Comparison: 2 Home safety  
 Outcome: 3 Home precautions



# 18 Figures

**18.1 FIGURE 1: FLOW OF LITERATURE THROUGH THE REVIEW**



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## 19 Sources of support

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### 19.1 INTERNAL SOURCES

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Canterbury Christ Church University, UK

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### 19.2 EXTERNAL SOURCES

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IMS, Sweden

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## 20 Appendices

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### 20.1 MEDLINE SEARCH STRATEGY

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Searched April 2009.

- 1 exp Mental Retardation/
- 2 (intellectual\$ adj3 disabl\$).tw.
- 3 (learning adj3 disabl\$).tw.
- 4 (learning adj3 difficult\$).tw.
- 5 (cognitive\$ adj3 (disabl\$ or impair\$)).tw.
- 6 mental\$ retard\$.tw.
- 7 (mental\$ adj3 disabl\$).tw.
- 8 (mental\$ adj3 impair\$).tw.
- 9 down\$ syndrome.tw.
- 10 mongol\$.tw.
- 11 (mental\$ adj3 deficie\$).tw.
- 12 idiocy.tw.
- 13 fragile x.tw.
- 14 prader-willi.tw.
- 15 or/1-14
- 16 (parent\$ adj3 program\$).tw.
- 17 (parent\$ adj3 train\$).tw.
- 18 (parent\$ adj3 (educat\$ or promot\$ or skill\$ or group\$ or support\$)).tw.
- 19 or/16-18
- 20 15 and 19

---

### 20.2 EMBASE SEARCH STRATEGY

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Searched April 2009.

- 1 exp Mental Deficiency/
- 2 (intellectual\$ adj3 disabl\$).tw.
- 3 (learning adj3 disabl\$).tw.
- 4 (learning adj3 difficult\$).tw.
- 5 (cognitive\$ adj3 (disabl\$ or impair\$)).tw.

- 6 mental\$ retard\$.tw.
- 7 (mental\$ adj3 disabl\$).tw.
- 8 (mental\$ adj3 impair\$).tw.
- 9 down\$ syndrome.tw.
- 10 mongol\$.tw.
- 11 (mental\$ adj3 deficie\$).tw.
- 12 idiocy.tw.
- 13 fragile x.tw.
- 14 prader-willi.tw.
- 15 or/1-14
- 16 (parent\$ adj3 program\$).tw.
- 17 (parent\$ adj3 train\$).tw.
- 18 (parent\$ adj3 (educat\$ or promot\$ or skill\$ or group\$ or support\$)).tw.
- 19 or/16-18
- 20 15 and 19

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### **20.3 ASSIA (CSA) SEARCH STRATEGY**

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Searched 7 May 2009.

((DE=("learning disabilities" or "aicardi syndrome" or "aspartylglucosaminuria" or "cri du chat syndrome" or "de lange syndrome" or "down s syndrome" or "fragile x syndrome" or "nonverbal learning disabilities" or "prader willi syndrome" or "mental retardation")) or(intellectual\* within 3 disabl\*) or(learning within 3 disabl\*) or(learning within 3 difficult\*) or((cognitive\* within 3 disabl\*) and (cognitive\* within 3 impair\*)) or (mental\* retard\*) or(mental\* within 3 disabl\*) or(mental\* within 3 impair\*) or(down\* syndrome) or(mongol\*) or(mental\* within 3 deficie\*) or(idiocy) or(fragile x) or(prader-willi)) and(((parent\* within 3 program\*) or (parent\* within 3 train\*) or (parent\* within 3 educat\*)) or ((parent\* within 3 promot\*) or (parent\* within 3 skill\*) or (parent\* within 3 group\*)) or (parent\* within 3 support\*))

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### **20.4 PSYCINFO SEARCH STRATEGY**

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Searched 7 May 2009

- 1 exp Mental Retardation/
- 2 (intellectual\$ adj3 disabl\$).tw.
- 3 (learning adj3 disabl\$).tw.
- 4 (learning adj3 difficult\$).tw.
- 5 (cognitive\$ adj3 (disabl\$ or impair\$)).tw.
- 6 mental\$ retard\$.tw.

- 7 (mental\$ adj3 disabl\$).tw.
- 8 (mental\$ adj3 impair\$).tw.
- 9 down\$ syndrome.tw.
- 10 mongol\$.tw.
- 11 (mental\$ adj3 deficie\$).tw.
- 12 idiocy.tw.
- 13 fragile x.tw.
- 14 prader-willi.tw.
- 15 or/1-14
- 16 (parent\$ adj3 program\$).tw.
- 17 (parent\$ adj3 train\$).tw.
- 18 (parent\$ adj3 (educat\$ or promot\$ or skill\$ or group\$ or support\$)).tw.
- 19 or/16-18
- 20 15 and 19

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## 20.5 SOCIOLOGICAL ABSTRACTS (CSA) SEARCH STRATEGY

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Searched 7 May 2009.

((parent\* within 3 program\*) or (parent\* within 3 train\*) or (parent\* within 3 educat\*) or ((parent\* within 3 promot\*) or (parent\* within 3 skill\*) or (parent\* within 3 group\*)) or (parent\* within 3 support\*)) and((intellectual\* within 3 disabl\*) or(learning within 3 disabl\*) or(learning within 3 difficult\*) or((cognitive\* within 3 disabl\*) and (cognitive\* within 3 impair\*)) or(mental\* retard\*) or(mental\* within 3 disabl\*) or(mental\* within 3 impair\*) or(down\* syndrome) or(mongol\*) or(mental\* within 3 deficie\*) or(idiocy) or(fragile x) or(prader-willi) or(DE="learning disabilities"))