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Parent training interventions for parents with intellectual disability (Review)

Coren E, Ramsbotham K, Gschwandtner M

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Parent training interventions for parents with intellectual disability.

Cochrane Database of Systematic Reviews 2018, Issue 7. Art. No.: CD007987.

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[Intervention Review]

Parent training interventions for parents with intellectual disability

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ABSTRACT

Background

Research suggests that the number of intellectually disabled people with children is increasing. Intellectual disabilities do not inevitably cause parenting difficulties, but it may impact on an individual's capacity to parent a child effectively. 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. Compared with other parents, those with intellectual disabilities are more likely to be involved in care proceedings.

Objectives

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

Search methods

In July 2017, we searched CENTRAL, Ovid MEDLINE, Embase, CINAHL and six other databases as well as two trials registers. We also searched reference lists of included studies and contacted experts in the field to identify additional ongoing and unpublished studies.

Selection criteria

Randomised controlled trials (RCTs) and quasi-RCTs comparing parent training interventions for parents with intellectual disabilities with treatment as usual or a control group.

Data collection and analysis

We used standardised Cochrane methods.

Main results

As of July 2017, we identified four trials with 192 participants that met the review inclusion criteria. Participating parents were mostly mothers (seven fathers were included in two studies), and children's ages ranged from one month to six years and five months.

One study was conducted in Australia, one in Canada, one in the Netherlands, and one in the USA. Each studied a different intervention and considered different outcomes. Three interventions were delivered at home, and one in a community venue (e.g. a church). Interventions varied in duration from seven weeks to 12 months. They included a range of practical childcare skills, home safety and developing parents' ability to respond sensitively to their children. Parents in the comparison groups included in the review received treatment as usual and most of these received the index intervention after the study was complete.

One study was funded by the Ontario Mental Health Foundation and the Ontario Ministry of Community and Social Services Research Grants Program; one by the Alabama Development Disabilities Council; one by the Best Practice Parenting Education Initiative of the Commonwealth Department of Family and Community Services and the New South Wales Aging and Disability Department; and one by ZonMw, The Netherlands Organisation for Health Research and Development.

It was not possible for us to conduct a meta-analysis. The GRADE quality assessment varied from very low to moderate across the studies.

Primary outcomes

No study reported on the 'attainment of specific parenting skill targets'.

'Safe home practices' and 'understanding of child health': one study (30 parents, very low-quality evidence) reported some improvements in parents' knowledge of life-threatening emergencies, ability to recognise dangers, and identify precautions, in favour of the intervention group. It also found limited, very low-quality evidence that parent training improved parents' ability to understand child health, implement precautions, use medicines safely, recognise child illness and symptoms, and seek medical advice (i.e. visit the doctor). Another study (22 mothers, very low-quality evidence) reported improved attainment of skills related to childcare and safety, in favour of the intervention group.

Secondary outcomes

'Parent-child interaction': one study (40 mothers, very low-quality evidence) reported improved maternal-child interaction following parent training at 12 months follow-up. Another study (83 mothers, 2 fathers, moderate-quality evidence) reported that inclusion in the intervention group led to a steeper decline in parenting stress related to the child compared to the control group.

'Parents' retention of child': one study (22 participants; very low-quality evidence) reported that before joining the programme nine of 11 (82%) families with a previous child had had the child removed from their care by child protection authorities due to maternal maltreatment, compared with only four of 22 (19%) families after participating in the programme (only one of these four mothers had also had a previous child removed).

No study reported data on: 'return to independent care of child' or 'lifting of child-related court order'.

Authors' conclusions

There is some very low-quality evidence that some parents, mainly mothers, with intellectual disabilities are able to provide adequate parenting if they are given appropriate training and support to learn the parenting skills they need. However, there are few studies exploring how interventions might work, for whom and in what circumstances. In particular, there have been few studies that include fathers with intellectual disabilities, or that explore the views of parents themselves.

There is a need for larger RCTs of parenting interventions, with longer follow-up, before conclusions can be drawn about the effectiveness of parent training for this group of parents.

PLAIN LANGUAGE SUMMARY

Parent training for parents with intellectual disabilities

Review question

Do parent training interventions help parents with intellectual disabilities to parent adequately?

Background

Parents with intellectual disabilities may find it more difficult than other parents to provide adequate childcare. Parent training programmes are one way of providing support. We reviewed the evidence about the effects of parent training programmes for parents with intellectual disabilities. We found four randomised controlled trials (RCT; a type of experiment where similar people are put into different groups).

Search Date

The evidence is current to July 2017.

Study characteristics

The four RCTs were conducted in Australia, Canada, the Netherlands and USA, and involved 192 parents. Each studied a different intervention and considered different outcomes. All but seven of the participating parents were mothers.

Children's ages ranged from one month to six years and five months. Three interventions were delivered at home, and one in a community venue (e.g. a church). Interventions varied in duration from seven weeks to 12 months. They included a range of practical childcare skills, home safety and developing parents' ability to respond sensitively to their children. Parents in the control groups all received treatment as usual.

Study funding sources

Each study was sponsored by different funders. One study was funded by the Ontario Mental Health Foundation and the Ontario Ministry of Community and Social Services Research Grants Program. Another was funded by the Alabama Development Disabilities Council. A third was funded by the Best Practice Parenting Education Initiative of the Commonwealth Department of Family and Community Services and the New South Wales Aging and Disability Department. The fourth study was funded by ZonMw, The Netherlands Organisation for Health Research and Development.

Key results

Compared to those parents without parent training, the studies reported some improvements in parents in the intervention group. One study reported improvement in safe home practices, recognition of child illness and safe use of medicines, in favour of the intervention group. Another study reported improvements in childcare and safety, also in favour of the intervention group; and a third study found that parents who had attended parent training reported less child-related parenting stress compared to the control group.

A fourth study reported improvement in mother-child interaction in the intervention group compared with the control group. No study reported that interventions caused harm.

Quality of the evidence

The quality of the evidence ranged from very low to moderate.

Conclusion

There is some low-quality evidence that parent training interventions for parents with intellectual disabilities may support their parenting. It may also help to establish good parent-child relations. However, given the low quality of the evidence, the results should be interpreted with caution. Better-quality research is needed to evaluate the effectiveness of parent training interventions for parents with intellectual disabilities. These studies should include fathers and follow-up participants over a longer time period.

SUMMARY OF FINDINGS FOR THE MAIN COMPARISON *[Explanation]*

| Parent training compared to treatment as usual for parents with intellectual disability | | | | | | |
|---|--|---|--------------------------|----------------------------------|--|----------|
| Patient or population: people with intellectual disability Settings: home visits Intervention: parenting training Comparison: treatment as usual | | | | | | |
| Outcomes | Illustrative comparative risks* (95% CI) | | Relative effect (95% CI) | Number of participants (studies) | Quality of the evidence (GRADE) | Comments |
| | Assumed risk | Corresponding risk | | | | |
| | Treatment as usual | Parenting training | | | | |
| <i>Safe home practices</i> | | | | | | |
| Recognising dangers Assessed with: home illustrations – dangers (parents asked to identify dangers in pictures of 6 areas of the home) Scale from: 0 to 104 Follow-up: mean 12 weeks postintervention | The mean recognising dangers score in the control group was 55.70 | The mean recognising dangers score in the intervention group was 20.55 higher (13.72 higher to 27.38 higher) | – | 30 (1 study) | ⊕○○○ Very low ^{a,b,c} | – |
| Identifying precautions Assessed with: home illustrations – precautions (parents asked to identify precautions for the dangers depicted in the 6 pictures) Scale from: total number of precautions iden- | The mean identifying precautions score in the control group was 47.10 | The mean identifying precautions score in the intervention group was 31.75 higher (20.36 higher to 43.14 higher) | – | 30 (1 study) | ⊕○○○ Very low ^{a,b,c} | – |

| | | | | | | |
|---|---|--|---|-----------------|---------------------------------------|---|
| tified Follow-up: mean 12 weeks postintervention | | | | | | |
| Home precautions Assessed with: Home Observation Checklist (parents asked to identify dangers in the home and precautions taken) Scale from: 0 to 114 Follow-up: mean 12 weeks postintervention | The mean home precautions score in the control group was 53.30 | The mean home precautions score in the intervention group was 7.05 higher (5.45 lower to 19.55 higher) | — | 30 (1 study) | ⊕○○○ Very low^{a,c} | — |
| Home precautions Assessed with: child-care and safety checklists Scale: 0 to 100 (outcomes presented as a mean percentage of correct performance) Follow-up: 14-week mean interval between pre-test and post-test | The mean score in the control group was 65.2% at pre-test and 60.6% at post-test (described as significant) | The mean score in the intervention group was 62.5% at pre-test and 88.1% at post-test (described as significant) | — | 22 (1 study) | ⊕○○○ Very low^{a,c} | — |
| <i>Understanding of child health</i> | | | | | | |
| Child health comprehension Assessed with: 2 subscales testing knowledge of health-related words and body parts Scale from: 0 to 6 Follow-up: mean 12 weeks postintervention | The mean health comprehension score in the control group was 5.80 | The mean health comprehension score in the intervention group was 0.70 lower (1.29 lower to 0.11 lower) | — | 30 (1 study) | ⊕○○○ Very low^{a,c} | — |

| | | | | | | |
|---|--|---|---|-----------------|--|---|
| Symptom recognition Assessed with: 7 subscales testing knowledge of symptoms of illness, common child health problems and practical tasks Scale from: 0 to 21 Follow-up: mean 12 weeks postintervention | The mean symptom recognition score in the control group was 10.80 | The mean symptom recognition score in the intervention group was 2.15 higher (0.17 lower to 4.47 higher) | — | 30 (1 study) | ⊕○○○ Very low ^{a,c} | — |
|---|--|---|---|-----------------|--|---|

Parent-child interaction

| | | | | | | |
|---|---|---|---|--------------|--|---|
| Maternal-child interaction Assessed with: Nursing Child Assessment Teaching Scale Scale from: 0 to 73 Follow-up: 12 months postintervention | The mean maternal-child interaction score in the control group was 50.3; reported as an increase of 0.4 from baseline | The mean maternal-child interaction score in the intervention group was 51.7; reported as an increase of 8.3 from baseline (described as significant) | — | 40 (1 study) | ⊕○○○ Very low ^{a,c} | — |
|---|---|---|---|--------------|--|---|

*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% CI) is based on the assumed risk in the comparison group and the **relative effect** of the intervention (and its 95% CI).
CI: confidence interval; **NCATS:** Nursing Child Assessment Teaching Scale.

GRADE Working Group grades of evidence
High quality: we are very confident that the true effect lies close to the that of the estimate of the effect
Moderate quality: we are moderately confident in the effect estimate: the true effect is likely to be close to the estimate of the effect, but there is a possibility that it is substantially different
Low quality: our confidence in the effect estimate is limited: the true effect may be substantially different from the estimate of effect
Very low quality: we have very little confidence in the effect estimate: the true effect is likely to be substantially different from the estimate of effect

^aDowngraded by one level due to there being only one study with a very small sample size.
^bDowngraded by two levels due to uncertainty about allocation concealment and blinding of participants and personnel. Also, fourth intervention group was not randomised and although they are not included in the data in this review, they remain a threat to validity.

^cPublished evidence is limited to a small number of trials, all of which are showing benefits of the studied intervention.

BACKGROUND

Description of the condition

Intellectual disability is characterised by significant limitations in both intellectual functioning and adaptive behaviour originating before the age of 18 years. 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 (Conder 2011). Historical definitions of intellectual disability were centred around those with an intelligence quotient (IQ) of below 70 (NASEM 2015), although this is no longer sufficient grounds for a diagnosis (Schalock 2010). The American Association of Intellectual and Developmental Disabilities (AAIDD) suggests 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). A wide range of functioning is 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; British Psychological Society 2015), 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. Whilst mild-to-moderate impairments per se may not be a useful indicator of parenting capacity, nor an insurmountable barrier to parent learning, diagnosis is arguably a relevant factor when reviewing the effect of, or designing interventions aimed at supporting parents with intellectual disability.

Research from various countries suggests that the number of people with intellectual disabilities with children is increasing (e.g. Department of Health 2000; Pixa-Kertner 2008; Wing Man 2017), 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 years of age 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 are a variety of terms used. These include 'learning disabilities' and 'learning difficulties', which predominate in the UK (BILD 2011); 'intellectual disability', which has replaced 'mental retardation' in the USA (though the latter may still be found in older publications (Friedman 2016), and various others, including 'mental disability', 'mental handicap' and 'cognitive impairment' (Hastings 1993).

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). What is known mostly comes from studies that focus on mother and child. Very little is known about fathers with intellectual disabilities. Llewellyn and Hindmarsh review the current state of knowledge in a broader population context and identify a number of reasons for the omission of fathers in research studies looking at parents with intellectual disabilities (Llewellyn 2015).

Low socioeconomic status, unemployment and social isolation or 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 and related disadvantages than other parents (Emerson 2013; Olsson 2008; Tarleton 2006). From reviewing population-based studies, the Llewellyn 2015 study identified that, from the beginning, mothers with intellectual disability are more likely to experience several risk factors of pregnancy, including younger maternal age, single parenthood, low birthweight newborns, poorer mental health and lower socioeconomic position and that, in the early years, parents (not disaggregated by sex) with intellectual disability also experience poorer mental health, socioeconomic circumstances and environmental adversities. Substantial scientific evidence indicates that these factors can harm the developing brain and impose heavy developmental burdens on young children, emphasising the need for partnership between appropriate service delivery to support parenting practices (Shonkoff 2000).

Children of parents with intellectual disabilities may be at increased risk of neglectful care, which could lead to health, developmental and behavioural problems (Collings 2012; Feldman 2002a), or increased risk of intellectual disability (James 2004). The first national survey of adults with learning disabilities 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 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). A more recent Dutch study of 134 parents with intellectual disabilities reported above-average mean scores for parental stress amongst the sample population, with 37% of the parents experiencing high or very high parenting stress (Meppelder 2015).

Description of the intervention

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 1999a; Llewellyn 2003; Llewellyn 2005). They may involve the use of pictorial manuals to demonstrate essential parenting tasks, which parents with intellectual disabilities may find easier to understand (e.g. Feldman 1997; Llewellyn 2002), or interventions may involve video-feedback (video-feedback intervention to promote positive parenting for parents with learning difficulties (VIPP-LD)), whereby the parent is filmed interacting with their child, after which the footage is reviewed by both the parent and a parenting coach (Hodes 2017). A growing awareness of parenting needs for parents with intellectual disabilities (Llewellyn 2015), and an increased awareness of the prevalence of parents with intellectual disability in child protection service caseloads (Wing Man 2017), suggest a greater need to understand the effectiveness of such interventions.

How the intervention might work

Parent training interventions, particularly those based at home, can and do help some intellectually disabled parents to learn a range of parenting skills that they might not otherwise master (Feldman 1999a). 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, such as modelling, practice, feedback, praise or tangible reinforcement. Interventions are likely to be more successful if the skills to be learned are broken down into smaller steps that 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 supplied in

a form that 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). The Hodes 2017 study notes that the quality of the therapeutic relationship, or alliance between support workers and parents, may be a moderating factor influencing the effectiveness of parenting interventions. The Meppelder 2014 study highlights the importance of positive alliances between parents with mild intellectual disabilities and their support staff, with agreement on tasks and goals of support, and a positive bond between parent and professional as a key factor.

Consideration of contextual factors (Feldman 2016), as well as parents' own perceptions of their difficulties (Meppelder 2015), might improve intervention outcomes. Parenting stress may be alleviated by equipping parents with mild intellectual disabilities with knowledge and skills for interacting in a supportive way with their children, and in turn, reducing the number or intensity of child behaviour problems (Hodes 2017). Interventions such as VIPP-LD may alleviate stress in parents with mild intellectual disabilities by reducing parent social isolation (Hodes 2017).

Why it is important to do this review

It is important to do this review so we can understand how to support families where one or more parent has an intellectual disability. Knowing about available parenting interventions will help people supporting families make good decisions about what is the best and most appropriate support to give in the context of family advantages and disadvantages. This is a very important topic because we know little about parenting interventions and how they work, for whom and in what circumstance. We do know that parenting interventions available to the general population have been assessed with mixed results, and there is even less good knowledge about parenting interventions for parents with a learning disability.

Wider pressures on parenting also merit attention. For example, the effect is not known of broader family circumstances that may increase family stress, such as poverty or inappropriate housing on outcomes of parent training interventions. Only recently have studies relating to the wider population begun to examine complicated interactions between parent and child relations and stress, parenting and behaviours in the parent-child dyad, and, to the authors' knowledge, the Hodes 2017 study is the first study to examine stress specifically. Parenting stress has been linked with a number of maladaptive child outcomes and reducing parenting stress may improve parenting and parent-child relations.

We do know that parental social support and mental ill health can directly influence child development outcomes, so supporting social participation and attending to parental mental health are both protective features that are supportive of parenting and children's well-being (Llewellyn 2015). 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 study 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 when 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.

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

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; Glazemakers 2013), self-directed learning (e.g. Feldman 1999a), home-based safety interventions (Llewellyn 2003), and by developing supportive social or peer relationships (Darbyshire 2012; McGaw 2002). A number of interventions have been recommended (WTPN 2016), however, few of these interventions have been rigorously evaluated.

A number of recent reviews have assessed the effectiveness of parent training interventions for parents with intellectual disabilities (Knowles 2015; Wade 2008; Wilson 2014); however, there are a number of reasons why it is important to undertake a Cochrane Review of the topic. First, the Wade 2008 and Wilson 2014 studies included different study designs as well as randomised controlled trials (RCTs); second, they included only peer-reviewed research, excluding grey literature; and third, they limited the search by date. Therefore, 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.

OBJECTIVES

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

METHODS

Criteria for considering studies for this review

Types of studies

Randomised controlled trials (RCTs) and quasi-RCTs.

Types of participants

Parents or primary caregivers with independent or shared care of one or more children aged from birth to 18 years, where the parent or caregiver has an intellectual disability, as defined above (Description of the condition). See also Table 1 and the protocol for this review (Coren 2009).

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, compared with treatment as usual or a control group.

Types of outcome measures

We included studies if they included one or more of the outcomes listed below, measured at pre- and postintervention time points. Parenting was assessed by observation, interviews or by means of standardised questionnaire measures or rating scales. We anticipated that measures may have been adapted to be more sensitive to parents with an intellectual disability.

Primary outcomes

- Attainment of specific parenting skills targets, which were the focus of the 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. For example, if the aim is to teach parents to bathe children safely then the outcome is likely to be attainment (or otherwise) of the specific skill taught in relation to this childcare activity. Such tasks may be broken down into very specific actions for the purpose of assessment.
- Safe home practices, that is awareness of safety and danger in the home, as measured by, for example, the Home Inventory of Dangers and Safety Precautions 2 (Tymchuck 1999).*

- Understanding of child health, that is, understanding of issues related to child health, development and illness; for example, symptoms, emergencies, use of medication and health care. Scales were based on a validated scale such as those derived from the University of California, Los Angeles (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, for example, affective elements of dyadic interactions, such as responsiveness, warmth, positivity or hostility, or stress.
- Parents' retention of child or return to independent care of the child, as reported in the study.
- Lifting of any child-related court order (although this depended on the jurisdiction), as reported in the study.

Search methods for identification of studies

For the original review (Coren 2010), Jo Abbott, Information Specialist of Cochrane Developmental, Psychosocial and Learning Problems (CDPLP), conducted the searches in consultation with Esther Coren (EC) and Jemeela Hutchfield (original author). The searches for this update were conducted by Margaret Anderson, Information Specialist for CDPLP, and by Manfred Gschwandtner (MG), Faculty Liaison Librarian for Health and Wellbeing, Canterbury Christ Church University, in consultation with EC, Kerry Ramsbotham (KR) and Margaret Anderson.

Electronic searches

We ran searches for the original version of this review in May 2009 (Appendix 1). We revised the search strategies for this update (Appendix 2), and searched the databases and trial registers listed below in May 2016 and July 2017.

- Cochrane Central Register of Controlled Trials EBM Reviews Ovid (CENTRAL; searched 13 July 2017); CENTRAL includes the Cochrane Developmental, Psychosocial and Learning Problems Group Specialised Register.
- MEDLINE Ovid (1948 to 13 July 2017).
- Embase Ovid (1974 to week 19 2016).
- CINAHL EBSCOhost (Cumulative Index to Nursing and Allied Health Literature; 1937 to 13 July 2017).
- PsycINFO Ovid (1806 to 13 July 2017).
- ASSIA Proquest (Applied Social Sciences Index and Abstracts; 1986 to 21 July 2017).
- *Cochrane Database of Systematic Reviews* EBM Reviews Ovid (CDSR; searched 13 July 2017).

- Database of Abstracts of Reviews of Effects EBM Reviews Ovid (DARE; searched 18 May 2016). DARE ceased to be maintained in 2015.

- Sociological Abstracts Proquest (1952 to 21 July 2017).
- ZETOC (limited to conference proceedings (zetoc.jisc.ac.uk; searched 13 July 2017)).
- ClinicalTrials.gov (clinicaltrials.gov; searched 13 July 2017).
- World Health Organization International Clinical Trials Registry Platform (WHO ICTRP; apps.who.int/trialsearch; searched 13 July 2017).

We did not apply any date or language restrictions. However, we did not retrieve any non-English language papers. We did not use RCT filters in order to avoid missing any potentially relevant records.

Searching other resources

We searched references from retrieved papers for any additional studies. We contacted leading authors to ask if they knew of other studies in the field, and we also contacted lead authors of included studies to clarify data or supply additional data, or both.

Data collection and analysis

Selection of studies

In the original review (Coren 2010), EC, JH and CB independently identified, read and reviewed titles and abstracts against the inclusion criteria (Criteria for considering studies for this review). EC and JH or MT obtained full copies of studies that appeared to meet the inclusion criteria or for which more information was needed and assessed them independently. There were no uncertainties concerning the appropriateness of studies for inclusion in the review, but had there been, we would have discussed these with the CDPLP editorial base.

For this updated review, this process was conducted by EC, RH and KR, with RH and KR selecting studies and EC acting as arbitrator and final decision maker.

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. We recorded our decisions in a Prisma flow diagram (Moher 2009).

Data extraction and management

We developed data extraction forms a priori and collected information on the following.

- 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 delivered the intervention, whether the intervention was individual- or group-based, where it was delivered.
- Other concurrent interventions or health problems, or both.
- Outcomes ([Types of outcome measures](#)).

For the original review ([Coren 2010](#)), EC and JH or MT extracted data independently and organised them using Review Manager 5 (Revman 5) ([Review Manager 2010](#)). For this update, the same process was followed by EC and KR using [Review Manager 2014](#). There were no disagreements between review authors.

Assessment of risk of bias in included studies

For each included study, two review authors (EC and JH or MT in the original review ([Coren 2010](#)); EC and KR in this update) independently completed Cochrane's tool for assessing risk of bias ([Higgins 2011a](#)). Review authors assessed the degree to which:

- the sequence was adequately generated ('random sequence generation');
- the allocation was adequately concealed ('allocation concealment');
- knowledge of the allocated interventions was adequately prevented from participants and personnel during the study ('blinding of participants and personnel'). Whilst acknowledging that it is generally not possible to blind participants and personnel in trials of this nature, it can nonetheless create bias;
- knowledge of the allocated interventions was adequately prevented from outcome assessors ('blinding of outcome assessment');
- incomplete outcome data were adequately addressed ('incomplete outcome data');
- study reports were free of suggestion of selective outcome reporting ('selective reporting');
- the study was apparently free of other problems that could put it at high risk of bias ('other bias').

We allocated each domain to one of three possible categories for each of the included studies: 'low risk of bias', 'high risk of bias', or 'unclear risk of bias'. There were no disagreements between review authors.

Measures of treatment effect

Continuous 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), which we presented with a 95% confidence interval (CI).

See [Table 1](#) and the protocol for this review ([Coren 2009](#)).

Unit of analysis issues

We did not encounter any unit of analysis issues in this review (see [Coren 2009](#); [Table 1](#)).

Dealing with missing data

When data were not available in the published trial reports, we contacted the study authors and asked them to supply the missing information. When we were unable to obtain the missing data we reported the available results only.

Assessment of heterogeneity

We did not assess heterogeneity as planned in this review (see [Coren 2009](#); [Table 1](#)).

Assessment of reporting biases

We were unable to draw funnel plots as we did not have a sufficient number (at least 10) of included studies (see [Coren 2009](#); [Table 1](#)).

Data synthesis

We performed no statistical meta-analysis as there were insufficient data in two of the four studies ([Feldman 1992](#); [Keltner 1995](#)), and the studies differed. Instead, we provided a narrative summary of the results (see [Coren 2009](#); [Table 1](#)).

'Summary of findings'

We summarised the evidence for parent training for intellectually disabled parents in two 'Summary of findings' tables, which we created using the GRADEpro Guideline Development Tool ([GRADEpro GDT 2015](#)). [Summary of findings for the main comparison](#) summarises the evidence for parent training compared to a treatment as usual for parents with intellectual disability for safe home practices (recognising dangers, identifying precautions, home precautions), understanding of child health (health comprehension, symptom recognition) and parent child interaction (specifically maternal-child interaction). [Summary of findings 2](#) summarises the evidence for video-feedback intervention to promote positive parenting for parents with learning difficulties (VIPP-LD) compared to treatment as usual for parents with intellectual disability for parent-child interaction (parenting stress — child domain, parent domain and total).

We also included in these tables our ratings of the quality of the evidence for each outcome, which we assessed using the GRADE approach; two review authors (EC, KR) assigned ratings of high-, moderate-, low- or very low-quality evidence, depending on the presence of limitations in design and implementation of studies

(high risk of bias), inconsistency of results (heterogeneity), indirectness of evidence (indirect population, intervention, control, outcome), imprecision of results (wide CIs), and high probability of publication bias (Schünemann 2011).

Subgroup analysis and investigation of heterogeneity

We found insufficient studies to undertake subgroup analyses (see Coren 2009; Table 1).

Sensitivity analysis

We found insufficient studies to undertake sensitivity analyses (see Coren 2009; Table 1).

Description of studies

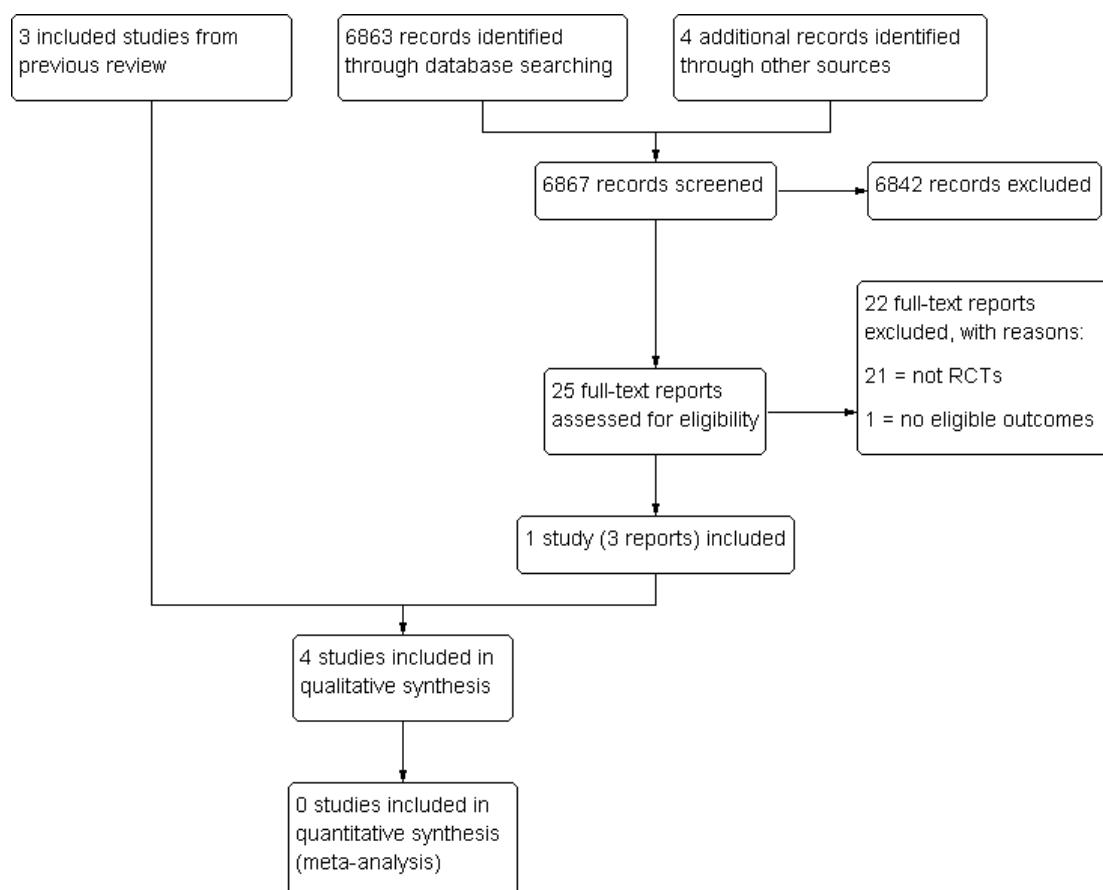
Results of the search

We conducted the searches for the previous version of this review in April 2009 (Coren 2010). Our searches identified 1259 citations. We read and assessed 23 full-text reports for eligibility and excluded 20. We assessed three studies to have met our inclusion criteria (Feldman 1992; Keltner 1995; Llewellyn 2003).

For this update, we conducted the searches in May 2016 and July 2017. Our electronic searches identified 5943 and 920 records respectively, as well as four from other sources. In total, we screened the titles and abstracts of 6867 records, of which we excluded 6842 as irrelevant. We obtained the full-text reports of the remaining 25 records for further inspection. We excluded 21 as ineligible, and identified one new study (from 3 reports) for inclusion in the review (Hodes 2017). Consequently, this updated review now includes four studies. See Figure 1.

RESULTS

Figure 1. Figure 1: Study flow diagram



Included studies

This review includes four studies, three of which were included in the original review (Feldman 1992; Keltner 1995; Llewellyn 2003), and one which is new to this update (Hodes 2017). See [Characteristics of included studies](#).

Location/setting of studies

One study was conducted in Canada (Feldman 1992), one in the Netherlands (Hodes 2017), one in the USA (Keltner 1995), and one in Australia (Llewellyn 2003). Three of the interventions were delivered in the family home and one used community spaces, including a church (Keltner 1995).

Study designs

All four included studies were randomised controlled trials (RCTs), published between 1992 and 2016. The sample sizes ranged from 22 parent participants in the Feldman 1992 study to 85 in the Hodes 2017 study, recruited from family support services, with a total of 192 parents included. All studies evaluated interventions aimed at supporting parenting in families where one or more parent had an intellectual disability. Three of the interventions offered one-to-one support for parents in their own homes (Feldman 1992; Hodes 2017; Llewellyn 2003), and the other was delivered with small groups of parents (three to four) in the community (Keltner 1995). Outcome assessors were blinded to group allocation in all studies.

Population/sample

The four studies recruited participants from a variety of family support services and care organisations. Randomisation in all included studies was by parent rather than child and there were a total of 192 parents included ranging in age from 16 years of age to 46.5 years, of which only seven were fathers (2 in the Hodes 2017 study and 5 in the Llewellyn 2003 study). It was not possible to determine the total number of child participants, though the child age range was from one month to 6.5 years.

Intellectual disability

All participants in the included studies were parents with intellectual disabilities, with diagnosis reported variably across the studies. Only the Keltner 1995 study reported employing a specific IQ test (Slosson Intelligence Test-Revised (SIT-R); Armstrong 1984). The other three studies identified eligible learning disabled parents using current or historic (educational) service records. The IQ of participants recorded in the studies varied from 49 to 88 (Hodes 2017).

Family circumstances

All of the parents were primary caregivers. Most parents appeared to live independently, although two were reported to be living with their mothers (Feldman 1992), and three to be living in supported accommodation (Llewellyn 2003). Up to 40% of parents in all studies were single parents with a high proportion being state welfare recipients. The Feldman 1992 study reported that all families had an income below CAD 15,000; the Llewellyn 2003 study reported that, of the 40 families, over half (55%) relied entirely on government pensions, with the remainder relying on some employment and government allowances. The Keltner 1995 study implied poverty both in the discussion and the description of the sample, but this was not explicitly reported. The Hodes 2017 study reported that 25 participants had a paid job, but details of partners or spouse circumstances were not reported.

Ethnicity/culture

The study participants in the review were culturally diverse and all were residents in the countries where the studies were conducted, at the time of the studies. The Keltner 1995 study reported that about 60% of parents in both groups were African American, and 40% white. The Feldman 1992 study reported that 21 mothers were Caucasian-Canadian and one was Japanese-Canadian. The Llewellyn 2003 study reported that 37 participants had an English-speaking background, six were non-English-speaking European and two were Aboriginal or Torres Strait Islander. The Hodes 2017 study reported that approximately one in four (24%) participants were immigrants and of these, 25% came from Suriname and 25% from Curaçao. The other 50% were from eight other countries.

Interventions

Interventions in the included studies lasted between 7.7 weeks (Feldman 1992), and 12 months (Keltner 1995). In all cases, trained workers delivered the intervention at a minimum of weekly for a duration of one to two hours. All interventions were adapted for parents with an intellectual disability.

The Feldman 1992 study developed a home-based, individual training programme focused on teaching infant and childcare skills. Trained parent trainers with relevant undergraduate degrees provided the intervention via weekly visits. The intervention included verbal instructions, specially designed picture books and skills-modelling 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. The mean training duration was 7.70 weeks (range = 2 to 29 weeks). Home visits lasted as long as it took for the mother to reach the target skills for the visit.

There was a treatment as usual control group and 10 of the mothers in this group subsequently received the intervention.

The Keltner 1995 study developed a maternal training intervention called Support to Access Rural Services (STARS) for mothers with intellectual disabilities and their one-to-three-year-old children. Small groups of three or four mothers met weekly in the

community in spaces provided by local churches, with a family service worker over 10 to 12 months. The intervention included demonstrations of play with children and topics covered included parenting, maternal-child interaction and some wider maternal social skills, as well as recognition of health and social disorders, crisis intervention, cultural sensitivity, community liaison skills, and realistic expectations. The control group received treatment as usual: a support intervention - monthly contact by telephone for 12 months, six monthly assessments, and appropriate referrals as necessary.

The [Llewellyn 2003](#) study used the Home Learning Programme (HLP), which is designed to equip parents of children under five years of age with knowledge and skills to manage home dangers, accidents and childhood illness. The intervention involved 10 one-to-one sessions delivered by a trained parent educator at the parent's home using a set of specially designed illustrated, plain English lesson booklets. Each visit typically addressed one issue related to home safety; for example, fire, cooking dangers and home safety precautions. Visits took place weekly over 10 to 12 weeks and each visit lasted 60 to 90 minutes.

There were three concurrent groups in this study: 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 those in the booklets group. This latter group is not included in the analysis for this review.

The [Hodes 2017](#) study adapted a video-feedback intervention to promote positive parenting for parents with learning difficulties (VIPP-LD) and sensitive discipline (VIPP-SD), adapted from the [Juffer 2008](#) study, for parents with mild intellectual disabilities. Adaptations were based on the recommendations of the [Feldman 1994](#) and [Feldman 2004](#) studies and six parents who took part in an earlier pilot (see [Hodes 2014](#)). The intervention aims to improve harmonious parent-child interaction and sensitive discipline by filming interactions between the parent and child, and afterwards reviewing the footage together, reinforcing positive behaviour. VIPP-LD was conducted by specifically trained professionals with experience of working with parents with intellectual disability. Fifteen home visits; seven recording sessions, seven feedback sessions and one closing visit were conducted over three months. The parents in the control group received treatment as usual, comprising support with household management, administrative matters, money issues, personal problems and general self-care. Treatment as usual did not include any form of video intervention or other structured parenting intervention.

Outcomes

The four studies all measured parenting ability in differing ways. The [Feldman 1992](#) study assessed daily childcare routines in the home using childcare and safety skills checklists, which were chosen in consultation with a range of professionals. Listed skills in-

cluded diapering, feeding, bathing, sleep safety, cleaning bottles, toilet training and others. Outcomes were presented in the study as a mean percentage of correct performance across the list of skills for each mother.

The [Keltner 1995](#) study assessed maternal-child interaction using mean scores from the NCATS (Nursing Child Assessment Teaching Scale) at baseline, six months and 12 months for each group ([Barnard 1990](#)). NCATS measures the mother's sensitivity to her child's cues, responsiveness to distress, socioemotional and cognitive growth fostering; and the child's clarity of cues and responsiveness to his/her parent. A higher score on this scale indicates improvement.

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

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

- **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 a series of six pictures; scores represent total number of precautions identified);

- **and home precautions** (assessor completed Home Observation Checklist, with parent identifying dangers in parent's home and precautions taken by parent; scores represent total number of precautions taken to deal with total of 114 possible dangers).

The five measures of child health were:

- **health comprehension** (health-related vocabulary and knowledge of body parts; comprised of 2 subscales scored from 0 to 3, where 0 = less than 20% of answers correct and 3 = more than 80% of answers correct; total score ranges from 0 to 6);

- **illness and symptom recognition** (knowledge about symptoms of illness and common child health problems, and practical tasks such as taking a child's temperature; comprised of 7 subscales scored 0 to 3 as above; total score ranges from 0 to 21);

- **life-threatening emergencies** (knowledge about life-threatening emergencies, including causes, prevention and response; comprised of 4 subscales scored 0 to 3 as above; total score ranges from 0 to 12);

- **going to the doctor** (knowledge about when to go to the doctor, including what to tell or ask them, and following directions; comprised of 3 subscales scored 0 to 3 as above; total score ranges from 0 to 9); and

- **using medicines safely** (knowledge of how to use medicines, including prescription medicines, as well reading and following information on labels; comprised of two subscales scored 0 to 3 as above; total score ranges from 0 to 6).

The [Hodes 2017](#) study measured parenting stress at pre-test, post-test and three-month follow-up using the parent and child domains of the NOSIK (Nijmeegse Ouderlijke Stress Index Kort (details below); [Brock 1992](#)).

The NOSIK comprises 25 items; 14 items measure stress in the child domain and 11 items measure stress in the parent domain. All items have a six-point, Likert-type response scale (1 = strongly disagree to 6 = strongly agree). In this study, the internal consistency reliability (Cronbach's alpha) was 0.89 for items in the child domain and 0.86 for items in the parent domain.

The [Hodes 2017](#) study report that they applied an intention-to-treat analysis for all missing data, as suggested by the [Fisher 1990](#) study, in such a way that missing data at post-test were replaced by pre-test scores (four cases) and missing data at follow-up were replaced by post-test scores (four cases).

Unreported outcomes

None of the included studies measured the secondary outcomes of parents' retention of child or return to independent care of the child, or lifting of any child-related court order.

Excluded studies

In the original review, we excluded 18 studies that evaluated parenting interventions for intellectually disabled parents ([Aanes 1975](#); [Bakken 1993](#); [Fantuzzo 1986](#); [Feldman 1989](#);

[Feldman 1993](#); [Feldman 1997](#); [Feldman 1998](#); [Feldman 1999a](#); [Feldman 1999b](#); [Feldman 2004](#); [Heinz 2003](#); [McConnell 2008a](#); [McConnell 2008b](#); [McGaw 2002](#); [Peterson 1983](#); [Thompson 1984](#); [Tymchuck 1991](#); [Whitman 1989](#)). Of these, we excluded 16 studies because they were not randomised and one study because it did not assess outcomes included in this review ([McGaw 2002](#)). We excluded the remaining [Feldman 1993](#) study because the control group received an alternative safety and emergency skills training programme. In addition, the study aimed to measure child speech development, which is 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.

In this update, we excluded a further 22 studies that evaluated parenting interventions for intellectually disabled parents ([Castell 2016](#); [Glazemakers 2013](#); [Heinz 2003](#); [Hodes 2014](#); [Jamieson 2016](#); [Knowles 2017b](#); [Knowles 2017a](#); [Maclean 2010](#); [McConnell 2016](#); [McGarry 2016](#); [Mildon 2008](#); [Milot 2016](#); [Rao 2013](#); [Starke 2013](#); [Strnadova 2017](#); [Tahir 2015](#); [Tymchuck 1988](#); [Tymchuck 1989](#); [Tymchuck 1990](#); [Tymchuck 1992](#); [Tymchuck 1993](#); [Young 2006](#)); 21 because they were not randomised and one because it did not report any eligible outcome data ([Hodes 2014](#)).

All of these studies are listed in the [Characteristics of excluded studies](#) table for clarity, as the field is small.

Risk of bias in included studies

For further details, please see the 'Risk of bias' tables, beneath the [Characteristics of included studies](#) tables. For a summary, please see [Figure 2](#).

Figure 2. Risk of bias summary: review authors' judgements about each risk of bias item for each included study.

| | Random sequence generation (selection bias) | Allocation concealment (selection bias) | Blinding of participants and personnel (performance bias) | Blinding of outcome assessment (detection bias) | Incomplete outcome data (attrition bias) | Selective reporting (reporting bias) | Other bias |
|----------------|---|---|---|---|--|--------------------------------------|------------|
| Feldman 1992 | ? | ? | ? | ? | - | + | ? |
| Hodes 2017 | + | + | ? | + | + | + | ? |
| Keltner 1995 | ? | + | ? | + | ? | + | ? |
| Llewellyn 2003 | + | ? | ? | + | + | + | - |

Sequence generation (selection bias)

We judged two studies to be at unclear risk of selection bias for this domain (Feldman 1992; Keltner 1995), neither of whom provided any information about sequence generation.

We judged two studies to be at low risk of selection bias for sequence generation (Hodes 2017; Llewellyn 2003). The Hodes 2017 study reported that participants were recruited over a time period of two years. Sequential block randomisation was executed by an independent third party using a computer programme to assign parents to the intervention group or the control group. The Llewellyn 2003 study stated that a random number table was used to allocate referrals to one of three groups.

Allocation

We judged two studies to be at unclear risk of selection bias due to allocation (Feldman 1992; Llewellyn 2003). The Feldman 1992 study provided no information about allocation or allocation concealment. The Llewellyn 2003 study stated that a project manager performed the allocation but the role this manager had in delivery of the intervention was not explained.

We judged two studies to be at low risk of selection bias due to allocation (Hodes 2017; Keltner 1995). The Hodes 2017 study reported randomisation as executed by an independent third party using a computer programme every time there were five or six parents available with a subclinical level of parenting stress. This resulted in 43 parents being assigned to the intervention (VIPP-LD) condition and 42 parents being assigned to the control (treatment as usual) condition. The Keltner 1995 study stated that random assignment was performed by a person not associated with the project and so we assessed this condition as met.

Blinding

Blinding of participants and personnel

We judged all four studies to be at unclear risk of performance bias due to insufficient information (Feldman 1992; Hodes 2017; Keltner 1995; Llewellyn 2003). The Feldman 1992 study reported that all participant mothers were told that they were participating in a study, “looking at the ways mothers interact with their young children” (p 20), but it was not clear whether this information concealed group allocation adequately. Also, it was not explicit whether the trainers delivering the intervention were blind, though it was reported that, as the primary observers were usually the parent trainers, “they were not naive to the fact that the mothers were or were not labelled mentally retarded, or to the skills being trained” (p 18). The Hodes 2016 study did not explicitly report any blinding of participants but did report that the VIPP-

LD intervention was delivered by trained professionals, including family support workers and psychologists from care organisations who had several years of experience working with parents with intellectual disability, but who were not involved in delivering treatment as usual for the family concerned. The Keltner 1995 study did not report whether the participants were blind to group allocation or whether the personnel employed to deliver the STARS programme were blinded. The Llewellyn 2003 study permitted all participants to receive the HLP intervention in a staggered sequence over the life of the project but did not report whether it was possible or appropriate to blind participants or personnel in this study design.

Blinding of outcome assessment

We judged three studies to be at low risk of detection bias as the outcome assessors were blind to treatment allocation (Hodes 2017; Keltner 1995; Llewellyn 2003).

In the absence of further information, we judged one study to be at unclear risk of detection bias (Feldman 1992). The Feldman 1992 study reported that both the primary observers and reliability checkers were not told of the between-group experimental design. However, these observers were sometimes (but not usually) naive to the specific skills being trained for each mother.

Incomplete outcome data

We judged two studies to be at low risk of attrition bias (Hodes 2017; Llewellyn 2003). The Hodes 2017 study reported that they applied intention-to-treat analyses, as suggested by the Fisher 1990 study, for all missing data in such a way that missing data at postintervention were replaced by pre-intervention scores (four cases) and missing data at follow-up were replaced by post-test scores (four cases). In the Llewellyn 2003 study, there is evidence of incomplete outcome data for which some explanations are given, although there also appears to be some unexplained attrition in this study. The sample size at baseline and postintervention was 45 and the sample size at follow-up was 17. The distribution of the remaining 17 participants among the groups is unclear.

All participants from the Feldman 1992 study included in the review completed the study and missing data only occurred after the outcomes of the intervention were assessed. However, at follow-up, data were presented on eight of the 11 intervention group mothers, so three mothers were lost to follow-up, consequently, we judged this study at high risk of bias.

We judged one study to be at unclear risk of attrition bias as it was unclear whether all participants completed the study (Keltner 1995).

Selective reporting

We judged all four studies to be at low risk of reporting bias (Feldman 1992; Hodes 2017; Keltner 1995; Llewellyn 2003). In none of the studies was there suggestion of selective outcome reporting from the published reports, and so we assessed this condition as met in all cases.

Other potential sources of bias

For the purposes of this review, we assessed the Llewellyn 2003 study at high risk of bias because the authors included a non-randomised group but this group was not included within the review. We assessed the Feldman 1992 study as unclear regarding other sources of bias. First, the intervention programme was developed by Maurice Feldman, so he cannot be stated as free from bias. Second, there is significant information missing on which to base assessment of key sources of bias, such as allocation concealment. Third, 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). We also assessed Keltner 1995 as being at unclear risk from other sources of bias, as reporting standards in the study were poor (the sample sizes of the groups and the standard deviations (SDs) were not reported). For the two remaining studies (Hodes 2017; Feldman 1992), it was unclear if they were free from any other sources of bias.

Effects of interventions

See: [Summary of findings for the main comparison Parent training compared to treatment as usual for parents with intellectual disability](#); [Summary of findings 2 Video-feedback intervention to promote positive parenting for parents with learning difficulties \(VIPP-LD\) compared to treatment as usual](#)
As indicated above, it was not possible to perform a meta-analysis in this review as the four included studies measured different outcomes, with the Feldman 1992 study measuring childcare skills (e.g. bathing and feeding), the Hodes 2017 study measuring stress in the parent-child relationship, the Keltner 1995 study measuring maternal-child interaction, and the Llewellyn 2003 study measuring parental health and safety behaviours (e.g. recognising symptoms of illness, and knowledge and skills necessary for managing life-threatening emergencies).

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 therefore it is not possible to impute SDs using relevant data (for example, using standard errors or P values). However, for the Support to Access Rural Services (STARS) group, the study reports a mean of 51.70 at 12 months postintervention, and a mean of 50.30 for the control group. The increase in mean Nursing Child Assessment Teaching Scale (NCATS) score at 12 months from baseline for the STARS group is 8.30 (12-month score compared

with 43.4 at baseline) (reported as significant with $P < 0.05$) and for the control group is 0.40 (compared with 49.9 at baseline).

The Llewellyn 2003 study 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. The sample comprised 45 participants at baseline; 17 parents were assessed at follow-up. Due to the cross-over design of this study, (involving between-group comparisons using multiple analysis of variance (MANOVA) with planned orthogonal contrasts), we included only baseline and postintervention data in this review at assessment phase two (see Llewellyn 2003, p 408).

We entered data from this study into Review Manager 2014 to compute effect sizes for the individual studies. The reported MDs for these outcomes varied considerably (see below), so to clarify the magnitude of these effects and facilitate comparison across these outcomes, we entered data from group one (20 participants) and control group three (10 participants) and computed standardised mean differences (SMDs) from the reported means and SD from the Llewellyn 2003 study (p 418 and 419). We found two very large effect sizes (recognising dangers: 2.02 and identifying precautions: 1.91), and one small effect size (home precautions: 0.35) from the home safety measure; and two large effect sizes (life-threatening emergency: 0.98 and using medicines: 1.30), and three medium effect sizes (health comprehension: 0.71, symptom recognition: 0.62 and visiting the doctor: 0.59) from the child health measures.

Parent training compared to treatment as usual

Three studies compared parent training to treatment as usual (Feldman 1992; Keltner 1995; Llewellyn 2003).

Primary outcomes

Attainment of specific parenting skill targets

None of the three studies included in this comparison reported data on this outcome (Feldman 1992; Keltner 1995; Llewellyn 2003)

Safe home practices

Two studies reported data on safe home practices (Feldman 1992; Llewellyn 2003).

Recognising dangers

Llewellyn 2003 found a significant difference in postintervention scores on the home illustrations - dangers measure (range 0 to 104), in favour of the Home Learning Programme (HLP) group

(MD 20.55 points, 95% confidence interval (CI) 13.72 points to 27.38 points; 30 participants at this time point).

Identifying precautions

Llewellyn 2003 found a significant difference in postintervention scores on the home illustrations - precautions measure (total number of precautions identified), in favour of the HLP group (MD 31.75 points, 95% CI 20.36 points to 43.14 points; 30 participants at this time point).

Home precautions

Llewellyn 2003 found a small, non-significant difference in postintervention scores on the home precautions measure (range 0 to 114), in favour of the HLP (MD 7.05 points, 95% CI -5.45 points to 19.55 points; 30 participants at this time point).

The Feldman 1992 study (22 participants) presented group mean pre- and post-test percentage scores on childcare 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%. The authors calculated the F statistic by conducting repeated measures analyses of variances (ANOVAs) to determine the significance of these differences. The results of these tests show some benefit. These results are presented as the main effect of group being $F(1,20) = 18.22$, tests as $F(1,20) = 24.79$ and significant interaction $F(1,20) = 50.94$, which are all statistically significant with $P < 0.01$. The study states that the training group scored significantly higher than the control group at post-test. All 11 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%.

The Feldman 1992 study (22 participants) also presented follow-up data for a period of between two and 76 weeks post-test (mean 28 weeks) on eight of the 11 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, assessed using the t statistic, were significant ($t(7) = 8.86$, $P < 0.01$), but the replication difference was not significant.

Understanding of child health

Only one study, Llewellyn 2003, reported postintervention data (30 participants at this time point) on understanding of child health; findings are presented below.

Child health comprehension

Llewellyn 2003 found very little difference between the groups in postintervention scores on the 'Child health comprehension' measure (range 0 to 6): MD -0.70 points, 95% CI -1.29 points to -0.11 points.

Symptom recognition

Llewellyn 2003 found very little difference between the groups in postintervention scores on the 'Illness and symptom recognition' measure (range 0 to 21): MD 2.15 points, 95% CI -0.17 points to 4.47 points.

Life-threatening emergencies

Llewellyn 2003 found a small, positive, significant difference in postintervention scores on the 'Life-threatening emergencies' measure (range 0 to 12), in favour of the HLP group (MD 1.95 points, 95% CI 0.46 points to 3.44 points).

Visiting the doctor

Llewellyn 2003 found very little difference between the groups in postintervention scores on the 'Going to the doctor' measure (range 0 to 9): MD 0.65 points, 95% CI -0.06 points to 1.36 points.

Using medicines

Llewellyn 2003 found very little difference between the groups in postintervention scores on the 'Using medicines safely' measure (range 0 to 6): MD 1.15 points, 95% CI 0.51 to 1.79.

Secondary outcomes

Parent-child interaction

One study (40 participants) reported data on maternal-child interaction assessed using the NCATS (Keltner 1995). No numbers or standard deviations were available in the study report or directly from the study authors. The study reported a mean of 51.7 for the STARS group and 50.3 for the control group at 12 months postintervention. The increase in mean NCATS scores from baseline to 12 months was 8.3 (reported as significant at $P < 0.05$) for the STARS group and 0.4 for the control group.

Parents' retention of child or return to independent care of the child

One study (22 participants) reported on the parents' retention of the target child (Feldman 1992). The study found that before joining the programme nine of 11 (82%) families with a previous child had had their child removed from their care. After participating in the programme only four of 22 (19%) families had the target child of this study subsequently removed by child protection authorities due to maternal maltreatment (only one of these four mothers had also had a previous child removed).

None of the three studies included in this comparison reported data on the lifting of any child-related court order (Feldman 1992; Keltner 1995; Llewellyn 2003).

Quality of the evidence

We downgraded the quality of the evidence from all analyses to very low because of the small sample sizes, missing data and because the published evidence was consistently poorly reported. We summarised the evidence for our primary outcomes for Feldman 1992; Keltner 1995 and Llewellyn 2003, in [Summary of findings for the main comparison](#).

Video-feedback compared to treatment as usual

Only one study (85 participants) compared video-feedback parent training to treatment as usual (Hodes 2017).

Primary outcomes

Hodes 2017 did not report data on our primary outcomes: attainment of specific parenting skills, safe home practices or understanding of child health.

Secondary outcomes

Parent-child interaction

Parenting stress

Hodes 2017 was the only study to measure parenting stress, using the Dutch, shortened version of the Parenting Stress Index (NOSIK, a 25-item scale, 0 to 6 range; Brock 1992), to obtain measures of parenting stress related to the child (child domain, 14 items), and parenting stress related to the parent's own functioning and situation (parent domain, 11 items) at post-test and

follow-up (Hodes 2017). A further outcome article from the same study (listed under Hodes 2017) reports parenting behaviour and parent-child interactions. We have not included these data in this review update as the details were not available to us at the time the eligibility assessment was finalised in 2017.

For parenting stress (child domain), the mean for the intervention group was 50.42 (standard deviation (SD) = 12.58, range = 21.00 to 80.00) at baseline; 43.26 (SD = 14.18, range = 19.00 to 74.00) at post-test; 42.05 (SD = 15.14, range = 14.00 to 80.00) at three-month follow-up. For the control group, the mean was 43.60 (SD = 13.99, range 14.00 to 70.00) at baseline; 40.62 (SD = 13.46, range 14.00 to 67.00) at post-test; and 42.64 (SD = 14.70, range = 14.00 to 79.00) at three-month follow-up. Both groups' stress levels declined, but more so for the intervention group (MD -0.59 points, 95% CI -6.93 points to 5.75 points).

For parenting stress (parent domain), the mean for the intervention group was 34.30 (SD = 10.98, range 13.00 to 61.00) at baseline; 28.72 (SD 10.94, range = 11.00 to 52.00) at post-test; and 28.35 (SD = 11.21; range = 11.00 to 52.00) at three-month follow-up. For the control group, the mean was 31.71 (SD 10.58, range 16.00 to 61.00) at baseline; 28.67 (SD = 10.47; range 11.00 to 59.00) at post-test follow-up; and 29.50 (SD = 11.92; range 11.00 to 65.00) at three-month follow-up. Again, both groups' results improved from baseline but the improvement for the intervention group was greater (MD -1.15 points, 95% CI -6.07 points to 3.77 points).

For parenting stress (total), the mean for the intervention group was 70.40 (SD = 24.87) at three-month follow-up and 84.72 (SD = 21.34) at baseline. The mean for the control group was 72.14 (SD = 24.75) at three-month follow-up; and 75.31 (SD = 22.45) at baseline. Parenting stress declined in both groups, but more so in the intervention group (MD -1.74 points, 95% CI -12.29 points to 8.81 points).

Parents' retention of child or return to independent care of child

Hodes 2017 did not report data on either parent's retention of child or return to independent care of child, or the lifting of any child-related court order.

Quality of the evidence

We downgraded the quality of the evidence to moderate because of the small sample size and because the published evidence was consistently limited to one study (Hodes 2017). We summarised the evidence related to parenting stress in [Summary of findings 2](#).

ADDITIONAL SUMMARY OF FINDINGS *[Explanation]*

| Video-feedback intervention to promote positive parenting for parents with learning difficulties (VIPP-LD) compared to treatment as usual | | | | | | |
|--|---|---|--------------------------|----------------------------------|-------------------------------------|----------|
| Patient or population: 85 parents (83 mothers and 2 fathers) with intellectual disabilities Settings: home visits Intervention: video-feedback intervention to promote positive parenting for parents with learning difficulties (VIPP-LD) Comparison: treatment as usual | | | | | | |
| Outcomes | Illustrative comparative risks* (95% CI) | | Relative effect (95% CI) | Number of participants (studies) | Quality of the evidence (GRADE) | Comments |
| | Assumed risk | Corresponding risk | | | | |
| | Treatment as usual | VIPP-LD | | | | |
| <i>Parent-child interaction</i> | | | | | | |
| Parenting stress: child domain Follow-up: 3 months | The mean parenting stress (child domain) score in the control group was 42.64 | The mean parenting stress (child domain) score in the intervention group was 0.59 lower (6.93 lower to 5.75 higher) | — | 85 (1 study) | ⊕⊕⊕○ Moderate^a | — |
| Parenting stress: parent domain Follow-up: 3 months | The mean parenting stress (parent domain) score in the control group was 29.50 | The mean parenting stress (parent domain) score in the intervention group was 1.15 lower (6.07 lower to 3.77 higher) | — | 85 (1 study) | ⊕⊕⊕○ Moderate^a | — |
| Parenting stress: total Follow-up: 3 months | The mean parenting stress (total) score in the control group was 72.14 | The mean parenting stress (total) score in the intervention group was 1.74 lower (12.29 lower to 8.81 higher) | — | 85 (1 study) | ⊕⊕⊕○ Moderate^a | — |

*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; **VIPP-LD:** video-feedback intervention to promote positive parenting for parents with learning difficulties

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.

^aDowngraded by one level due to there being only one study with a small sample size.

DISCUSSION

Summary of main results

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 (RCTs) and some addressed outcomes that were not relevant to this review, leaving only four studies that met the inclusion criteria ([Criteria for considering studies for this review](#)).

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.

The [Hodes 2017](#) study reported an observed reduction in parenting stress in both intervention and control groups over time, and a greater reduction for the intervention group.

From the information available in the [Keltner 1995](#) study, it appears that the Support to Access Rural Services (STARS) programme may have conferred 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.

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

Overall completeness and applicability of evidence

The four studies included in this review were conducted in different countries; one each in Canada ([Feldman 1992](#)), the Netherlands ([Hodes 2017](#)), a rural USA location ([Keltner 1995](#)), and an urban Australian location ([Llewellyn 2003](#)). All were small, so applicability is inevitably limited. Two studies included mothers only ([Feldman 1992](#); [Keltner 1995](#)), whilst the others included both fathers and mothers, although there were only a few men included: five fathers in the [Llewellyn 2003](#) study and two in the [Hodes 2017](#) study and, for the [Llewellyn 2003](#) study, they were the partners of the included women. Although the diagnostic criteria for intellectual disability in the included studies were broad, any general applicability of the evidence to this population is compromised by the small overall numbers included in the review and the varied historical, cultural, social and economic contexts

within which parents with intellectual disabilities live. The literature search at both time points was confused by the quantity of studies retrieved on the subject of parents of intellectually disabled children or adults. Furthermore, including RCT evidence only, excludes evidence from other study designs such as single case experimental designs and studies that observe both parent and child outcomes such as the [Feldman 1993](#) study.

Quality of the evidence

The quality of the evidence in the included studies ranged from moderate to very low, with limited information available for assessment of some domains of bias, as well as incomplete data for the computation of effect sizes in the [Feldman 1992](#) and [Keltner 1995](#) studies, as described in [Summary of findings for the main comparison](#) and [Summary of findings 2](#). The small sample size further compromises the confidence in the available data. At update, the [Hodes 2017](#) study had a larger sample (85 participants) and lower risk of bias, particularly in the areas of allocation concealment and blinding of outcome assessment, but overall the numbers remain small.

Potential biases in the review process

We believe that we identified all of the published RCTs of parenting interventions for parents with intellectual disabilities published up to the cut-off date through the review process, although we are yet to include the outcome data from the further Hodes paper relating to the [Hodes 2017](#) study. Studies retrieved included an unpublished PhD thesis, which we excluded at data extraction stage on the grounds of incomplete randomisation. Contact to the authors of the [Keltner 1995](#) study for supply of incomplete data was not successful. We contacted Feldman who confirmed that he had not conducted further RCTs beyond those we found and also pointed us to the Hodes team. At update stage, we contacted the Hodes team, and retrieved the [Hodes 2017](#) report. We made no other contact with study authors, so it is possible that we missed some studies, although the [Characteristics of excluded studies](#) tables demonstrate 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 one ineligible PhD thesis, we did not find any unpublished studies in the search, so all of the studies that we 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.

Agreements and disagreements with other studies or reviews

We are aware of three existing reviews of parent training interventions for parents with intellectual disabilities (Knowles 2017b; Wade 2008; Wilson 2014). The conclusions of these reviews 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. They all included wider study designs than RCTs only, and based on the evidence included, the authors' conclusions are made more firmly than those made within this review. The findings of these reviews also support the retrieval in this review of four included studies for the time period covered. These reviews also call for more research in this area.

AUTHORS' CONCLUSIONS

Implications for practice

The results of this review offer sufficient 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. Interventions could be evaluated over a longer time period to determine the development of age-appropriate parenting skills and maintenance of acquired skills, to identify the most comprehensive support for parents with intellectual disabilities and their children. However, the studies included are small, with risks 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.

Implications for research

Much more evidence of effectiveness is needed in this area. The evidence base would benefit from larger, possibly multicentre RCTs, 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; for example,

the manner of delivery, whether home- or centre-based, whether group- or individual-based, 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. To improve parent-child interactions and relationships, parenting support may need to be adapted to the specific learning capacities and deficits of parents with intellectual disability. For example, the Hodes 2014 study made eight adaptations to the video-feedback intervention to promote positive parenting for parents with learning difficulties (VIPP-LD) to support the process of learning new knowledge and skills for parents with a learning disability. There may be other parenting programmes that could be adapted to support the parenting and learning needs of parents with intellectual disability. Furthermore, little is known about the parenting needs of fathers who have an intellectual disability, about the views of parents with an intellectual disability or their children, or about parenting interventions for older children. The evidence base would be enhanced if future research attended to these areas.

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* Indicates the major publication for the study

CHARACTERISTICS OF STUDIES

Characteristics of included studies [ordered by study ID]

Feldman 1992

| | | |
|---|---|--|
| Methods | Randomised controlled trial | |
| Participants | <p>Sample size: 22 mothers</p> <p>Dropouts/withdrawal: 0</p> <p>IQ: low. Assessed as having learning disability in school days, and with IQ tests to determine eligibility for services in adulthood</p> <p>Mean IQ: 71.6 in the training group; 72.1 in the control group</p> <p>Mean maternal age: 25.2 years in the training group; 26.6 years in the control group</p> | |
| Interventions | <p>Intervention: weekly home visits by trainer focused on improving parenting skills assessed as deficient. 11 participants in intervention group</p> <p>Control: treatment as usual. No training received by this group. 11 participants in control group</p> | |
| Outcomes | Childcare and home safety checklists devised in consultation with relevant professionals | |
| Notes | <p>Study start and end dates: no information provided</p> <p>Conflicts/declarations of interest: no information provided</p> <p>Funding: this research was sponsored by the Ontario Mental Health Foundation and the Ontario Ministry of Community and Social Services Research Grants Program (administered by the Research and Program Evaluation Unit)</p> | |
| Risk of bias | | |
| Bias | Authors' judgement | Support for judgement |
| Random sequence generation (selection bias) | Unclear risk | Comment: not stated |
| Allocation concealment (selection bias) | Unclear risk | Comment: random assignment performed. No other details |
| Blinding of participants and personnel (performance bias) All outcomes | Unclear risk | Comment: all the participant mothers were told that they were participating in a study (quote p 20): "looking at the ways mothers interact with their young children", but it was not clear whether this information concealed group allocation adequately. Also, it was not explicit whether the trainers delivering the intervention were blind, though it is reported that as the primary observers were usually the parent trainers who (quote p 18): "were not naive to the fact that the mothers were or were not labelled mentally retarded, or to the skills being trained" |

Feldman 1992 (Continued)

| | | |
|---|--------------|---|
| Blinding of outcome assessment (detection bias) All outcomes | Unclear risk | Comment: outcome assessors were not told of the experiment design but potentially were aware of each mother's training |
| Incomplete outcome data (attrition bias) NCATS | High risk | Comment: data were presented on 8 of the 11 intervention group mothers at follow-up, so three mothers were lost to follow-up |
| Selective reporting (reporting bias) | Low risk | Comment: it appears that all included outcomes were reported |
| Other bias | Unclear risk | Comment: participation in the groups did not preclude involvement with other services. No further information was given in the study |

Hodes 2017

| | |
|---------------|---|
| Methods | Randomised controlled trial |
| Participants | <p>Sample size: 85 parents with mild learning disabilities, including 83 mothers and two fathers who were selected from the participants of a broader study on families with parents with MID (e.g. Meppelder 2014)</p> <p>Inclusion criteria: primary caregiver (mother or father) of a young child (aged 1 to 7 years) who was in their care at least four days per week</p> <p>Characteristics of 85 parents included in intervention phase of study</p> <p>Mean age: 30.3 (SD = 6.7; range = 20.6 to 46.5) years at pre-test</p> <p>Mean IQ: 71 (SD = 9.0; range = 49 to 88)</p> <p>Migration status: approximately 1 in 4 (24%) were immigrants</p> <p>Country of origin: of the parents who had immigrated to the Netherlands, 25% came from Suriname and 25% from Curaçao. The other 50% came from eight other countries</p> <p>Mean number of children: 2</p> <p>Mean age of youngest child: 3.1 (SD = 1.4; range = 1.1 to 6.5) years at pre-test</p> <p>Sex of children: 52% female</p> |
| Interventions | <p>Parents with mild intellectual disabilities or borderline intellectual functioning were randomised to intervention (n = 43) and control (n = 42) conditions. Parents in both groups received treatment as usual. The intervention group also received an adapted version of VIPP-LD. Measures of parenting stress were obtained pre-test, post-test and at 3-month follow-up</p> <p>Intervention (43 participants): a video-based intervention programme based on attachment and coercion theory (VIPP-SD) was tailored to parents with intellectual disability. Adaptations included shortening the duration of each session by conducting separate home visits for video recording (recording sessions) and feedback (feedback sessions). VIPP-LD therefore consisted of 15 home visits, including 7 recording sessions, 7 feedback sessions and 1 closing visit, delivered over a period of 3 months on average. After specific training and under intensive supervision the VIPP-LD was conducted by trained professionals, including family support workers and psychologists from care organisations who had several years of experience working with parents with intellectual</p> |

| | | |
|--|---|---|
| | <p>disability, but who were not involved in delivering the treatment as usual for the family concerned</p> <p>Control (22 participants): treatment as usual for all participants included the care normally given by their care organisation. This care consisted of support with running the household, administrative matters, money issues, personal problems and with general self-care. Occasionally, support is given on general child rearing questions. Treatment as usual did not include any form of video intervention or other structured parenting intervention. Parents in the control condition were offered, and most elected, to receive the VIPP-LD intervention upon completion of the study</p> | |
| <p>Outcomes</p> | <ul style="list-style-type: none"> • The NOSIK was employed to obtain measures of parenting stress related to the child (mentioned as child domain), and parenting stress related to the parent's own functioning and situation (mentioned as parent domain) • The NOSIK comprises 25 items; 14 items measure stress in the child domain and 11 items measure stress in the parent domain. All items have a 6-point, Likert-type response scale (1 = strongly disagree to 6 = strongly agree). In this study, the internal consistency reliability (Cronbach's alpha) was 0.89 for items in the child domain and 0.86 for items in the parent domain • Harmonious quality was indexed by 10 rating scales: parents' supportive presence, respect for autonomy, stimulation of cognitive development, hostility, and confidence, as well as children's enthusiasm, persistence, negativity, affection towards the parent and the dyadic scale affective mutuality. The scores were rated on an anchored scale from 'very low' (1) to 'very high' (7). All the recordings were rated by 2 out of 3 trained coders, blind to condition (intervention or control group), time point (pre-test, post-test or follow-up level), and any other participant data • Sensitive discipline coding was based on existing guidelines. The Do and Don't tasks were rated with 4 subscales for measuring physical discipline, harsh discipline, verbally harsh discipline and laxness, on a scale ranging from 1 (never) to 5 (most of the time), as well as with a supportive presence scale, on a scale ranging from 1 (complete lack of support) to 7 (skilful support throughout the session). The internal consistency of the aggregate scale for measuring sensitive discipline was 0.70 for the Do task and 0.65 for the Don't task at pre-test | |
| <p>Notes</p> | <p>Study start and end dates: not stated</p> <p>Conflicts/declarations of interests: Carlo Schuengel, Sabina Kef, Marja Hodes, and Marieke Meppelder have received funding (grant 57000006) from ZonMw, The Netherlands Organisation for Health Research and Development, for research on intervention for parents with intellectual disability. Marja Hodes is employed by ASVZ, a care organisation for people with intellectual disability that offers support to parents with intellectual disabilities such as described in the article</p> | |
| <p><i>Risk of bias</i></p> | | |
| <p>Bias</p> | <p>Authors' judgement</p> | <p>Support for judgement</p> |
| <p>Random sequence generation (selection bias)</p> | <p>Low risk</p> | <p>Comment: sequential block randomisation, using a computer programme</p> |

Hodes 2017 (Continued)

| | | |
|---|--------------|--|
| Allocation concealment (selection bias) | Low risk | Comment: participants randomly assigned by an independent researcher blind to other information |
| Blinding of participants and personnel (performance bias) All outcomes | Unclear risk | Comment: reported that the VIPP-LD intervention was delivered by trained professionals, including family support workers and psychologists from care organisations who had several years of experience working with parents with intellectual disability, but who were not involved in delivering the treatment as usual for the family concerned. Did not explicitly report any blinding of participants |
| Blinding of outcome assessment (detection bias) All outcomes | Low risk | Comment: reported that assessments at post-test and follow-up were undertaken by researchers and research assistants blind to group assignment and not involved in conducting either the intervention or treatment as usual. Personnel were not involved with the participants who received treatment as usual |
| Incomplete outcome data (attrition bias) NCATS | Low risk | Comment: for all missing data, the Hodes 2017 study applied intention-to-treat, as suggested by the Fisher 1990 study, in such a way that missing data at post-test were replaced by pre-test scores (4 cases) and missing data at follow-up were replaced by post-test scores (4 cases) |
| Selective reporting (reporting bias) | Low risk | Comment: outcomes of observed parenting behaviour and parent-child interactions are due to be published in a further article (awaiting publication). No other evidence of selective reporting |
| Other bias | Unclear risk | Comment: participants were taken from a broader study, Mepplender 2015 . Elevated stress levels at pre-test in the intervention group |

Keltner 1995

| | |
|---------------|--|
| Methods | Randomised controlled trial |
| Participants | Sample size: 40 mothers Dropouts/withdrawals: not stated IQ: less than 85 |
| Interventions | Intervention: 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. Number in intervention group not given Control: treatment as usual. Received monthly telephone contact, 6-monthly assessments and appropriate onward referrals. Number in control group not given |

Keltner 1995 (Continued)

| | | |
|---|---|--|
| Outcomes | Maternal-child interaction (NCATS means scores). Assessed at baseline, 6 months, 12 months | |
| Notes | <p>Comment: information in study very limited and no response was received to our attempts to contact the authors</p> <p>Study start and end dates: not stated</p> <p>Conflicts/declarations of interests: not stated</p> <p>Funding: this work was supported by the Alabama Development Disabilities Council</p> | |
| Risk of bias | | |
| Bias | Authors' judgement | Support for judgement |
| Random sequence generation (selection bias) | Unclear risk | Comment: no information |
| Allocation concealment (selection bias) | Low risk | Comment: random assignment performed by a person not associated with the project |
| Blinding of participants and personnel (performance bias) All outcomes | Unclear risk | Comment: no information. Did not report whether the participants were blind to group allocation or whether the personnel employed to deliver the STARS programme were blinded |
| Blinding of outcome assessment (detection bias) All outcomes | Low risk | Comment: assessors were described as trained professionals blind to group assignment |
| Incomplete outcome data (attrition bias) NCATS | Unclear risk | Comment: unclear whether all participants completed the study |
| Selective reporting (reporting bias) | Low risk | Comment: no suggestion of selective outcome reporting from published report |
| Other bias | Unclear risk | Comment: poor reporting standards (i.e. no sample sizes for each group provided or SDs for outcomes) |

Llewellyn 2003

| | |
|--------------|--|
| Methods | Randomised controlled trial. Design similar to cross-over in that all participants got the intervention in sequence over a period of time. To compensate for possible effects, we included data from the first period only for intervention and treatment as usual only groups |
| Participants | <p>Sample size: 63 parents recruited; 45 completed study</p> <p>Inclusion criteria: diagnosed intellectual disability, or history of special education for students with intellectual disability, or identified by referrer as having cognitive limitations and showing no benefit from usual intervention</p> |

| | | |
|---|---|---|
| | Dropouts/withdrawals: none | |
| Interventions | <p>Intervention: Home Learning Programme designed to equip parents of children under 5 years of age with knowledge and skills to manage home dangers, accidents and childhood illness. 10 1-to-1 sessions using booklets designed to meet parents needs. Weekly visits, 60 to 90 minutes over 10 to 12 weeks</p> <p>Control: treatment as usual. 2 groups. Each received different interventions: current services only with no intervention from the project team; and lesson booklets only by mail for one lesson per week for 10 weeks. Control data only included in review for control group 1</p> | |
| Outcomes | 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) | |
| Notes | <p>Study start and end dates: August 1998 to November 2000</p> <p>Conflicts/declarations of interests: none declared</p> <p>Funding: Best Practice Parenting Education Initiative of the Commonwealth Department of Family and Community Services and the New South Wales Aging and Disability Department</p> | |
| <i>Risk of bias</i> | | |
| Bias | Authors' judgement | Support for judgement |
| Random sequence generation (selection bias) | Low risk | Comment: 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 |
| Allocation concealment (selection bias) | Unclear risk | Comment: unclear what the role was of the person performing the allocation (service delivery or evaluation) |
| Blinding of participants and personnel (performance bias) All outcomes | Unclear risk | Comment: no information |
| Blinding of outcome assessment (detection bias) All outcomes | Low risk | <p>Quote p 409: "trained parent assessors who were blind to each parents group allocation administered curriculum related outcome measures at baseline, pre- and post-intervention"</p> <p>Comment: trained parent assessors who were blind to group allocation</p> |

| | | |
|---|-----------|---|
| Incomplete outcome data (attrition bias) NCATS | Low risk | Comment: no missing data for outcomes of interest. Overall attrition rate reduced from 45 at baseline to 17 at follow-up |
| Selective reporting (reporting bias) | Low risk | Comment: no suggestion of selective outcome reporting from published report |
| Other bias | High risk | Comment: fourth group recruitment and allocation not fully random but not included in the data we extracted or included. This review only includes first-time-point data for Home Learning Programme and comparison group, so review not affected by possible bleed-out from groups all receiving intervention in a different sequence |

IQ: intelligence quotient; **MID:** mild intellectual disability; **NCATS:** Nursing Child Assessment Teaching Scale; **NOSIK:** Nijmeegse Ouderlijke Stress Index Kort; **SD:** standard deviation; **STARS:** Support to Access Rural Services; **VIPP-LD:** video-feedback intervention to promote positive parenting for parents with learning difficulties; **VIPP-SD:** video-feedback intervention to promote positive parenting and sensitive discipline for parents with learning difficulties.

Characteristics of excluded studies [ordered by study ID]

| Study | Reason for exclusion |
|-------------------------------|--|
| Aanes 1975 | Not a RCT |
| Bakken 1993 | Not a RCT |
| Castell 2016 | Not a RCT |
| Fantuzzo 1986 | Not a RCT |
| Feldman 1986 | Not a RCT |
| Feldman 1989 | Not a RCT |
| Feldman 1993 | Does not 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. Control group also given an intervention |
| Feldman 1997 | Not a RCT |
| Feldman 1998 | Not a RCT |

(Continued)

| | |
|----------------------------------|--|
| Feldman 1999a | Not a RCT |
| Feldman 1999b | Not a RCT |
| Feldman 2004 | Not a RCT |
| Glazemakers 2013 | Not a RCT |
| Heinz 2003 | Not a RCT |
| Hodes 2014 | No eligible outcomes reported. Separate study from the Hodes 2017 included study |
| Jamieson 2016 | Not a RCT |
| Knowles 2017a | Not a RCT |
| Knowles 2017b | Not a RCT |
| Maclean 2010 | Not a RCT |
| McConnell 2008a | Not a RCT |
| McConnell 2008b | Not a RCT |
| McConnell 2016 | Not a RCT |
| McGarry 2016 | Not a RCT |
| McGaw 2002 | No relevant outcomes included |
| Mildon 2008 | Not a RCT |
| Milot 2016 | Not a RCT |
| Peterson 1983 | Not a RCT |
| Rao 2013 | Not a RCT |
| Starke 2013 | Not a RCT |
| Strnadova 2017 | Not a RCT |
| Tahir 2015 | Not a RCT |
| Thompson 1984 | Not a RCT |
| Tymchuck 1988 | Not a RCT |
| Tymchuck 1989 | Not a RCT |

(Continued)

| | |
|---------------|-----------|
| Tymchuck 1990 | Not a RCT |
| Tymchuck 1991 | Not a RCT |
| Tymchuck 1992 | Not a RCT |
| Tymchuck 1993 | Not a RCT |
| Whitman 1989 | Not a RCT |
| Young 2006 | Not a RCT |

RCT: randomised controlled trial.

DATA AND ANALYSES

Comparison 1. Parent training compared to treatment as usual

| Outcome or subgroup title | No. of studies | No. of participants | Statistical method | Effect size |
|------------------------------|----------------|---------------------|--------------------------------------|---------------------|
| 1 Recognising dangers | 1 | | Mean Difference (IV, Random, 95% CI) | Totals not selected |
| 2 Identifying precautions | 1 | | Mean Difference (IV, Random, 95% CI) | Totals not selected |
| 3 Home precautions | 1 | | Mean Difference (IV, Random, 95% CI) | Totals not selected |
| 4 Child health comprehension | 1 | | Mean Difference (IV, Random, 95% CI) | Totals not selected |
| 5 Symptom recognition | 1 | | Mean Difference (IV, Random, 95% CI) | Totals not selected |
| 6 Life-threatening emergency | 1 | | Mean Difference (IV, Random, 95% CI) | Totals not selected |
| 7 Visiting the doctor | 1 | | Mean Difference (IV, Random, 95% CI) | Totals not selected |
| 8 Using medicines | 1 | | Mean Difference (IV, Random, 95% CI) | Totals not selected |

Comparison 2. Video-feedback compared to treatment as usual

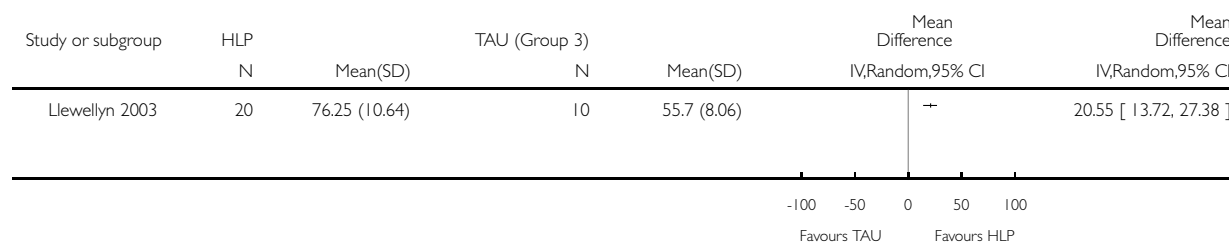
| Outcome or subgroup title | No. of studies | No. of participants | Statistical method | Effect size |
|-----------------------------------|----------------|---------------------|-------------------------------------|---------------------|
| 1 Parenting stress: child domain | 1 | | Mean Difference (IV, Fixed, 95% CI) | Totals not selected |
| 2 Parenting stress: parent domain | 1 | | Mean Difference (IV, Fixed, 95% CI) | Totals not selected |
| 3 Parenting stress: total | 1 | | Mean Difference (IV, Fixed, 95% CI) | Totals not selected |

Analysis 1.1. Comparison 1 Parent training compared to treatment as usual, Outcome 1 Recognising dangers.

Review: Parent training interventions for parents with intellectual disability

Comparison: 1 Parent training compared to treatment as usual

Outcome: 1 Recognising dangers

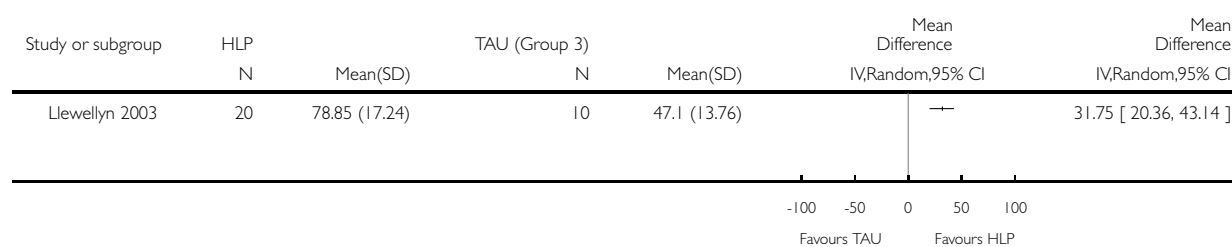


Analysis 1.2. Comparison 1 Parent training compared to treatment as usual, Outcome 2 Identifying precautions.

Review: Parent training interventions for parents with intellectual disability

Comparison: 1 Parent training compared to treatment as usual

Outcome: 2 Identifying precautions

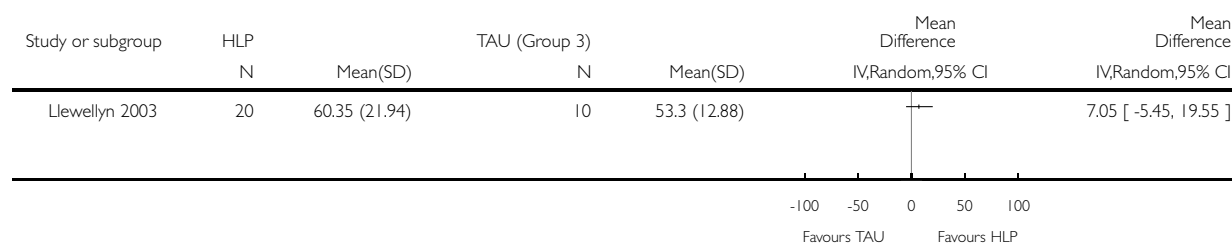


Analysis 1.3. Comparison 1 Parent training compared to treatment as usual, Outcome 3 Home precautions.

Review: Parent training interventions for parents with intellectual disability

Comparison: 1 Parent training compared to treatment as usual

Outcome: 3 Home precautions

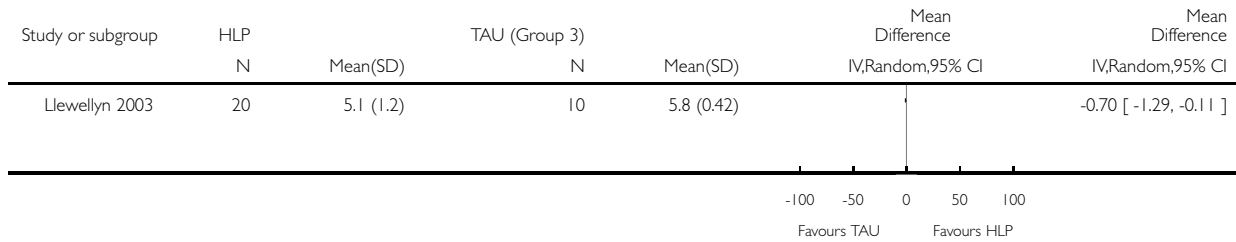


Analysis 1.4. Comparison 1 Parent training compared to treatment as usual, Outcome 4 Child health comprehension.

Review: Parent training interventions for parents with intellectual disability

Comparison: 1 Parent training compared to treatment as usual

Outcome: 4 Child health comprehension

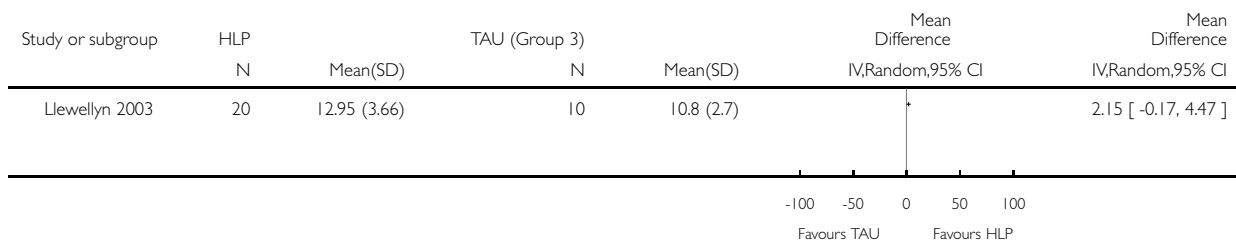


Analysis 1.5. Comparison 1 Parent training compared to treatment as usual, Outcome 5 Symptom recognition.

Review: Parent training interventions for parents with intellectual disability

Comparison: 1 Parent training compared to treatment as usual

Outcome: 5 Symptom recognition

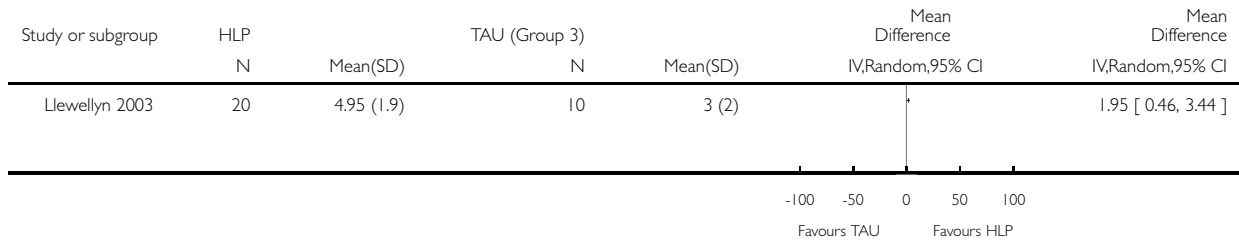


Analysis 1.6. Comparison 1 Parent training compared to treatment as usual, Outcome 6 Life-threatening emergency.

Review: Parent training interventions for parents with intellectual disability

Comparison: 1 Parent training compared to treatment as usual

Outcome: 6 Life-threatening emergency

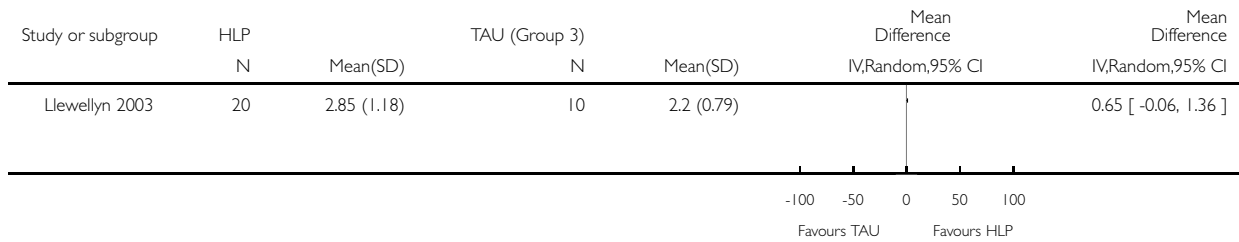


Analysis 1.7. Comparison 1 Parent training compared to treatment as usual, Outcome 7 Visiting the doctor.

Review: Parent training interventions for parents with intellectual disability

Comparison: 1 Parent training compared to treatment as usual

Outcome: 7 Visiting the doctor

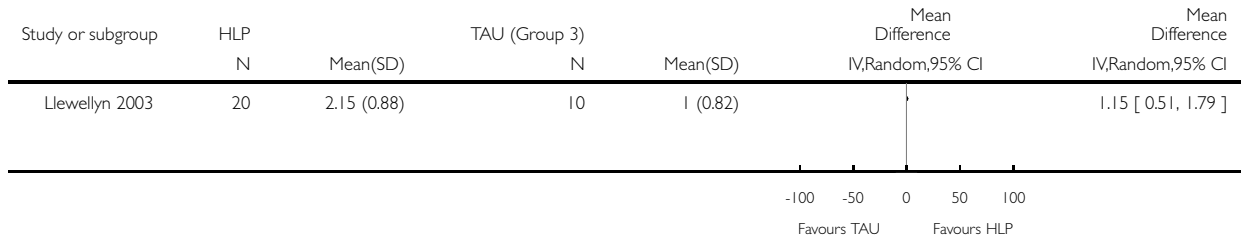


Analysis 1.8. Comparison 1 Parent training compared to treatment as usual, Outcome 8 Using medicines.

Review: Parent training interventions for parents with intellectual disability

Comparison: 1 Parent training compared to treatment as usual

Outcome: 8 Using medicines

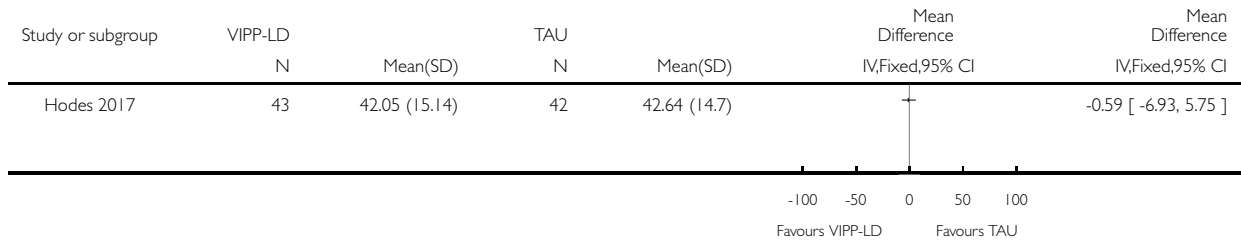


Analysis 2.1. Comparison 2 Video-feedback compared to treatment as usual, Outcome 1 Parenting stress: child domain.

Review: Parent training interventions for parents with intellectual disability

Comparison: 2 Video-feedback compared to treatment as usual

Outcome: 1 Parenting stress: child domain

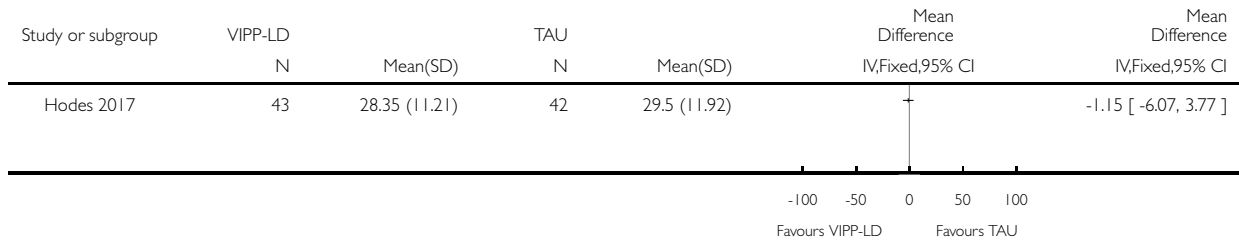


Analysis 2.2. Comparison 2 Video-feedback compared to treatment as usual, Outcome 2 Parenting stress: parent domain.

Review: Parent training interventions for parents with intellectual disability

Comparison: 2 Video-feedback compared to treatment as usual

Outcome: 2 Parenting stress: parent domain

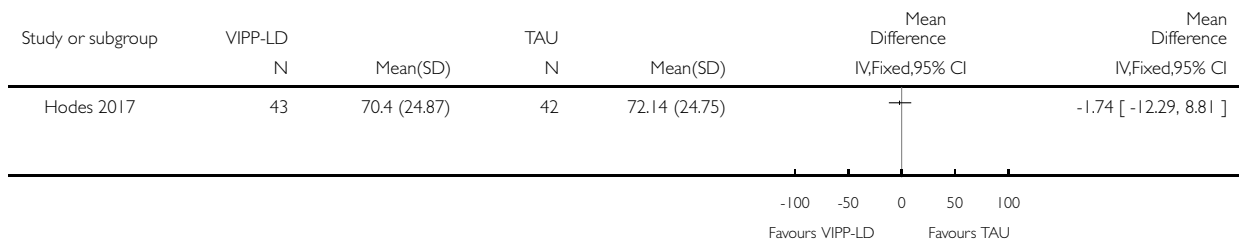


Analysis 2.3. Comparison 2 Video-feedback compared to treatment as usual, Outcome 3 Parenting stress: total.

Review: Parent training interventions for parents with intellectual disability

Comparison: 2 Video-feedback compared to treatment as usual

Outcome: 3 Parenting stress: total



ADDITIONAL TABLES

Table 1. Methods not required in current version of review

| Issue | Proposed approach |
|-------------------------------------|---|
| Types of participants | We will exclude studies that include participants whose intellectual disabilities are caused by head injury or substance misuse problems, unless results for intellectual disability are presented separately |
| Measures of treatment effect | <p>Dichotomous data</p> <p>For dichotomous (binary) data, we will use risk ratios (RRs) with a 95% confidence interval (CI) to summarise results within each study. The risk ratio is chosen over the odds ratio (OR) because it is more accessible to understanding and interpretation by non-research or statistically-trained stakeholders</p> |
| Unit of analysis issues | <p>Cluster-randomised trials</p> <p>We do not anticipate that cluster designs are likely within this topic area. However, if this does arise, we would hope that study investigators would have presented their results in the units in which participants were analysed. If it is unclear whether this has taken place, we will contact the study investigators for further information. If further information is not available, we will seek statistical guidance from the Cochrane Developmental, Psychosocial and Learning Problems editorial team 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</p> <p>Cross-over trials</p> <p>For cross-over trials, to avoid possible bleed-out from comparison groups having received the intervention, we will only include data up to the first time point in the review, incorporating the first group to receive the intervention compared with the treatment as usual group at that time point</p> <p>Multiple time points</p> <p>Where a study presents results for several periods of follow-up, to avoid double-counting of the participants in studies, we will undertake separate meta-analyses for the various time points: immediate post-test, six-month follow-up, and 12-month follow-up. Where a study presents data from a different time point to the other studies, we will present those data separately</p> <p>Multiple treatment groups</p> <p>Where multiple treatment or control group types are presented in study reports, we will aim to present the data from each study as consistently as possible with the primary comparison of treatment compared with control group. We will present or analyse data from studies comparing different types of treatment or control groups separately</p> |
| Dealing with missing data | We will contact the original investigators to request any missing data and information on whether or not it can be assumed to be 'missing at random'. In addition to the steps outlined below, we will report proportions of missing participants in a 'Risk of bias' table |

Table 1. Methods not required in current version of review (Continued)

| | |
|--|--|
| | <p>Dichotomous data</p> <p>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 when all participants with missing outcomes in the intervention condition had good outcomes, and all those with missing outcomes in the control condition had poor outcomes; the 'worst-case' scenario is the converse (Deeks 2011).</p> <p>Continuous data</p> <p>If there are missing continuous data, we will provide a narrative summary. The standard deviations of the outcome measures should be reported for each group in each trial. If these are not given, where possible, we will impute standard deviations using relevant data (for example, using standard errors or P values). The <i>Cochrane Handbook for Systematic Reviews of Interventions</i> suggest that it is plausible to assume a fixed difference for the missing data (Higgins 2011b), for example, averaging two units more or less than the intervention or control arms. When 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</p> <p>We will report separately all data from studies where more than 50% of participants in any group were lost to follow-up, and explore the impact of this on the review findings by means of sensitivity analysis</p> |
| <p>Assessment of heterogeneity</p> | <p>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 Chi² test of heterogeneity (where a significance level less than 0.10 is interpreted as evidence of heterogeneity), and by examining the I² statistic (Deeks 2011). The I² statistic describes approximately the proportion of variation in point estimates that is due to heterogeneity. We will consider I² 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. We will also report Tau² - an estimate of between-study variance.</p> |
| <p>Assessment of reporting biases</p> | <p>We will draw funnel plots (plotting of sample size against effect) to assess publication and related biases if sufficient studies are found</p> |
| <p>Data synthesis</p> | <p>As referenced in the <i>Cochrane Handbook for Systematic Reviews of Interventions</i>, 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</p> |

Table 1. Methods not required in current version of review (Continued)

| | |
|--|--|
| | <p>can be inappropriate and can obscure genuine effects (Deeks 2011). If a statistical meta-analysis is possible, in the likely event that the studies found are small and heterogenous, 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 (Deeks 2011). 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> |
| <p>Subgroup analysis and investigation of heterogeneity</p> | <p>If enough studies are found, we will undertake the following subgroup analyses to examine the effect on the primary outcomes of the following</p> <ul style="list-style-type: none"> • Severity of intellectual disability. • Participants living independently with children or in a supervised care situation; • Date of diagnosis of intellectual disability: within last 10 years or 10 to 20 years ago, or 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 participant 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. • Instructor-led or self-taught intervention. • Individual- or group-based intervention. • Length of intervention. • Whether delivered at home or at a centre. |
| <p>Sensitivity analysis</p> | <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> <ul style="list-style-type: none"> • concealment of allocation; • blinding of outcome assessors; and • extent of dropouts. |

DSM-IV: *Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition*; **MID:** mild intellectual disability.

APPENDICES

Appendix I. Original search strategies 2009

Ovid MEDLINE

- 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

Embase (Ovid)

- 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

PsycINFO Ovid

- 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

ASSIA (Applied Social Sciences Index and Abstracts)

((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*))

Appendix 2. Updated search strategies 2017

Cochrane Central Register of Controlled Trials EBM Reviews Ovid (CENTRAL)

- 1 Intellectual Disability.kw.
- 2 (intellectual\$ adj3 disab\$).tw.
- 3 (intellectual\$ adj3 impair\$).tw.
- 4 (learning adj3 disab\$).tw.
- 5 (learning adj3 difficult\$).tw.
- 6 (cognit\$ adj3 (disab\$ or impair\$)).tw.
- 7 mental\$ retard\$.tw.
- 8 (mental\$ adj3 disab\$).tw.
- 9 (mental\$ adj3 impair\$).tw.
- 10 down\$ syndrome.tw.
- 11 mongol\$.tw.
- 12 (mental\$ adj3 deficie\$).tw.
- 13 idiocy.tw.
- 14 fragile x.tw.
- 15 prader-willi.tw.

16 or/1-15
 17 Parents.kw.
 18 Parenting.kw.
 19 17 or 18
 20 Education.kw.
 21 19 and 20
 22 Parents Education.kw
 23 21 or 22
 24 (parent\$ adj3 (intervention\$ or program\$ or train\$)).tw.
 25 (parent\$ adj3 (educat\$ or promot\$ or skill\$ or group\$ or support\$)).tw.
 26 ((mother\$ or father\$) adj1 (intervention\$ or program\$ or train\$)).tw.
 27 ((mother\$ or father\$) adj1 (educat\$ or promot\$ or skill\$ or group\$ or support\$)).tw.
 28 23 or 24 or 25 or 26 or 27
 29 16 and 28

Ovid MEDLINE

1 exp Intellectual Disability/
 2 (intellectual\$ adj3 disab\$).tw.
 3 (intellectual\$ adj3 impair\$).tw.
 4 (learning adj3 disab\$).tw.
 5 (learning adj3 difficult\$).tw.
 6 (cognit\$ adj3 (disab\$ or impair\$)).tw.
 7 mental\$ retard\$.tw.
 8 (mental\$ adj3 disab\$).tw.
 9 (mental\$ adj3 impair\$).tw.
 10 down\$ syndrome.tw.
 11 mongol\$.tw.
 12 (mental\$ adj3 deficie\$).tw.
 13 idiocy.tw.
 14 fragile x.tw.
 15 prader-willi.tw.
 16 or/1-15
 17 exp Parents/
 18 Parenting/
 19 17 or 18
 20 Education/
 21 19 and 20
 22 exp Parents/ed [Education]
 23 21 or 22
 24 (parent\$ adj3 (intervention\$ or program\$ or train\$)).tw.
 25 (parent\$ adj3 (educat\$ or promot\$ or skill\$ or group\$ or support\$)).tw.
 26 ((mother\$ or father\$) adj1 (intervention\$ or program\$ or train\$)).tw.
 27 ((mother\$ or father\$) adj1 (educat\$ or promot\$ or skill\$ or group\$ or support\$)).tw.
 28 23 or 24 or 25 or 26 or 27
 29 16 and 28

Embase Ovid

1 intellectual impairment/
 2 exp mental deficiency/
 3 (intellectual\$ adj3 disab\$).tw.
 4 (intellectual\$ adj3 impair\$).tw.

5 (learning adj3 disab\$).tw.
 6 (learning adj3 difficult\$).tw.
 7 (cognit\$ adj3 (disab\$ or impair\$)).tw.
 8 mental\$ retard\$.tw.
 9 (mental\$ adj3 disab\$).tw.
 10 (mental\$ adj3 impair\$).tw.
 11 down\$ syndrome.tw.
 12 mongol\$.tw.
 13 (mental\$ adj3 defici\$).tw.
 14 idiocy.tw.
 15 fragile x.tw.
 16 prader-willi.tw.
 17 or/1-16
 18 parent/
 19 mother/
 20 father/
 21 or/18-20
 22 *education/
 23 21 and 22
 24 "parenting education"/
 25 (parent\$ adj3 (intervention\$ or program\$ or train\$)).tw.
 26 (parent\$ adj3 (educat\$ or promot\$ or skill\$ or group\$ or support\$)).tw.
 27 ((mother or father\$) adj1 (intervention\$ or program\$ or train\$)).tw.
 28 ((mother\$ or father\$) adj1 (educat\$ or promot\$ or skill\$ or group\$ or support\$)).tw.
 29 or/23-28
 30 17 and 29

CINAHL EBSCOhost (Cumulative Index to Nursing and Allied Health Literature)

S1 (SU "Intellectual Disability+")
 S2 intellectual* N3 disab*
 S3 intellectual* N3 impair*
 S4 learning N3 disab*
 S5 learning N3 difficult*
 S6 cognit* N3 (disab* OR impair*)
 S7 mental* retard*
 S8 mental* N3 disab*
 S9 mental* N3 impair*
 S10 down* syndrome
 S11 mongol*
 S12 mental* N3 deficie*
 S13 idiocy
 S14 fragile x
 S15 prader-willi
 S16 S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15
 S17 (SU "Parents+")
 S18 (SU "Parenting+")
 S19 17 OR 18
 S20 (SU "Education")
 S21 19 AND 20
 S22 (SU "Parents Education+")
 S23 21 OR 22
 S24 parent* N3 (intervention* OR program* OR train*)

S25 parent* N3 (educat* OR promot* OR skill* OR group* OR support*)
 S26 (mother OR father*) N1 (intervention* OR program* OR train*)
 S27 (mother* OR father*) N1 (educat* OR promot* OR skill* OR group* OR support*)
 S28 23 OR 24 OR 25 OR 26 OR 27
 29 16 AND 28

PsycINFO Ovid

1 exp Intellectual Development Disorder/
 2 (intellectual\$ adj3 disab\$).tw.
 3 (intellectual\$ adj3 impair\$).tw.
 4 (learning adj3 disab\$).tw.
 5 (learning adj3 difficult\$).tw.
 6 (cognit\$ adj3 (disab\$ or impair\$)).tw.
 7 mental\$ retard\$.tw.
 8 (mental\$ adj3 disab\$).tw.
 9 (mental\$ adj3 impair\$).tw.
 10 down\$ syndrome.tw.
 11 mongol\$.tw.
 12 (mental\$ adj3 deficie\$).tw.
 13 idiocy.tw.
 14 fragile x.tw.
 15 prader-willi.tw.
 16 or/1-15
 17 exp Parents/
 18 exp Parenting Skills/
 19 17 or 18
 20 Education/
 21 19 and 20
 22 exp Parent Training/
 23 21 or 22
 24 (parent\$ adj3 (intervention\$ or program\$ or train\$)).tw.
 25 (parent\$ adj3 (educat\$ or promot\$ or skill\$ or group\$ or support\$)).tw.
 26 ((mother or father\$) adj1 (intervention\$ or program\$ or train\$)).tw.
 27 ((mother\$ or father\$) adj1 (educat\$ or promot\$ or skill\$ or group\$ or support\$)).tw.
 28 23 or 24 or 25 or 26 or 27
 29 16 and 28

ASSIA Proquest

((intellectual* N/3 disab*) OR ((intellectual* N/3 impair*) OR (learning N/3 disab*) OR (learning N/3 difficult*) OR (cognit* N/3 (disab* or impair*)) OR (mental* retard*) OR (mental* N/3 disab*) OR (mental* N/3 impair*) OR (down* syndrome) OR mongol* OR (mental* N/3 deficie*) OR idiocy OR fragile x OR prader-willi)) AND (((SU.EXACT("Parents") OR SU.EXACT("Parenting")) AND (SU.EXACT("Education")) OR (Parents Education)) OR (parent* N/3 (intervention* or program* or train*)) OR (parent* N/3 (educat* or promot* or skill* or group* or support*)) OR ((mother or father*) N/1 (intervention* or program* or train*)) OR ((mother* or father*) N/1 (educat* or promot* or skill* or group* or support*)))

Cochrane Database of Systematic Reviews EBM Reviews Ovid (CDSR)

1 Intellectual Disability.kw.
 2 (intellectual\$ adj3 disab\$).tw.
 3 (intellectual\$ adj3 impair\$).tw.
 4 (learning adj3 disab\$).tw.

5 (learning adj3 difficult\$.tw.
 6 (cognit\$ adj3 (disab\$ or impair\$)).tw.
 7 mental\$ retard\$.tw.
 8 (mental\$ adj3 disab\$).tw.
 9 (mental\$ adj3 impair\$).tw.
 10 down\$ syndrome.tw.
 11 mongol\$.tw.
 12 (mental\$ adj3 deficie\$).tw.
 13 idiocy.tw.
 14 fragile x.tw.
 15 prader-willi.tw.
 16 or/1-15
 17 Parents.kw.
 18 Parenting.kw.
 19 17 or 18
 20 Education.kw.
 21 19 and 20
 22 Parents Education.kw
 23 21 or 22
 24 (parent\$ adj3 (intervention\$ or program\$ or train\$)).tw.
 25 (parent\$ adj3 (educat\$ or promot\$ or skill\$ or group\$ or support\$)).tw.
 26 ((mother or father\$) adj1 (intervention\$ or program\$ or train\$)).tw.
 27 ((mother\$ or father\$) adj1 (educat\$ or promot\$ or skill\$ or group\$ or support\$)).tw.
 28 23 or 24 or 25 or 26 or 27
 29 16 and 28

Database of Abstracts of Reviews of Effects EBM Reviews Ovid (DARE)

1 Intellectual Disability.kw.
 2 (intellectual\$ adj3 disab\$).tw.
 3 (intellectual\$ adj3 impair\$).tw.
 4 (learning adj3 disab\$).tw.
 5 (learning adj3 difficult\$.tw.
 6 (cognit\$ adj3 (disab\$ or impair\$)).tw.
 7 mental\$ retard\$.tw.
 8 (mental\$ adj3 disab\$).tw.
 9 (mental\$ adj3 impair\$).tw.
 10 down\$ syndrome.tw.
 11 mongol\$.tw.
 12 (mental\$ adj3 deficie\$).tw.
 13 idiocy.tw.
 14 fragile x.tw.
 15 prader-willi.tw.
 16 or/1-15
 17 Parents.kw.
 18 Parenting.kw.
 19 17 or 18
 20 Education.kw.
 21 19 and 20
 22 Parents Education.kw
 23 21 or 22
 24 (parent\$ adj3 (intervention\$ or program\$ or train\$)).tw.
 25 (parent\$ adj3 (educat\$ or promot\$ or skill\$ or group\$ or support\$)).tw.

26 ((mother or father\$) adj1 (intervention\$ or program\$ or train\$)).tw.
27 ((mother\$ or father\$) adj1 (educat\$ or promot\$ or skill\$ or group\$ or support\$)).tw.
28 23 or 24 or 25 or 26 or 27
29 16 and 28

Sociological Abstracts Proquest

((SU.EXACT("Parents") AND SU.EXACT("Education")) OR (SU.EXACT("Parents") AND SU.EXACT("Educational Programs")) OR (SU.EXACT("Parent Training")) OR ALL (parent* NEAR/3 (intervention* OR program* OR train*)) OR ALL (parent* NEAR/3 (educat* OR promot* OR skill* OR group* OR support*)) OR ALL ((mother OR father*) NEAR/3 (intervention* OR program* OR train*)) OR ALL((mother* OR father*) NEAR/3 (educat* OR promot* OR skill* OR group* OR support*))) AND (SU.EXACT("Mentally Retarded") OR SU.EXACT("Handicapped") OR SU.EXACT("Congenitally Handicapped") OR SU.EXACT("Downs Syndrome") OR SU.EXACT("Learning Disabilities") OR ALL (intellectual* NEAR/3 disab*) OR ALL(intellectual* NEAR/3 impair*) OR ALL (learning NEAR/3 disab*) OR ALL(learning NEAR/3 difficult*) OR ALL(cognit* NEAR/3 (disab* OR impair*)) OR ALL("mental* retard*") OR ALL(mental* NEAR/3 disab*) OR ALL(mental* NEAR/3 impair*) OR ALL (mental* NEAR/3 deficie*) OR ALL("down* syndrome" OR mongol* OR idiocy OR "fragile x" OR "prader-willi"))

ZETOC

(zetoc.jisc.ac.uk)

Parent* intellectual* disab*
Parent* intellectual* impair*
Parent* learning disab*
Parent* learning difficult*
Parent* cognit* disab*
Parent* cognit* impair*
Parent* mental* retard*
Parent* mental*disab*
Parent* mental* impair*
Parent* down* syndrome
Parent* mongol*
Parent* mental* deficie*
Parent* idiocy
Parent* fragile x
parent* prader-willi
Mother intellectual* disab*
Mother intellectual* impair*
Mother learning disab*
Mother learning difficult*
Mother cognit* disab*
Mother cognit* impair*
Mother mental* retard*
Mother mental*disab*
Mother mental* impair*
Mother down* syndrome
Mother mongol*
Mother mental* deficie*
Mother idiocy
Mother fragile x
Mother prader-willi

ClinicalTrials.gov

(clinicaltrials.gov)

Due to limited number of characters allowed, two separate search strings were run:

(Intellectual Disability OR learning disabilities OR learning difficulties OR cognitive disabilities OR cognitive impairment OR down syndrome) AND (Parents OR Parenting OR Parent Education OR parents training OR mother OR father OR educator)

(intellectual impairment OR mental retard OR mental disabilities OR mental impairment OR idiocy OR fragile x OR prader-willi OR mongoloism) AND (Parents OR Parenting OR Parent Education OR parents training OR mother OR father OR educator)

World Health Organisation International Clinical Trials Registry Platform (WHO ICTRP)

(apps.who.int/trialsearch)

Condition | (Intellectual Disab* OR learning disab* OR learning difficult* OR cognitive disab* OR cognitive impair* OR down syndrome OR intellectual* impair* OR mental retard* OR mental disab* OR mental impair* OR idiocy OR fragile x OR prader-willi OR mongol*)

AND

Intervention | (Parent* OR Parenting OR Parent* Education OR OR mother OR father OR educator)

WHAT'S NEW

Last assessed as up-to-date: 13 July 2017.

| Date | Event | Description |
|--------------|--|--|
| 19 July 2017 | New search has been performed | Updated following a new search in May 2016 and July 2017 |
| 19 July 2017 | New citation required but conclusions have not changed | We found one new study. The conclusions remain unchanged |

HISTORY

Protocol first published: Issue 3, 2009

Review first published: Issue 6, 2010

| Date | Event | Description |
|------------------|---------|--|
| 16 December 2010 | Amended | Change of author affiliation for Carina Gustafsson |
| 10 November 2010 | Amended | Typographical error in Summary of Findings Table corrected |

CONTRIBUTIONS OF AUTHORS

Conceiving the original review: Esther Coren and Carina Gustafsson.

Designing the review and review guarantor: Esther Coren.

Co-ordinating the review: Esther Coren.

Writing the protocol and conducting and writing the review: Esther Coren, Jemeela Hutchfield and Manuela Thomae (original review); Esther Coren and Kerry Ramsbotham (update).

Conducting and reporting the updated searches: Manfred Gschwandtner.

DECLARATIONS OF INTEREST

Esther Coren is an Editor with Cochrane Developmental, Psychosocial and Learning Problems Group.

Kerry Ramsbotham - none known.

Manfred Gschwandtner - none known.

SOURCES OF SUPPORT

Internal sources

- Canterbury Christ Church University, UK.

Support for Esther Coren's role and infrastructure, enabling her to recruit research staff to support work when funds are available

External sources

- IMS, Sweden.

IMS funded the original version of the review

DIFFERENCES BETWEEN PROTOCOL AND REVIEW

1. Title

i) At update, the title of the review was changed from 'Parent training support for intellectually disabled parents' to 'Parent training interventions for parents with intellectual disability', to reflect current usage of language.

2. Types of interventions

i) We relabelled 'usual care' as 'treatment as usual' to ensure consistency in terminology throughout the review.

3. Types of participants

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

4. Types of outcome measures

i) Only recently have studies begun to examine transactional relations among stress, parenting and behaviours in the parent-child dyad, and to the review authors' knowledge, the Hodes 2017 study is the first to specifically examine stress. Parenting stress has

been linked with a number of child maladaptive outcomes and reducing parenting stress may improve parent-child relations and parenting. Therefore, a further difference between protocol is the inclusion of this outcome.

5. Electronic searches

i) In this update, we added the World Health Organization (WHO) International Clinical Trials Registry Platform to our sources.

ii) Margaret Anderson, Information Specialist (Cochrane Developmental, Psychosocial and Learning Problems), and Manfred Gschwandtner, Faculty Liaison Librarian for Health and Wellbeing (Canterbury Christ Church University), conducted updated searches of the following sources: CENTRAL, MEDLINE, Embase, CINAHL, PsycINFO, ASSIA, *CDSR*, DARE, Sociological Abstracts, ZETOC, ClinicalTrials.gov, and WHO International Clinical Trials Registry Platform.

6. Unit of analysis issues

i) Where a study presented data from a different time point to the other studies, we planned to present those data separately. In the event, we only presented endpoint data, for consistency between studies.

7. Data synthesis

i) Beneath this section, we included a new section on 'Summary of findings', consistent with current Cochrane guidance.

NOTES

This review is co-registered with the Campbell Collaboration and the original version was published simultaneously on the Cochrane Library and the Campbell Library. We will discuss publication on the Campbell Library of this update following publication on the Cochrane Library.

INDEX TERMS

Medical Subject Headings (MeSH)

*Child Rearing; *Mentally Disabled Persons; *Parenting; Child of Impaired Parents; Fathers [*education]; Mother-Child Relations; Mothers [*education]; Randomized Controlled Trials as Topic; Safety

MeSH check words

Child; Child, Preschool; Female; Humans; Infant; Male