# Parent training support for intellectually disabled parents

## Protocol information


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### What's new

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# Abstract

## Background

## Objectives

## Search strategy

## Selection criteria

## Data collection and analysis

## Main results

## Authors' conclusions

# Plain language summary

### [Summary title]

[Summary text]

# Background

### Description of the condition

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

Research from various countries suggests that the number of people with intellectual disability with children is increasing (e.g., Department of Health 2000; Pixa-Kettner 2008), although it is not clear whether this reflects an increase in actual numbers or in reporting levels (IASSID 2008). Accurate figures are not available and estimates of the number of parents with intellectual disability vary widely. In the UK, estimates range from 60,000 to 250,000, whilst in Australia it is estimated that 1-2% of families with child under 18 has at least one parent with 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, 'intellectual disability', which has replaced 'mental retardation' in the USA (the latter may still be found in older publications) and various others including 'mental disability', 'mental handicap' and 'cognitive impairment'.

What is known about parents with intellectual disability 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 reflect the situation in relation to intellectual disability figures more generally (Kelly 2007).

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

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

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

## Description of the intervention

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

## How the intervention might work

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

## Why it is important to do this review

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

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

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

Although we maintain that RCTs are both feasible and ethical in this population we are nevertheless aware that in this subject area there is common use of single case experimental designs (SCED), for a number of clinical and practical reasons. It may

therefore be the case that much of the existing evidence arises from such designs, rather than from RCTs as planned for in this review. However, there are currently no recognised ways of synthesizing data collected in studies utilising SCEDs. If this situation changes, the methods section of the protocol will be amended and the review updated.

# Objectives

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

# Methods

## Criteria for considering studies for this review

### *Types of studies*

Designs to be included will be randomised controlled trials and quasi randomised studies. Studies will be included which compare parent training with other interventions, with usual care or with a control group.

### *Types of participants*

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

Studies will be excluded if they include participants whose intellectual disabilities were caused by head injury or who have comorbid mental health conditions or substance misuse problems, unless results for intellectual disability are presented separately.

### *Types of interventions*

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

### *Types of outcome measures*

Studies will be included if they include one or more of the following outcomes.

#### Primary outcomes

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

- Attainment of specific parenting skill targets which are the focus of intervention - Given the nature of interventions for intellectually disabled parents, outcome measures may be based explicitly on the skills taught in a particular intervention rather than any 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 skills taught in relation to this child-care activity. Such tasks may be broken down into very specific actions for the purpose of assessment;
- Safe-home practices -awareness of safety and danger in the home e.g. as measured by the Home Inventory of Dangers and Safety Precautions 2 (Tymchuck 1999);*
- Understanding of child health i.e., understanding of issues related to child health, development and illness e.g., symptoms, emergencies, use of medication and

healthcare. Scales may have been developed specifically for individual programmes as above or be based on a validated scale e.g., those derived from the UCLA Parent-Child Health and Wellness Project (Tymchuck 2003).*

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

### Secondary outcomes

- Parent-child interaction
- Parents retention of child/return to independent care of the child
- Lifting of any child-related court order (although this may depend on the jurisdiction)

## Search methods for identification of studies

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

### *Electronic searches*

The databases to be searched are:

Cochrane Central Register of Controlled Trials (CENTRAL)

MEDLINE

EMBASE

CINAHL

PsycINFO

ASSIA

Sociological Abstracts

Dissertation Abstracts International

MetaRegister of Controlled Trials

ZETOC

The following search strategy will be used to search MEDLINE and modified, where necessary, for the other databases accordingly:

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

No language or date restriction will be applied. No RCT filters will be used as it is felt that they will restrict the search too much and may result in potentially relevant records being missed.

## Data collection and analysis

### *Selection of studies*

Titles and abstracts will be identified, read and reviewed independently by two reviewers against the inclusion criteria. Full copies of studies which appear to meet the inclusion criteria will be obtained and assessed by two independent reviewers. Uncertainties concerning the appropriateness of studies for inclusion in the review will be resolved through consultation with the editorial base or a third reviewer. Reviewers will not be blinded to the name(s) of the study author(s), their institution(s) or publication sources at any stage of the review.

### *Data extraction and management*

Data extraction forms will be developed a priori and include information regarding:

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

Data will be extracted independently by two reviewers and will be organised using Review Manager 5.

Where data are not available in the published trial reports, we will contact the authors and ask them to supply the missing information. This will be reported in the review.

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

For each included study, two reviewers will independently complete the Cochrane Collaboration's tool for assessing risk of bias (Higgins 2008a). Any disagreement will be resolved through consultation with the editorial base. We will assess the degree to which:

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

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

### *Measures of treatment effect*

For dichotomous (binary) data, risk ratios with a 95% confidence interval will be used to summarise results within each study. The relative risk is chosen over the odds ratio because it is more accessible to understanding and interpretation by non research/statistically trained stakeholders.

For continuous data, including measurements on scales, the mean score for each outcome as determined by a standardised tool will be compared between the two groups to give a mean difference (MD), again with a 95% confidence interval.

We will use the weighted mean difference (WMD) where the same outcome measures are reported in more than one study. Previous experience of reviews considering psycho-social outcomes indicates that in many cases, there may be a number of different measures of the same outcome within a review (Barlow 2003). If this is the case, data will be reported as standardized mean differences, where scales are transformed to units of standard deviation in order to combine results across scales. Where possible, and relevant data are available, these data will be back transformed to units of one of the included scales which will be more readily interpretable in clinical terms than units of standard deviation as generated by standardised mean differences. If this is not possible, these data will be presented as effect sizes.

Where scales measuring the same outcome have different directions of benefit, a minus sign will be added to that measuring a negative direction to ensure that all measurements can be read in the same direction.

Continuous data that are skewed will be reported separately. Skew will be identified when, for a scale or measure with positive values and a minimum value of zero, the mean is less than twice the standard deviation (Altman 1996).

### *Unit of analysis issues*

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-ups, 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.

Where multiple treatment/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. Data from studies comparing different types of treatment/control group will be presented or analysed separately.

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, the study investigators will be contacted for further information. If further information is not available, statistical guidance will be sought from the review group as to which method to apply to the published results in order to manage data errors arising from clustering, for example by identifying an intra-class correlation coefficient to utilise in adjusting the data.

## *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, proportions of missing participants will be reported in a 'risk of bias' table.

For dichotomous data, we will report missing data and dropouts for each included study and report the number of participants who are 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 will assess the extent to which the results of the review could be altered by the missing data by, for example, a sensitivity analysis based on consideration of 'best-case' and 'worst-case' scenarios (Gamble 2005). Here, the 'best-case' scenario is that where all participants with missing outcomes in the experimental condition had good outcomes, and all those with missing outcomes in the control condition had poor outcomes; the 'worst-case' scenario is the converse (Higgins 2008b).

For 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).

Higgins, Deeks and Altman (Higgins 2008b) suggest that it is plausible to assume a fixed difference for the missing data e.g. averaging 2 units more or less than the intervention or control arms. Where possible we will assess studies with missing continuous data in this way for the intervention and control groups, seeking advice from the statistical editor about specific details.

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.

## *Assessment of heterogeneity*

We will assess the extent of between-trial differences and the consistency of results of any meta-analysis in three ways: by visual inspection of the forest plots, by performing the Chi

squared test of heterogeneity (where a significance level less than 0.10 will be interpreted as evidence of heterogeneity), and by examining the $I^2$ statistic (Deeks 2008)). The $I^2$ statistic describes approximately the proportion of variation in point estimates that is due to heterogeneity. We will consider $I^2$ 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 attempt to identify any significant determinants of heterogeneity categorised at moderate or high by examining any clinical heterogeneity in the sample.

### *Assessment of reporting biases*

Funnel plots (plotting of sample size against effect) will be drawn to assess publication and related biases if sufficient studies are found.

### *Data synthesis*

As explicitly referenced in the Cochrane Handbook (Higgins, 2008, section 9.1.3), statistical meta-analysis may be a useful tool in the synthesis of studies, although where studies are clinically diverse, or at risk of bias, can be inappropriate , and obscure genuine effects (Higgins, 2008, section 9.1.4). A decision will be made on examination of the studies retrieved as to the appropriateness of performing statistical meta-analysis, taking these factors into account.

If proceeding with a statistical meta-analysis, 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 the included studies may be estimating similar but different treatment effects (Higgins, 2008, section 9.4.4.3; 9.5.4). Statistical heterogeneity will be assessed as described in the section above, with clinical heterogeneity assessed according to similarities in participants, interventions, outcomes and types of measurement.

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.

### *Subgroup analysis and investigation of heterogeneity*

If sufficient studies are found, we will undertake subgroup analysis to examine the effect on primary outcomes of:

(1) severity of intellectual disability

(2) participants living independently with children or in a supervised care situation

(3) date of diagnosis of intellectual disability: within last 10 years/10-20 years ago/more than 30 years ago. These subgroups are of clinical relevance given that the process of assessing intellectual disability has changed over the last 30 years from a sometimes perfunctory assessment using loose criteria to the use of standardised diagnostic tools (e.g., DSM-IV). Depending on when the patient was last assessed, their diagnosis may be more or less concurrent with current knowledge on intellectual disabilities. Early diagnoses may have been less sensitive to diagnostic nuances so that service users with mild intellectual impairments may have been grouped with others whose impairments were much more severe. As a result of this, studies that include participants with older

diagnoses may potentially be significantly different to studies which include only participants diagnosed more recently.

(4) instructor led or self-taught intervention

(5) individual or group based intervention

(6) length of intervention

(7) delivered at home or at a centre

#### *Sensitivity analysis*

If there is 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:

(1) concealment of allocation

(2) blinding of outcome assessors

(3) extent of dropouts

# Results

## Description of studies

### *Results of the search*

### *Included studies*

### *Excluded studies*

## Risk of bias in included studies

### *Allocation*

### *Blinding*

### *Incomplete outcome data*

### *Selective reporting*

### *Other potential sources of bias*

## Effects of interventions

# Discussion

## Summary of main results

## Overall completeness and applicability of evidence

## Quality of the evidence

## Potential biases in the review process

## Agreements and disagreements with other studies or reviews

# Authors' conclusions

## Implications for practice

## Implications for research

## Acknowledgements

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## Contributions of authors

Conceiving the review: Esther Coren and Carina Gustafsson

Designing the review: Esther Coren

Coordinatining the review: Esther Coren

Writing the protocol: Esther Coren and Jemeela Hutchfield

Providing general advice on the review: Jane Dennis

Securing funding for the review: Esther Coren and Carina Gustafsson

## Declarations of interest

None.

## Differences between protocol and review

## Published notes

## Characteristics of studies

### Characteristics of included studies

*Footnotes*

### Characteristics of excluded studies

*Footnotes*

### Characteristics of studies awaiting classification

*Footnotes*

### Characteristics of ongoing studies

*Footnotes*

## Summary of findings tables

## Additional tables

## References to studies

### Included studies

### Excluded studies

### Studies awaiting classification

### Ongoing studies

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### Other published versions of this review

### Classification pending references

## Data and analyses

## Figures

## Sources of support

### Internal sources

- Canterbury Christ Church University, Not specified

### External sources

- IMS, Not specified

## Feedback

## Appendices