

Proposal for a new Campbell/Cochrane co-registered review within the Developmental, Psychosocial and Learning Problems Group

Useful notes for completing this form appear at the end of this document. Please consult before beginning.

Authors completing this form are also advised to note that whilst preparing their review they are required to read and follow: Higgins JPT, Green S (editors). *Cochrane Handbook for Systematic Reviews of Interventions* Version 5.0.0 [updated February 2008]. The Cochrane Collaboration, 2008. Available in a browsable form from www.cochrane-handbook.org and in book form from Wiley from September 2008.

Campbell Collaboration guidelines for authors may also be viewed at:
<http://www.campbellcollaboration.org/guidelines.asp>

Authors are also advised that if their title registration is accepted, a modified version of this form will be published on the website of the Campbell Collaboration (www.campbellcollaboration.org)

Proposed Title: (Using Standard Format) Parent-training interventions to support intellectually disabled parents.

Contact Author Name: Esther Coren

Motivation for review: Children of parents with intellectual disabilities are at increased risk of neglectful care which may lead to health, developmental and behavioural problems (Feldman, 2002a). Research suggests that the problems experienced by parents with intellectual disabilities that may affect their ability effectively to parent, can be alleviated through a number of interventions including parent training programmes (e.g., Feldman, 1994), self-directed learning (e.g., Feldman & Case, 1999), home based safety interventions (Llewellyn et al, 2003) and developing supportive peer relationships (McGaw, Ball & Clark, 2002). To date, there is no Cochrane review assessing the effectiveness of parent-training interventions for parents with intellectual disabilities. A recent published review (Wade et al, 2008) assesses the effectiveness of parent training interventions for parents with intellectual disabilities but includes a wide range of studies types and would not be suitable for Cochrane or Campbell publication. In addition support for parents with all types of disability including intellectual disability is “patchy and underdeveloped” (DoH, 2000) so any review of the available interventions is likely to help this situation.

Has the review already been carried out or published? As above. A recent review published in 2008 (Wade et al, 2008) assessing the effectiveness of parent training interventions included a range of study types and would not be suitable for Cochrane and Campbell publication

If yes, where has it been published?

Description of proposal

- (a) **Objective of review (briefly stated):** To review training interventions for parents with intellectual disabilities designed to support parenting, parent-child relations, safe parenting or family environments or develop parenting skills.
- (b) **Types of study:** Randomised controlled trials and quasi experimental designs. Studies will be included which compare the interventions of interest with other interventions, or with usual care or with a control group.
- (c) **Participants:** Mothers, fathers or primary caregivers of children aged 0-18, living with their parent or caregiver, where the parent or caregiver has an intellectual disability, where intellectual disability is defined as originating before the age of 18 and being “characterised by significant limitations in both intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills” (American Association of Intellectual and Developmental Disabilities, 2008). Studies using this definition or similar (e.g., DSM-IV; BPS) will be included as well as those with an inclusion criteria of an IQ below 70. 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 such participants are separated from general intellectual disability).
- (d) **Interventions and specific comparisons to be made:** Comparisons will be made where possible with usual care, no treatment or an alternative type of intervention.
- (e) **Outcomes:** Parenting skills
Safe-home practices,
Parent-child interaction
Child development
Child safety

It is likely that standardised scales e.g. the HOME inventory (Caldwell & Bradley, 1984)), are largely unsuitable for use with intellectually impaired people. We anticipate that studies in many cases will develop scales appropriate for an intellectually impaired population, as most standard scales are not validated or appropriate for use in this population. For inclusion in the review we expect that such scales are based on evidence, subjected to some peer-review with the authors reporting content validity and inter-rater reliability as well as describing specifically what the scale is intended to measure. For example, Feldman (2004) developed a checklist to correspond specifically to elements of his training programme.

Scales measuring parenting skills, parenting attitudes and safe home practices (e.g.,

HOME inventory, PAS) or parent child interaction would be included in the review if included in primary studies. Where measured in the primary studies, outcomes for child development e.g., Bayley scales (Bayley, 2006a) and child safety e.g., the Home Accident Prevention Inventory (Tertinger et al., 1984) will also be included in the review.

(f) What subgroup analyses do you intend to undertake? Where there is sufficient data, subgroup analyses will be conducted for particular types of training intervention, ages of children, and possibly severity of intellectual disability.

(g) Other information relevant to this proposal

References included

Bayley, N. (2006a). Bayley Scales of Infant and Toddler Development—Third Edition: Administration manual. San Antonio, TX: Harcourt Assessment.

Caldwell, B.M., and R.H. Bradley. (1984). *Home Observation for Measurement of the Environment*. Little Rock, Ark.: University of Arkansas. Available from <http://www.friendsnrc.org/download/outcomeresources/toolkit/annot/home.pdf>

Department of Health (2000). *Valuing People: A New Strategy for Learning Disability for the 21st Century*. London: The Stationary Office.

Feldman, M.A. (2002a). Children of parents with intellectual disabilities. In R., McMahon & R deV Peters (Eds.), *The Effects of Parental Dysfunction on Children*. (pp. 205–223). New York: Kluwer Academic.

Feldman, M.A. (1994) Parenting education for parents with intellectual disabilities: A review of outcome studies. *Research in Developmental Disabilities, 15*, 299–332.

Feldman, M.A., & Case, L. (1999). Teaching child-care and safety skills to parents with intellectual disabilities via self-learning. *Journal on Intellectual and Developmental Disability, 24*, 27–44.

Feldman, M.A. (2004) Self-directed learning of child-care skills by parents with intellectual disabilities. *Infants and Young Children, 17, 1*, 17–31.

Llewellyn, G., McConnell, D., Honey, A., Mayes, R., & Russo, D. (2003). Promoting health and home safety for children of parents with intellectual disability: A randomized controlled trial. *Research in Developmental Disabilities, 24*, 405–431.

McGaw, S., Ball, K., & Clark, A. (2002). The effect of group interventions on the relationships of parents with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 15*, 354–366.

Tertinger, D. A., Greene, B. F., and Lutzker, J. R. (1984). Home safety: Development and validation of one component of an ecobehavioral treatment program for abused and neglected children. *Journal of Applied Behavior Analysis, 17*, 159–174.

Wade, C., Llewellyn, G., & Matthews, J. (2008). Review of parent training interventions for parents with intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 21*, 351–366.

Review author team and area of expertise

	Name	Area of expertise (please indicate the background and skills of each review author and the expertise they bring to the review team e.g. content, methodology; statistics)
Contact author:	Esther Coren	Experience of Cochrane review

		methodology and some knowledge of subject
Co-author(s) :	Jemeela Hutchfield	Researcher
<p>We are also in the process of contacting individuals with experience in the field of intellectual disability including expertise in relation to parents with intellectual disabilities.</p> <p>Do you or your co-authors have any interests in this topic that could be perceived as conflicts of interest?</p> <p>Campbell/Cochrane Reviews should be free of any real or perceived bias introduced by the receipt of any benefit in cash or kind, any hospitality, or any subsidy derived from any source that may have or be perceived to have an interest in the outcome of the review. It is a matter of Cochrane Collaboration policy that direct funding from a single source with a vested interest in the results of the review is not acceptable. See http://www.cochrane.org/docs/commercialsponsorship.htm</p> <p>Yes <input type="checkbox"/> No <input checked="" type="checkbox"/></p> <p>If 'yes', what are they?</p> <p>Is this review the subject of specific funding and/or does it need to be finished within a specific timeframe? If yes, please give details.</p> <p>The review is funded by IMS Sweden and is subject to a deadline of June 2009 for initial report.</p>		

Roles and responsibilities	
TASK	WHO HAS AGREED TO UNDERTAKE THE TASK?
Draft the protocol	Esther Coren
Develop a search strategy	DPLPG Consult with content experts
Select which trials to include (2 people + 1 arbiter in the event of dispute)	<u>Esther Coren and Jemeela Hutchfield + an other</u>
Extract data from trials (2 people)	<u>Esther Coren and Jemeela Hutchfield</u>
Enter data into RevMan (Cochrane software)	<u>Jemeela Hutchfield and possibly Esther Coren+ an other</u>
Carry out the analysis	<u>Esther Coren and Jemeela Hutchfield</u>
Interpret the analysis	<u>Esther Coren and Jemeela Hutchfield and content experts</u>
Draft the final review	<u>Esther Coren and Jemeela Hutchfield + an other</u>
Keep the review up to date	<u>Jemeela Hutchfield Esther Coren</u>

Other information

Have you or a co-author written a systematic review before?.....	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>
If yes, was it a Campbell or Cochrane Review?.....	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>
Have you attended a Campbell or Cochrane Review training workshop?.....	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>
If yes, which one?.....	
Jemeela Hutchfield needs to attend Not necessary for EC	
If no, do you require assistance in planning to?	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>
What type of computer do you use?.....	Mac <input type="checkbox"/> PC <input checked="" type="checkbox"/>
Do you have a copy of RevMan 5.0, the latest version Cochrane Review Manager software?	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>
Do you have access to a statistician (strongly recommended?)? Not on site.	Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>
Some telephone access	
Do you predominantly speak / write in a language other than English?	Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>
Do you have access to electronic databases relevant to your review topic (eg MEDLINE, PubMed, <i>The Cochrane Library</i> , PsycINFO?) Mostly	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>
Do you have access to a medical / University library:	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>
If yes, can you order journal articles not held in the Library?	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>
Have you experience of searching databases yourself?	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>
Do you have access to reference management software (eg Procite, EndNote, Reference Manager): If yes, which software, and what version? RefWorks	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>

Provisional dates for submission of drafts to editorial base

(A) Draft PROTOCOL November 2008

(B) Draft REVIEW June 2009

Agreement to Editorial Review and Publication in The Cochrane and Campbell Library

By completing this title registration form, **you agree to submit a draft protocol within 6 months.** If there is no correspondence from you during this period, or no draft protocol has been received, the Cochrane Review Group reserves the right to de-register the title or transfer the title to a new author.

Please note that the CDPLPG does not undertake to publish all protocols submitted (however many

iterations are submitted) if they do not meet editorial standards. Please note that the CDPLPG routinely requests that **data extraction sheets** be submitted along with drafts of completed reviews.

By completing and returning this form, you are accepting responsibility for maintaining and updating the review in accordance with Cochrane Collaboration policy, i.e. you will be responsible for ensuring the review is updated at least every two years. If you are unable to update this review the Review Group reserves the right to transfer the review to a new author.

The support of the editorial team in producing your review is conditional upon your agreement to publish the protocol and finished review, together with subsequent updates, in the Cochrane Library and within the Campbell Library. By completing and signing this form you undertake to publish firstly in The Cochrane Library/ the Campbell Library (concurrent publication in other journals may be allowed in certain circumstances with prior permission of the editorial team). Signatures from all authors on permission-to-publish forms will be required when protocols, reviews and updates are published.

I understand the long-term commitment necessary when undertaking a Campbell/Cochrane Review.

Form completed by: Jemeela Hutchfield/Esther Coren..... Date:
13.10.2008

Details of contact author (who may or may not be first author on the review)

Prefix (e.g. Ms, Dr): Ms First name: Esther
Middle names: Family Coren
name:
Email address: esther.coren@canterbury.ac.uk Web address:
Job Title/Position: Departmental Research Coordinator
Department: Social Work, Community and Mental Health
Organisation: Canterbury Christ Church University
Street/Address: North Holmes Road
City: Canterbury
State/Province: Kent
Post/Zip code: CT1 1QU Country: United Kingdom
Telephone number: 01227 782532 Fax number:
Mobile number: 07515 191712

Details of contact author (who may or may not be first author on the review)

Prefix (e.g. Ms, Dr): Miss First name: Jemeela
Middle names: Family Hutchfield
name:
Email address: jemeela.hutchfield@canterbury.ac.uk Web address:
Job Title/Position: Research Assistant

Department: Social Work, Community and Mental Health
Organisation: Canterbury Christ Church University
Street/Address: North Holmes Road
City: Canterbury
State/Province: Kent
Post/Zip code: CT1 1QU Country: United Kingdom
Telephone number: 01227 767700 ext 3884 Fax number:
Mobile number: 07515 191711

Details of contact author (who may or may not be first author on the review)

Prefix (e.g. Ms, Dr): First name: Manuela
Middle names: Family name: Thomae
Email address: mt96@kent.ac.uk Web
address:

Details of contact author (who may or may not be first author on the review)

Prefix (e.g. Ms, Dr): First name: Carina
Middle names: Family name: Gustafsson
name:
Email address: Carina.gustafsson@socialstyrelsen.se Web
address:

Title approved 28 Oct 2008