# CH 1: Caregiver skills training for the management of developmental disorders. [Updated 2015]

## SCOPING QUESTION: What is the effectiveness of caregiver skills training in the management of children and adolescents with developmental disorders?

### *BACKGROUND*

Developmental disorders, including intellectual disabilities and autism spectrum disorders, affect individuals worldwide and account for more than 0.4% of all disability-adjusted life years (Murray et al., 2012). Although effective comprehensive treatment programs have been identified (Grey and Hastings, 2005; Barton et al., 2014), the provision of these interventions often requires significant resource output (Chasson et al., 2007; Ganz, 2007). The scale-up of such resource-intensive programmes is challenging, especially in low-resource settings (including lower- and middle-income countries), which is where the majority of people with developmental disorders reside. The treatment gap in these areas has been estimated to be as high as 85% (Demyttenaere et al., 2004). Therefore, finding feasible and effective treatments to help people with developmental disorders and their families is a high priority.

The role of caregivers (such as parents and other family members or guardians who are raising a child or adolescent) is critical in ensuring optimal child developmental outcomes and positive parenting is related to fewer behavioural problems during childhood and adolescence, as well as improved emotional and social competence (Irwin et al., 2007). The empowerment of caregivers is increasingly being recognized as a critical component of care interventions for children with developmental disorders. Caring for a child with developmental disorders can be challenging and these caregivers more frequently report experiencing feelings of inadequacy and poor self-confidence. Therefore, caregiver skills training becomes particularly useful in this context.

Moreover, several systematic reviews of the literature suggest that caregivers are able to learn the necessary skills to deliver psychosocial therapies to their children with intellectual disability and autism spectrum disorders and that children benefit from these interventions (Oono et al., 2013; Matson et al., 2009; McConachie and Dingle, 2007). Evidence supports the notion that training for caregivers of children with intellectual disability and autism spectrum disorders can be effectively delivered by non-specialists in community settings. Even low intensity programmes lead to improved child developmental and behavioural outcomes as well as improved family wellbeing (Reichow et al., 2013). In the 2009 mhGAP intervention guide, WHO previously recommended that caregiver skills training be considered in the management of children with intellectual disabilities and pervasive developmental disorders. The current scoping question aims to evaluate the role of caregiver skills training in light of Riechow et al.'s (2014) commission review of the available.

[Updated 2015]

## *PART 1: EVIDENCE REVIEW*

### Population/ Intervention / Comparison / Outcome (PICO)

- **Population:** Children and adolescents with intellectual disabilities, children and adolescents with pervasive developmental disorders

- **Intervention:** Caregiver skills training
- **Comparison:** No treatment, waitlist control or standard care
- **Outcomes:**
  - **Critical –** Child functioning, family functioning, reduction in problem behaviour
  - **Important –** User and family satisfaction

### Search strategy

Given that no suitable systematic reviews were retrieved, a systematic review and meta-analysis was commissioned using the same strategy used by Reichow et al. (2014). Relevant studies were identified through a search of the following databases, in addition to the use of a snowballing method: African Index Medicus, AFRO Library, the Cochrane Central Register of Controlled Trials, Cumulative Index to Nursing and Allied Health, Dissertation Abstracts International, EMBASE, Education Resources Information Center, Western Pacific Region Index Medicus, Literatura Latinoamericana y del Caribe en Ciencias de la Salud, MEDLINE and PsycINFO. Filters (such as language, publication in peer-reviewed sources or randomisation) were not used in order to avoid missing any relevant studies.

Study selection:

*Types of studies*

- Randomised control trial (RCT) designs.
- The authors included only those studies with at least 10 participants per pairwise comparison in order to ensure the consistency of the inclusion criteria.

*Types of participants*

- Caregivers who have a child (irrespective of the child's age) with the following developmental disabilities:
  - Disorders of intellectual development (intellectual disability, mental retardation);
  - Developmental delay;
  - Down syndrome;

    - Autism spectrum disorders; and
    - Additional developmental disorders or groups of mixed disabilities in cases where the average IQ for the child participants is lower than two standard deviations (SDs) below the mean (i.e., IQ <70).

*Types of interventions*

- All published and unpublished studies (irrespective of language) comparing a group of caregivers receiving a caregiver skills training programme to a group of caregivers in a no-treatment control group, including waitlist control or a treatment as usual comparison group.

*Types of settings*

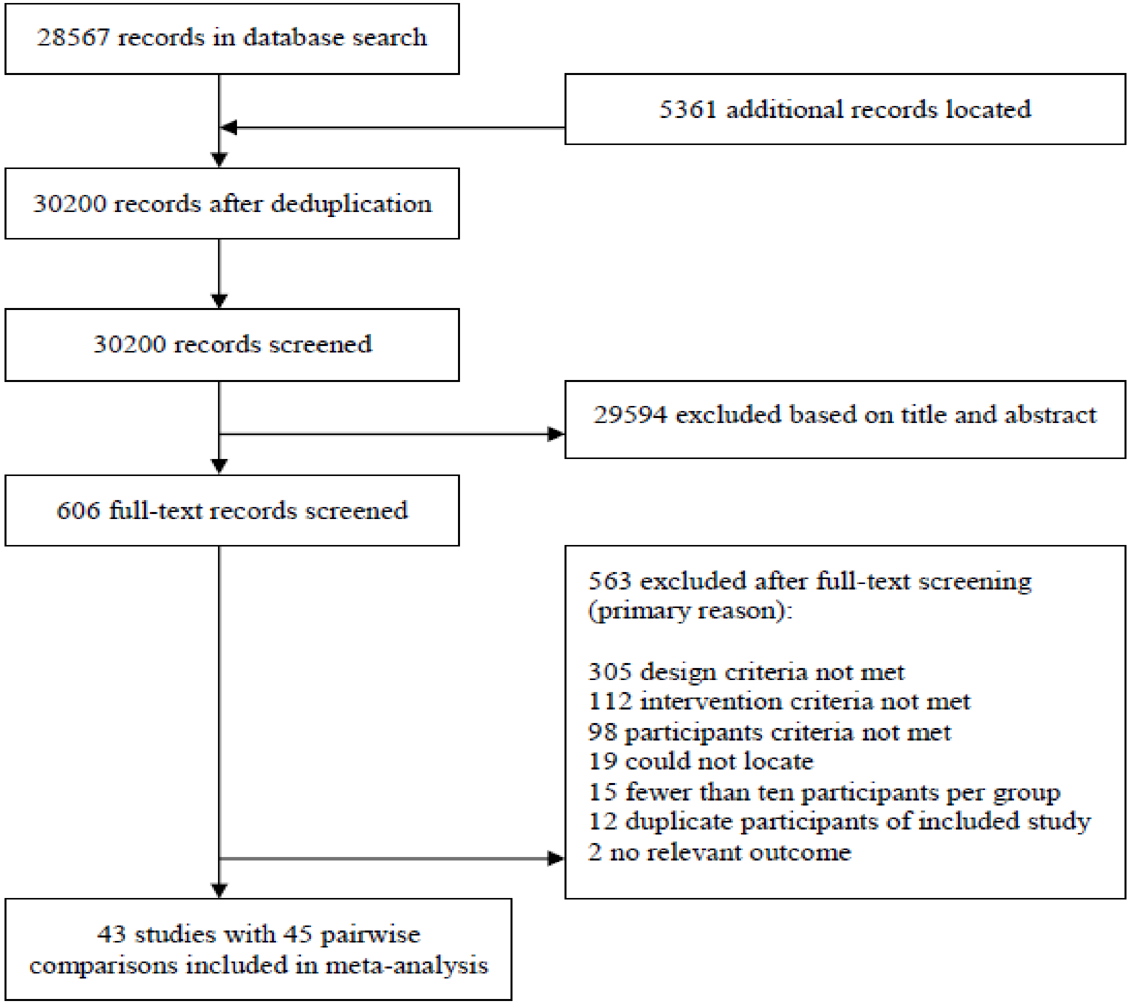
- Studies in which the caregiver skills training programmes were delivered in community clinics, homes, university clinics and schools.
- No study was excluded based on the delivery location of the programme.

*Types of outcome measures*

- Effects of caregiver skills training programmes on child outcomes and caregiver outcomes, specifically:
    - Primary child outcome – Adaptive behaviour (e.g., functional skills, daily skills)
    - Secondary child outcomes – Child development and problem behaviour
    - Primary caregivers outcome – Quality of life
    - Secondary caregivers outcomes – Psychological health, parent skills and family quality
    - Family functioning
    - Consumer satisfaction and attrition

A flow diagram detailing the study selection process and results is represented in Figure 1 below.

**Figure 1. Study selection process and results for the commissioned review**



## Included in GRADE tables or footnotes

Reichow B, Kogan C, Barbui C, Maggin D, Smith IM, Yasamy M and Servili C. Caregiver skills training for caregivers of children with developmental disorders. Commissioned review: 2014.

## Excluded from GRADE tables and footnotes

Reichow B, Servili C, Taghi Yasamy M, Barbui C, Saxena S (2013). Non-specialist psychosocial interventions for children and adolescents with intellectual disability or lower functioning autism spectrum disorders: A systematic review. PLoS Medicine.10(12):e1001572. doi:10.1371/journal.pmed.1001572.
*REASON FOR EXCLUSION:* This paper investigated interventions delivered to children and the intervention of interest (not caregiver skills training interventions).

Oono IP, Honey EJ, McConachie H (2013). Parent-mediated early intervention for young children with autism spectrum disorders. Cochrane Database of Systematic Reviews.4:CD009774. doi:0.1002/14651858.CD009774.pub2.
*REASON FOR EXCLUSION:* This review included children aged 1 year to 6 years and 11 months old (i.e., restricted age range) with Autism spectrum disorder only.

## PICO Table

**Population:** Children and adolescents with intellectual disabilities and pervasive developmental disorders

| **Intervention** | **Comparison** | **Outcome** | **Systematic reviews used for GRADE** | **Justification for systematic review used** |
|---|---|---|---|---|
| Caregiver skills training | Treatment as usual or no treatment control | Child functioning (i.e., adaptive behaviour, child development) | Reichow et al.'s (2014) commissioned review. | The Reichow et al. (2014) review was commissioned for mhGAP IG revision and includes a published protocol detailing rigorous methods. |
| | | Family functioning (i.e., interpersonal family relations, caregiver psychological health, caregiver skills) | | |
| | | Reduction in problem behaviour | | |
| | | User and family satisfaction | | |

[Updated 2015]

## Narrative description of the studies that went into the analysis

The Reichow B et al. (2014) commissioned review included RCTs comparing caregiver skills training programs to no-treatment control, waitlist control or standard care.[i] Primary and secondary outcomes included adaptive behaviour, child development, problem behaviour, caregiver's psychological health, caregiving skills and interpersonal family relations. The review included 45 treatment cohorts from 43 studies. Nearly two-thirds of the studies were conducted in North America (k=15, 35%), Europe (k=9, 21%) and Australia (k=8, 19%), with 13 (30%) studies conducted in low- and middle-income countries (LAMIC). The study samples contained children and adolescents (mean age = 6.6 years; SD = 6.2) and had moderate levels of intellectual impairment (mean IQ = 58.8; SD = 8.1) with the caregivers having a mean age of 37.7 years (SD = 8.2). On average, the caregivers had very high levels of education, with a mean years of education of 12.8 years (SD = 2.7), which is equivalent to one year of post-secondary education in the United States of America (USA). Among the children sampled in the studies of this review, 80% of families were married or living in two-parent households. Across all studies, the average caregiver skills training program had 12.3 sessions (SD = 10.0) with an average density of 1.1 sessions per week (SD = 0.7). There were 18 programmes (40%) that used individual session formats exclusively, with on average 1.0 sessions per week (SD = 0.7) and an average session duration of 68.4 minutes (SD = 39.4). The mean number of sessions was 13.8 (SD = 10.7) over a span of 22.4 weeks (SD = 17.8) for a total of 14.4 hours of time spent in caregiver skills training sessions (SD = 12.5). There were 16 programmes (36%) that used group session formats exclusively, with on average 1.3 sessions per week (SD = 0.9) and an average session duration of 124 minutes (SD = 57.7). The mean number of sessions was 8.1 (SD = 5.1) over a span of 7.9 weeks (SD = 4.2) for a total of 14.3 hours of time spent in caregiver skills training sessions (SD = 9.1). There were 10 programmes (22%) that used a combination of individual and group session formats, with on average 1.0 sessions per week (SD = 0.4) with average session duration of 138.8 minutes (SD = 54.0). The mean number of sessions was 12.7 over a span of 18.4 weeks (SD = 14.7) for a total of 23.1 hours of time spent in caregiver skills training sessions (SD = 5.6). Effect size estimates were pooled using a random-effects meta-analysis.

[Updated 2015]

# GRADE Tables

## Table 1. Caregiver skills training vs. control group for treatment of developmental disorders in children and adolescents

**Authors:** Reichow B and Servili C

**Question: Is caregiver skills training effective for the management of children and adolescents with developmental disorders compared to controls (i.e., no treatment, waitlist control or standard care)?**

**Bibliography:** Reichow B, Kogan C, Barbui C, Maggin D, Smith IM, Yasamy M and Servili C. Caregiver skills training for caregivers of children with developmental disorders. Commissioned review: 2014.

| Quality assessment | | | | | | | No. of patients | | Effect | | Quality | Importance |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **No. of studies** | **Design** | **Risk of bias** | **Inconsistency** | **Indirectness** | **Imprecision** | **Other considerations** | **Caregiver skills training** | **Control** | **Relative (95% CI)** | **Absolute** | | |
| **Child functioning – Xhild development (measured with standardized assessments and standardized parent reports; better indicated by higher values)** | | | | | | | | | | | | |
| 18 | Randomized trials | Serious[1] | Serious[2] | No serious indirectness | No serious imprecision | None | 491 | 443 | - | SMD 0.36 higher (0.05 to 0.66 higher)[3] | ⊕⊕OO LOW | IMPORTANT |
| **Family Functioning – Psychological health (measured with self-report; better indicated by higher values)** | | | | | | | | | | | | |
| 28 | Randomized trials | Very serious[1] | No serious inconsistency | No serious indirectness | No serious imprecision | Reporting bias[4] | 756 | 682 | - | SMD 0.49 higher (0.29 to 0.68 higher)[3] | ⊕OOO VERY LOW | IMPORTANT |
| **Family functioning – Interpersonal relations (measured with standardized self-report measures; better indicated by higher values)** | | | | | | | | | | | | |
| 14 | Randomized trials | Very serious[1] | Very serious[5] | No serious indirectness | No serious imprecision | Reporting bias[4] | 456 | 385 | - | SMD 0.65 higher (0.19 to 1.10 higher)[3] | ⊕OOO VERY LOW | IMPORTANT |
| **Family functioning – Caregiver skills (measured with standardized and unstandardized self-report measures and behavioural observations; better indicated by higher values)** | | | | | | | | | | | | |
| 23 | Randomized trials | Very serious[1] | No serious inconsistency | No serious indirectness | No serious imprecision | None | 612 | 574 | - | SMD 0.82 higher (0.62 to 1.02 higher)[3] | ⊕⊕OO LOW | IMPORTANT |
| **Reduction in problem behaviour (measured with standardized parent report measures; better indicated by higher values)** | | | | | | | | | | | | |
| 15 | Randomized trials | Serious[1] | No serious inconsistency | No serious indirectness | No serious imprecision | None | 407 | 338 | - | SMD 0.39 higher (0.17 to 0.60 higher)[3] | ⊕⊕⊕O MODERATE | IMPORTANT |
| **User and family satisfaction (assessed with satisfaction checklist [post-treatment and treatment groups only])** | | | | | | | | | | | | |
| 16 | No methodology chosen[6] | | | | | None | - | -<br>0% | - | -<br>- | | IMPORTANT |

[1] Lack of blinding of outcome assessors.

[2] Visual examination of the forest plot in Figure 2 shows considerable heterogeneity, $I^2$= 67%.

[3] 99% CI.

[4] Possible publication bias, which suggests that the effect size might be larger than pooled estimate.

[5] Visual examination of the forest plot in Figure 6 considerable heterogeneity, $I^2$= 83%.

[6] Assessed in randomized control trials, but no comparison group (i.e., only participants in treatment group provided data on satisfaction). Majority of participants in all studies reported treatment being acceptable and satisfactory.

## Results of a new meta-analysis

### Figure 2. Outcome 1: Child developmental outcomes

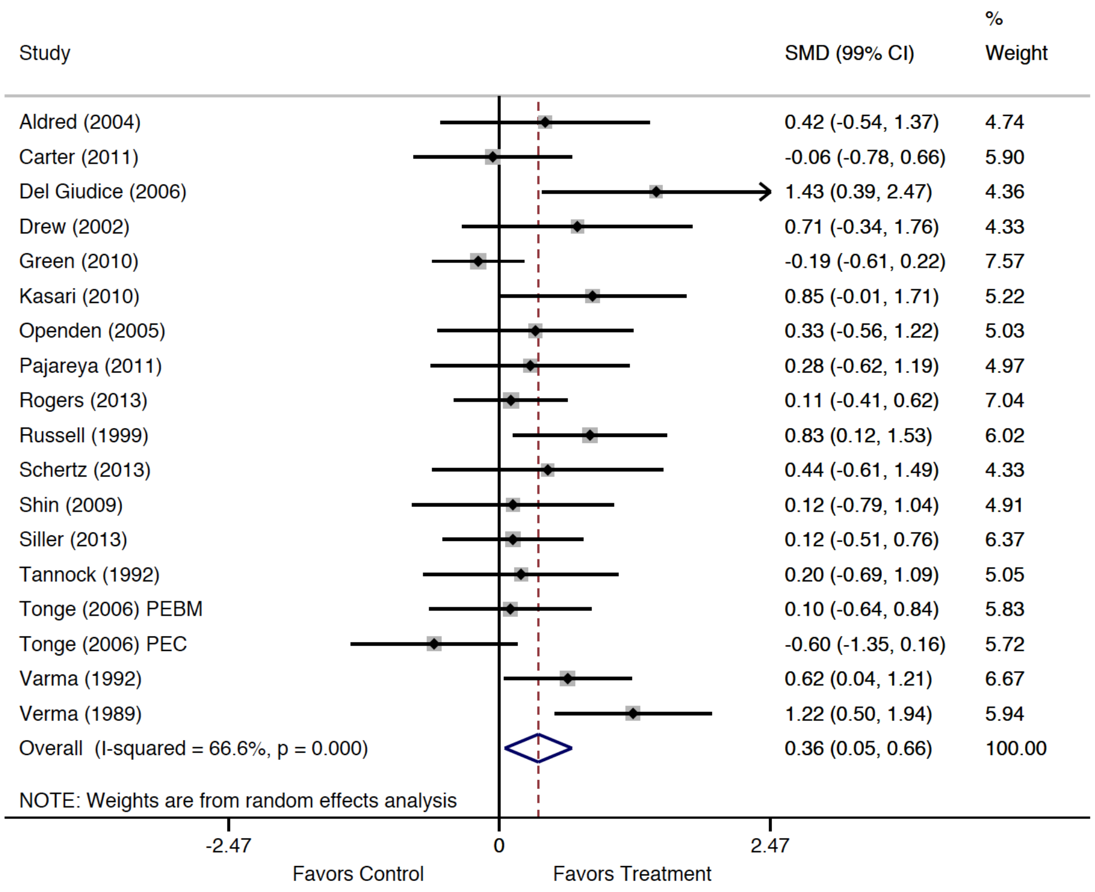
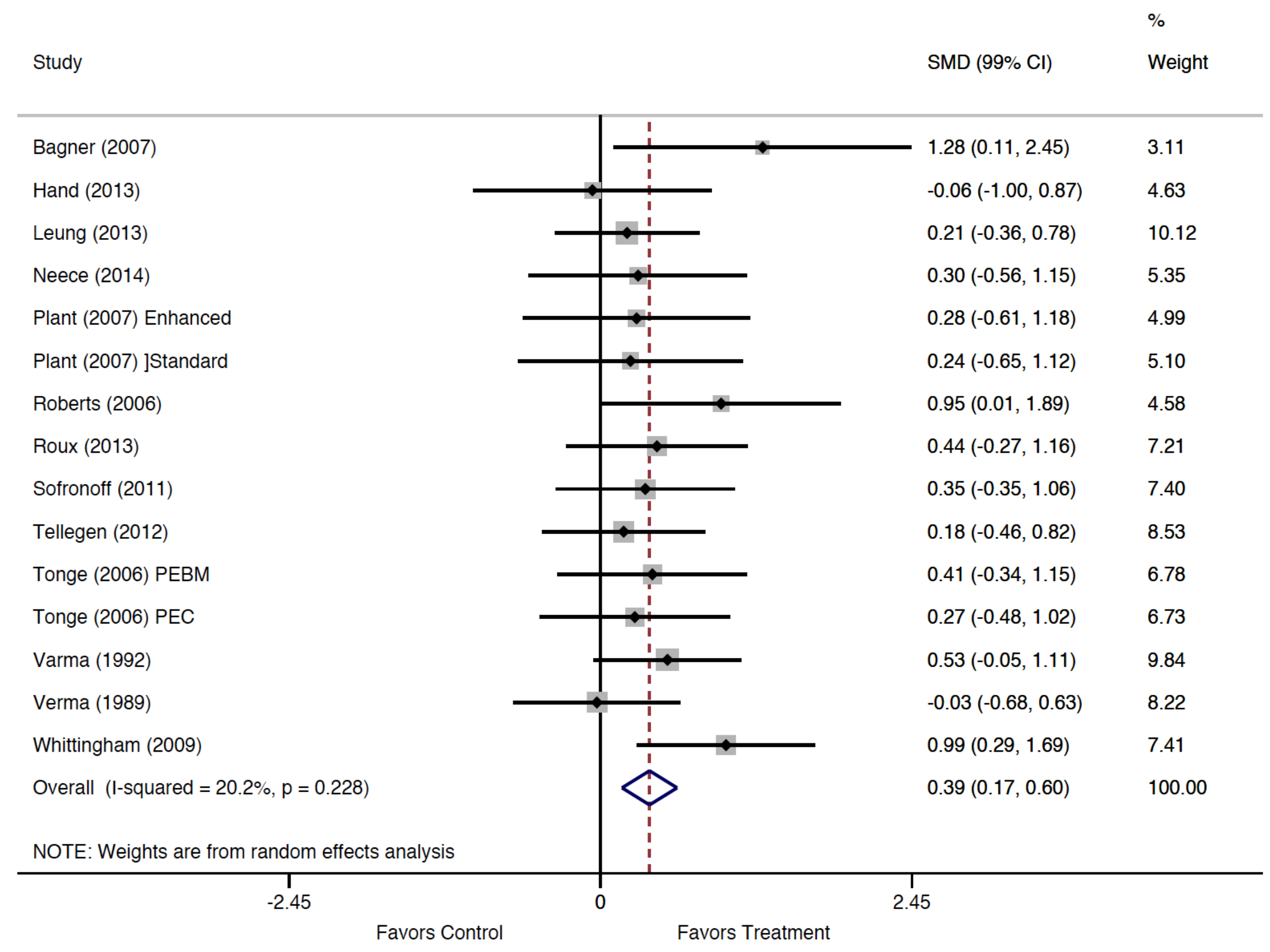
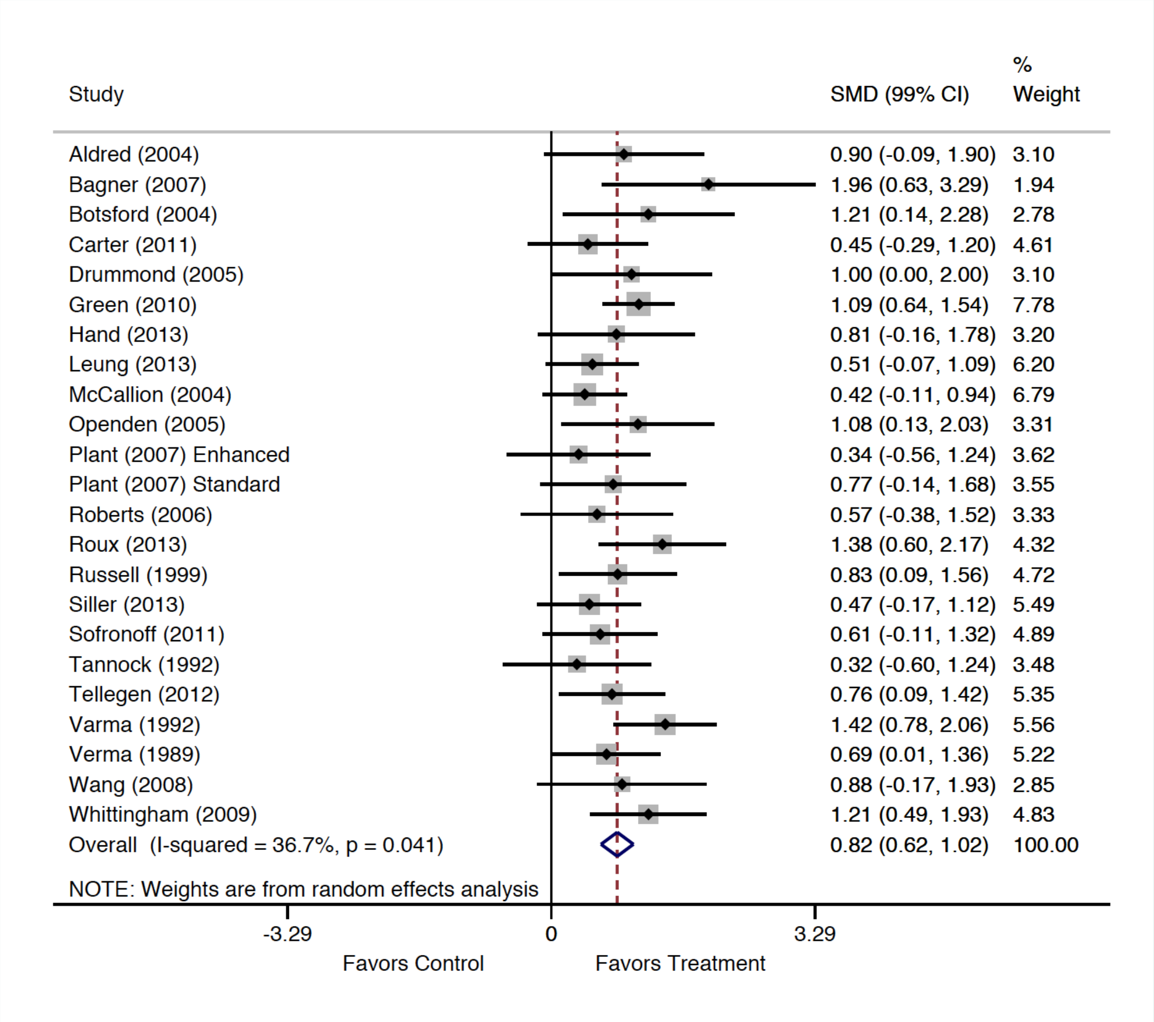


**Figure 3. Outcome 2: Problem behaviour**



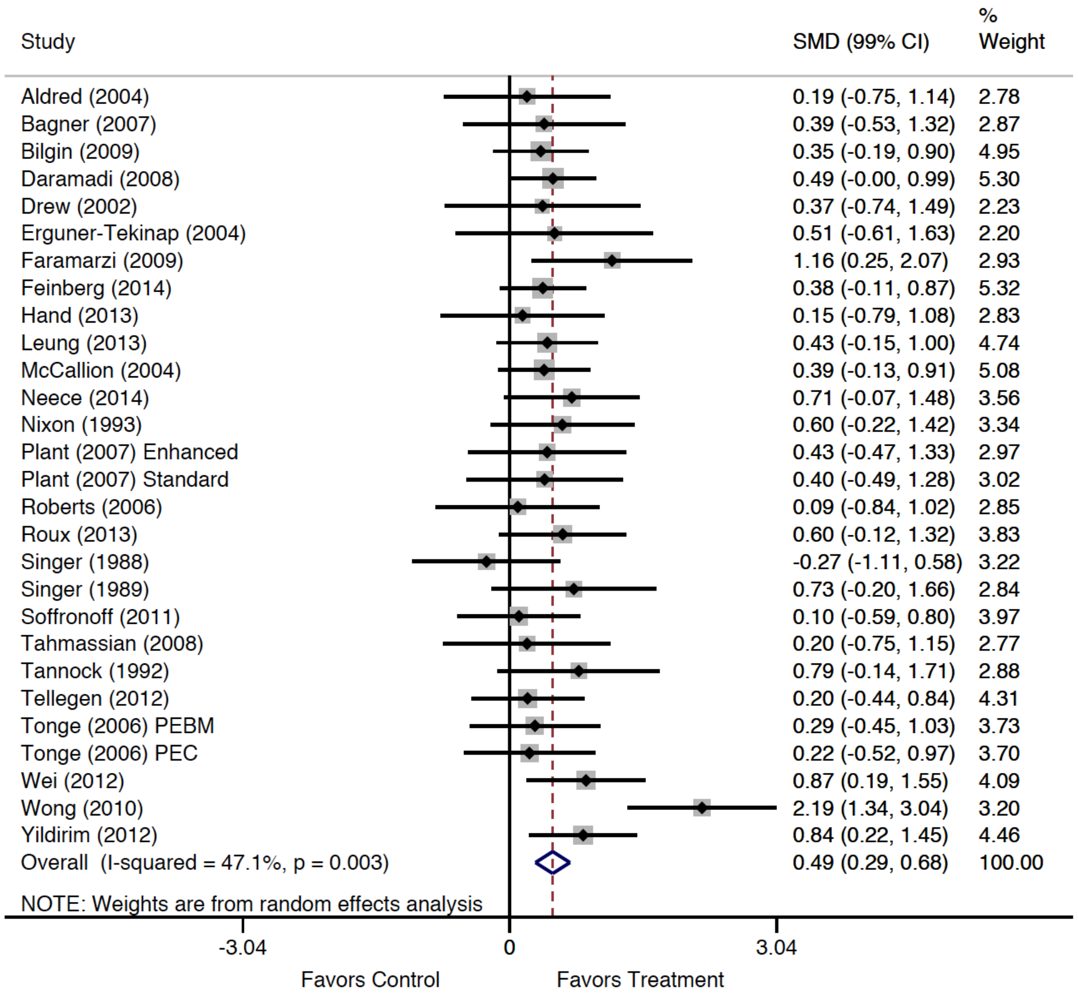
## Figure 4. Outcome 3: Family functioning - Caregiver skills



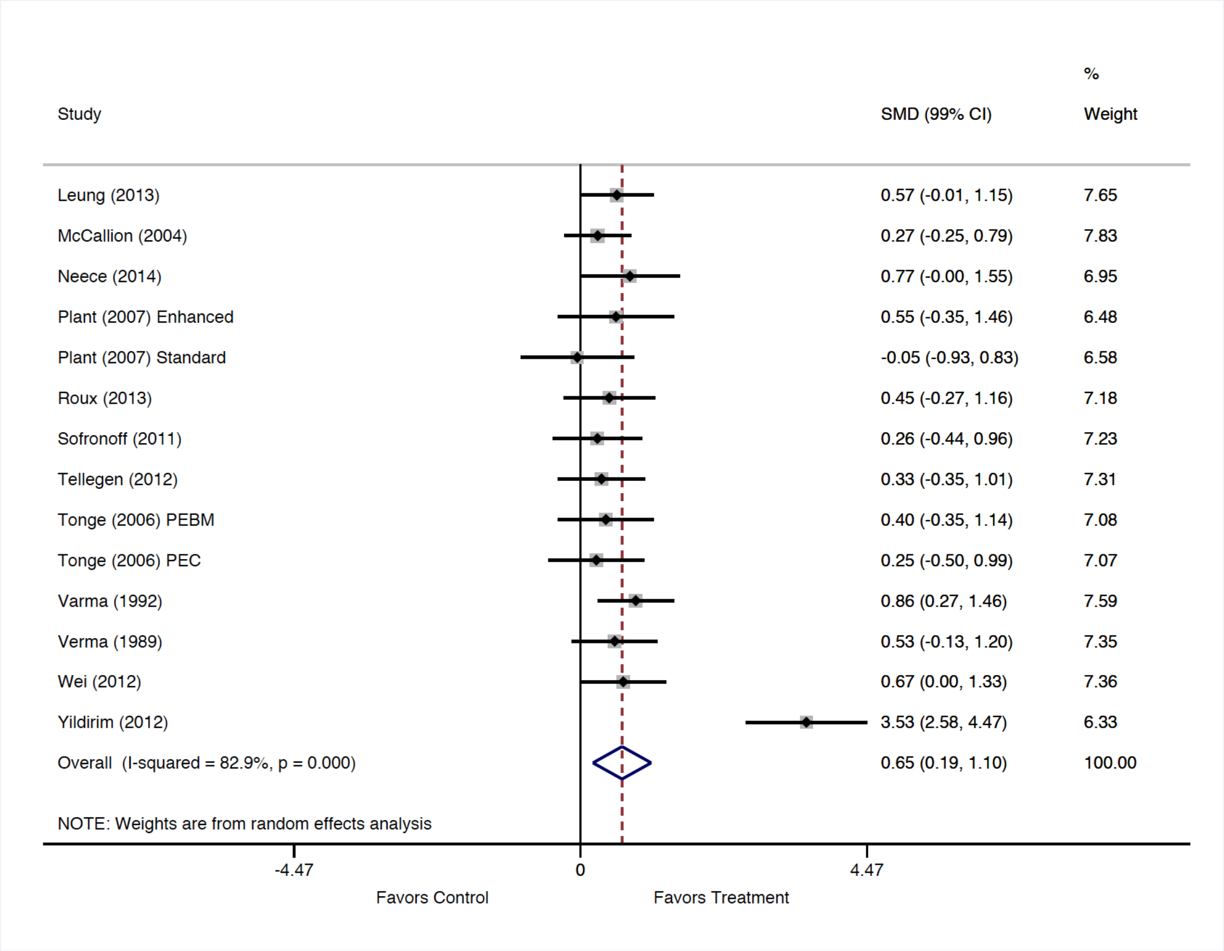
| Study | SMD (99% CI) | % Weight |
|---|---|---|
| Aldred (2004) | 0.90 (-0.09, 1.90) | 3.10 |
| Bagner (2007) | 1.96 (0.63, 3.29) | 1.94 |
| Botsford (2004) | 1.21 (0.14, 2.28) | 2.78 |
| Carter (2011) | 0.45 (-0.29, 1.20) | 4.61 |
| Drummond (2005) | 1.00 (0.00, 2.00) | 3.10 |
| Green (2010) | 1.09 (0.64, 1.54) | 7.78 |
| Hand (2013) | 0.81 (-0.16, 1.78) | 3.20 |
| Leung (2013) | 0.51 (-0.07, 1.09) | 6.20 |
| McCallion (2004) | 0.42 (-0.11, 0.94) | 6.79 |
| Openden (2005) | 1.08 (0.13, 2.03) | 3.31 |
| Plant (2007) Enhanced | 0.34 (-0.56, 1.24) | 3.62 |
| Plant (2007) Standard | 0.77 (-0.14, 1.68) | 3.55 |
| Roberts (2006) | 0.57 (-0.38, 1.52) | 3.33 |
| Roux (2013) | 1.38 (0.60, 2.17) | 4.32 |
| Russell (1999) | 0.83 (0.09, 1.56) | 4.72 |
| Siller (2013) | 0.47 (-0.17, 1.12) | 5.49 |
| Sofronoff (2011) | 0.61 (-0.11, 1.32) | 4.89 |
| Tannock (1992) | 0.32 (-0.60, 1.24) | 3.48 |
| Tellegen (2012) | 0.76 (0.09, 1.42) | 5.35 |
| Varma (1992) | 1.42 (0.78, 2.06) | 5.56 |
| Verma (1989) | 0.69 (0.01, 1.36) | 5.22 |
| Wang (2008) | 0.88 (-0.17, 1.93) | 2.85 |
| Whittingham (2009) | 1.21 (0.49, 1.93) | 4.83 |
| Overall (I-squared = 36.7%, p = 0.041) | 0.82 (0.62, 1.02) | 100.00 |

NOTE: Weights are from random effects analysis

**Figure 5. Outcome 4: Caregiver psychological health**



## Figure 6. Outcome 5: Family functioning - Interpersonal relations



## *PART 2: FROM EVIDENCE TO RECOMMENDATIONS*

### Summary of evidence table

| **Outcome** | **Caregiver Skills Training**<br>*(Number of studies, Hedge's g [95% CI], quality)* |
|---|---|
| Child functioning | 18 studies,<br>Hedge's g 0.36 (99% CI 0.05 to 0.66)<br>Favours caregiver skills training,<br>LOW quality |
| Family functioning (caregiver psychological health) | 28 studies,<br>Hedge's g 0.49 (99% CI 0.29 to 0.68),<br>Favours caregiver skills training,<br>VERY LOW quality |
| Family functioning (interpersonal relations) | 14 studies,<br>Hedge's g 0.65 (99% CI 0.19 to 1.10),<br>Favours caregiver skills training,<br>VERY LOW quality |
| Family functioning (caregiver skills) | 23 studies,<br>Hedge's g 0.82 (99% CI 0.62 to 1.02)<br>Favours caregiver skills training,<br>LOW quality |
| Reduction in problem behaviour | 16 studies,<br>Hedge's g 0.39 (99% CI 0.17 to 0.60)<br>Favours caregiver skills training,<br>MODERATE quality |

### Evidence to recommendation table

| | |
|---|---|
| **Benefits** | For children and adolescents with intellectual disabilities and pervasive developmental disorders whose caregivers receive caregiver skills training, there is low quality evidence demonstrating better outcomes in child development and moderate quality evidence showing reductions in problem behaviours.<br><br>For caregivers of a child with an intellectual disability or pervasive developmental disorder who participate in caregiver skills training programmes, there is low quality evidence of improvements in |

| | |
|---|---|
| | caregiving skills, attitudes and knowledge. There is very low quality evidence of improved psychological health and family functioning. |
| **Harms** | There is no evidence of adverse effects or harms of caregiver-mediated interventions for children and adolescents with intellectual disabilities or pervasive developmental disorders. |
| **Summary of the quality of evidence** | The evidence is of low quality. |

| **Value and preferences** | |
|---|---|
| **In favour** | Children and adolescents with intellectual disabilities or pervasive developmental disorders have the right to a supportive and understanding family environment. Training and education of caregivers and other family members could ensure that children with intellectual disabilities or pervasive developmental disorders are given the dignity and opportunities that they are entitled to.<br>Caregivers and family members also require support from health services because they may experience psychological distress and other problems associated with caring for a child with intellectual disabilities or pervasive developmental disorders. |
| **Against** | There is potential stigma for being identified as the caregiver of a child with an intellectual disability or a pervasive developmental disorder. |
| **Uncertainty or variability?** | It is generally  agreed that it is important for caregivers to acquire skills to better enable and support the development, functioning and participation of children with developmental disorders. |

| | |
|---|---|
| **Feasibility (including resource use considerations)** | Evidence supports the notion that training for caregivers of children and adolescents with intellectual disabilities and pervasive developmental disorders can be effectively delivered by non-specialists in community settings. Even low-intensity programmes lead to improved child developmental and behavioural outcomes, as well as improved family wellbeing |

| | |
|---|---|
| | The feasibility of implementing the intervention should take into consideration the additional workload imposed on primary care providers, community volunteers or other non-specialist providers (including peer caregivers). |
| **Uncertainty or variability**? | There is variability in the feasibility of implementing caregiver skills training interventions for caregivers of children and adolescents with intellectual disabilities and pervasive developmental disorders, depending on the availability of human resources. |

## Recommendation and remarks

### Recommendation

Caregiver skills training should be provided for management of children and adolescents with developmental disorders, including intellectual disabilities and pervasive developmental disorders (including autism).

**Rationale**: A strong recommendation was made even with low quality evidence based on the benefits outweighing harms and the values and preferences indicating that children and adolescents with intellectual disabilities or pervasive developmental disorders have the right to a supportive and understanding family environment. Low-quality evidence suggests that caregiver skills training is associated with better outcomes in child development and reductions in problem behaviours. It is generally agreed that it is important for caregivers to acquire skills to better enable and support the development, functioning and participation of children with developmental disorders. In terms of feasibility, evidence supports the notion that training for caregivers of children and adolescents with intellectual disabilities and pervasive developmental disorders can be effectively delivered by non-specialists in community settings.

### Remarks

Caregiver skills training should use culturally appropriate training material relevant for those disorders to improve development, functioning, and participation of the children and adolescents within families and communities.

Health-care providers need additional training to be able to offer caregiver skills training.

Training and education of caregivers and other family members could ensure that children with intellectual disabilities or pervasive developmental disorders are given the dignity and opportunities that they are entitled to.

## Judgements about the strength of a recommendation

| Factor | Decision |
|---|---|
| Quality of the evidence | ☐ High<br>☐ Moderate<br>**X Low**<br>☐ Very low |
| Balance of benefits versus harms | **X Benefits clearly outweigh harms**<br>☐ Benefits and harms are balanced<br>☐ Potential harms clearly outweigh potential benefits |
| Values and preferences | **X No major variability**<br>☐ Major variability |
| Resource use | **X Less resource-intensive**<br>☐ More resource-intensive |
| Others (Acceptability/Feasibility/Equity/Accessibility) | All in favour |
| **Strength** | **STRONG** |

## *OTHER REFERENCES*

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Oono IP, Honey EJ, McConachie H (2013). Parent-mediated early intervention for young children with autism spectrum disorders. Cochrane Database of Systematic Reviews.4:CD009774. doi:10.1002/14651858.CD009774.pub2.

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Reichow B, Servili C, Yasamy MT, Barbui C, Saxena S (2013). Non-specialist psychosocial interventions for children and adolescents with intellectual disability or lower functioning autism spectrum disorders: A systematic review. PLoS Medicine.10(12):e1001572.
doi:10.1371/journal/pmed.1001572.

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## *APPENDIX 1*

### Search terms used for commissioned review

Sample Search Strategy for Cumulative Index for Nursing and Allied Health (CINAHL)
1. (MH “child development disorders, pervasive+”)
2. (MH “Mental Retardation+”)
3. TX rett*
4. TX autis*
5. TX Asperger*
6. TX pervasive development* disorder*
7. TX PDD OR PDDs
8. TX developmental delay*
9. TX developmental disorder*
10. TX developmental disability
11. TX developmental disabilities
12. TX developmental difference*
13. TX down* syndrome
14. TX fragile X
15. TX mental retard*
16. TX intellectual disorder*
17. TX intellectual disability
18. TX intellectual disabilities
19. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18
20. (MH “Family+”)21. (MH “Parents+”)
22. TX parent* or family or families or mother* or father* or maternal* or paternal*

23. TX at home or home based or home-based
24. (MH “Caregivers”)
25. TX carer* or care-giver* or caregiver*
26. 20 or 21 or 22 or 23 or 24 or 25
27. 19 and 26
28. (MH “Treatment Outcomes+”)
29. TX educat* or train* or program* or therap* or intervention* or treatment*
30. 28 or 29
31. 27 and 30
32. (MH “Qualitative Studies+”)
33. 31 not 32
34. (MH “Research+”)
35. 33 and 34
36. 35 (Limiters – Exclude MEDLINE records)

Search strategy for Cochrane Central Register of Controlled Trials (CENTRAL)
1. autis*
2. pervasive development* disorder*
3. PDD
4. intellectual disability
5. intellectual disabilities
6. intellectual disorder* 7. mental retardation
8. developmental disability
9. developmental disabilities
10. developmental disorder*
11. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10

Sample Search Strategy for MEDLINE
1. exp child development disorders, pervasive/
2. exp Intellectual Disability/
3. developmental disabilities/
4. rett*.tw.
5. autis*.tw.
6. asperger*.tw
7. (pervasive development* disorder* or PDD or PDDs).tw.
8. (developmental adj delay*).tw.
9. (developmental adj disorder*).tw.

10. (developmental adj disability).tw.
11. (developmental adj disabilities).tw.
12. (developmental adj differen*).tw.
13. ((down* adj syndrome) or (fragile adj X)).tw.
14. (mental adj retard*).tw.
15. (intellectual adj disorder*).tw.
16. (intellectual adj disability).tw.
17. (intellectual adj disabilities).tw.18. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17
19. Family/
20. exp Parents/
21. (parent* or family or families or mother* or father* or maternal* or paternal*).tw.
22. (at home or (in adj3 home) or home based or home-based).tw.
23. Caregivers/
24. (carer* or care-giver* or caregiver*).tw.
25. 19 or 20 or 21 or 22 or 23 or 24
26. 18 and 25
27. exp treatment outcome/
28. (educat* or train* or program* or therap* or intervention* or treatment*).tw.
29. 27 or 28
30. 26 and 29
31. qualitative.mp.
32. 30 not 31
33. exp Epidemiologic Methods/
34. 32 and 33

Search Strategy for PsycINFO and Education Resource Information Center
1. developmental disabilities/
2. rett*.tw.
3. autis*.tw.
4. asperger*.tw
5. (pervasive development* disorder* or PDD or PDDs).tw.6. (developmental adj delay*).tw.
7. (developmental adj disorder*).tw.
8. (developmental adj disability).tw.
9. (developmental adj disabilities).tw.
10. (developmental adj differen*).tw.
11. ((down* adj syndrome) or (fragile adj X)).tw.
12. (mental adj retard*).tw.

13. (intellectual adj disorder*).tw.
14. (intellectual adj disability).tw.
15. (intellectual adj disabilities).tw.
16. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15
17. Family/
18. exp Parents/
19. (parent* or family or families or mother* or father* or maternal* or paternal*).tw.
20. (at home or (in adj3 home) or home based or home-based).tw.
21. Caregivers/
22. (carer* or care-giver* or caregiver*).tw.
23. 17 or 18 or 19 or 20 or 21 or 22
24. 16 and 23
25. exp treatment outcome/
26. (educat* or train* or program* or therap* or intervention* or treatment*).tw.
27. 25 or 26
28. 24 and 2729. qualitative.mp.
30. 28 not 29
31. limit 30 to (“1800 quantitative study”)

Sample search strategy for African Index Medicus (AIM) and Afro Library (AFROLIB)
1. autism
2. autistic
3. autism spectrum disorder
4. ASD
5. Asperger’s
6. pervasive developmental disorder
7. PDD
8. intellectual disability
9. developmental disability
10. developmental disorder
11. mental retardation
12. autistique
13. troubles du spectre autistique
14. troubles envahissants du developpement
15. deficience intellectuelle
16. troubles du developpement
17. retard mental

18. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17

Search strategy for Literatura Latino Americana em Ciências da Saúde (LILACS):1. autism
2. autistic
3. autism spectrum disorder
4. ASD
5. Asperger's
6. pervasive developmental disorder
7. PDD
8. intellectual disability
9. developmental disability
10. developmental disorder
11. mental retardation
12. autismo
13. autista
14. trastorno del desarrollo
15. discapacidad intelectual
16. discapacidad del desarrollo
17. retraso mental

Index Medicus for the Western Pacific (WPRIM)
1. autism
2. autistic
3. autism spectrum disorder
4. ASD
5. Asperger's6. pervasive developmental disorder
7. PDD
8. intellectual disability
9. developmental disability
10. developmental disorder
11. mental retardation
12. autistique
13. troubles du spectre autistique
14. troubles envahissants du developpement
15. deficience intellectuelle
16. troubles du developpement
17. retard mental

18. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17
19. education OR educate OR l'éducation OR éduquer
20. train OR training OR former OR formation
21. program OR d’un programme
22. therapy OR traitement OR therapie cognative
23. treatment OR traitement
24. intervention OR entremise
25. 19 or 20 or 21 or 22 or 23 or 24
26. 18 and 25