

## **APPENDIX 11:**

### **SEARCH STRATEGIES FOR THE IDENTIFICATION OF HEALTH ECONOMIC EVIDENCE**

Search strategies for the identification of health economics and quality-of-life studies.

The search strategies should be referred to in conjunction with information set out in Chapter 3, Section 3.6.1. Each search was constructed using the groups of terms as set out in the summary of systematic search strategies for the identification of health economic evidence table, below. The full set of terms constructed for use in MEDLINE follow.

## Summary of systematic search strategies for the identification of health economic evidence

<b>Chapters 5 to 8: case identification, assessment and diagnosis; organisation and delivery of care; psychosocial interventions; biomedical interventions</b>				
<b>Review question<sup>1</sup></b>	<b>Search type</b>	<b>Search construction</b>	<b>Study design limit</b>	<b>Databases/ date range</b>
RQ - A1, A2/A2a RQ - B1, B2, B3 RQ - C1, C2, C3, C4, C5, C6 RQ - D1, D2 RQ - E1, E2 RQ - F1, F2	Generic <sup>2</sup>	[(Autism terms) AND (health economics/quality of life study design filter)]	Health economic/quality of life	Databases searched: EconLit, Embase, HTA database, MEDLINE, NHS EED, PsycINFO  Date range searched: 1996 up to 09.09.2011.
<b>Chapter 6: organisation and delivery of care</b>				
<b>Review question<sup>4</sup></b>	<b>Search type</b>	<b>Search construction</b>	<b>Study design limit</b>	<b>Databases/ date range</b>
RQ - E2 [subsection of question - search limited to residential care only]	Focused <sup>5</sup> , supplements generic search on autism	[(Learning disability terms) AND (residential care terms) AND (health economic/quality of life study design filter)]	Health economic/quality of life	Databases searched: EconLit, Embase, HTA database, MEDLINE, NHS EED, PsycINFO  Date range searched: 1996 up to 09.09.2011.
<b>Chapter 7: psychological and psychosocial interventions (includes support for families, partners and carers)</b>				
<b>Review question<sup>1</sup></b>	<b>Search type</b>	<b>Search construction</b>	<b>Study design limit</b>	<b>Databases/ date range</b>
RQ - C1 [subsection of question - search limited to psychosocial interventions aimed at behaviour management only]	Focused <sup>3</sup> , supplements generic search for evidence on autism	[(Learning disability terms) AND (behaviour management terms) AND (health economic/quality of life study design filter)]	Health economic/quality of life	Databases searched: EconLit, Embase, HTA database, MEDLINE, NHS EED, PsycINFO  Date range searched: 1996 up to 09.09.2011.

<sup>1</sup> See Appendix 7 for full details of review questions.

<sup>2</sup> Generic = broad search comprising terms for population and study design only.

<sup>3</sup> Focused = specific search comprising terms for population, intervention and study design.

RQ - D1	Focused <sup>3</sup> , supplements generic search for evidence on autism	[(Learning disability terms) AND (support for families, partners and carers terms) AND (health economic/quality of life study design filter)]	Health economic/quality of life	Databases searched: EconLit, Embase, HTA database, MEDLINE, NHS EED, PsycINFO  Date range searched: 1996 up to 09.09.2011.
<b>Chapter 8: biomedical interventions</b>				
<b>Review question<sup>4</sup></b>	<b>Search type</b>	<b>Search construction</b>	<b>Study design limit</b>	<b>Databases/ date range</b>
RQ - C4 [subsection of question - search limited to biomedical interventions aimed at behaviour management only]	Focused <sup>5</sup> , supplements generic search on autism	[(Learning disability terms) AND (behaviour management terms) AND (health economic/quality of life study design filter)]	Health economic/quality of life	Databases searched: EconLit, Embase, HTA database, MEDLINE, NHS EED, PsycINFO  Date range searched: 1996 up to 09.09.2011.

<sup>4</sup> See Appendix 7 for full details of review questions.

<sup>5</sup> Focused = specific search comprising terms for population, intervention and study design.

## Population search terms

### *a) Autism – population search terms*

MEDLINE – Ovid SP interface

1. asperger syndrome/ or autistic disorder/ or child development disorders, pervasive/ or rett syndrome/
2. (asperger\$ or autis\$ or cerebroatrophic hyperammonemia\$ or (kanner\$ adj (disorder\$ or syndrome\$)) or (pervasive\$ adj2 (development\$ or neurodevelopment\$)) or pddnos or pdd nos or (rett\$ adj (disorder\$ or syndrome\$))).ti,ab.
3. or/1-2

### *b) Learning disability – population search terms*

MEDLINE – Ovid SP interface

1. developmental disabilities/ or disabled persons/ or "education of mentally retarded"/ or education, special/ or exp learning disorders/ or exp mental retardation/ or mentally disabled persons/ or phenylketonurias/
2. ((developmental\$ or intellect\$ or language or learning or neurodevelopmental or phonologic\$ or speech or vocabular\$) adj2 delay\$).ti,ab.
3. ((developmental\$ or intellect\$ or language or learning or neuro developmental\$ or neurodevelopment\$) adj2 (defect\$ or deficien\$ or deficit\$ or difficult\$ or disorder\$ or disturbanc\$ or dysfunction\$ or impair\$ or problem\$ or subnormal\$ or sub\$ normal\$)).ti,ab.
4. ((disabilit\$ or disabled) adj3 (adult\$ or aged or client\$ or consumer\$ or elderly or female\$ or geriatric\$ or individual\$ or latelife or late life or male\$1 or men or middle aged or midlife or mid life or old or older or patient\$ or people\$ or person\$ or population\$ or seniors or women)).ti,ab.
5. ((disabilit\$ or disabled) adj3 (communicat\$ or defect\$ or deficien\$ or deficit\$ or developmental\$ or dysfunction\$ or functional or impair\$ or multiple or intellect\$ or language or learning or neurodevelopmental\$ or phonologic\$ or receptive or speech or subnormal\$ or sub\$ normal\$ or vocabular\$)).ti,ab.
6. ((down\$ adj2 syndrom\$) or (fragile adj3 syndrome) or oligophren\$ or phenylketonuria).ti,ab.
7. ((handicap\$ or handi cap\$ or retard\$1 or retardates or retarded) adj3 (developmental\$ or functional or motor\$ or multiple or neurodevelomental or psychomotor or severe)).ti,ab.
8. ((handicap\$ or handi cap\$ or retard\$1 or retardates or retarded) adj3 (adult\$ or aged or client\$ or consumer\$ or elderly or female\$ or geriatric\$ or individual\$ or latelife or late life or male\$1 or men or middle aged or midlife or mid life or old or older or patient\$ or people\$ or person\$ or population\$ or seniors or women)).ti,ab.

9. (mental\$ adj2 (defect\$ or deficien\$ or deficit\$ or disable\$ or disabilit\$ or impair\$ or incapacit\$ or subnormal\$ or sub\$1 normal\$)).ti,ab.
10. (special adj (educat\$ or need\$)).ti,ab.
11. (cognitiv\$ adj2 impair\$).ti.
12. or/1-11

### **Question specific search strategies**

#### ***a) Interventions aimed at behavioural management (subsection of RQ - C1,C4)***

*RQ – C1: For adults with autism, what are the benefits and/or potential harms associated with different psychosocial interventions (for example, applied behavioural analysis, cognitive behavioural therapy, mentoring, social groups, and befriending schemes)?*

*RQ – C4: For adults with autism, what is the effectiveness of biomedical interventions (for example, dietary interventions, pharmacotherapy, and physical-environmental adaptations)?*

#### **Area searched: subsection of RQs – search limited to interventions aimed at behaviour management only**

MEDLINE – Ovid SP interface

1. behaviour/ or behavior control/
2. learning disorders/rh or mental retardation/rh
3. (adaptive adj (behavio?r\$ or skill\$)).ti,ab.
4. (behav\$ adj3 (challenging or difficult\$ or destructiv\$ or disruptiv\$ or disturbance\$ or dysfunction\$ or problem\$)).ti,ab.
5. ((behav\$ or challenging or destructiv\$ or disruptiv\$ or disturbance\$ or dysfunction\$ or interfering) adj2 (disorder\$ or problem\$ or symptom\$ or syndrome\$)).ti,ab.
6. ((decreas\$ or improv\$ or lower\$ or reduc\$) adj2 (behav\$ or destructive\$ or disruptive\$ or interfering symptom\$)).ti,ab.
7. aggression/ or exp anger/ or \*"attention deficit and disruptive behavior disorders"/ or hostility/ or restraint, physical/ or self-injurious behaviour/ or self mutilation/ or violence/
8. (agitat\$ or aggress\$ or anger\$ or hostil\$ or rebel\$ or retaliat\$).ti,ab.
9. (biting or headbut\$ or head but\$ or hitting or kick\$ or scream\$ or spit or spitting or tantrum\$ or troublesome).ti,ab.
10. (compulsive\$ or repetitive\$ or stereotypy).ti,ab.
11. (physical\$ adj2 restrain\$).ti,ab.
12. (selfharm\$ or self harm\$ or selfinjur\$ or self injur\$ or selfmutilat\$ or self mutilat\$ or selfdestruct\$ or self destruct\$ or (self adj2 cut\$) or cutt\$ or selfimmolat\$ or self immolat\$ or selfinflict\$ or self inflict\$ or automutilat\$ or auto mutilat\$).ti,ab.
13. or/1-12
14. exp behavior therapy/

15. "reinforcement (psychology)" /
16. (((behav\$ or cognitiv\$) adj3 (analy\$ or interven\$ or manag\$ or program\$ or therap\$ or treat\$ or workshop\$ or work shop\$)) or (behav\$ adj2 (modif\$ or control\$)) or cbt).ti,ab.
17. (model?ing or prompting or reinforcement or re inforcement or self evaluat\$).ti,ab.
18. (self care/ and (cognit\$ or behavio?r\$ or metacognit\$ or recover\$).tw,hw.) or (selfinstruct\$ or selfmanag\$ or selfattribut\$ or (self\$ adj (instruct\$ or manag\$ or attribution\$)) or (rational\$ adj3 emotiv\$) or (rational adj (living or psychotherap\$ or therap\$)) or (ret adj (psychotherap\$ or therap\$)) or rebt or (active directive adj (psychotherap\$ or therap\$))).ti,ab.
19. (\*activities of daily living/ and ((ed or rh or th).fs. or (educat\$ or program\$ or skill\$ or teach\$ or therap\$).hw.)) or toilet training/
20. "education of mentally retarded" /
21. (self care or ((bathing or dressing or eating or feeding or grooming or homemak\$ or hygien\$ or leisure or toilet\$ or undress\$) adj3 (educat\$ or instruct\$ or interven\$ or learn\$ or program\$ or promot\$ or skill\$ or taught\$ or teach\$ or train\$))).ti,ab.
22. ((independen\$ or life or living or (self adj (care or protect\$)) or social or survival) adj2 (educat\$ or instruct\$ or interven\$ or learn\$ or program\$ or skill\$ or taught or teach\$ or train\$)).ti,ab.
23. (((communicat\$ or interact\$ or interpersonal\$ or language\$) adj3 (educat\$ or instruct\$ or interven\$ or learn\$ or program\$ or skill\$ or taught\$ or teach\$ or train\$)) or social learn\$).ti,ab.
24. ((adrenocorticotrophic hormone/ or exp amantadine/ or exp anti-anxiety agents/ or exp anticonvulsants/ or exp antidepressive agents/ or exp antipsychotic agents/ or exp central nervous system stimulants/ or exp chelating agents/ or exp cholinesterase inhibitors/ or galantamine/ or melatonin/ or oxytocin/ or secretin/) or (diet/ or exp dietary supplements/ or exp minerals/ or exp vitamins/) or exp testosterone/) and behav\$.ti,ab,hw.
25. or/14-24
26. or/13,25

**b) Support for families, partners and carers (RQ - D1)**

*RQ - D1: What information and day-to-day support do families, partners and carers need:*

- *during the initial period of assessment and diagnosis*
- *when treatment and care is provided (for example, telephone helpline, information packs, advocates or respite care, interpreters and other language tools)*
- *during periods of crisis?*

MEDLINE - Ovid SP interface

1. caregivers/ or family/ or family health/ or family relations/ or intergenerational relations/ or exp maternal behaviour/ or exp parent-child

- relations/ or parenting/ or exp parents/ or paternal behavior/ or professional-family relations/ or sibling relations/
2. (carer\$1 or caregiv\$ or care taker\$ or caretaker\$ or custodian\$ or family or families or father\$ or guardian\$ or mother\$ or parent\$ or spouse\$ or stepparent\$ or ((communicat\$ or conversation\$ or familiar or interact\$ or language or speech) adj2 partner\$)).ti,ab.
  3. or/1-2
  4. audiovisual aids/ or books, illustrated/ or books/ or books, illustrated/ or cellular phone/ or computer user training/ or computers/ or education, distance/ or educational technology/ or electronic mail/ or exp health education/ or health knowledge, attitudes, practice/ or exp health promotion/ or hotlines/ or information dissemination/ or information seeking behaviour/ or exp internet/ or multimedia/ or pamphlets/ or software/ or exp tape recording/ or teaching materials/ or telemedicine/ or telephone/ or therapy, computer assisted/ or exp videodisc recording/ or writing/
  5. day care/
  6. family health/
  7. friends/ or self help groups/ or exp social environment/
  8. home care services/ or home care services, hospital based/ or exp home nursing/ or home health aides/ or social support/
  9. interpersonal relations/ or professional-family relations/ or social facilitation/
  10. ed.fs. and 1
  11. (advocate\$ or advocacy).ti,ab.
  12. ((audio\$ or cd\$1 or cd rom\$ or cdrom\$ or computer\$ or cyber\$ or dvd\$1 or electronic\$ or floppy or handheld or hand held or interactive or internet\$ or manual\$1 or mobile or online or palmtop or palm top or pc\$1 or phone\$1 or read\$1 or reading or sms\$1 or telephone\$ or text or texts or texting or video\$ or virtual or web\$ or written or www) adj3 (approach\$ or assist\$ or coach\$ or club\$ or class\$ or help\$ or interven\$ or learn\$ or module\$ or program\$ or psychotherap\$ or rehab\$ or strateg\$ or support\$ or therap\$ or treat\$ or workshop\$ or work shop\$)).ti,ab.
  13. (book\$1 or booklet\$ or brochure\$ or educat\$ or information\$ or instruct\$ or knowledge or leaflet\$ or manual\$1 or material\$ or multi media or multimedia or ((oral or printed or written) adj3 inform\$) or pamphlet\$ or poster\$ or psycho educat\$ or psychoeducat\$ or teach\$ or train\$ or video\$ or workbook\$ or work book\$).ti,ab.
  14. (call in or callline\$ or call line\$ or help line\$ or helpline\$ or hotline\$ or hot line\$ or phone in or phonein or (caller\$1 adj3 (interven\$ or program\$ or therap\$ or treat\$))).ti,ab.
  15. ((carer\$1 or caregiv\$ or care taker\$ or caretaker\$ or custodian\$ or family or families or father\$ or guardian\$ or mother\$ or parent\$ or spouse\$ or stepparent\$ or ((communicat\$ or conversation\$ or familiar or interact\$ or language or speech) adj2 partner\$)) adj3 (approach\$ or assist\$ or coach\$ or club\$ or class\$ or group\$ or help\$ or interven\$ or learn\$ or module\$ or

- program\$ or psychotherap\$ or rehab\$ or skill\$ or strateg\$ or support\$ or therap\$ or treat\$ or workshop\$ or work shop\$)).ti,ab.
16. ((carer\$1 or caregiv\$ or care taker\$ or caretaker\$ or custodian\$ or family or families or father\$ or guardian\$ or mother\$ or parent\$ or spouse\$ or stepparent\$ or ((communicat\$ or conversation\$ or familiar or interact\$ or language or speech) adj2 partner\$)) adj3 burden\$).ti,ab.
  17. ((carer\$1 or caregiv\$ or care taker\$ or caretaker\$ or custodian\$ or family or families or father\$ or guardian\$ or mother\$ or parent\$ or spouse\$ or stepparent\$ or ((communicat\$ or conversation\$ or familiar or interact\$ or language or speech) adj2 partner\$)) adj5 (protect\$ or relief or service\$)).ti,ab.
  18. ((carer\$1 or caregiv\$ or care taker\$ or caretaker\$ or custodian\$ or family or families or father\$ or guardian\$ or mother\$ or parent\$ or spouse\$ or stepparent\$ or ((communicat\$ or conversation\$ or familiar or interact\$ or language or speech) adj2 partner\$)) adj8 (communicat\$ or conversation\$ or interact\$)).ti,ab.
  19. ((carer\$1 or caregiv\$ or care taker\$ or caretaker\$ or custodian\$ or family or families or father\$ or guardian\$ or mother\$ or parent\$ or spouse\$ or stepparent\$ or ((communicat\$ or conversation\$ or familiar or interact\$ or language or speech) adj2 partner\$)) adj10 (communicat\$ or interact\$ or interpersonal or inter personal or talk\$) adj10 (approach\$ or assist\$ or coach\$ or club\$ or class\$ or group\$ or help\$ or interven\$ or learn\$ or module\$ or program\$ or psychotherap\$ or rehab\$ or strateg\$ or support\$ or therap\$ or treat\$)).ti,ab.
  20. day care.ti,ab.
  21. (health adj2 promot\$).ti,ab.
  22. ((home adj2 (care\$ or nurs\$ or service\$)) or respite).ti,ab.
  23. (interpreter\$ or ((communicat\$ or language or learning\$ or speech) adj2 tool\$) or special educator\$).ti,ab.
  24. (mutual adj (help or aid or support\$)).ti,ab.
  25. (selfhelp\$ or self help\$ or social support or (support\$ adj2 (group\$ or network\$ or professional\$))).ti,ab.
  26. or/1-25

**c) Residential care (subsection of RQ - E2)**

*RQ-E2: For adults with autism, what are the essential elements in the effective provision of:*

- *support services for the individual (including accessing and using services)*
- *day care*
- *residential care?*



## Area searched: subsection of RQ – search limited to residential care only

### MEDLINE – Ovid SP interface

1. deinstitutionalization/ or home care services / or home care aides/ or home care services, hospital-based/ or exp home nursing/ or exp housing/ or independent living programs/ or institutionalization/ or long term care/ or exp residential facilities/ or residential treatment/
2. accommodation.ti,ab.
3. (aged care facilit\$ or ((care or group\$ or nursing or old age) adj2 home\$)).ti,ab.
4. apartment\$.ti,ab.
5. ((campus\$ or cluster\$ or dispersed) adj3 (accomodat\$ or centre\$ or center\$ or communit\$ or complex\$ or facilit\$ or home\$ or hous\$ or institution\$ or living or model\$ or neighbour\$ or place\$1 or placement\$ or resident\$ or setting\$ or unit\$)).ti,ab.
6. (communit\$ adj3 (accomodat\$ or campus\$ or complex\$ or facilit\$ or home\$ or hous\$ or institution\$ or living or place\$1 or placement\$ or resident\$ or unit\$)).ti,ab.
7. (communit\$ adj2 (discharg\$ or move\$ or moving or relocat\$)).ti,ab.
8. concept hous\$.ti,ab.
9. (deinstitutionali\$ or institutional\$).ti,ab.
10. developmental cent\$.ti,ab.
11. (disabled adj2 communit\$).ti,ab.
12. dwelling\$.ti,ab.
13. (flatemate or housemate\$ or ((flat or house) adj mate\$)).ti,ab.
14. ((home\$1 or hous\$ or living or resident\$) adj4 (assist\$ or support\$)).ti,ab.
15. (home adj2 (care\$ or nurs\$ or service\$)).ti,ab.
16. (hostel\$ or shelter\$).ti,ab.
17. housing.ti,ab.
18. (independ?n\$ adj3 (accomodat\$ or care or centre\$ or center\$ or communit\$ or complex\$ or facilit\$ or home\$ or hous\$ or institution\$ or living or placement\$ or resident\$ or setting\$ or unit\$)).ti,ab.
19. ((intentional or congregat\$ or village\$) adj2 (communit\$ or setting\$)).ti,ab.
20. ((institution\$ or intensive or out of\$1) adj3 (care\$ or living or placement\$ or place\$1 or resident\$ or setting\$)).ti,ab.
21. (live in\$1 or (out adj2 home\$)).ti,ab.
22. (((long term or extended) adj care) or long stay).ti,ab.
23. ((rent\$ or own\$) adj2 (accomodat\$ or home\$1 or hous\$ or resident\$)).ti,ab.
24. (residence\$ or residential).ti,ab.
25. (resident\$ adj3 (accomodat\$ or care or centre\$ or center\$ or communit\$ or complex\$ or facilit\$ or home\$ or hous\$ or institution\$ or living or model\$ or neighbour\$ or place\$1 or placement\$ or program\$ or provision\$ or service\$ or setting\$ or unit\$)).ti,ab.
26. ((special or support\$) adj2 living).ti,ab.

27. (staffed adj3 (accomodat\$ or centre\$ or center\$ or complex\$ or facilit\$ or home\$ or hous\$ or institution\$ or living\$ or model\$ or neighbourhood\$ or placement\$ or resident\$ or setting\$ or unit\$)).ti,ab.
28. [TEXTWORD SEARCHES FOR LEARNING DISABILITY POPULATION SEARCH TERMS] adj5 (accomodat\$ or home\$1 or hous\$ or living or resident\$).ti,ab.
29. or/1-28

### Study design search filters

a) *Health economics and quality of life search filter – an adaptation of a filter designed by the CRD (2007)*

MEDLINE – Ovid SP interface

1. exp budgets/ or exp “costs and cost analysis” /or economics/ or exp economics, hospital/or exp economics, medical/ or economics, nursing/ or economics, pharmaceutical/ or exp “fees and charges” / or exp resource allocation/ or value of life/
2. (budget\$ or cost\$ or econom\$ or expenditure\$ or fee or fees or financ\$ or fund or funds or funding\$ or funded or (expenditure\$ not energy) or pharmaco-economic\$ or price or prices or pricing or ration or rations or rationing\$ or rationed or resource\$ allocat\$ or saving or (value adj2 (monetary or money))).ti,ab.
3. ec.fs. and [SUBJECT HEADING SEARCH FOR AUTISM POPULATION]
4. or/1-3
5. exp decision theory/ or markov chains/ or exp models, economic/ or \*models, organizational/ or \*models, theoretical/ or monte carlo method/
6. (decision adj (analy\$ or model\$ or tree\$)).ti,ab.
7. economic model\$.ti,ab.
8. markov.ti,ab.
9. monte carlo.ti,ab.
10. or/5-9
11. quality-adjusted life years/ or sickness impact profile/
12. (((disability or quality) adj adjusted) or (adjusted adj2 life)).ti,ab.
13. (disutili\$ or (utilit\$ adj1 (health or score\$ or value\$ or weigh\$))).ti,ab.
14. (health year equivalent or hye or hyes).ti,ab.
15. (daly or qal or qald or qale or qaly or qtime\$ or qw\$b\$).ti,ab.
16. discrete choice.ti,ab.
17. (euroqol\$ or euro qol\$ or eq5d\$ or eq 5d\$).ti,ab.
18. (hui or hui1 or hui2 or hui3).ti,ab.
19. ((quality or value\$) adj3 (life or survival or well\$)).ti,ab.
20. (qol or hql\$ or hqol\$ or h qol\$ or hrqol or hr qol or hr ql or hrql).ti,ab.
21. rosser.ti,ab.
22. sickness impact profile.ti,ab.
23. (standard gamble or time trade\$ or tto or willingness to pay).ti,ab.

24. (sf36 or sf 36 or short form 36 or shortform 36 or sf thirtysix or sf thirty six or shortform thirtysix or shortform thirty six or short form thirtysix or short form thirty six).ti,ab.
25. (sf6 or sf 6 or short form 6 or shortform 6 or sf six or sfsix or shortform six or short form six).ti,ab.
26. (sf12 or sf 12 or short form 12 or shortform 12 or sf twelve or sftwelve or shortform twelve or short form twelve).ti,ab.
27. (sf16 or sf 16 or short form 16 or shortform 16 or sf sixteen or sfsixteen or shortform sixteen or short form sixteen).ti,ab
28. (sf20 or sf 20 or short form 20 or shortform 20 or sf twenty or sftwenty or shortform twenty or short form twenty).ti,ab.
29. or/11-28
30. or/4,10,29