APPENDIX 14A: CLINICAL EVIDENCE –STUDY CHARACTERISTICS TABLES: EXPERIENCE OF CARE

1.1 CHARACTERISTICS OF INCLUDED STUDIES

1.1.1 ALLARD2009

Study ID	ALLARD2009
Bibliographic reference	Allard A. Transition to adulthood: inquiry into transition to adulthood for young people with autism. The All-Party Parliamentary Group on Autism. London: National Autistic Society; 2009.
Methods	**Data collection method:** Oral and written evidence submitted to a parliamentary inquiry
Participants	**Population:** Service user and carer experience **N:** 8 service users; 187 carers **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** Not reported **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of information/support at key transitions
Study Design	Qualitative
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.2 ALLGOOD2005

Study ID	ALLGOOD2005
Bibliographic reference	Allgood N. Parents' perceptions of family-based group music therapy for children with autism spectrum disorders. Music Therapy Perspectives. 2005;23:92-99.
Methods	**Data collection method:** Focus group
Participants	**Population:** Carer experience **N:** 5 **Autism Population Axis I/II disorders**: 50% PDD-NOS; 25% Autism; 25% Seizure disorder with autism **Service user age (range[mean]):** 4-6 (4.75) **Service user sex (% female):** 80 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 80
Outcomes	**Focus of study:** Experience of specific intervention (music therapy)
Study Design	Qualitative

Setting	Not reported
Country	USA
Notes	Not applicable

1.1.3 ALTIERE2009B

Study ID	ALTIERE2009B
Bibliographic reference	Altiere MJ, von Kluhe S. Searching for acceptance: challenges encountered while raising a child with autism. Journal of Intellectual and Developmental Disability. 2009;34:142–152.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Carer experience **N:** 52 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 3-16 (7.54) **Service user sex (% female):** 50 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 50
Outcomes	**Focus of study:** Experience of accessing interventions (timing) and specific intervention (support group)
Study Design	Qualitative
Setting	Home
Country	USA
Notes	Not applicable

1.1.4 AUERT2012

Study ID	AUERT2012
Bibliographic reference	Auert E-J, Trembath D, Arciuli J, Thomas D. Parentd' expectations, awareness, and experiences of accessing evidence-based speech-language pathology services for their children with autism. International Journal of Speech-Language Pathology. 2012;14:109-118.
Methods	**Data collection method:** Focus group
Participants	**Population:** Carer experience **N:** 20 **Autism Population Axis I/II disorders**: Not reported **Service user age (range[mean]):** 3-6 (Not reported) **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 85
Outcomes	**Focus of study:** Experience of speech-language pathology services

Study Design	Qualitative
Setting	Not reported
Country	Australia
Notes	Not applicable

1.1.5 BEATSON2002

Study ID	BEATSON2002
Bibliographic reference	Beatson JE, Prelock PA. The Vermont rural autism project: sharing experiences, shifting attitudes. Focus on Autism and Other Developmental Disabilities. 2002;17:48-54
Methods	**Data collection method:** Face-to-face (40%) or telephone (60%) interview
Participants	**Population:** Carer experience **N:** 5 **Autism Population Axis I/II disorders**: 40% autism; 40%: characteristics of autism but did not fit all of the DSM-IV criteria; 20% PDD-NOS **Service user age (range[mean]):** 3-10 (Not reported) **Service user sex (% female):** 80 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 80
Outcomes	**Focus of study:** Experience of specific intervention (staff training - The Vermont Rural Autism Project)
Study Design	Qualitative
Setting	Home
Country	USA
Notes	Not applicable

1.1.6 BENDERIX2007A

Study ID	BENDERIX2007A
Bibliographic reference	Benderix Y, Nordström B, Sivberg B. Parents' experience of having a child with autism and learning disabilities living in a group home: a case study. Autism. 2007;10:629-641.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Carer experience **N:** 10 **Autism Population Axis I/II disorders**: 100% autism **Service user age (range[mean]):** 10-11(Not reported) **Service user sex (% female):** 50

	Service user IQ: 100% ID (20% moderate ID; 60% severe ID; 20% profound ID) **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 50
Outcomes	**Focus of study:** Experience of residential setting (group home)
Study Design	Qualitative
Setting	Community-based Centre for Child and Youth Care
Country	Sweden
Notes	Not applicable

1.1.7 BENDERIX2007B

Study ID	BENDERIX2007B
Bibliographic reference	Benderix Y, Sivberg B. Siblings experiences of having a brother or sister with autism and mental retardation: a case study of 14 siblings from five families. International Pediatric Nursing. 2007;22:410-418.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Sibling experience **N:** 14 **Autism Population Axis I/II disorders**: 100% Autism **Service user age (range[mean]):** 10-11(Not reported) **Service user sex (% female):** 43 **Service user IQ:** 100% ID **Family/carer age (range[mean]):** 5-29 (Not reported) **Family/carer sex (% female):** 43
Outcomes	**Focus of study:** Experience of residential setting (group home)
Study Design	Qualitative
Setting	Home (21%) or in the municipal Center for Child and Youth Habilitation (79%)
Country	Sweden
Notes	Not applicable

1.1.8 BERESFORD2007

Study ID	BERESFORD2007
Bibliographic reference	Beresford B, Tozer R,Rabiee P, Sloper P. Desired outcomes for children and adolescents with autistic spectrum disorders. Children and Society. 2007;21:89-98.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Service user experience **N:** 5 **Autism Population Axis I/II disorders**: 40% Asperger syndrome; 60% autism **Service user age (range[mean]):** 5-19(11) **Service user sex (% female):** n/a

	Service user IQ: Not reported **Family/carer age (range[mean]):** n/a **Family/carer sex (% female):** n/a
Outcomes	**Focus of study:** Barriers to accessing services
Study Design	Qualitative
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.9 BERESFORD2010

Study ID	BERESFORD2010
Bibliographic reference	Beresford B, Stuttard L, Clarke S, Maddison J, Beecham J. Managing behaviour and sleep problems in disabled children: an investigation into the effectiveness and costs of parent-training interventions. Research Report DFE-RR204. London: Department for Education; 2010. Available at: https://www.education.gov.uk/publications/RSG/AllPublications/Page1/DFE-RR204.
Methods	**Data collection method:** Face-to-face interview (63%) or fiocus group (37%)
Participants	**Population:** Carer experience **N:** 103 **Autism Population Axis I/II disorders**: 49% autism only; 25% autism plus another disability; 26% other disability only **Service user age (range[mean]):** Not reported **Service user sex (% female):** 83 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 83
Outcomes	**Focus of study:** Experience of specific interventions (parent training for managing behaviour or sleep problems)
Study Design	Qualitative
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.10 BERESFORD2013

Study ID	BERESFORD2013
Bibliographic reference	Beresford B, Moran N, Sloper P, Cusworth L, Mitchell W, Spiers G, et al. Transition to Adult Services and Adulthood for Young People with Autistic Spectrum Conditions: Final Report. York: Social Policy Research Unit, University of York; 2013. Available from: http://www.york.ac.uk/inst/spru/research/summs/transitionsASC.html.

Methods	**Data collection method:** Interview (38% face-to-face and 72% telephone for carers; 100% face-to-face for sevice users)
Participants	**Population:** Service user and carer experience **N:** 36 carers; 18 service users **Autism Population Axis I/II disorders**: Carer sample: 5% ASC; 22% Autism; 62% Asperger's syndrome; 11% HFA **Service user age (range[mean]):** CYP of carers: 15-21 years (mean: 16 years); Service users: 16-25 (mean: 18.6 years) **Service user sex (% female):** CYP of carers: 22% female. Service users: 22% female **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 84
Outcomes	**Focus of study:** Experience of transition
Study Design	Mixed method (Qualitative)
Setting	Not reported for carers; Home for service users
Country	UK
Notes	Not applicable

1.1.11 BEVANBROWN2010

Study ID	BEVANBROWN2010
Bibliographic reference	Bevan-Brown J. Messages from parents of children with autism spectrum disorder (ASD). Kairaranga. 2010;11:16-22.
Methods	**Data collection method:** Online survey (open-ended)
Participants	**Population:** Carer experience **N:** 137 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** Not reported **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of education/school
Study Design	Qualitative
Setting	n/a
Country	New Zealand
Notes	Not applicable

1.1.12 BIRKIN2008

Study ID	BIRKIN2008

Bibliographic reference	Birkin C, Anderson A, Seymour F, Moore DW. A parent-focused early intervention program for autism: who gets access? Journal of Intellectual and Developmental Disability. 2008;33:108-116.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Carer experience **N:** 12 **Autism Population Axis I/II disorders**: Not reported **Service user age (range[mean]):** Not reported **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Barriers to accessing intervention (cultural differences & EarlyBird)
Study Design	Mixed method (Qualitative)
Setting	Not reported
Country	New Zealand
Notes	Not applicable

1.1.13 BRAIDEN2010

Study ID	BRAIDEN2010
Bibliographic reference	Braiden HJ, Bothwell J, Duffy J. Parents' experience of the diagnostic process for autistic spectrum disorders. Child Care in Practice. 2010;16:377-389.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Carer experience **N:** 11 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 5-11 (Not reported) **Service user sex (% female):** 100 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 100
Outcomes	**Focus of study:** Experience of post-diagnosis information and support Process
Study Design	Qualitative
Setting	Home
Country	UK
Notes	Not applicable

1.1.14 BREWIN2008

Study ID	BREWIN2008
Bibliographic reference	Brewin BJ, Renwick R, Schormans AF.Parental perspectives of the quality of life in school environments for children with Asperger Syndrome. Focus on Autism and Other Developmental Disabilities. 2008;23:242-252.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Carer perception of service user experience **N:** 9 **Autism Population Axis I/II disorders**: 100% Asperger Syndrome **Service user age (range[mean]):** 4-13 (9.8) **Service user sex (% female):** 67 **Service user IQ:** Not reported **Family/carer age (range[mean]):** 27-56 (46.1) **Family/carer sex (% female):** 67
Outcomes	**Focus of study:** Experience of education/school
Study Design	Qualitative
Setting	Locations of parent choosing
Country	Canada
Notes	Not applicable

1.1.15 BREWSTER2010

Study ID	BREWSTER2010
Bibliographic reference	Brewster S, Coleyshaw L. Participation or exclusion? perspectives of pupils with autistic spectrum disorders on their participation in leisure activities. British Journal of Learning Disabilities. 2010;39:284-291.
Methods	**Data collection method:** Focus group
Participants	**Population:** Service user experience **N:** 20 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 8-17(Not reported) **Service user sex (% female):** n/a **Service user IQ:** Not reported **Family/carer age (range[mean]):** n/a **Family/carer sex (% female):** n/a
Outcomes	**Focus of study:** Barriers to accessing leisure activities
Study Design	Qualitative
Setting	School
Country	UK
Notes	Not applicable

1.1.16 BROOKMANFRAZEE2012

Study ID	BROOKMANFRAZEE2012
Bibliographic reference	Brookman-Frazee L, Baker-Ericzén M, Stadnick N, Taylor R. Parent perspectives on community mental health services for children with autism spectrum disorders. Journal of Child and Family Studies. 2012'21:533-544.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Carer experience **N:** 23 **Autism Population Axis I/II disorders**: Not reported **Service user age (range[mean]):** 6-19 (11.7) **Service user sex (% female):** 43 **Service user IQ:** Not reported **Family/carer age (range[mean]):** 29-78 (45.8) **Family/carer sex (% female):** 83
Outcomes	**Focus of study:** Experience of community mental health services
Study Design	Qualitative
Setting	Home or office at research centre
Country	USA
Notes	Not applicable

1.1.17 BROWN2012

Study ID	BROWN2012
Bibliographic reference	Brown HK, Ouellette-Kuntz H, Hunter D, Kelley E, Cobigo V. Unmet needs of families of school-aged children with an autism spectrum disorder. Journal of Applied Research in Intellectual Disabilities. 2012;25:497-508.
Methods	**Data collection method:** Telephone interview
Participants	**Population:** Carer experience **N:** 101 (N=98 completed the open-ended question) **Autism Population Axis I/II disorders**: 42.6% Autistic disorder; 7.9% PDD-NOS; 24.8% Asperger's disorder; 24.8% ASD **Service user age (range[mean]):** Not reported (9.49) **Service user sex (% female):** 14 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 92
Outcomes	**Focus of study:** Experience of accessing services
Study Design	Mixed method (Qualitative)
Setting	Not applicable (telephone)
Country	Canada
Notes	Not applicable

1.1.18 BUNDY2009

Study ID	BUNDY2009
Bibliographic reference	Bundy MB, Kunce LJ. Parenting stress and high functioning children with autism. International Journal on Disability and Human Development. 2009;8:401–410.
Methods	**Data collection method:** Survey (open-ended)
Participants	**Population:** Carer experience **N:** 24 **Autism Population Axis I/II disorders**: 100% high functioning autism **Service user age (range[mean]):** 5-12(9.5) **Service user sex (% female):** 83 **Service user IQ:** 71-120(Not reported) **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 83
Outcomes	**Focus of study:** Unmet needs and experience of education/school
Study Design	Qualitative
Setting	Not reported
Country	USA
Notes	Not applicable

1.1.19 BURROWS2008

Study ID	BURROWS2008
Bibliographic reference	Burrows KE, Adams CL. Challenges of service-dog ownership for families with autistic children: lessons for veterinary practitioners. Journal of Veterinary Medical Education. 2008;35:559-566.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Carer experience **N:** 10 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 4-14(Not reported) **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of specific intervention (service dog)
Study Design	Qualitative
Setting	Home
Country	Canada
Notes	Not applicable

1.1.20 BURROWS2010

Study ID	BURROWS2010
Bibliographic reference	Burrows R. Is anyone listening? A report on stress, trauma and resilience and the supports needed by parents of children and individuals with ASD and professionals in the fild of autism in Northern Ireland. Belfast: Autism NI; 2010.
Methods	**Data collection method:** Focus group
Participants	**Population:** Carer experience **N:** 126 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** Not reported **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of specific intervention (support group)
Study Design	Qualitative
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.21 CAMARENA2009

Study ID	CAMARENA2009
Bibliographic reference	Camarena PM, Sarigiani PA. Postsecondary educational aspirations of high-functioning adolescents with autism spectrum disorders and their parents. Focus on Autism and Other Developmental Disabilities. 2009;24:115-128.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Service user and carer experience **N:** 21 service users; 33 carers **Autism Population Axis I/II disorders**: 67% Asperger syndrome; 33% autism **Service user age (range[mean]):** 12-19 (14.71) **Service user sex (% female):** 61 **Service user IQ:** Not reported **Family/carer age (range[mean]):** 37-55 (46.89) **Family/carer sex (% female):** 61
Outcomes	**Focus of study:** Experience of education/school (secondary-university transition)
Study Design	Qualitative
Setting	Home
Country	USA
Notes	Not applicable

1.1.22 CARBONE2010

Study ID	CARBONE2010
Bibliographic reference	Carbone PS, Behl DD, Azor V, Murphy N. The medical home for children with autism spectrum disorders: parent and pediatrician perspectives. Journal of Autism and Developemtal Disorders. 2010;40:317–324.
Methods	**Data collection method:** Focus group
Participants	**Population:** Carer experience **N:** 5 **Autism Population Axis I/II disorders**: 29% Asperger's disorder; 57% Autistic disorder; 14% PDD-NOS **Service user age (range[mean]):** 5-14 (7) **Service user sex (% female):** 80 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 80
Outcomes	**Focus of study:** Experience of primary care
Study Design	Qualitative
Setting	Department of Health
Country	USA
Notes	Not applicable

1.1.23 CARRINGTON2003A

Study ID	CARRINGTON2003A
Bibliographic reference	Carrington S, Papinczak T, Templeton E. A phenomenological study: the social world of five adolescents who have Asperger's syndrome. Australian Journal of Learning Difficulties. 2003;8:15-20.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Service user experience **N:** 5 **Autism Population Axis I/II disorders**: 100% Asperger syndrome **Service user age (range[mean]):** 14-18(15.8) **Service user sex (% female):** n/a **Service user IQ:** Not reported **Family/carer age (range[mean]):** n/a **Family/carer sex (% female):** n/a
Outcomes	**Focus of study:** Unmet needs (social skills)
Study Design	Qualitative
Setting	School
Country	Australia
Notes	Not applicable

1.1.24 CARTER2004

Study ID	CARTER2004
Bibliographic reference	Carter C, Meckes L, Pritchard L, Swensen S, Wittman PP, Velde B. The friendship club: an after-school program for children With Asperger syndrome. Family and Community Health. 2004;27:143-150.
Methods	**Data collection method:** Face-to-face interview (for service users) and survey (open-ended; for parents)
Participants	**Population:** Service user and carer experience **N:** 11 service users; N not reported for carers **Autism Population Axis I/II disorders**: 91% Asperger syndrome **Service user age (range[mean]):** 8-15(10.9) **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of specific intervention (Friendship club)
Study Design	Qualitative
Setting	Not reported
Country	USA
Notes	Not applicable

1.1.25 CASSIDY2008

Study ID	CASSIDY2008
Bibliographic reference	Cassidy A, McConkey R, Truesdale-Kennedy M, Slevin E. Preschoolers with autism spectrum disorders: the impact on families and the supports available to them. Early Child Development and Care. 2008;178:115-128.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Carer experience **N:** 104 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 2-4(Not reported) **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported-49(Not reported) **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of information and support
Study Design	Mixed method (Qualitative)
Setting	Home
Country	Ireland
Notes	Not applicable

1.1.26 CHELL2006

Study ID	CHELL2006
Bibliographic reference	Chell N. Experiences of parenting young people with a diagnosis of Asperger syndrome: a focus group study. International Journal of Psychiatric Nursing Research. 2006;11:1348-58.
Methods	**Data collection method:** Focus group
Participants	**Population:** Carer experience **N:** 13 **Autism Population Axis I/II disorders**: 100% Aspergers syndrome **Service user age (range[mean]):** 3.5-16(Not reported) **Service user sex (% female):** 77 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 77
Outcomes	**Focus of study:** Experience of post-diagnosis information and support
Study Design	Qualitative
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.27 CONNOR2000

Study ID	CONNOR2000
Bibliographic reference	Connor M. Asperger syndrome (autistic spectrum disorder) and the self-reports of comprehensive school students. Educational Psychology in Practice. 2000;16:285-296.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Service user experience **N:** 16 **Autism Population Axis I/II disorders**: 100% Asperger Syndrome **Service user age (range[mean]):** 11-16(Not reported) **Service user sex (% female):** n/a **Service user IQ:** Not reported **Family/carer age (range[mean]):** n/a **Family/carer sex (% female):** n/a
Outcomes	**Focus of study:** Experience of education/school
Study Design	Qualitative
Setting	School
Country	UK
Notes	Not applicable

1.1.28 CULLEN2002A/2002B/2005

Study ID	CULLEN2002A/2002B/2005
Bibliographic reference	Cullen L, Barlow J. 'Kiss, cuddle, squeeze': the experiences and meaning of touch among parents of children with autism attending a touch therapy programme. Journal of Child Health Care. 2002;6:171-181. Cullen L, Barlow J. Parents' experiences of caring for children with autism and attending a touch therapy programme. Child Care in Practice. 2002;8:35-45. Cullen LA, Barlow JH, Cushway D. Positive touch, the implications for parents and their children with autism: an exploratory study. Complementary Therapies in Clinical Practice. 2005;11:182-189.
Methods	**Data collection method:** Telephone interview
Participants	**Population:** Carer experience **N:** 12 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 3-13 (median=5) **Service user sex (% female):** 92 **Service user IQ:** Not reported **Family/carer age (range[mean]):** 28-44 (median=38) **Family/carer sex (% female):** 92
Outcomes	**Focus of study:** Experience of specific intervention (touch therapy)
Study Design	Qualitative
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.29 DANN2011

Study ID	DANN2011
Bibliographic reference	Dann R. Secondary transition experiences for pupils with autistic spectrum conditions (ASCs). Educational Psychology in Practice. 2011;27:293-312.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Service user and carer experience **N:** 6 service users; 6 carers **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** Not reported **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of education/school (primary-secondary

	transition)
Study Design	Qualitative
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.30 DILLENBURGER2010

Study ID	DILLENBURGER2010
Bibliographic reference	Dillenburger K, Keenan M, Doherty A, Byrne , Gallagher S. Living with children diagnosed with autistic spectrum disorder: parental and professional views. British Journal of Special Education. 2010;37:13-23.
Methods	**Data collection method:** Focus group
Participants	**Population:** Carer experience **N:** 10 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** Not reported **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of information and support
Study Design	Mixed method (Qualitative)
Setting	Local hotel
Country	Ireland
Notes	Not applicable

1.1.31 DILLENBURGER2004

Study ID	DILLENBURGER2004
Bibliographic reference	Dillenburger K, Keenan M, Gallagher S, McElhinney M. Parent education and home-based behaviour analytic intervention: an examination of parents' perceptions of outcome. Journal of Intellectual & Developmental Disability. 2004;29:119–130.
Methods	**Data collection method:** Survey (open-ended)
Participants	**Population:** Carer experience **N:** 22 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 3-13 (7.7) **Service user sex (% female):** 64 **Service user IQ:** Not reported

	Family/carer age (range[mean]): 31-52(39) **Family/carer sex (% female):** 64
Outcomes	**Focus of study:** Experience of specific intervention (ABA)
Study Design	Qualitative
Setting	55% postal; 45% training centre
Country	UK
Notes	Not applicable

1.1.32 DILLENBURGER2012

Study ID	DILLENBURGER2012
Bibliographic reference	Dillenburger K, Keenan M, Doherty A, Byrne T, Gallagher S. ABA-based programs for children diagnosed with autism spectrum disorder: parental and professional experiences at school and at home. Child and Family Behavior Therapy. 2012;34:111-129.
Methods	**Data collection method:** Focus group
Participants	**Population:** Carer experience **N:** 10 **Autism Population Axis I/II disorders**: Not reported **Service user age (range[mean]):** Not reported **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Access to specific intervention (ABA)
Study Design	Mixed method (Qualitative)
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.33 DILLON2012

Study ID	DILLON2012
Bibliographic reference	Dillon GV, Underwood JDM. Parental perspectives of students with autism spectrum disorders transitioning from primary to secondary school in the United Kingdom. Focus on Autism and Other Developmental Disabilities. 2012;27:111-121.
Methods	**Data collection method:** Focus group and follow-up face-to-face interview
Participants	**Population:** Carer experience **N:** 15 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 11-14 (Not reported) **Service user sex (% female):** 13

	Service user IQ: Not reported (40% had SEN statement) **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 93
Outcomes	**Focus of study:** Experience of education/school (primary-secondary transition)
Study Design	Qualitative
Setting	University for focus groups and home for interviews
Country	UK
Notes	Not applicable

1.1.34 DITTRICH2011

Study ID	DITTRICH2011
Bibliographic reference	Dittrich R, Burgess L, Bartolomeo K. Autism participation-have your say! Responses. Hampshire's pre-consultation: developing a Hampshire autism strategy to meet local needs. Hampshire: Hampshire County Council; 2011. Available from: http://www.hants.gov.uk/pdf/autism-participation-report-september2011.pdf.
Methods	**Data collection method:** Online survey (open-ended)
Participants	**Population:** Service user, carer and sibling experience **N:** 30 service users; 181 carers; 2 siblings **Autism Population Axis I/II disorders**: 30% autism; 44% Asperger's syndrome; 7% high-functioning autism; 4% waiting for diagnosis; 15% other **Service user age (range[mean]):** 7->75 (42% <19; 27% 19-25; 31% >25) **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of information and support
Study Design	Mixed method (Qualitative)
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.35 DONALDSON2011

Study ID	DONALDSON2011
Bibliographic reference	Donaldson SO, Elder JH, Self EH, Christie MB. Fathers’ perceptions of their roles during in-home training for children with autism. Journal of Child and Adolescent Psychiatric Nursing. 2011;24:200–207.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Carer experience **N:** 10

	Autism Population Axis I/II disorders: 100% Autism **Service user age (range[mean]):** 4-6(4.8) **Service user sex (% female):** 0 **Service user IQ:** Not reported **Family/carer age (range[mean]):** 31-51(38.8) **Family/carer sex (% female):** 0
Outcomes	**Focus of study:** Experience of specific intervention (Father-directed in-home training)
Study Design	Qualitative
Setting	Home
Country	USA
Notes	Not applicable

1.1.36 DYMOND2007

Study ID	DYMOND2007
Bibliographic reference	Dymond SK, Gilson GL, Myran SP. Services for children with autism spectrum disorders. Journal of Disability Policy Studies. 2007;18:133-147.
Methods	**Data collection method:** Postal survey (open-ended)
Participants	**Population:** Carer experience **N:** 783 **Autism Population Axis I/II disorders**: 55.81% Autistic disorder; 13.41% Asperger disorder; 0.13% Childhood disintegrative disorder; 27.46% PDD; 13.54% PDD-NOS; 0.38% Rett's disorder **Service user age (range[mean]):** 0-22(Not reported) **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Suggested improvements for education/school and community-based services
Study Design	Qualitative
Setting	Not reported
Country	USA
Notes	Not applicable

1.1.37 FISH2006

Study ID	FISH2006
Bibliographic reference	Fish W.W. Perceptions of Parents of Students with Autism towards the IEP Meeting: A Case Study of One Family Support Group Chapter. Education. 2006: 126: 56-68.

Methods	**Data collection method:** Interviews (face-to-face)/Focus group
Participants	**Population:** Carer experience **N:** 7 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** Not reported **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of education/school (IEP)
Study Design	Qualitative
Setting	Not reported
Country	USA
Notes	Not applicable

1.1.38 FLYNN2010

Study ID	FLYNN2010
Bibliographic reference	Flynn K, Tosh J, Hackett L, Todd S, Bond C, Hunter A. Supporting families post-diagnosis: an evaluation of parent workshops. Good Autism Practice. 2010;11:31-35.
Methods	**Data collection method:** Survey (open-ended)
Participants	**Population:** Carer experience **N:** 43 **Autism Population Axis I/II disorders**: 66% ASD; 33% Aspergers symdrome **Service user age (range[mean]):** Not reported **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of post-diagnosis information and support (parent workshops)
Study Design	Mixed method (Qualitative)
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.39 GLAZZARD2012

Study ID	GLAZZARD2012
Bibliographic reference	Glazzard J, Overall K. Living with autistic spectrum disorder: parental experiences of raising a child with autistic spectrum disorder (ASD). British

	Journal of Learning Support. 2012;27:37-45.
Methods	**Data collection method:** Postal survey (open-ended) and Interview (format not reported)
Participants	**Population:** Carer experience **N:** 22 **Autism Population Axis I/II disorders**: Not reported **Service user age (range[mean]):** Not reported **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 86
Outcomes	**Focus of study:** Experience of post-diagnosis information and support
Study Design	Qualitative
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.40 GRANGER2012

Study ID	GRANGER2012
Bibliographic reference	Granger S, des Rivières-Pigeon C, Sabourin G, Forget J. Mothers' reports of their involvement in early intensive behavioral intervention. Topics in Early Childhood Special Education. 2012;32:68-77.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Carer experience **N:** 13 **Autism Population Axis I/II disorders**: 69.2% Autism; 7.7% Autism & ADHD; 23.1% PDD-NOS **Service user age (range[mean]):** 4-6 (5) **Service user sex (% female):** 8 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 100
Outcomes	**Focus of study:** Experience of specific intervention (EIBI)
Study Design	Qualitative
Setting	Home or rehabilitation center premises
Country	Canada
Notes	Not applicable

1.1.41 GREEN2007

Study ID	GREEN2007
Bibliographic reference	Green VA. Parental experience with treatments for autism. Journal of Developmental and Physical Disabilities. 2007;19:91-101.
Methods	**Data collection method:** Telephone interview
Participants	**Population:** Carer experience **N:** 19 **Autism Population Axis I/II disorders**: 10% Asperger's Syndrome; 60% autism (mild; high functioning); 30% autism (severe) **Service user age (range[mean]):** <5->21; only N=2 were >21 (Not reported) **Service user sex (% female):** 0 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 0
Outcomes	**Focus of study:** Experience of specific intervention (ABA)
Study Design	Qualitative
Setting	Not reported
Country	USA
Notes	Not applicable

1.1.42 GREY2010

Study ID	GREY2010
Bibliographic reference	Grey IM, Lynn E, McClean B. Parents of children with autism: experiences of education service provision in the Republic of Ireland. Irish Journal of Psychology. 2010; 31:111-124.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Carer experience **N:** 15 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 4-10(Not reported) **Service user sex (% female):** 67 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 67
Outcomes	**Focus of study:** Experience of education/school (ABA versus non-ABA schools)
Study Design	Qualitative
Setting	School
Country	Ireland
Notes	Not applicable

1.1.43 GRINDLE2009

Study ID	GRINDLE2009
Bibliographic reference	Grindle CF, Kovshoff H, Hastings RP, Remington B. Parents' experiences of home-based applied behavior analysis programs for young children with autism. Journal of Autism and Developmental Disorders, 2009;39:42-56.
Methods	**Data collection method:** Interview (format not reported)
Participants	**Population:** Carer experience **N:** 53 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 4.5-6.4 (5.5) **Service user sex (% female):** 60 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 60
Outcomes	**Focus of study:** Experience of specific intervention (EIBI)
Study Design	Qualitative
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.44 HACKETT2009

Study ID	HACKETT2009
Bibliographic reference	Hackett L, Shaikh S, Theodosiou L. Parental perceptions of the assessment of autistic spectrum disorders in a tier three service. Child and Adolescent Mental Health. 2009;14:127–132.
Methods	**Data collection method:** Postal (70%) or telephone (28%) survey (open-ended)
Participants	**Population:** Carer experience **N:** 40 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** Not reported **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of post-diagnosis information and support
Study Design	Qualitative
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.45 HALL2010

Study ID	HALL2010
Bibliographic reference	Hall HR, Graff JC. Parenting challenges in families of children with autism: a pilot study. Issues in Comprehensive Pediatric Nursing. 2010;33:187–204.
Methods	**Data collection method:** Focus group
Participants	**Population:** Carer experience **N:** 11 **Autism Population Axis I/II disorders**: 100% Autism **Service user age (range[mean]):** 2-12 (6.5) **Service user sex (% female):** 82 **Service user IQ:** Not reported **Family/carer age (range[mean]):** 31-64 (41) **Family/carer sex (% female):** 82
Outcomes	**Focus of study:** Experience of information and support
Study Design	Qualitative
Setting	A location familiar to the parents
Country	USA
Notes	Not applicable

1.1.46 HARE2004

Study ID	HARE2004
Bibliographic reference	Hare DJ, Pratt C, Burton M, Bromley J, Emerson E. The health and social care needs of family carers supporting adults with autistic spectrum disorders. Autism. 2004;8:425-444.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Retrospective carer experience **N:** 26 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** Not reported(27) **Service user sex (% female):** 77 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 77
Outcomes	**Focus of study:** Experience of transition
Study Design	Qualitative
Setting	Home
Country	UK
Notes	Not applicable

1.1.47 ECOTEC2010

Study ID	ECOTEC2010
Bibliographic reference	ECOTEC. Research study on age appropriate services for young people with neurodevelopmental disorders: a research study for Big Lottery Fund. Birmingham: ECOTEC Research and Consulting Ltd; 2010.
Methods	**Data collection method:** Face-to-face interview or focus group
Participants	**Population:** Service user experience **N:** 35 (focus group); 8 (interview) **Autism Population Axis I/II disorders**: ASD or ADHD **Service user age (range[mean]):** 17-25(Not reported) **Service user sex (% female):** n/a **Service user IQ:** Not reported **Family/carer age (range[mean]):** n/a **Family/carer sex (% female):** n/a
Outcomes	**Focus of study:** Information/support at key transitions
Study Design	Qualitative
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.48 HAY2005

Study ID	HAY2005
Bibliographic reference	Hay I, Winn S. Students with Asperger's syndrome in an inclusive secondary school environment: teachers', parents' and students' perspectives. Australasian Journal of Special Education. 2005;29:140-154.
Methods	**Data collection method:** Face-to-face interview and focus group
Participants	**Population:** Service user and carer experience **N:** 26 **Autism Population Axis I/II disorders**: 100% Asperger syndrome **Service user age (range[mean]):** 13-15 (Not reported) **Service user sex (% female):** 53 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 53
Outcomes	**Focus of study:** Experience of education/school
Study Design	Qualitative
Setting	School
Country	Australia
Notes	Not applicable

1.1.49 HUMPHREY2008A/B

Study ID	HUMPHREY2008A/B
Bibliographic reference	Humphrey N, Lewis S. What does 'inclusion' mean for pupils on the autistic spectrum in mainstream secondary schools? Journal of Research in Special Educational Needs. 2008;8:132-140. Humphrey N, Lewis S. 'Make me normal': the views and experiences of pupils on the sutistic spectrum in mainstream secondary schools. Autism. 2008;12:23-46.
Methods	**Data collection method:** Interview (format not reported) and student diaries
Participants	**Population:** Service user and carer experience **N:** 19/20 (2008A/2008B) **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 11-17(Not reported) **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of education/school
Study Design	Qualitative
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.50 HURLBUTT2011

Study ID	HURLBUTT2011
Bibliographic reference	Hurlbutt KS. Experiences of parents who homeschool their children with autism spectrum disorders. Focus on Autism and Other Developmental Disabilities. 2011;26:239-249.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Carer experience **N:** 10 **Autism Population Axis I/II disorders**: 62% Asperger syndrome; 31% ASD; 8% PDD-NOS **Service user age (range[mean]):** 7-25(13.8) **Service user sex (% female):** 90 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 90
Outcomes	**Focus of study:** Barriers to accessing services/unmet needs (reasons for homeschooling)
Study Design	Qualitative

Setting	Not reported
Country	USA
Notes	Not applicable

1.1.51 HUTTON2005

Study ID	HUTTON2005
Bibliographic reference	Hutton AM, Caron SL. Experiences of families with children with autism in rural New England. Focus on Autism and Other Developmental Disabilities.2005;20:180-189.
Methods	**Data collection method:** Telephone interview
Participants	**Population:** Carer experience **N:** 21 **Autism Population Axis I/II disorders**: 100% autism **Service user age (range[mean]):** 3-16(Not reported) **Service user sex (% female):** 90 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 90
Outcomes	**Focus of study:** Experience of accessing services
Study Design	Qualitative
Setting	Not reported
Country	USA
Notes	Not applicable

1.1.52 JEGATHEESAN2010/2011

Study ID	JEGATHEESAN2010/2011
Bibliographic reference	Jegatheesan B, Fowler S, Miller PJ. From symptom recognition to services: how South asian muslim immigrant families navigate autism. Disability and Society. 2010;25:797-811. Jegatheesan B. Multilingual development in children with autism:perspectives of south asian muslim immigrant parents on raising a child with a communicative disorder in multilingual contexts. Bilingual Research Journal. 2011;34:185-200.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Carer experience **N:** 6 **Autism Population Axis I/II disorders**: 100% autism **Service user age (range[mean]):** 5-6(5.3) **Service user sex (% female):** 50 **Service user IQ:** Not reported

	Family/carer age (range[mean]): 30-50(Not reported) **Family/carer sex (% female):** 50
Outcomes	**Focus of study:** Experience of services (cultural differences)
Study Design	Qualitative
Setting	Home
Country	USA
Notes	Not applicable

1.1.53 JINDALSNAPE2005/2006

Study ID	JINDALSNAPE2005/2006
Bibliographic reference	Jindal-Snape D, Douglas W, Topping KJ, Kerr C, Smith EF. Effective education for children with autistic spectrum disorder: perceptions of parents and professionals. International Journal of Special Education. 2005;20:77-87. Jindal-Snape D, Douglas W, Topping KJ, Kerr C, Smith EF. (2006) Autism spectrum disorders and primary-secondary transition. International Journal of Special Education. 2006;21:18-31.
Methods	Data collection method: Face-to-face interview
Participants	**Population:** Service user and carer experience **N:** 5 service users; 5 carers **Autism Population** Axis I/II disorders: 80% Asperger's; 20% Autism **Service user age (range[mean]):** 12-13(12.4) **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of education/school (primary-secondary transition)
Study Design	Qualitative
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.54 JOHNSON2002

Study ID	JOHNSON2002
Bibliographic reference	Johnson E, Hastings RP. Facilitating factors and barriers to the implementation of intensive home-based behavioural intervention for young children with autism. Child: Care, Health & Development. 2002;28:123-129.
Methods	**Data collection method:** Postal survey (open-ended)
Participants	**Population:** Carer experience **N:** 141

	Autism Population Axis I/II disorders: 100% autism **Service user age (range[mean]):** Not reported(5.01) **Service user sex (% female):** 8 **Service user IQ:** Not reported **Family/carer age (range[mean]):** 26-53(37.4) **Family/carer sex (% female):** 8
Outcomes	**Focus of study:** Access to autism intervention
Study Design	Qualitative
Setting	Home
Country	UK
Notes	Not applicable

1.1.55 JONES2008A

Study ID	JONES2008A
Bibliographic reference	Jones G, Hack E. Chapter 3. Parent/carer involvement in the commissioning of services for children and young people with autism spectrum disorder in the East Midlands. Journal of Research in Special Educational Needs. 2008;8:167–182.
Methods	**Data collection method:** Interview/questionnaire
Participants	**Population:** Carer experience **N:** 43 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** Not reported **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of accessing services (commissioning and direct payments)
Study Design	Qualitative
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.56 JONES2008C

Study ID	JONES2008C
Bibliographic reference	Jones G, English A, Guldberg K, Jordan R, Richardson P, Waltz M. Educational provision for children and young people on the autism spectrum living in England: a review of current practice, issues and challenges. London: Autism Education Trust; 2008. Available from: http://www.autismeducationtrust.org.uk/resources/research.aspx.

Methods	**Data collection method:** Postal (77%) or email (23%) survey (open-ended)
Participants	**Population:** Carer experience **N:** 173 **Autism Population Axis I/II disorders**: 44% autism; 26% Asperger syndrome; 17% ASD; 6% High-functioning autism; 3% atypical autism; 3& PDD **Service user age (range[mean]):** <5-21(Not reported) **Service user sex (% female):** 92 **Service user IQ:** 31% ID **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 92
Outcomes	**Focus of study:** Experience of education/school
Study Design	Mixed method (Qualitative)
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.57 KEANE2012

Study ID	KEANE2012
Bibliographic reference	Keane E, Aldridge FJ, Costley D, Clark T. Students with autism in regular classes: a long-term follow-up study of a satellite class transtion model. International Journal of Inclusive Education. 2012;16:1001-1017.
Methods	**Data collection method:** Postal survey (open-ended)
Participants	**Population:** Carer experience **N:** 43 (for open-ended questions) **Autism Population Axis I/II disorders**: Not reported **Service user age (range[mean]):** Not reported **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of education/school (primary-secondary transition)
Study Design	Mixed method (Qualitative)
Setting	Not applicable (postal)
Country	Australia
Notes	Not applicable

1.1.58 KEENAN2010

Study ID	KEENAN2010

Bibliographic reference	Keenan M, Dillenburger K , Doherty A, Byrne T, Gallagher S. The experiences of parents during diagnosis and forward planning for children with autism spectrum disorder. Journal of Applied Research in Intellectual Disabilities. 2010;23: 390–397.
Methods	**Data collection method:** Focus group
Participants	**Population:** Carer experience **N:** Not reported ('small') **Autism Population Axis I/II disorders**: Not reported **Service user age (range[mean]):** Not reported **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of post-diagnosis information and treatment planning
Study Design	Mixed method (Qualitative)
Setting	Not reported
Country	Ireland
Notes	Not applicable

1.1.59 KERRELL2001

Study ID	KERRELL2001
Bibliographic reference	Kerrell H. Service evaluation of an autism diagnostic clinic for children. Nursing Standard. 2001;15:33-37.
Methods	**Data collection method:** Face-to-face questionnaire (open-ended)
Participants	**Population:** Carer experience **N:** 11 **Autism Population Axis I/II disorders**: 18% Asperger syndrome; 82% autism **Service user age (range[mean]):** Not reported(3.7) **Service user sex (% female):** 91 **Service user IQ:** Not reported **Family/carer age (range[mean]):** 25-42(35) **Family/carer sex (% female):** 91
Outcomes	**Focus of study:** Experience of information and support
Study Design	Qualitative
Setting	Home
Country	UK
Notes	Not applicable

1.1.60 KIDD2010

Study ID	KIDD2010
Bibliographic reference	Kidd T, Kaczmarek E. The experiences of mothers home educating their children with autism spectrum disorder. Issues in Educational Research. 2010;20:257-275.
Methods	**Data collection method:** Interview (format not reported)
Participants	**Population:** Carer experience **N:** 10 **Autism Population Axis I/II disorders**: 20% Asperger syndrome; 80% autism **Service user age (range[mean]):** 8-14(10) **Service user sex (% female):** 100 **Service user IQ:** 10% borderline ID **Family/carer age (range[mean]):** 37-46(42) **Family/carer sex (% female):** 100
Outcomes	**Focus of study:** Experience of education/school (reasons for homeschooling)
Study Design	Qualitative
Setting	Not reported
Country	Australia
Notes	Not applicable

1.1.61 KIMURA2010

Study ID	KIMURA2010
Bibliographic reference	Kimura M, Yamazaki Y, Mochizuki M, Omiya T. Can I have a second child? dilemmas of mothers of children with pervasive developmental disorder: a qualitative study. BMC Pregnancy and Childbirth. 2010;10: 69.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Carer experience **N:** 10 **Autism Population Axis I/II disorders**: 100% PDD **Service user age (range[mean]):** 7-15(10) **Service user sex (% female):** 100 **Service user IQ:** Not reported **Family/carer age (range[mean]):** 37-47(42) **Family/carer sex (% female):** 100
Outcomes	**Focus of study:** Genetic counselling
Study Design	Qualitative
Setting	Not reported
Country	Japan
Notes	Not applicable

1.1.62 KOYDEMIROZDEN2010

Study ID	KOYDEMIROZDEN2010
Bibliographic reference	Koydemir-Özden S, Tosun U. A qualitative approach to understanding Turkish mothers of children with autism: implications for counselling. Australian Journal of Guidance and Counselling. 2010;20:55-68.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Carer experience **N:** 13 **Autism Population Axis I/II disorders**: 100% autism **Service user age (range[mean]):** 7-14 (Not reported) **Service user sex (% female):** 100 **Service user IQ:** Not reported **Family/carer age (range[mean]):** 30-48 (Not reported) **Family/carer sex (% female):** 100
Outcomes	**Focus of study:** Experience of specific service (Special Education Centre)
Study Design	Qualitative
Setting	Special Education & Rehabilitation Centre
Country	Turkey
Notes	Not applicable

1.1.63 KUHANECK2010

Study ID	KUHANECK2010
Bibliographic reference	Kuhaneck HM, Burroughs T, Wright J, Lemanczyk T, Darragh AR. A qualitative study of coping in mothers of children with an autism spectrum disorder. Physical and Occupational Therapy in Pediatrics. 2010;30:340-350.
Methods	**Data collection method:** Face-to-face (91%) or telephone (9%) interview
Participants	**Population:** Carer experience **N:** 11 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 6-11(8.3) **Service user sex (% female):** 100 **Service user IQ:** Not reported **Family/carer age (range[mean]):** 40-46(42.9) **Family/carer sex (% female):** 100
Outcomes	**Focus of study:** Experience of specific intervention (support group)
Study Design	Qualitative
Setting	Home (90%) or work (10%)
Country	USA
Notes	Not applicable

1.1.64 LARSON2010

Study ID	LARSON2010
Bibliographic reference	Larson E. Ever vigilant: maternal support of participation in daily life for boys with autism. Physical and Occupational Therapy in Pediatrics. 2010;30:16-27.
Methods	**Data collection method:** Face-to-face or telephone interview
Participants	**Population:** Carer experience **N:** 9 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 3-14(Not reported) **Service user sex (% female):** 100 **Service user IQ:** Not reported **Family/carer age (range[mean]):** 27-47(Not reported) **Family/carer sex (% female):** 100
Outcomes	**Focus of study:** Barriers to accessing services (respite)
Study Design	Qualitative
Setting	Home or phone
Country	USA
Notes	Not applicable

1.1.65 LILLEY2011

Study ID	LILLEY2011
Bibliographic reference	Lilley R. Maternal intimacies: talking about autism diagnosis. Australian Feminist Studies. 2011;26:207-224.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Carer experience **N:** 13 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** Not reported **Service user sex (% female):** 100 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 100
Outcomes	**Focus of study:** Experience of information and support
Study Design	Qualitative
Setting	Home
Country	Australia
Notes	Not applicable

1.1.66 LILLY2004

Study ID	LILLY2004
Bibliographic reference	Lilly JD, Reed D, Wheeler KG. Perceptions of psychological contract violations in school districts that serve children with autism spectrum disorder. Journal of Applied School Psychology. 2004;20:27-45.
Methods	**Data collection method:** Interview (format not reported)
Participants	**Population:** Carer experience **N:** 5 **Autism Population Axis I/II disorders**: Not reported **Service user age (range[mean]):** Upper range: 12 **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of education/school (ARD meetings)
Study Design	Qualitative
Setting	Not reported
Country	USA
Notes	Not applicable

1.1.67 LIN2008

Study ID	LIN2008
Bibliographic reference	Lin C, Tsai Y, Chang H. Coping mechanisms of parents recently diagnosed with autism in Taiwan: a qualitative study. Journal of Clinical Nursing. 2008;17:2733-2740.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Carer experience **N:** 17 **Autism Population Axis I/II disorders**: 100% autism **Service user age (range[mean]):** Not reported(4.5) **Service user sex (% female):** 76 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 76
Outcomes	**Focus of study:** Experience of specific intervention (support group)
Study Design	Qualitative
Setting	Hospital
Country	Taiwan
Notes	Not applicable

1.1.68 LUONG2009

Study ID	LUONG2009
Bibliographic reference	Luong J, Yoder MK, Canham D. Southeast asian parents raising a child with autism: a qualitative investigation of coping styles. The Journal of School Nursing. 2009;25:222-229.
Methods	**Data collection method:** Face-to-face (78%) or telephone (22%) interview
Participants	**Population:** Carer experience **N:** 9 **Autism Population Axis I/II disorders**: 100% autism **Service user age (range[mean]):** 3-10(Not reported) **Service user sex (% female):** 89 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 89
Outcomes	**Focus of study:** Experience of specific intervention (treatment planning)
Study Design	Qualitative
Setting	Not reported
Country	USA
Notes	Not applicable

1.1.69 MACKINTOSH2012

Study ID	MACKINTOSH2012
Bibliographic reference	Mackintosh VH, Goin-Kochel RP, Myers BJ. "What do you like/dislike about the treatments you're currently using?": a qualitative study of parents of children with autism spectrum disorders. Focus on Autism and Other Developmental Disabilities. 2012;27:51-60.
Methods	**Data collection method:** Online survey (open-ended)
Participants	**Population:** Carer experience **N:** 486 **Autism Population Axis I/II disorders**: 59.7% autism; 23.6% Asperger syndrome; 16.7% PDD-NOS **Service user age (range[mean]):** 2-21 (8.3) **Service user sex (% female):** 20 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported (37.8) **Family/carer sex (% female):** 92
Outcomes	**Focus of study:** Experience of treatment/care
Study Design	Mixed method (Qualitative)
Setting	Not applicable (online)
Country	77% USA; 5.6% Canada; 2.4% Australia; 1.5% New Zealand; 3.4% England; 3.2% Ireland; 1.5% Other
Notes	Not applicable

1.1.70 MANSELL2004

Study ID	MANSELL2004
Bibliographic reference	Mansell W, Morris K. A survey of parent's reactions to the diagnosis of an autistic spectrum disorder by a local service: access to information and use of services. Autism. 2004;8:387-407.
Methods	**Data collection method:** Postal survey (open-ended)
Participants	**Population:** Carer experience **N:** 55 **Autism Population Axis I/II disorders**: 33% Asperger syndrome; 44% autism; 22% ASD-NOS **Service user age (range[mean]):** Not reported **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of accessing information and services
Study Design	Mixed method (Qualitative)
Setting	Home
Country	UK
Notes	Not applicable

1.1.71 MCCABE2008A

Study ID	MCCABE2008A
Bibliographic reference	McCabe H. Autism and family in the People's Republic of China: learning from parents' perspectives. Research and Practice for Persons with Severe Disabilities. 2008;33: 37-47.
Methods	**Data collection method:** Survey (open-ended) and face-to-face follow-up interview (for 17% of sample)
Participants	**Population:** Carer experience **N:** 78 (for survey); 13 (for interview) **Autism Population Axis I/II disorders**: 100% Autism **Service user age (range[mean]):** 3-12 (Not reported) **Service user sex (% female):** 90 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 90
Outcomes	**Focus of study:** Experience of information and support
Study Design	Qualitative
Setting	Not reported
Country	China
Notes	Not applicable

1.1.72 MCCABE2008B

Study ID	MCCABE2008B
Bibliographic reference	McCabe H. The importance of parent-to-parent support among families of children with autism in the People's Republic of China. International Journal of Disability, Development and Education. 2008; 55:303-314.
Methods	**Data collection method:** Face-to-face interview and follow-up survey (open-ended)
Participants	**Population:** Carer experience **N:** 43 **Autism Population Axis I/II disorders**: 98% autism, 2% autistic tendencies **Service user age (range[mean]):** 3-11 (5.2) **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of specific intervention (parent-parent support during parent training intervention)
Study Design	Qualitative
Setting	Not reported
Country	China
Notes	Not applicable

1.1.73 MCCONKEY2011

Study ID	MCCONKEY2011
Bibliographic reference	McConkey R, MacLeod S, Cassidy A. The Keyhole® Rainbow Resource Kit: meeting the needs of parents of newly diagnosed preschoolers with ASD. Early Child Development and Care. 2011; 181:321-334.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Carer experience **N:** 29 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 2.3-4.9 (3.6) **Service user sex (% female):** 100 **Service user IQ:** Not reported **Family/carer age (range[mean]):** 30-39 (76%); >40 (7%); <30 (7%) **Family/carer sex (% female):** 100
Outcomes	**Focus of study:** Experience of specific intervention (Keyhole rainbow resource kit)
Study Design	Qualitative
Setting	Home (90%) or nursery (10%)

Country	UK
Notes	Not applicable

1.1.74 MEIRSSCHAUT2010

Study ID	MEIRSSCHAUT2010
Bibliographic reference	Meirsschaut M, Roeyers H, Warreyn P. Parenting in families with a child with autism spectrum disorder and a typically developing child: mother's experiences and cognitions. Research in Autism Spectrum Disorders. 2010;4:661-669.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Carer experience **N:** 17 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 3.8-7(5.7) **Service user sex (% female):** 100 **Service user IQ:** Not reported **Family/carer age (range[mean]):** 27-47(34) **Family/carer sex (% female):** 100
Outcomes	**Focus of study:** Experience of information and support
Study Design	Qualitative
Setting	Not reported
Country	Belgium
Notes	Not applicable

1.1.75 MIDENCE1999

Study ID	MIDENCE1999
Bibliographic reference	Midence K, O'Neill M. The experience of parents in the diagnosis of autism: a pilot study. Autism. 1999;3:273-285.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Carer experience **N:** 6 **Autism Population Axis I/II disorders**: 100% autism **Service user age (range[mean]):** 9-12(Not reported) **Service user sex (% female):** 50 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 50
Outcomes	**Focus of study:** Experience of post-diagnosis support
Study Design	Qualitative
Setting	Not reported

Country	UK
Notes	Not applicable

1.1.76 MINNES2009

Study ID	MINNES2009
Bibliographic reference	Minnes P, Steiner K. Parent views on enhancing the quality of health care for their children with fragile X syndrome, autism or down syndrome. Child: Care, Health & Development. 2009;35:250-256.
Methods	**Data collection method:** Focus group interview
Participants	**Population:** Carer experience **N:** 3 **Autism Population Axis I/II disorders**: 100% autism **Service user age (range[mean]):** 6-8(Not reported) **Service user sex (% female):** 100 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 100
Outcomes	**Focus of study:** Experience of accessing information and services
Study Design	Qualitative
Setting	Not reported
Country	Canada
Notes	Not applicable

1.1.77 MORRISON2009

Study ID	MORRISON2009
Bibliographic reference	Morrison JQ, Sansosti FJ, Hadley WM. Parent perceptions of the anticipated needs and expectations for support for their college-bound students with Asperger's syndrome. Journal of Post-secondary Education and Disability. 2009;22:78-87.
Methods	**Data collection method:** Focus group
Participants	**Population:** Carer experience **N:** 4 **Autism Population Axis I/II disorders**: 100% Asperger syndrome **Service user age (range[mean]):** 8-16(13) **Service user sex (% female):** 100 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 100
Outcomes	**Focus of study:** Experience of education/school (secondary-university transition)
Study Design	Qualitative

Setting	University
Country	USA
Notes	Not applicable

1.1.78 MOYSON2011

Study ID	MOYSON2011
Bibliographic reference	Moyson T, Roeyers H. The quality of life of siblings of children with autism spectrum disorder. Exceptional Children. 2011;78:41-55.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Sibling experience **N:** 17 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 5-16(9.65) **Service user sex (% female):** 59 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported(10.41) **Family/carer sex (% female):** 59
Outcomes	**Focus of study:** Experience of support
Study Design	Qualitative
Setting	Home
Country	Belgium
Notes	Not applicable

1.1.79 MULLIGAN2010

Study ID	MULLIGAN2010
Bibliographic reference	Mulligan J, Steel L, Macculloch R, Nicholas D. Evaluation of an information resource for parents of children with autism spectrum disorder. Autism. 2010;14:113-126.
Methods	**Data collection method:** Focus group
Participants	**Population:** Carer experience **N:** 9 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 5-13(Not reported) **Service user sex (% female):** 100 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 100
Outcomes	**Focus of study:** Experience of post-diagnosis information
Study Design	Qualitative
Setting	Not reported
Country	Canada
Notes	Not applicable

1.1.80 MYERS2009

Study ID	MYERS2009
Bibliographic reference	Myers BJ, Mackintosh VH, Goin-Kochel RP. "My greatest joy and my greatest heart ache:" parents' own words on how having a child in the autism spectrum has affected their lives and their families' lives. Research in Autism Spectrum Disorders. 2009;3:670-684.
Methods	**Data collection method:** Online survey (open-ended)
Participants	**Population:** Carer experience **N:** 493 **Autism Population Axis I/II disorders**: 23.5% Asperger syndrome; 59.8% autism; 16.6% PDD-NOS **Service user age (range[mean]):** <21; 75% 3-11 (8.6) **Service user sex (% female):** 92.2 **Service user IQ:** Not reported **Family/carer age (range[mean]):** 22-72(38) **Family/carer sex (% female):** 92.2
Outcomes	**Focus of study:** Experience of services
Study Design	Qualitative
Setting	Not reported
Country	USA
Notes	Not applicable

1.1.81 NASUNO2003

Study ID	NASUNO2003
Bibliographic reference	Nasuno M, Takeuchi K, Yamamoto J. Feasibility of parents of children with autism using an applied behaviour analytic early treatment program: a preliminary study in Malaysia. Japanese Journal of Special Education. 2003;40:723-732.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Carer experience **N:** 8 **Autism Population Axis I/II disorders**: 100% autism **Service user age (range[mean]):** Not reported **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of specific intervention (ABA)
Study Design	Qualitative
Setting	Not reported
Country	Malaysia
Notes	Not applicable

1.1.82 NASUNPUBLISHED

Study ID	NASUNPUBLISHED
Bibliographic reference	National Autistic Society. Child mental health research report; Unpublished.
Methods	**Data collection method:** Face-to-face interview (100% for service users; 4% for carers) and focus group (96% for carers)
Participants	**Population:** Service user and carer experience **N:** 14 service users; 23 carers **Autism Population Axis I/II disorders**: 100% ASD (participants had experienced one or more coexisting mental health problem including anxiety, depression, ADHD, OCD, PTSD, psychosis, self-harm, delusions, phobias, eating disorders, suicidal thoughts and attempted suicide, pathological demad avo **Service user age (range[mean]):** Not reported **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of CAMHS
Study Design	Mixed method (Qualitative)

Setting	Not reported
Country	UK
Notes	Not applicable

1.1.83 NICHOLS2010

Study ID	NICHOLS2010
Bibliographic reference	Nichols S, Blakeley-Smith A. "I'm not sure we're ready for this…": working with families toward facilitating healthy sexuality for individuals with autism spectrum disorders. Social Work in Mental Health. 2010;8:72-91.
Methods	**Data collection method:** Focus group
Participants	**Population:** Carer experience **N:** 21 **Autism Population Axis I/II disorders**: 38% Asperger syndrome; 52% autism; 10% PDD-NOS **Service user age (range[mean]):** 8-18(13) **Service user sex (% female):** 95 **Service user IQ:** 15% FIQ<65; 20% FIQ>115; 30% FIQ 65-84; 35% FIQ 85-114 **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 95
Outcomes	**Focus of study:** Unmet needs and experience of specific intervention (parent training for dealing with sexuality of their child)
Study Design	Qualitative
Setting	Not reported
Country	USA
Notes	Not applicable

1.1.84 NISSENBAUM2002

Study ID	NISSENBAUM2002
Bibliographic reference	Nissenbaum MS, Tollefson N, Reese RM. The interpretative conference: sharing a diagnosis of autism with families. Focus on Autism and Other Developmental Disabilities. 2002;17:30-43.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Carer experience **N:** 17 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** Not reported **Service user sex (% female):** 88 **Service user IQ:** Not reported **Family/carer age (range[mean]):** 22-43 (35.5) **Family/carer sex (% female):** 88
Outcomes	**Focus of study:** Experience of post-diagnosis information and support

Study Design	Qualitative
Setting	Home
Country	USA
Notes	Not applicable

1.1.85 OLIVIER2009

Study ID	OLIVIER2009
Bibliographic reference	Olivier MA, Hing ADA. Autistic spectrum disorder (ASD): parental challenges and strategies. Vulnerable Children and Youth Studies. 2009;4:58-66.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Carer experience **N:** 8 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** Not reported **Service user sex (% female):** 25 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 25
Outcomes	**Focus of study:** Experience of unmet needs
Study Design	Qualitative
Setting	Home
Country	South Africa
Notes	Not applicable

1.1.86 OSBORNE2008

Study ID	OSBORNE2008
Bibliographic reference	Osborne LA, Reed P. Parents' perceptions of communication with professionals during the diagnosis of autism. Autism. 2008;12:309-324.
Methods	**Data collection method:** Focus group
Participants	**Population:** Carer experience **N:** 70 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** Not reported **Service user sex (% female):** 80 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 80
Outcomes	**Focus of study:** Experience of post-diagnosis information and support
Study Design	Qualitative
Setting	Not reported

Country	UK
Notes	Not applicable

1.1.87 PARSONS2009A

Study ID	PARSONS2009A
Bibliographic reference	Parsons S, Lewis A, Ellins J. The views and experiences of parents of children with autistic spectrum disorder about educational provision: comparisons with parents of children with other disabilities from an online survey. European Journal of Special Needs Education. 2009;24:37-58.
Methods	**Data collection method:** Online survey (open-ended)
Participants	**Population:** Carer experience **N:** 66 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 5-24(Not reported) **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of education/school
Study Design	Qualitative
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.88 PATTERSON2011

Study ID	PATTERSON2011
Bibliographic reference	Patterson SY, Smith V. The experience of parents of toddlers diagnosed with autism spectrum disorder in the More Than Words parent education program. Infants and Young Children. 2011;24:329-343.
Methods	**Data collection method:** Face-to-face interview and focus group
Participants	**Population:** Carer experience **N:** 8 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 2-3(2.6) **Service user sex (% female):** 63 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 63
Outcomes	**Focus of study:** Experience of specific intervention (Hanen More than Words)
Study Design	Qualitative

Setting	Home (interview); University (focus group)
Country	Not reported
Notes	Not applicable

1.1.89 PETALAS2009

Study ID	PETALAS2009
Bibliographic reference	Petalas MA, Hastings RP, Nash S, Dowey A, Reilly D. "I like that he always shows who he is": the perceptions and experiences of siblings with a brother with autism spectrum disorder. International Journal of Disability, Development and Education. 2009;56:381-399.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Sibling experience **N:** 8 **Autism Population Axis I/II disorders**: 38% ASD; 62% Asperger syndrome **Service user age (range[mean]):** 8-17(11.99) **Service user sex (% female):** 62 **Service user IQ:** 38% ID **Family/carer age (range[mean]):** 9-12(11.19) **Family/carer sex (% female):** 62
Outcomes	**Focus of study:** Experience of support
Study Design	Qualitative
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.90 PHELPS2009

Study ID	PHELPS2009
Bibliographic reference	Phelps KW, Hodgson JL, McCammon SL, Lamson AL. Caring for an individual with autism disorder: a qualitative analysis. Journal of Intellectual and Developmental Disability. 2009;34:27-35.
Methods	**Data collection method:** Postal survey (open-ended)
Participants	**Population:** Carer experience **N:** 80 **Autism Population Axis I/II disorders**: 100% autism **Service user age (range[mean]):** 3-35(10.75) **Service user sex (% female):** 97 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 97
Outcomes	**Focus of study:** Experience of support

Study Design	Qualitative
Setting	Not reported
Country	USA
Notes	Not applicable

1.1.91 PICKERING2005

Study ID	PICKERING2005
Bibliographic reference	Pickering A, Goode S. Family-centred approach to information provision for families with a child diagnosed with an autistic spectrum disorder. Clinical Psychology Forum. 2005;155:12-15.
Methods	**Data collection method:** Survey (open-ended)
Participants	**Population:** Carer experience **N:** 20 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** Not reported **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of post-diagnosis information and support
Study Design	Mixed method (Qualitative)
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.92 PREECE2009A

Study ID	PREECE2009A
Bibliographic reference	Preece D, Jordan R. Obtaining the views of children and young people with autism spectrum disorders about their experience of daily life and social care support. British Journal of Learning Disabilities. 2009;38:10-20.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Service user experience **N:** 14 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 7-18(12.5) **Service user sex (% female):** n/a **Service user IQ:** 7% severe ID **Family/carer age (range[mean]):** n/a **Family/carer sex (% female):** n/a
Outcomes	**Focus of study:** Experience of residential setting (short breaks)

Study Design	Qualitative
Setting	Home
Country	UK
Notes	Not applicable

1.1.93 PRUNTY2011

Study ID	PRUNTY2011
Bibliographic reference	Prunty A. Implementation of children's rights: what is in 'the best interests of the child' in relation to the individual education plan (IEP) process for pupils with autistic spectrum disorders (ASD)? Irish Educational Studies. 2011;30:23-44.
Methods	**Data collection method:** Focus group
Participants	**Population:** Service user and carer experience **N:** 3 service users; 5 carers **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 8-10(9) **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of education/school (IEP)
Study Design	Qualitative
Setting	School
Country	Ireland
Notes	Not applicable

1.1.94 REID2011

Study ID	REID2011
Bibliographic reference	Reid B. Great expectations: the chance of a lifetime for children with autism. London: National Autistic Society; 2011.
Methods	**Data collection method:** Focus group and online survey (open-ended)
Participants	**Population:** Service user and carer experience **N:** Focus group (7 service users; Not reported carers); Survey (295 service users; 739 carers) **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 13-20(Not reported) for focus group; <19 for survey **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported

Outcomes	**Focus of study:** Experience of education/school
Study Design	Mixed method (Qualitative)
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.95 RENTY2006A

Study ID	RENTY2006A
Bibliographic reference	Renty J, Roeyers H. Satisfaction with formal support and education for children with autism spectrum disorder: the voices of the parents. Child: Care, Health & Development. 2006;32:371-385.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Carer experience **N:** 15 **Autism Population Axis I/II disorders**: 20% Autistic disorder; 53% ASD; 20% PDD-NOS; 7% Asperger's disorder **Service user age (range[mean]):** 4-18(10.8) **Service user sex (% female):** Not reported **Service user IQ:** 13% mild ID; 27% moderate ID; 7% severe ID **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of education/school
Study Design	Mixed method (Qualitative)
Setting	Not reported
Country	Belgium
Notes	Not applicable

1.1.96 RYAN2009

Study ID	RYAN2009
Bibliographic reference	Ryan S, Cole SR. From advocate to activist? mapping the experiences of mothers of children on the autism spectrum. Journal of Applied Research in Intellectual Disabilities. 2009;22:43-53.
Methods	**Data collection method:** Interview (format not reported)
Participants	**Population:** Carer experience **N:** 2 (full sample was N=36 but mixed age population and only disaggregated <19 year-old data extracted) **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 5-15(10) **Service user sex (% female):** 100 **Service user IQ:** Not reported

	Family/carer age (range[mean]): Not reported **Family/carer sex (% female):** 100
Outcomes	**Focus of study:** Experience of specific intervention (support group)
Study Design	Qualitative
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.97 SANSOSTI2012

Study ID	SANSOSTI2012
Bibliographic reference	Sansosti FJ, Lavik KB, Sansosti JM. Family experiences through the autism diagnostic process. Focus on Autism and Other Developmental Disabilities. 2012;27:81-92.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Carer experience **N:** 16 **Autism Population Axis I/II disorders**: 56% autistic disorder; 38% Asperger disorder; 6% PDD-NOS **Service user age (range[mean]):** 2-6 (5.4) **Service user sex (% female):** 25 **Service user IQ:** Not reported **Family/carer age (range[mean]):** 31-35 (Not reported) **Family/carer sex (% female):** 81
Outcomes	**Focus of study:** Experience of post-diagnosis information and support
Study Design	Mixed method (Qualitative)
Setting	62.5% University; 37.5% public place at request of family (e.g. library)
Country	USA
Notes	Not applicable

1.1.98 SELKIRK2009

Study ID	SELKIRK2009
Bibliographic reference	Selkirk CG, McCarthy Veach P, Lian F, Schimmenti L, LeRoy BS. Parents' perceptions of autism spectrum disorder etiology and recurrence risk and effects of their perceptions on family planning: recommendations for genetic counselors. Journal of Genetic Counselling. 2009;18:507-519.
Methods	**Data collection method:** Online survey (open-ended)
Participants	**Population:** Carer experience **N:** 255 **Autism Population Axis I/II disorders**: 39.4% Asperger syndrome; 41.6% autism; 17.9 % PDD-NOS **Service user age (range[mean]):** Not reported

	Service user sex (% female): 92.1 **Service user IQ:** Not reported **Family/carer age (range[mean]):** 26->60(42.4) **Family/carer sex (% female):** 92.1
Outcomes	**Focus of study:** Suggested improvements for genetic couselling
Study Design	Qualitative
Setting	Not reported
Country	USA
Notes	Not applicable

1.1.99 SERPENTINE2011

Study ID	SERPENTINE2011
Bibliographic reference	Serpentine EC, Tarnai B, Drager KDR, Finke EH. Decision making of parents of children with autism spectrum disorder concerning augmentative and alternative communication in Hungary. Communication Disorders Quarterly. 2011;32:221-231.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Carer experience **N:** 10 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 6-14(Not reported) **Service user sex (% female):** 0 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 0
Outcomes	**Focus of study:** Experience of specific interventions (interventions aimed at communication)
Study Design	Qualitative
Setting	Service
Country	Hungary
Notes	Not applicable

1.1.100 SHYU2010

Study ID	SHYU2010
Bibliographic reference	Shyu YL, Tsai J, Tsai W. Explaining and selecting treatments for autism: parental explanatory models in Taiwan. Journal of Autism and Developmental Disorders. 2010;40:1323-1331.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Carer experience **N:** 13

	Autism Population Axis I/II disorders: 100% autism **Service user age (range[mean]):** 3-7.42(4.66) **Service user sex (% female):** 92 **Service user IQ:** 69% ID **Family/carer age (range[mean]):** 34-45(37.38) **Family/carer sex (% female):** 92
Outcomes	**Focus of study:** Experience of interventions
Study Design	Qualitative
Setting	Home or place of parental choosing
Country	Taiwan
Notes	Not applicable

1.1.101 ROSE2009

Study ID	ROSE2009
Bibliographic reference	Rose R, Anketell C. The benefits of social skills groups for young people with autism spectrum disorder: a pilot study. Child Care in Practice. 2009;15:127-144.
Methods	**Data collection method:** Focus group and survey (open-ended)
Participants	**Population:** Service user and carer experience **N:** 31 service users; 5 carers **Autism Population Axis I/II disorders**: 80% Asperger's; 20% Autism **Service user age (range[mean]):** 6-13(Not reported) **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of specific intervention (social skills group)
Study Design	Qualitative
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.102 SMYTH2010

Study ID	SMYTH2010
Bibliographic reference	Smyth C, Slevin E. Experiences of family life with an autism assistance dog. Learning Disability Practice. 2010;13:12-17.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Carer experience **N:** 7 **Autism Population Axis I/II disorders**: 100% autism

	Service user age (range[mean]): 5-12(8.3) **Service user sex (% female):** 57 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 57
Outcomes	**Focus of study:** Experience of specific intervention (service dog)
Study Design	Qualitative
Setting	Home or workplace
Country	Ireland
Notes	Not applicable

1.1.103 SPANN2003

Study ID	SPANN2003
Bibliographic reference	Spann SJ, Kohler FW, Soenksen D. Families in a parent support group examining parents' involvement in and perceptions of special education services : an interview with families in a parent support group. Focus on Autism and Other Developmental Disabilities. 2003;18:228-237.
Methods	**Data collection method:** Telephone interview
Participants	**Population:** Carer experience **N:** 45 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 4-18 (Not reported) **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of education/school
Study Design	Qualitative
Setting	Not reported
Country	USA
Notes	Not applicable

1.1.104 SPERRY1999

Study ID	SPERRY1999
Bibliographic reference	Sperry LA, Whaley KT, Shaw E, Brame K. Services for young children with autism spectrum disorder: voices of parents and providers. Infants and Young Children. 1999;11:17-33.
Methods	**Data collection method:** Focus group
Participants	**Population:** Carer experience **N:** 30

	Autism Population Axis I/II disorders: 100% ASD **Service user age (range[mean]):** 2-2.5(Not reported) **Service user sex (% female):** 93 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 93
Outcomes	**Focus of study:** Suggested improvements for information and support
Study Design	Qualitative
Setting	Not reported
Country	USA
Notes	Not applicable

1.1.105 STARR2001

Study ID	STARR2001
Bibliographic reference	Starr EM, Foy JB, Cramer KM. Parental perceptions of the education of children with pervasive developmental disorders. Education and Training in Mental Retardation and Developmental Disabilities. 2001;36:55-68.
Methods	**Data collection method:** Survey (open-ended)
Participants	**Population:** Carer experience **N:** 69 **Autism Population Axis I/II disorders**: 21.7% Asperger syndrome; 26.1% autism; 44.9% PDD; 7.2% PDD-NOS **Service user age (range[mean]):** 4-19(10.4) **Service user sex (% female):** 88.2 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 88.2
Outcomes	**Focus of study:** Experience of education/school
Study Design	Mixed method (Qualitative)
Setting	Conference
Country	Canada
Notes	Not applicable

1.1.106 STARR2012

Study ID	STARR2012
Bibliographic reference	Starr EM, Foy JB. In parents' voices: the education of children with autism spectrum disorders. Remedial and Special Education. 2012;33:207-216.
Methods	**Data collection method:** Postal survey (open-ended)
Participants	**Population:** Carer experience **N:** 144

	Autism Population Axis I/II disorders: Not reported **Service user age (range[mean]):** 4-18 (8.75) **Service user sex (% female):** 17 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 90
Outcomes	**Focus of study:** Experience of education/school
Study Design	Mixed method (Qualitative)
Setting	Not applicable (postal)
Country	Canada
Notes	Not applicable

1.1.107 STEIN2012

Study ID	STEIN2012
Bibliographic reference	Stein LI, Polido JC, Cermak SA. Oral care and sensory concerns in autism. American Journal of Occupational Therapy. 2012;66:e73-e76.
Methods	**Data collection method:** Focus group
Participants	**Population:** Carer experience **N:** 5 **Autism Population Axis I/II disorders**: Not reported **Service user age (range[mean]):** 6-18 (Not reported) **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 100
Outcomes	**Focus of study:** Experience of primary care (dentist)
Study Design	Mixed method (Qualitative)
Setting	Not reported
Country	USA
Notes	Not applicable

1.1.108 STIRLING1999

Study ID	STIRLING1999
Bibliographic reference	Stirling A, Prior A. Opening the door: a report on diagnosis and assessment of autism and Asperger syndrome based on personal experiences. London: National Autistic Society; 1999.
Methods	**Data collection method:** Postal survey (open-ended)
Participants	**Population:** Carer experience **N:** 294 **Autism Population Axis I/II disorders**: 76% ASD

	Service user age (range[mean]): 1-31+(Not reported) **Service user sex (% female):** Not reported **Service user IQ:** 11% ID **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of post-diagnosis information and support
Study Design	Mixed method (Qualitative)
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.109 STONER2005/2006/2007

Study ID	STONER2005/2006/2007
Bibliographic reference	Stoner JB, Bock SJ, Thompson JR, Angell ME, Heyl BS, Crowley EP. Welcome to our world: parent perceptions of interactions between parents of young children with ASD and education professionals. Focus on Autism and Other Developmental Disabilities. 2005;20:39-51 Stoner JB, Angell ME. Parent perspectives on role engagement:an investigation of parents of children with ASD and their self-reported roles with education professionals. Focus on Autism and Other Developmental Disabilities,2006;20:39-51 Stoner JB, Angell ME, House JJ, Bock SJ. Transitions: perspectives from parents of young children with autism spectrum disorder (ASD). Journal of Developmental and Physical Disabilities. 2007;19:23-39.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Carer experience **N:** 8 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 6-8 (7) **Service user sex (% female):** 50 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 50
Outcomes	**Focus of study:** Experience of education/school (IEP)
Study Design	Qualitative
Setting	Not reported
Country	USA
Notes	Not applicable

1.1.110 STUART2006

Study ID	STUART2006
Bibliographic reference	Stuart SK, Flis LD, Rinaldi C. Connecting with familes: parents speak up about preschool services for their children with autism spectrum disorders. Teaching Exceptional Children. 2006;39:46-51.
Methods	**Data collection method:** Postal survey (open-ended)
Participants	**Population:** Carer experience **N:** 24 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** Not reported **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of education/school (specialist preschool program)
Study Design	Mixed method (Qualitative)
Setting	Not reported
Country	USA
Notes	Not applicable

1.1.111 TIPPETT2004

Study ID	TIPPETT2004
Bibliographic reference	Tippett J. The educational experiences of students with Asperger syndrome. Kairaranga. 2004;5:12-18.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Service user and carer experience **N:** 3 service users; 3 carers **Autism Population Axis I/II disorders**: 100% Asperger syndrome **Service user age (range[mean]):** 6-12(8.67) **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of education/school
Study Design	Qualitative
Setting	Not reported
Country	New Zealand
Notes	Not applicable

1.1.112 TISSOT2006/2011

Study ID	TISSOT2006/2011
Bibliographic reference	Tissot C, Evans R. Securing provision for children with autistic spectrum disorders: the views of parents. Perspectives in Education. 2006;24:73-86. Tissot C. Working together? parent and local authority views on the process of obtaining appropriate educational provision for children with autism spectrum disorders. Educational Research. 2011;53:1–15.
Methods	**Data collection method:** Survey (open-ended)
Participants	**Population:** Carer experience **N:** 738 **Autism Population Axis I/II disorders**: 96% ASD **Service user age (range[mean]):** Mean: 8-9 **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of education/school (obtaining appropriate educational provision)
Study Design	Mixed method (Qualitative)
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.113 TOBIAS2009

Study ID	TOBIAS2009
Bibliographic reference	Tobias A. Supporting students with autistic spectrum disorder (ASD) at secondary school: a parent and student perspective. Educational Psychology in Practice. 2009;2:151-165.
Methods	**Data collection method:** Focus group
Participants	**Population:** Service user and carer experience **N:** 10 service users; 5 carers **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 14-16(Not reported) **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of education/school
Study Design	Qualitative
Setting	Not reported

Country	UK
Notes	Not applicable

1.1.114 TRUDGEON2007

Study ID	TRUDGEON2007
Bibliographic reference	Trudgeon C, Carr D. The impacts of home-based early behavioural intervention programmes on families of children with autism. Journal of Applied Research in Intellectual Disabilities. 2007;20:285-296.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Carer experience **N:** 16 **Autism Population Axis I/II disorders**: 100% autism **Service user age (range[mean]):** 4-9(Not reported) **Service user sex (% female):** 56 **Service user IQ:** 56% moderate LD and 22% mild LD (based on parental report) **Family/carer age (range[mean]):** 31-45(Not reported) **Family/carer sex (% female):** 56
Outcomes	**Focus of study:** Experience of specific intervention (EIBI)
Study Design	Qualitative
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.115 VALENTINE2010

Study ID	VALENTINE2010
Bibliographic reference	Valentine K. A consideration of medicalisation: choice, engagement and other responsibilities of parents of children with autism spectrum disorder. Social Science and Medicine. 2010;71:950-957.
Methods	**Data collection method:** Face-to-face or telephone interview
Participants	**Population:** Carer experience **N:** 32 **Autism Population Axis I/II disorders**: 100% autism **Service user age (range[mean]):** Modal age 3-5 years **Service user sex (% female):** 94 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 94
Outcomes	**Focus of study:** Experience of treatment/care information and support
Study Design	Qualitative

Setting	Not reported
Country	Australia
Notes	Not applicable

1.1.116 WADDINGTON2006

Study ID	WADDINGTON2006
Bibliographic reference	Waddington EM, Reed P. Parents' and local education authority officers' perceptions of the factors affecting the success of inclusion of pupils with autistic spectrum disorders. International Journal of Special Education. 2006;21:151-164.
Methods	**Data collection method:** Focus group
Participants	**Population:** Carer experience **N:** 23 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** Not reported **Service user sex (% female):** 87 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 87
Outcomes	**Focus of study:** Experience of education/school (inclusion)
Study Design	Qualitative
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.117 WEBSTER2003/2004

Study ID	WEBSTER2003/2004
Bibliographic reference	Webster A, Feiler A, Webster V. Early intensive family intervention and evidence of effectiveness: lessons from the South West autism programme. Early Child Development and Care. 2003;173:383-398. Webster A, Feiler A, Webster V, Lovell C. Parental perspectives on early intensive intervention for children diagnosed with autistic spectrum disorder. Journal of Early Childhood Research. 2004;2:25-49.
Methods	**Data collection method:** Face-to-face interview and survey (open-ended)
Participants	**Population:** Carer experience **N:** 15 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 2-6 (5.1) **Service user sex (% female):** Not reported **Service user IQ:** Not reported

	Family/carer age (range[mean]): Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of specific intervention (EIBI)
Study Design	Qualitative
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.118 WEIDLE2006

Study ID	WEIDLE2006
Bibliographic reference	Weidle B, Bolme B, Hoeyland AL. Are peer support groups for adolescents with Asperger's syndrome helpful? Clinical Child Psychology and Psychiatry. 2006;11:45-67.
Methods	**Data collection method:** Survey (open-ended)
Participants	**Population:** Service user and carer experience **N:** 21 **Autism Population Axis I/II disorders**: 100% Asperger syndrome **Service user age (range[mean]):** 11-16(13) **Service user sex (% female):** Not reported **Service user IQ:** 70-142(108) **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of specific intervention (support group)
Study Design	Mixed method (Qualitative)
Setting	Not reported
Country	Norway
Notes	Not applicable

1.1.119 WELSHASSEMBLY2006

Study ID	WELSHASSEMBLY2006
Bibliographic reference	Welsh Assembly Government New Ideas Research Fund. Identifying and supporting people with autistic spectrum disorders within the youth justice system in Wrexham and Flintshire. Wales: Wales' National Charity for Autism; 2006.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Service user experience **N:** Not reported **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** Not reported (secondary school) **Service user sex (% female):** n/a

	Service user IQ: Not reported **Family/carer age (range[mean]):** n/a **Family/carer sex (% female):** n/a
Outcomes	**Focus of study:** Unmet needs (Criminal Justice System)
Study Design	Qualitative
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.120 WHITAKER2002

Study ID	WHITAKER2002
Bibliographic reference	Whitaker P. Supporting families of preschool children with autism: what parents want and what helps. Autism. 2002;6:411-426.
Methods	**Data collection method:** Face-to-face interview (open questions)
Participants	**Population:** Carer experience **N:** 18 **Autism Population Axis I/II disorders**: 22% Asperger syndrome; 22% autism; 56% ASD **Service user age (range[mean]):** Not reported **Service user sex (% female):** 100 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 100
Outcomes	**Focus of study:** Experience of specific intervention (EarlyBird)
Study Design	Mixed method (Qualitative)
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.121 WHITAKER2007

Study ID	WHITAKER2007
Bibliographic reference	Whitaker P. Provision for youngsters with autistic spectrum disorders in mainstream schools: what parents say - and what parents want. British Journal of Special Education. 2007;34:170-178.
Methods	**Data collection method:** Postal survey (open-ended)
Participants	**Population:** Carer experience **N:** 172 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** Not reported **Service user sex (% female):** Not reported

	Service user IQ: Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of education/school
Study Design	Mixed method (Qualitative)
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.122 WHITTINGHAM2006

Study ID	WHITTINGHAM2006
Bibliographic reference	Whittingham K, Sofronoff K, Sheffield JK. Stepping Stones Triple P: a pilot study to evaluate acceptability of the program by parents of a child diagnosed with an autism spectrum disorder. Research in Developmental Disabilities. 2006;27:364-380.
Methods	**Data collection method:** Focus group
Participants	**Population:** Carer experience **N:** 4 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** Not reported(10.25) **Service user sex (% female):** 100 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 100
Outcomes	**Focus of study:** Experience of specific intervention (Stepping Stones Triple P)
Study Design	Qualitative
Setting	Not reported
Country	Australia
Notes	Not applicable

1.1.123 WHITTINGHAM2009

Study ID	WHITTINGHAM2009
Bibliographic reference	Whittingham K, Sofronoff K, Sheffield J, Sanders MR. Behavioural family intervention with parents of children with ASD: what do they find useful in the parenting programme stepping stones triple p? Research in Autism Spectrum Disorders. 2009;3:702-713.
Methods	**Data collection method:** Survey (open-ended)
Participants	**Population:** Carer experience **N:** 59 **Autism Population Axis I/II disorders**: 38% ASD; 14% autism; 41%

	Asperger's; 7% ASD-NOS **Service user age (range[mean]):** Not reported (5.62) **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of specific intervention (Stepping Stones Triple P)
Study Design	Mixed method (Qualitative)
Setting	Not reported
Country	Australia
Notes	Not applicable

1.1.124 WILLIAMS2003

Study ID	WILLIAMS2003
Bibliographic reference	Williams KR, Wishart JG. The Son-Rise Program intervention for autism: an investigation into family experiences. Journal of Intellectual Disability Research. 2003;47:291-299.
Methods	**Data collection method:** Survey (open-ended)
Participants	**Population:** Carer experience **N:** 57 **Autism Population Axis I/II disorders**: 56% autism; 4% Aspergers; 30% Autistic tendencies; 11% awaiting or did not specify ASD diagnosis **Service user age (range[mean]):** 2-12.7(5.7) **Service user sex (% female):** Not reported **Service user IQ:** 21% ID **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of specific intervention (Son-Rise program)
Study Design	Mixed method (Qualitative)
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.125 WITTEMEYER2011

Study ID	WITTEMEYER2011
Bibliographic reference	Wittemeyer K, Charman T, Cusak J, Guldberg K, Hastings R, Howlin P, et al. Educational provision and outcomes for people on the autism spectrum: Full technical report. London: Autism Education Trust; 2011.
Methods	**Data collection method:** Focus group and online survey (open-ended)
Participants	**Population:** Service user and carer experience

	N: Focus group/interview (16 service users; 35 carers); survey (30 service users; 382 carers) **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** Focus group/interview 6-16(Not reported) **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of unmet needs and education/school
Study Design	Mixed method (Qualitative)
Setting	Not reported
Country	UK
Notes	Not applicable

1.1.126 WOODGATE2008

Study ID	WOODGATE2008
Bibliographic reference	Woodgate RL, Ateah C, Secco L. Living in a world of our own: the experience of parents who have a child with autism. Qualitative Health Research. 2008;18:1075-1083.
Methods	**Data collection method:** Face-to-face interview
Participants	**Population:** Carer experience **N:** 21 **Autism Population Axis I/II disorders**: 100% autism **Service user age (range[mean]):** 3-9(Not reported) **Service user sex (% female):** 76 **Service user IQ:** Not reported **Family/carer age (range[mean]):** early 30's-late 40's(Not reported) **Family/carer sex (% female):** 76
Outcomes	**Focus of study:** Experience of support
Study Design	Qualitative
Setting	Not reported
Country	Canada
Notes	Not applicable

1.1.127 WRIGHT2011

Study ID	WRIGHT2011
Bibliographic reference	Wright C, Diener ML, Dunn L, Wright SD, Linnell L, Newbold K, et al. SketchUp™: A technology tool to facilitate intergenerational family relationships for children with autism spectrum disorders (ASD). Family and Consumer Sciences Research Journal. 2011;40:135-149.

Methods	**Data collection method:** Focus group
Participants	**Population:** Carer experience **N:** 13 (7 parents; 6 grandparents) **Autism Population Axis I/II disorders**: 86% autism **Service user age (range[mean]):** 8-17(Not reported) **Service user sex (% female):** 77 **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 77
Outcomes	**Focus of study:** Experience of specific intervention (SketchUp™ workshops)
Study Design	Qualitative
Setting	Not reported
Country	USA
Notes	Not applicable

1.2 CHARACTERISTICS OF EXCLUDED STUDIES

1.2.1 ALDERSON1999

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care

1.2.2 ALLEN2008

Reason for exclusion	Age of participants (range 18-61 years) and no recollections of childhood experience

1.2.3 ALQAHTANI2012

Reason for exclusion	Healthcare system not comparable to UK healthcare system

1.2.4 AMBIKILE2012

Reason for exclusion	Healthcare system not comparable to UK healthcare system

1.2.5 ASHBY2010

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care

1.2.6 AVDI2000A

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on assessment and diagnosis with no implications for post-diagnosis care or management

1.2.7 AVDI2000B

Reason for exclusion	Less than 50% of the sample had a diagnosis of ASD

1.2.8 AYLOTT2001

Reason for exclusion	Non-systematic review

1.2.9 BACHRAZ2009

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Paper is on impact of autism on sibling relationships

1.2.10 BAGBY2012

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on how sensory experiences impact the

	family

1.2.11 BENFORD2009

Reason for exclusion	Age of participants (range 16-59 years) and no recollections of childhood experience

1.2.12 BILGIN2010

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care

1.2.13 BILLINGTON2006

Reason for exclusion	Non-systematic review

1.2.14 BLOCH2007

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on access to diagnosis with no implications for post-diagnosis care or management

1.2.15 BLOCH2010

Reason for exclusion	Non-systematic literature review

1.2.16 BOSTROM2009

Reason for exclusion	Mixed autism and intellectual disability population, and not possible to extract disaggregated autism data

1.2.17 BROWNING2009

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on concerns regarding transition but no direct implications for managing transition

1.2.18 BROWNLOW2009

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care

1.2.19 CARLON2012

Reason for exclusion	Systematic review with no new useable data

1.2.20 CARRINGTON2001

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care

1.2.21 CARRINGTON2003B

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care

1.2.22 CARTER2009

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on carer use of the internet to access information

1.2.23 CHILDRENINSCOTLAND2007

Reason for exclusion	Mixed disabilities sample, and not possible to extract disaggregated autism data

1.2.24 CHONG2012

Reason for exclusion	Healthcare system not comparable to UK healthcare system

1.2.25 CHURCH2000

Reason for exclusion	Retrospective chart review

1.2.26 CLAVERING2007

Reason for exclusion	Mixed disabilities sample, and not possible to extract disaggregated autism data

1.2.27 CORMAN2009

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care

1.2.28 DALE2006

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on the impact of the mother's attribution on mother's experience/well-being post-diagnosis

1.2.29 DALY2008

Reason for exclusion	Age of participants (adults) and no recollections of childhood experience

1.2.30 DANIEL2010

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on making and keeping friends

1.2.31 DEGRACE2004

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care

1.2.32 DELLVE2000

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is impact on sibling's life experiences

1.2.33 DESANTOS2008

Reason for exclusion	No demographic information reported for participants and not explicitly stated that parents surveyed had children with autism

1.2.34 DICKIE2009

Reason for exclusion	Experiences of autism with no explicit implications for management, planning and/or delivery of care. Focus is on childs' sensory experiences

1.2.35 DONNELLAN1992

Reason for exclusion	Non-systematic review

1.2.36 DUNSTAN2008

Reason for exclusion	Case study methodology

1.2.37 ELDER2009

Reason for exclusion	Non-systematic review

1.2.38 FARRUGIA2009

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on the stigmatisation of parents of children with autism

1.2.39 FLEISCHMANN2005

Reason for exclusion	Website analysis

1.2.40 FLETCHER2012

Reason for	Experience of autism with no explicit implications for management, planning

exclusion	and/or delivery of care

1.2.41 FREEDMAN2000

Reason for exclusion	Mixed developmental disabilities population and not possible to extract disaggregated autism data

1.2.42 FULLERTON1999

Reason for exclusion	Age of participants (16-28 years) and no recollections of childhood experience

1.2.43 GILL2011

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on mothers' experience of stigma

1.2.44 GIVEN2011

Reason for exclusion	Age of participants (5-33 years old) and not possible to extract disaggregated <19 year-olds data

1.2.45 GRAY1995

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care

1.2.46 GRAY1997

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on parents' expectations and judgements about normal family life

1.2.47 GRAY2001

Reason for exclusion	Case study methodology

1.2.48 GRAY2002A

Reason for exclusion	Age of participants (range 13-27 years) and no recollections of childhood experience

1.2.49 GRAY2002B

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on parental experience of stigma

1.2.50 GRAY2003

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on differences between mothers and fathers in coping strategies

1.2.51 GRAY2006

Reason for exclusion	Age of participants (median: 18 years) and no recollections of childhood experience

1.2.52 GRIFFIN2009

Reason for exclusion	Age of participants (mean age: 30 years) and no recollections of childhood experience

1.2.53 GRIFFIITH2012

Reason for exclusion	Age of participants (>35 years)

1.2.54 HALL2012

Reason for exclusion	Mixed disabilities population and not possible to extract disaggregated autism data

1.2.55 HIEBERTMURPHY2008

Reason for exclusion	Mixed developmental disabilities population and not possible to extract disaggregated autism data

1.2.56 HINES2011

Reason for exclusion	Age of participants (31-43 years old) and no recollections of childhood experience

1.2.57 HOWARD2006

Reason for exclusion	Case study methodology

1.2.58 HUMPHREY2010B

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on experience of bullying

1.2.59 HURLBURT1994

Reason for exclusion	Case study methodology

1.2.60 HURLBUTT2002

Reason for exclusion	Age of participants. Adult sample with some retrospective views provided but not possible to disaggregate which views pertain specifically to childhood

1.2.61 HUWS2008

Reason for exclusion	Age of participants (range 16-21 years) and no recollections of childhood experience

1.2.62 JANTZ2011

Reason for exclusion	Age of participants (24-77 years old) and no recollections of childhood experience

1.2.63 JONES2008B

Reason for exclusion	Duplicates data from JONES2008A

1.2.64 JORDAN1997

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on rates of service utilisation rather than experience of these services

1.2.65 KAYAMA2012

Reason for exclusion	Case study methodology

1.2.66 KELLY2005

Reason for exclusion	Mixed autism and intellectual disability population, and not possible to extract disaggregated autism data

1.2.67 KENNY2008

Reason for exclusion	Age of participants (21-47 years old) and no recollections of childhood experience

1.2.68 KING2006

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on changes in belief systems

1.2.69 KING2009

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care

1.2.70 KING2012

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care

1.2.71 KNIGHT2009

Reason for exclusion	Mixed disabilities population and not possible to extract disaggregated autism data

1.2.72 KOH2010

Reason for exclusion	Paper unavailable

1.2.73 KRAUSZ2005

Reason for exclusion	Case study methodology

1.2.74 LANGAN2011

Reason for exclusion	Non-systematic review

1.2.75 LARSON2006

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on child's need for routines and effects on family activities

1.2.76 LASSER2008

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care

1.2.77 LITTLE2006

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care

1.2.78 LORD2008

Reason for	Case study methodology

exclusion	

1.2.79 MACLEOD1999

Reason for exclusion	Case study methodology

1.2.80 MACLEOD2007

Reason for exclusion	Case study methodology

1.2.81 MACLEOD2010

Reason for exclusion	Age of participants (university students) and no recollections of childhood experience

1.2.82 MAGANA2010

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on the relationship between co-residency and maternal well-being

1.2.83 MAKELA2009

Reason for exclusion	Mixed autism and intellectual disability population, and not possible to extract disaggregated autism data

1.2.84 MARGETTS2006

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on the experience of being a grandparent of a child with autism

1.2.85 MARKOULAKIS2012

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care

1.2.86 MARKS2000

Reason for exclusion	Case study methodology

1.2.87 MARTIN2011

Reason for exclusion	Non-systematic review

1.2.88 MASCHA2006

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on experience of living with a sibling with ASD

1.2.89 MATTHEWS2011

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on work-family challenges for parents of children with ASD

1.2.90 MCCABE2007

Reason for exclusion	Focus is on schooling opportunities but as the study was conducted in China the service infrastructure is not considered to be similiar enough to the UK to allow extrapolation

1.2.91 MCCABE2010

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on employment experiences for mothers of children with autism

1.2.92 MCCONKEY2010

Reason for exclusion	Paper unavailable

1.2.93 MEADAN2010A

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on impact of autism on quality of sibling relationships

1.2.94 MEADAN2010B

Reason for exclusion	Systematic review with no new useable data

1.2.95 MEDHURST2008

Reason for exclusion	Focus is on carer experience of perceived intervention effectiveness for child outcomes where an RCT approach would have been more appropriate

1.2.96 MOORE1999

Reason for exclusion	Mixed professional and carer respondents, and not possible to extract disaggregated carer data

1.2.97 MORAN2006

Reason for	Non-systematic review

exclusion	

1.2.98 MOYSON2012

Reason for exclusion	Child sample had intellectual disability and not ASD

1.2.99 MULLER2003

Reason for exclusion	Age of participants (18-62 years old) and no recollections of childhood experience

1.2.100 MULLER2008

Reason for exclusion	Age of participants (18-62 years old) and no recollections of childhood experience

1.2.101 NALLY2000

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on parental management of television and video watching

1.2.102 NAS2009

Reason for exclusion	Case study methodology

1.2.103 NEELYBARNES2010

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care

1.2.104 NEELYBARNES2011

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care

1.2.105 NORWICH2004

Reason for exclusion	Mixed intellectual disability population and not possible to extract disaggregated autism data

1.2.106 NUEHRING2003

Reason for exclusion	Case study methodology

1.2.107 OBRIEN2007

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care

1.2.108 OBRIEN2009

Reason for exclusion	Systematic review with no new useable data

1.2.109 OGSTON2011

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on hope and worries of mothers of children with an ASD

1.2.110 ORME2005

Reason for exclusion	Mixed autism and down syndrome population and not possible to extract disaggregated autism data

1.2.111 PAPAGEORGIOU2010

Reason for exclusion	No useable data

1.2.112 PARETTE2004

Reason for exclusion	Mixed developmental disabilities population and not possible to extract disaggregated autism data

1.2.113 PARSONS2006

Reason for exclusion	Case study methodology

1.2.114 PATERSON2008

Reason for exclusion	Case study methodology

1.2.115 PENGELLY2009

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on the home environment

1.2.116 PHILLIPS2003

Reason for exclusion	Non-systematic review

1.2.117 PORTWAY2003

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care

1.2.118 PORTWAY2005

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care

1.2.119 PREECE2002

Reason for exclusion	Case study methodology

1.2.120 PREECE2009B

Reason for exclusion	Non-systematic review

1.2.121 PUNSHON2009

Reason for exclusion	Age of participants (21-44 years) and no recollections of childhood experience

1.2.122 RANDALL1995A

Reason for exclusion	No participant demographics or sample size reported

1.2.123 RANDALL1995B

Reason for exclusion	No participant demographics or sample size reported

1.2.124 READ2010

Reason for exclusion	Not primary research (and non-systematic review). Report which is referred to is included (NASUNPUBLISHED)

1.2.125 REID2006

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on experience of bullying

1.2.126 RIDLEY2005

Reason for	Age of participants (17-47 years old) and no recollections of childhood experience

exclusion	

1.2.127 ROBLEDO2008

Reason for exclusion	Age of participants (20-32 years) and no recollections of childhood experience

1.2.128 ROBLEDO2012

Reason for exclusion	Age of participants (19-57 years) and no recollections of childhood experience

1.2.129 ROCQUE2010

Reason for exclusion	No participant demographics or sample size reported

1.2.130 ROPER2007

Reason for exclusion	Mixed developmental disabilities sample, and not possible to extract disaggregated autism data

1.2.131 RUEF1999

Reason for exclusion	Mixed autism and intellectual disability population, and not possible to extract disaggregated autism data

1.2.132 RUEF2001

Reason for exclusion	Mixed autism and intellectual disability population, and not possible to extract disaggregated autism data

1.2.133 RUEF2002

Reason for exclusion	Age of participants (24-45 years) and no recollections of childhood experience

1.2.134 RYAN2008

Reason for exclusion	Experiences of autism with no explicit implications for management, planning and/or delivery of care. Focus is on how mothers make sense of, and respond to their child's behaviour and condition when in public

1.2.135 RYAN2010

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on parent/carer emotion management when with child with ASD in public place

1.2.136 SAGE2010

Reason for exclusion	Case study methodology

1.2.137 SCHAAF2011

Reason for exclusion	Experiences of autism with no explicit implications for management, planning and/or delivery of care. Focus is on family impact of the childs' sensory difficulties

1.2.138 SCORGIE2008

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus on 'life management' in parents of children with autism

1.2.139 SCOTTISHEXECUTIVE2006

Reason for exclusion	Mixed intellectual disability population and not possible to extract disaggregated autism data

1.2.140 SHAKED2006

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on how the jewish ultraorthodox community in Israel cope with autism

1.2.141 SHARPE2007

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on financial problems in families that have a child with autism

1.2.142 SHU2001

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care

1.2.143 SIVBERG2003

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on parents' detection of early signs of autism

1.2.144 SKILLSFORCARE2011

Reason for exclusion	No participant demographics reported

1.2.145 SMITH2001

Reason for exclusion	Focus is on carer experience of perceived intervention effectiveness for child outcomes where an RCT approach would have been more appropriate

1.2.146 SMITH2010B

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on impact of autism on quality of sibling relationships

1.2.147 SPERRY2005

Reason for exclusion	Age of participants (22-49 years) and no recollections of childhood experience

1.2.148 STEFANATOU2008

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on childrens' perceptions of reasons for hospitalization

1.2.149 TANAKA2011

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on how parents informed typically developing children about their siblings' diagnosis of ASD

1.2.150 THOMPSON2011

Reason for exclusion	Mixed autism and ADHD population, and not possible to extract disaggregated autism data

1.2.151 TOWNSON2007

Reason for exclusion	Age of participants ('adults') and no recollections of childhood experience

1.2.152 TSAI2008

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care

1.2.153 TSAO2012

Reason for exclusion	Non-systematic review

1.2.154 WARD2004

Reason for exclusion	Not primary research (and non-systematic review)

1.2.155 WATSON2008

Reason for exclusion	Mixed developmental disabilities population and not possible to extract disaggregated autism data

1.2.156 WHITEHURST2006

Reason for exclusion	Participants were professionals rather than service users or carers

1.2.157 WHITNEYTHOMAS1998

Reason for exclusion	Mixed developmental disabilities population and not possible to extract disaggregated autism data

1.2.158 WINTERMESSIERS2007

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on special interests of children with autism

1.2.159 WOLFBERG1999

Reason for exclusion	Mixed developmental disabilities population and not possible to extract disaggregated autism data

1.2.160 WONG1999

Reason for exclusion	Mixed developmental disabilities population and not possible to extract disaggregated autism data

1.2.161 YAMAMOTO2008

Reason for exclusion	Not clear if results are based on interview or observation

1.2.162 ZAGER2010

Reason for exclusion	Non-systematic review

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