APPENDIX 12A: CLINICAL EVIDENCE –STUDY CHARACTERISTICS TABLES: EXPERIENCE OF CARE

1.1 CHARACTERISTICS OF INCLUDED QUALITATIVE 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

Study ID	CULLEN2002A
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

1.1.49HUMPHREY2008A

Study ID	HUMPHREY2008A
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

1.1.50HURLBUTT2011

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

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

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

Study ID	STONER2005
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

Study ID	TISSOT2006
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

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 INCLUDED QUANTITATIVE STUDIES

1.2.1 AHMEDANI2012

Study ID	AHMEDANI2012
Bibliographic reference	Ahmedani, B.K & Hock, R.M. Health care access and treatment for children with co-morbid autism and psychiatric conditions. Social Psychiatry and Psychiatric Epidemiology. 2012; 47:1807-1814
Methods	**Data collection method:** Telephone survey
Participants	**Population:** Carer experience **N:** 1424 **Autism Population Axis I/II disorders**: 100% ASD (66% coexisting psychiatric condition) **Service user age (range[mean]):** 2-17(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:** Treatment/Intervention
Study Design	Quantitative
Setting	Telephone
Country	USA
Notes	

1.2.2 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:** Postal survey
Participants	**Population:** Service user and carer experience **N:** 205 **Autism Population Axis I/II disorders**: 12% high functioning autism; 46% Asperger's syndrome; 32% autism; 15% ASD **Service user age (range[mean]):** 13-24 (16) **Service user sex (% female):** 84% mothers **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported

	Family/carer sex (% female): 84% mothers
Outcomes	**Focus of study:** Experience of transitions from school
Study Design	Mixed method (Quantitative)
Setting	Postal questionnaire
Country	UK
Notes	56 service users; 149 parents and carers

1.2.3 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:** Telephone survey
Participants	**Population:** Carer experience **N:** 12 **Autism Population Axis I/II disorders**: Not reported **Service user age (range[mean]):** Range 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 (Quantitative)
Setting	Not reported
Country	New Zealand
Notes	

1.2.4 BITTERMAN2008

Study ID	BITTERMAN2008
Bibliographic reference	Bitterman, A., Daley, T.C., Misra, S et al. A national sample of preschoolers with autism spectrum disorders: special education services and parent satisfaction. Journal of Autism and Developmental Disorders. 2008;38:1509-1517
Methods	**Data collection method:** Telephone survey
Participants	**Population:** Carer experience **N:** 186 **Autism Population Axis I/II disorders**: Not reported **Service user age (range[mean]):** Not reported (3-5)

	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:** Education/School
Study Design	Quantitative
Setting	Not reproted
Country	USA
Notes	

1.2.5 BRICKHOUSE2009

Study ID	BRICKHOUSE2009
Bibliographic reference	Brickhouse, T.H., Farrington, F.H., Best, A.M et al. Barriers to dental care for children in virginia with autism spectrum disorders. Journal of Dentistry for Children. 2009;76:188-193
Methods	**Data collection method:** Postal questionnaire
Participants	**Population:** Carer experience **N:** 188 **Autism Population Axis I/II disorders**: 65% autism; 24% aspergers syndrome; 11% PDD-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:** Access to health care
Study Design	Quantitative
Setting	Home
Country	USA
Notes	

1.2.6 BROMLEY2004

Study ID	BROMLEY2004
Bibliographic reference	Bromley, J., Hare, D.J., Davison, K. et al. Mothers supporting children with autistic spectrum disorders. Autism, 2004;8:409-423
Methods	**Data collection method:** Face-to-face interview (quantitative inventories)
Participants	**Population:** Carer experience

	N: 68 **Autism Population Axis I/II disorders**: 54.9% ASD; 26.7% Asperger Syndrome; 12.7% Autistic 'tendencies' or 'trends'; 5.6% No formal ASD-related diagnosis **Service user age (range[mean]):** <5-18 (not reported) **Service user sex (% female):** 100% female **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 100% female
Outcomes	**Focus of study:** Psychological impact/ coping
Study Design	Quantitative
Setting	Home
Country	UK
Notes	

1.2.7 BROWN2012

Study ID	BROWN2012
Bibliographic reference	Brown, H.K., Ouellette-Kuntz, H., Hunter, D et al. 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:** Postal survey/telephone interview
Participants	**Population:** Carer experience **N:** 101 **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):** 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 autism services
Study Design	Mixed method (Quantitative)
Setting	Postal questionnaire
Country	Canada
Notes	

1.2.8 CALLAHAN2008

Study ID	CALLAHAN2008
Bibliographic reference	Callahan, K., Henson, R.K & Cowan, A.K. Social validation of evidence-based practices in autism by parents, teachers and administrators. Journal of Autism and Developmental Disorders. 2008;38:678-692

Methods	**Data collection method:** Postal survey
Participants	**Population:** Carer experience **N:** 95 **Autism Population Axis I/II disorders**: Not reported **Service user age (range[mean]):** Not reported **Service user sex (% female):** 94% female **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 94% female
Outcomes	**Focus of study:** Treatment/Intervention
Study Design	Quantitative
Setting	Postal questionnaire
Country	USA
Notes	

1.2.9 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 (closed questions)
Participants	**Population:** Carer experience **N:** 104 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 2-4(NR) **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** NR-49(NR) **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of information and support
Study Design	Mixed method (Quantitative)
Setting	Home
Country	Ireland
Notes	

1.2.10 CHEN2012

Study ID	CHEN2012

Bibliographic reference	Chen, P & Schwartz, I.S. Bullying and victimization experiences of students with autism spectrum disorders in elementary schools. Focus on Autism and Other Developmental Disabilities. 2012; 27:200-212.
Methods	**Data collection method:** Survey
Participants	**Population:** Service user and carer experience **N:** 33 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 8-13(9.7) **Service user sex (% female):** 64% female **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 64% female
Outcomes	**Focus of study:** Experience of bullying
Study Design	Quantitative
Setting	School
Country	USA
Notes	

1.2.11 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:** Survey (pre-coded)
Participants	**Population:** Carer experience **N:** 95 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 1-16(8) **Service user sex (% female):** 91% **Service user IQ:** 56% ID **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 91%
Outcomes	**Focus of study:** Experience of information and support
Study Design	Mixed method (Quantitative)
Setting	Not reported
Country	Ireland
Notes	

1.2.12 DILLENBURGER2012

Study ID	DILLENBURGER2012
Bibliographic reference	Dillenburger K, Keenan M, Doherty A, Byrne , 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:** Survey
Participants	**Population:** Carer experience **N:** 95 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** Not reported(8) **Service user sex (% female):** 92% female **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported (40) **Family/carer sex (% female):** 92% female
Outcomes	**Focus of study:** Treatment/Intervention
Study Design	Mixed method (Quantitative)
Setting	Not reported
Country	Ireland
Notes	

1.2.13 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 (pre-coded)
Participants	**Population:** Service user and carer experience **N:** 211 **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 (Quantitative)
Setting	NR
Country	UK

Notes	30 service users; 181 carers

1.2.14 DUNLAP1994

Study ID	DUNLAP1994
Bibliographic reference	Dunlap, G., Robbins, F.R. & Darrow, M.A. Parents' reported of their children's challenging behaviors: Results of a statewide survey. Mental Retardation. 1994;32:206-212
Methods	**Data collection method:** Postal questionnaire
Participants	**Population:** Carer experience **N:** 79 **Autism Population Axis I/II disorders**: 91% autism or autism and learning disability **Service user age (range[mean]):** NR(11.6 years) **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:** Care (general)
Study Design	Quantitative
Setting	Home
Country	USA
Notes	

1.2.15 FALKMER2012

Study ID	FALKMER2012
Bibliographic reference	Falkmer, M., Granlund, M., Nilholm, C et al. From my perspective - perceived participation in mainstream school in students with autism spectrum conditions. Developmental Neurorehabilitation. 2012; 15:191-201
Methods	**Data collection method:** Survey
Participants	**Population:** Service user experience **N:** 22 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 9-13(10.7) **Service user sex (% female):** Not applicable **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not applicable **Family/carer sex (% female):** Not applicable
Outcomes	**Focus of study:** Education/School
Study Design	Quantitative
Setting	School
Country	Sweden

Notes	

1.2.16 FERRERI2011

Study ID	FERRERI2011
Bibliographic reference	Ferreri, S & Bolt, S. Educating Michigan's students with Autism Spectrum Disorder (ASD): An initial exploration of programming "The ASD Michigan Project". 2011; Available from http://education.msu.edu/epc/forms/Policy-and-research-Reports/Special-Report-Ferreri-Bolt-September-2011.pdf
Methods	**Data collection method:** Survey
Participants	**Population:** Carer experience **N:** 34 **Autism Population Axis I/II disorders**: 88% ASD: 3% developmental delay: 3% moderate/severe cognitive delay; 3% autism and down's syndrome; 3% fragile X syndrome (Autism Spectrum diagnosis: 50% autistic disorder; 24% Asperger's Syndrome; 18% PDD-NOS; 9% unsure **Service user age (range[mean]):** Not reported **Service user sex (% female):** 97% female **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 97% female
Outcomes	**Focus of study:** Care (general)
Study Design	Quantitative
Setting	NR
Country	USA
Notes	

1.2.17 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 (pre-coded)
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 (Quantitative)
Setting	NR
Country	UK
Notes	

1.2.18 GASPARDEALBA2011

Study ID	GASPARDEALBA2011
Bibliographic reference	Gaspar de Alba, M.J. & Bodfish, J.W. Addressing parental concerns at the initial diagnosis of an autism spectrum disorder. Research in Autism Spectrum Disorders. 2011; 5:633-639.
Methods	**Data collection method:** Online survey
Participants	**Population:** Carer experience **N:** 438 **Autism Population Axis I/II disorders**: 50% Autism; 27% Asperger syndrome; 23% PDD-NOS **Service user age (range[mean]):** Not reported **Service user sex (% female):** 92.9% mothers **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 92.9% mothers
Outcomes	**Focus of study:** Experience of diagnosis
Study Design	Quantitative
Setting	Home
Country	USA
Notes	

1.2.19 HANEY2012

Study ID	HANEY2012
Bibliographic reference	Haney, M.R. After school care for children on the autism spectrum. Journal of Child and Family Studies. 2012; 21:466-473.
Methods	**Data collection method:** Postal survey
Participants	**Population:** Carer experience **N:** 54 **Autism Population Axis I/II disorders**: 60.6% Autism; 4.3% PDD-NOS; 13% Asperger's syndrome; 15.2% more than one ASD condition; 6.5% Other) **Service user age (range[mean]):** 03-Nov

	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:** After-school care
Study Design	Mixed method (Quantitative)
Setting	Postal questionnaire
Country	USA
Notes	

1.2.20 HUMPHREY2010A

Study ID	HUMPHREY2010A
Bibliographic reference	Humphrey, N & Symes, W. Perceptions of social support and experience of bullying among pupils with autistic spectrum disorders in mainstream secondary schools. European Journal of Special Needs. 2010;25:77-91.
Methods	**Data collection method:** Face-to-face questionnaire
Participants	**Population:** Service user experience **N:** 40 **Autism Population Axis I/II disorders**: Not reported **Service user age (range[mean]):** Autism population: NR (Mean age of all participants: 13.9 years) **Service user sex (% female):** Not applicable **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not applicable **Family/carer sex (% female):** Not applicable
Outcomes	**Focus of study:** Experience of bullying and social support
Study Design	Quantitative
Setting	School
Country	UK
Notes	Autism population: 40 (120 participants in study; 40 with dyslexia and 40 controls)

1.2.21 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 (pre-coded)

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(NR) **Service user sex (% female):** 92% female **Service user IQ:** 31% ID **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 92% female
Outcomes	**Focus of study:** Experience of education/school
Study Design	Mixed method (Quantitative)
Setting	NR
Country	UK
Notes	

1.2.22 KEANE2012

Study ID	KEANE2012
Bibliographic reference	Keane, E., Aldridge, F.J., Costley, D et al. Students with autism in regular classess: a long-term follow-up study of a satellite class transition model. International Journal of Inclusive Eduation. 2012; 16:1001-1017.
Methods	**Data collection method:** Postal survey
Participants	**Population:** Carer experience **N:** 63 **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:** Transition
Study Design	Mixed method (Quantitative)
Setting	Postal questionnaire
Country	Australia
Notes	

1.2.23 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:** Survey (pre-coded)
Participants	**Population:** Carer experience **N:** 95 **Autism Population Axis I/II disorders**: 100% ASD; 78% had dual diagnoses, such as ASD and intellectual disability (56%), physical and sensory disability (22%), and/or other concurrent diagnoses (28%). **Service user age (range[mean]):** 1-16 (8) **Service user sex (% female):** 92% female **Service user IQ:** 56% ID **Family/carer age (range[mean]):** NR(40) **Family/carer sex (% female):** 92% female
Outcomes	**Focus of study:** Experience of post-diagnosis information and treatment planning
Study Design	Mixed method (Quantitative)
Setting	NR
Country	Ireland
Notes	

1.2.24 KOGAN2008

Study ID	KOGAN2008
Bibliographic reference	Kogan, D., Strickland, B.B., Blumberg, S.J et al. A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005-2006. Pediatrics. 2008;122:e1149-e1158
Methods	**Data collection method:** Telephone survey
Participants	**Population:** Carer experience **N:** 2088 **Autism Population Axis I/II disorders**: Not reported **Service user age (range[mean]):** 3-7(NR) **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 health-care services and impact on family
Study Design	Quantitative
Setting	Home
Country	USA
Notes	

1.2.25 KOHLER1999

Study ID	KOHLER1999
Bibliographic reference	Kohler, F.W. Examining the services received by young people with autism and their families: A survey of parent responses. Focus on Autism and Other Developmental Disabilities. 1999;14: 150-158
Methods	**Data collection method:** Telephone survey
Participants	**Population:** Carer experience **N:** 25 **Autism Population Axis I/II disorders**: Autism / PDD (no further information reported) **Service user age (range[mean]):** 3-9 (NR) **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 early intervention services
Study Design	Quantitative
Setting	Home
Country	USA
Notes	

1.2.26 KRAUSS2003

Study ID	KRAUSS2003
Bibliographic reference	Krauss, M.W., Gulley, S., Sciegaj, M et al. Acces to speciality medical care for children with mental retardation, autism and other special health care needs. Mental Retardation, 2003; 5:329-339.
Methods	**Data collection method:** Postal survey
Participants	**Population:** Carer experience **N:** 152 **Autism Population Axis I/II disorders**: Autism (no further information reported) **Service user age (range[mean]):** NR(8.4) **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 health-care services
Study Design	Quantitative
Setting	Postal questionnaire
Country	USA
Notes	

1.2.27 LAI2011

Study ID	LAI2011
Bibliographic reference	Lai, B., Milano, M., Roberts, M.W et al. Unmet needs and barriers to dental care among children with autism spectrum disorders. Journal of Autism and Developmental Disorders. 2012; 42:1294-1303.
Methods	**Data collection method:** Postal survey
Participants	**Population:** Carer experience **N:** 568 **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 health-care services
Study Design	Quantitative
Setting	Postal questionnaire
Country	USA
Notes	Demographic information on 555 participants

1.2.28 LIPTAK2006

Study ID	LIPTAK2006
Bibliographic reference	Liptak, G.S., Orlando, M., Yingling, J.T et al. Satisfaction with primary health care received by families of children with developmental disabilities. Journal of Pediatric Health Care. 2006;20:245-252
Methods	**Data collection method:** Postal survey
Participants	**Population:** Carer experience **N:** 41 **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 health-care services
Study Design	Quantitative
Setting	Postal questionnaire
Country	USA
Notes	

1.2.29 LITTLE2003

Study ID	LITTLE2003
Bibliographic reference	Little, L. Maternal perceptions of the importance of needs and resources for children with asperger syndrome and non-verbal learning disorders. Focus on Autism and Other Developmental Disabilities. 2003;18:258-267
Methods	**Data collection method:** Postal survey
Participants	**Population:** Carer experience **N:** 404 **Autism Population Axis I/II disorders**: 75% Aspergers syndrome; 16% non-verbal learning disability; 9% both Aspergers syndrome and non-verbal learning disability **Service user age (range[mean]):** Whole sample: 4-17(10.4) **Service user sex (% female):** 100% female **Service user IQ:** Not reported **Family/carer age (range[mean]):** Whole sample: 23-58(41.3) **Family/carer sex (% female):** 100% female
Outcomes	**Focus of study:** Access to autism intervention
Study Design	Quantitative
Setting	Postal questionnaire
Country	USA
Notes	Mixed sample

1.2.30 LUTHER2005

Study ID	LUTHER2005
Bibliographic reference	Luther, E.H., Canham, D.L & Cureton, V.Y. Coping and social support for parents of children with autism. The Journal of School Nursing. 2005;21:40-47.
Methods	**Data collection method:** Postal survey
Participants	**Population:** Carer experience **N:** 18 **Autism Population Axis I/II disorders**: Not reported **Service user age (range[mean]):** NR (8.3) **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:** Psychological impact/ coping
Study Design	Quantitative
Setting	Postal questionnaire

Country	USA
Notes	

1.2.31 MACKINTOSH2012

Study ID	MACKINTOSH2012
Bibliographic reference	Mackintosh, V.H., Goin-Kochel, R.P 7 Myers, B.J. "What do you like about the treatments you're currently using?": A qualitative study of parents of children with autism spectrum disorders. Focus on Autism and Other Developmental Disorders. 2012; 27:51
Methods	**Data collection method:** Online survey
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):** 91% female **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported (37.8) **Family/carer sex (% female):** 91% female
Outcomes	**Focus of study:** Treatment/Intervention
Study Design	Mixed method (Quantitative)
Setting	Not reported
Country	Multiple
Notes	

1.2.32 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 (pre-coded)
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 (Quantitative)
Setting	Home
Country	UK
Notes	

1.2.33 MILLER2012

Study ID	MILLER2012
Bibliographic reference	Miller, V.A., Schreck, K.A., Mulick, J.A et al. Factors relation to parents' choices of treatments for their childrenw ith autism spectrum disorders. Research in Autism Spectrum Disorders. 2012; 6:87-95.
Methods	**Data collection method:** Online survey
Participants	**Population:** Carer experience **N:** 400 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** Not reported **Service user sex (% female):** 88.8 % mothers **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 88.8 % mothers
Outcomes	**Focus of study:** Treatment/Intervention
Study Design	Quantitative
Setting	Not reported
Country	USA
Notes	

1.2.34 MOH2012

Study ID	MOH2012
Bibliographic reference	Moh, T.A & Magiati, I. Factors associated with parental stress and satisfaction during the process of diagnosis of children with Autism Spectrum Disorders. Research in Autism Spectrum Disorders. 2012;6:293-303
Methods	**Data collection method:** Postal survey
Participants	**Population:** Carer experience **N:** 102 **Autism Population Axis I/II disorders**: 25.2% autism; 65.7 ASD; 2% Asperger's syndrome/disorder; 7.1% PDD-NOS **Service user age (range[mean]):** 2-17.3(7.3)

	Service user sex (% female): 83.3% female **Service user IQ:** Not reported **Family/carer age (range[mean]):** 32-63(39.8) **Family/carer sex (% female):** 83.3% female
Outcomes	**Focus of study:** Experience of diagnosis
Study Design	Quantitative
Setting	Postal questionnaire
Country	Singapore
Notes	

1.2.35 MONTES2009

Study ID	MONTES2009
Bibliographic reference	Montes, G., Halterman, J.S & Magyar, C.I. Access to and satisfaction with school and community health services for US children with ASD. American Academy of Pediatrics. 2009;124:S407-S414
Methods	**Data collection method:** Survey
Participants	**Population:** Carer experience **N:** 2123 **Autism Population Axis I/II disorders**: Not reported **Service user age (range[mean]):** 0-17 (NR) **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:** Education/School
Study Design	Quantitative
Setting	NR
Country	USA
Notes	

1.2.36 MORENO2008

Study ID	MORENO2008
Bibliographic reference	Moreno, J., Aguilera, A., & Saldana, D. Do Spanish parents prefer special schools for their children with autism? Education and Training in Developmental Disabilities. 2008;43:162-173.
Methods	**Data collection method:** Telephone survey
Participants	**Population:** Carer experience

	N: 60 **Autism Population Axis I/II disorders**: 30% autism; 26% asperger syndrome; 44 % PDD-NOS **Service user age (range[mean]):** 3.09-21.02 (11.05) **Service user sex (% female):** 70% female **Service user IQ:** Not reported **Family/carer age (range[mean]):** Mothers: 31-52 (41.01) Fathers: 32-56 (42.04) **Family/carer sex (% female):** 70% female
Outcomes	**Focus of study:** Education/School
Study Design	Quantitative
Setting	Home
Country	Spain
Notes	

1.2.37 NASUNPUBLISHED

Study ID	NASUNPUBLISHED
Bibliographic reference	National Autistic Society. Child mental health research report; Unpublished.
Methods	**Data collection method:** Online survey (pre-coded)
Participants	**Population:** Carer experience **N:** 455 **Autism Population Axis I/II disorders**: 43% Asperger disorder/high-functioning autism; 38% ASD/autism; 4% other; 15% prefer not to say (participants had experienced one or more coexisting mental health problem including anxiety, depression, ADHD, OCD, PTSD, psychosis, self-harm, delusions, phob **Service user age (range[mean]):** Not reported **Service user sex (% female):** Not reported **Service user IQ:** 12% ID **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of CAMHS
Study Design	Mixed method (Quantitative)
Setting	Not reported
Country	UK
Notes	

1.2.38 NEWSOME2000

Study ID	NEWSOME2000
Bibliographic reference	Newsome, W.S. Parental perceptions during periods of transition: implications for social workers service families coping with autism. Journal of Family Social Work. 2000; 5:17-31

Methods	**Data collection method:** Survey
Participants	**Population:** Carer experience **N:** 120 **Autism Population Axis I/II disorders**: Not reported **Service user age (range[mean]):** 2-49 (Not reported) 62.5% were aged 2-17 **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:** Transition
Study Design	Mixed method (Quantitative)
Setting	Not reported
Country	USA
Notes	

1.2.39 PERRY2010

Study ID	PERRY2010
Bibliographic reference	Perry, A. & Condillac, R.A. The TRE-ADD preschool parent training program: Program evaluation of an innovative service delivery model. Journal of Developmental Disabilities. 2010;16:8-16.
Methods	**Data collection method:** Face-to-face questionnaire
Participants	**Population:** Carer experience **N:** 27 **Autism Population Axis I/II disorders**: 67% Autistic disorder; 33% PDD-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:** Treatment/Intervention
Study Design	Quantitative
Setting	Not reported
Country	Canada
Notes	

1.2.40 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 (pre-coded)
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 (Quantitative)
Setting	Not reported
Country	UK
Notes	

1.2.41 PISULA2011

Study ID	PISULA2011
Bibliographic reference	Pisula, E & Lukowska, E. Perception of scoaial relationships with classmates and social support in adolescents with Asperger syndrome attending mainstream schools in Poland. School Psychology International. 2011; 33:185-206
Methods	**Data collection method:** Survey
Participants	**Population:** Service user experience **N:** 25 **Autism Population Axis I/II disorders**: 100% Asperger syndrome **Service user age (range[mean]):** 12-17(15.32) **Service user sex (% female):** Not applicable **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not applicable **Family/carer sex (% female):** Not applicable
Outcomes	**Focus of study:** Education/School
Study Design	Quantitative
Setting	School
Country	Poland
Notes	

1.2.42 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:** Online survey (pre-coded)
Participants	**Population:** Service user and carer experience **N:** 1034 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** <19(NR) **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 (Quantitative)
Setting	Not reported
Country	UK
Notes	295 service users; 739 carers

1.2.43 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:** Survey (pre-coded)
Participants	**Population:** Carer experience **N:** 244 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 2-17(8.9) **Service user sex (% female):** Not reported **Service user IQ:** 35% 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 (Quantitative)
Setting	Not reported
Country	Belgium
Notes	

1.2.44 ROWLEY2012

Study ID	ROWLEY2012
Bibliographic reference	Rowley, E., Chandler, S., Baird, G et al. The experience of friendship, victimisation and bullying in children with an autism spectrum disorder: associations with child chracteristics and school placement. Research in Autism Spectrum Disorders. 2012; 6:1126-1134.
Methods	**Data collection method:** Survey
Participants	**Population:** Carer experience **N:** 100 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 10-12(11.4) **Service user sex (% female):** Not reported **Service user IQ:** 80.2 **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** Not reported
Outcomes	**Focus of study:** Experience of bullying
Study Design	Mixed method (Quantitative)
Setting	Not reported
Country	UK
Notes	

1.2.45 SANSOSTI2012

Study ID	SANSOSTI2012
Bibliographic reference	Sansosti, F.J., Lavik, K.B & Sansosti, J.M. Family experiences through the autism diagnostic process. Focus on Autism and Other Developmental Disabilities. 2012; 27:81
Methods	**Data collection method:** Face-to-face questionnaire
Participants	**Population:** Carer experience **N:** 16 **Autism Population Axis I/II disorders**: 56.3% autistic disorder; 37.5% Asperger disorder; 6.3% PDD-NOS **Service user age (range[mean]):** 2.10-6.9(6.9) **Service user sex (% female):** 81% mothers **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 81% mothers
Outcomes	**Focus of study:** Experience of diagnosis
Study Design	Mixed method (Quantitative)

Setting	Multiple (adademic and public plces e.g. Cafes)
Country	USA
Notes	

1.2.46 SIKLOS2006

Study ID	SIKLOS2006
Bibliographic reference	Siklos, S & Kerns, K.A. Assessing need for social support in parents of children with autism and down syndrome. Journal of Autsm and Developmental Disorders. 2006;36:921-933.
Methods	**Data collection method:** Postal survey
Participants	**Population:** Carer experience **N:** 56 **Autism Population Axis I/II disorders**: Not reported **Service user age (range[mean]):** 3.5-18(7.98) **Service user sex (% female):** 91.1% mothers **Service user IQ:** Not reported **Family/carer age (range[mean]):** 24-50(38.5) **Family/carer sex (% female):** 91.1% mothers
Outcomes	**Focus of study:** Care (general)
Study Design	Quantitative
Setting	Postal questionnaire
Country	Canada
Notes	

1.2.47 SIKLOS2007

Study ID	SIKLOS2007
Bibliographic reference	Siklos, S. & Kerns, K.A. Assessing the diagnostic experiences of a small sample of parents of children with autism spectrum disorders. Research in Developmental Disabilities. 2007;28:9-22.
Methods	**Data collection method:** Postal survey
Participants	**Population:** Carer experience **N:** 56 **Autism Population Axis I/II disorders**: 76.2% autistic disorder; 7.9% asperger's syndrome; 4.8% PDD-NOS; 6.3% autistic traits or features; 4.8% other **Service user age (range[mean]):** 3.5-18.00(7.98) **Service user sex (% female):** Not reported **Service user IQ:** Not reported **Family/carer age (range[mean]):** 24-50(38.54)

	Family/carer sex (% female): Not reported
Outcomes	**Focus of study:** Experience of diagnosis
Study Design	Quantitative
Setting	Postal questionnaire
Country	Canada
Notes	

1.2.48 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 (pre-coded)
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):** 88.20% **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 88.20%
Outcomes	**Focus of study:** Experience of education/school
Study Design	Mixed method (Quantitative)
Setting	Conference
Country	Canada
Notes	

1.2.49 STARR2006

Study ID	STARR2006
Bibliographic reference	Starr EM, Foy JB, Cramer KM. How are schools doing? Parental perceptions of children with autism spectrum disorders, down syndrome and learning disabilities: A comparative analysis. Education and Training in Developmental Disabilities. 2006;41:315-332.
Methods	**Data collection method:** Postal survey
Participants	**Population:** Carer experience **N:** 144

	Autism Population Axis I/II disorders: 40% autism; 60% other 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:** Education/School
Study Design	Quantitative
Setting	Postal questionnaire
Country	Canada
Notes	

1.2.50 STARR2012

Study ID	STARR2012
Bibliographic reference	Starr, E.M. & Foy, J.B. In parents voices: the education of childrenw ith autism spectrum disorders. Remedial and Special Education. 2012; 33:207
Methods	**Data collection method:** Postal survey
Participants	**Population:** Carer experience **N:** 144 **Autism Population Axis I/II disorders**: 40% autism; 60% other ASD **Service user age (range[mean]):** 4-18(8.9) **Service user sex (% female):** 90% mothers **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 90% mothers
Outcomes	**Focus of study:** Education/School
Study Design	Mixed method (Quantitative)
Setting	Postal questionnaire
Country	Canada
Notes	

1.2.51 STEIN2012

Study ID	STEIN2012
Bibliographic reference	Stein, L.I., Polido, J.C., Cermak, S.A. Oral care and sensory concerns in autism. The American Journal of Occupational Therapy. 2012; 66:e73-e76.
Methods	**Data collection method:** Postal survey
Participants	**Population:** Carer experience

	N: 196 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 2-18(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:** Access to health care
Study Design	Mixed method (Quantitative)
Setting	Postal questionnaire
Country	USA
Notes	

1.2.52 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 (pre-coded)
Participants	**Population:** Carer experience **N:** 294 **Autism Population Axis I/II disorders**: 76% ASD **Service user age (range[mean]):** 1-31+(NR) **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 (Quantitative)
Setting	Not reported
Country	UK
Notes	

1.2.53 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 (pre-coded)
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 (Quantitative)
Setting	Not reported
Country	USA
Notes	

1.2.54 SWIEZY1996

Study ID	SWIEZY1996
Bibliographic reference	Swiezy, N.B & Summers, J. Parents perceptions of the use of medication with children who are autistic. Journal of Developmental and Physical Disabilities. 1996;8:407-413
Methods	**Data collection method:** Survey
Participants	**Population:** Carer experience **N:** 7 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 5-15(10.7) **Service user sex (% female):** 100% female **Service user IQ:** Not reported **Family/carer age (range[mean]):** Not reported **Family/carer sex (% female):** 100% female
Outcomes	**Focus of study:** Treatment/Intervention: medication
Study Design	Quantitative
Setting	Not reported
Country	USA
Notes	

1.2.55 TISSOT2006

Study ID	TISSOT2006
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.

Methods	**Data collection method:** Survey (pre-coded)
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 (Quantitative)
Setting	Not reported
Country	UK
Notes	

1.2.56WEBB2004

Study ID	WEBB2004
Bibliographic reference	Webb, B.J., Miller, S.P., Pierce, T.B et al. Efects of social skil instruction for high-functioning adolescents with autism spectrum disorders. Focus on Autism and Other Developmental Disabilities. 2004;19:53-62.
Methods	**Data collection method:** Face-to-face questionnaire
Participants	**Population:** Service user experience **N:** 10 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 12.3-17.2(14.8) **Service user sex (% female):** Not applicable **Service user IQ:** 81-132(100.5) **Family/carer age (range[mean]):** Not applicable **Family/carer sex (% female):** Not applicable
Outcomes	**Focus of study:** Treatment/Intervention
Study Design	Mixed method (Quantitative)
Setting	Community public agency building
Country	USA
Notes	

1.2.57WEIDLE2006

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 (pre-coded)
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 (Quantitative)
Setting	Not reported
Country	Norway
Notes	

1.2.58WHITAKER2002

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 (closed 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 (Quantitative)
Setting	Not reported
Country	UK
Notes	

1.2.59WHITAKER2007

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 (pre-coded)
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 (Quantitative)
Setting	Not reported
Country	UK
Notes	

1.2.60WHITE2010B

Study ID	WHITE2010B
Bibliographic reference	White, S.W., Koenig, K., & Scahill, L. Group social skills instruction for adolescents with high-functioning autism spectrum disorders. Focus on Autism and Other Developmental Disabilities. 2010;25:209-219
Methods	**Data collection method:** Survey
Participants	**Population:** Carer experience **N:** 16 **Autism Population Axis I/II disorders**: 62% Asperger syndrome; 19% Autistic Disorder; 19% PDD-NOS) **Service user age (range[mean]):** NR(12.55) **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:** Treatment/Intervention
Study Design	Mixed method (Quantitative)
Setting	Academic
Country	USA
Notes	

1.2.61WHITTINGHAM2009

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 (pre-coded)
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 (Quantitative)
Setting	Not reported
Country	Australia
Notes	

1.2.62WILLIAMS2003

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 (pre-coded)
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 (Quantitative)
Setting	Not reported

Country	UK
Notes	

1.2.63WITTEMEYER2011

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:** Online survey (pre-coded)
Participants	**Population:** Service user and carer experience **N:** 482 **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 (Quantitative)
Setting	Not reported
Country	UK
Notes	30 service users; 382 carers of CYP; 70 parents of adults (retrospective)

1.2.64WONG2006

Study ID	WONG2006
Bibliographic reference	Wong, H.L.H., Smith, R.G. Patterns of complementary and alternative medical therapy use in children diagnosed with autism spectrum disorders. Journal of Autism and Developmental Disorders, 2006; 36:901-909.
Methods	**Data collection method:** Telephone survey
Participants	**Population:** Carer experience **N:** 50 **Autism Population Axis I/II disorders**: 100% ASD **Service user age (range[mean]):** 4-17(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:** Treatment/Intervention

Study Design	Quantitative
Setting	Telephone
Country	Canada
Notes	

1.3 CHARACTERISTICS OF EXCLUDED QUALITATIVE STUDIES

1.3.1 ALDERSON1999

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

1.3.2 ALLEN2008

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

1.3.3 ALQAHTANI2012

Reason for exclusion	Healthcare system not comparable to UK healthcare system

1.3.4 AMBIKILE2012

Reason for exclusion	Healthcare system not comparable to UK healthcare system

1.3.5 ASHBY2010

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

1.3.6 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

1.3.7 AVDI2000B

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

1.3.8 AYLOTT2001

Reason for exclusion	Non-systematic review

1.3.9 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

1.3.10 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

1.3.11 BENFORD2009

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

1.3.12 BILGIN2010

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

1.3.13 BILLINGTON2006

Reason for exclusion	Non-systematic review

1.3.14 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

1.3.15 BLOCH2010

Reason for exclusion	Non-systematic literature review

1.3.16 BOSTROM2009

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

1.3.17 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

1.3.18 BROWNLOW2009

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

1.3.19 CARLON2012

Reason for exclusion	Systematic review with no new useable data

1.3.20 CARRINGTON2001

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

1.3.21 CARRINGTON2003B

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

1.3.22 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

1.3.23 CHILDRENINSCOTLAND2007

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

1.3.24 CHONG2012

Reason for exclusion	Healthcare system not comparable to UK healthcare system

1.3.25 CHURCH2000

Reason for exclusion	Retrospective chart review

1.3.26 CLAVERING2007

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

1.3.27 CORMAN2009

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

1.3.28 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

1.3.29 DALY2008

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

1.3.30 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

1.3.31 DEGRACE2004

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

1.3.32 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

1.3.33 DESANTOS2008

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

1.3.34 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

1.3.35 DONNELLAN1992

Reason for exclusion	Non-systematic review

1.3.36 DUNSTAN2008

Reason for exclusion	Case study methodology

1.3.37 ELDER2009

Reason for exclusion	Non-systematic review

1.3.38 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

1.3.39 FLEISCHMANN2005

Reason for exclusion	Website analysis

1.3.40 FLETCHER2012

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

1.3.41 FREEDMAN2000

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

1.3.42 FULLERTON1999

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

1.3.43 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

1.3.44 GIVEN2011

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

1.3.45 GRAY1995

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

1.3.46 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

1.3.47 GRAY2001

Reason for exclusion	Case study methodology

1.3.48 GRAY2002A

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

1.3.49 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

1.3.50 GRAY2003

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

exclusion	delivery of care. Focus is on differences between mothers and fathers in coping strategies

1.3.51 GRAY2006

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

1.3.52 GRIFFIN2009

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

1.3.53 GRIFFIITH2012

Reason for exclusion	Age of participants (>35 years)

1.3.54 HALL2012

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

1.3.55 HIEBERTMURPHY2008

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

1.3.56 HINES2011

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

1.3.57 HOWARD2006

Reason for exclusion	Case study methodology

1.3.58 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

1.3.59 HURLBURT1994

Reason for exclusion	Case study methodology

1.3.60 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

1.3.61 HUWS2008

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

1.3.62 JANTZ2011

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

1.3.63 JONES2008B

Reason for exclusion	Duplicates data from JONES2008A

1.3.64 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

1.3.65 KAYAMA2012

Reason for exclusion	Case study methodology

1.3.66 KELLY2005

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

1.3.67 KENNY2008

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

1.3.68 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

1.3.69 KING2009

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

1.3.70 KING2012

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

1.3.71 KNIGHT2009

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

1.3.72 KOH2010

Reason for exclusion	Paper unavailable

1.3.73 KRAUSZ2005

Reason for exclusion	Case study methodology

1.3.74 LANGAN2011

Reason for exclusion	Non-systematic review

1.3.75 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

1.3.76 LASSER2008

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

1.3.77 LITTLE2006

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

1.3.78 LORD2008

Reason for exclusion	Case study methodology

1.3.79 MACLEOD1999

Reason for exclusion	Case study methodology

1.3.80 MACLEOD2007

Reason for exclusion	Case study methodology

1.3.81 MACLEOD2010

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

1.3.82 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

1.3.83 MAKELA2009

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

1.3.84 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

1.3.85 MARKOULAKIS2012

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

1.3.86 MARKS2000

Reason for exclusion	Case study methodology

1.3.87 MARTIN2011

Reason for exclusion	Non-systematic review

1.3.88 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

1.3.89 MATTHEWS2011

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

exclusion	delivery of care. Focus is on work-family challenges for parents of children with ASD

1.3.90 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

1.3.91 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

1.3.92 MCCONKEY2010

Reason for exclusion	Paper unavailable

1.3.93 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

1.3.94 MEADAN2010B

Reason for exclusion	Systematic review with no new useable data

1.3.95 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

1.3.96 MOORE1999

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

1.3.97 MORAN2006

Reason for exclusion	Non-systematic review

1.3.98 MOYSON2012

Reason for exclusion	Child sample had intellectual disability and not ASD

1.3.99 MULLER2003

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

1.3.100 MULLER2008

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

1.3.101 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

1.3.102 NAS2009

Reason for exclusion	Case study methodology

1.3.103 NEELYBARNES2010

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

1.3.104 NEELYBARNES2011

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

1.3.105 NORWICH2004

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

1.3.106 NUEHRING2003

Reason for exclusion	Case study methodology

1.3.107 OBRIEN2007

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

1.3.108 OBRIEN2009

Reason for exclusion	Systematic review with no new useable data

1.3.109 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

1.3.110 ORME2005

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

1.3.111 PAPAGEORGIOU2010

Reason for exclusion	No useable data

1.3.112 PARETTE2004

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

1.3.113 PARSONS2006

Reason for exclusion	Case study methodology

1.3.114 PATERSON2008

Reason for exclusion	Case study methodology

1.3.115 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

1.3.116 PHILLIPS2003

Reason for exclusion	Non-systematic review

1.3.117 PORTWAY2003

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

1.3.118 PORTWAY2005

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

1.3.119 PREECE2002

Reason for exclusion	Case study methodology

1.3.120 PREECE2009B

Reason for exclusion	Non-systematic review

1.3.121 PUNSHON2009

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

1.3.122 RANDALL1995A

Reason for exclusion	No participant demographics or sample size reported

1.3.123 RANDALL1995B

Reason for exclusion	No participant demographics or sample size reported

1.3.124 READ2010

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

1.3.125 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

1.3.126 RIDLEY2005

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

1.3.127 ROBLEDO2008

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

1.3.128 ROBLEDO2012

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

1.3.129 ROCQUE2010

Reason for exclusion	No participant demographics or sample size reported

1.3.130 ROPER2007

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

1.3.131 RUEF1999

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

1.3.132 RUEF2001

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

1.3.133 RUEF2002

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

1.3.134 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

1.3.135 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

1.3.136 SAGE2010

Reason for exclusion	Case study methodology

1.3.137 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

1.3.138 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

1.3.139 SCOTTISHEXECUTIVE2006

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

1.3.140 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

1.3.141 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

1.3.142 SHU2001

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

1.3.143 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

1.3.144 SKILLSFORCARE2011

Reason for exclusion	No participant demographics reported

1.3.145 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

1.3.146 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

1.3.147 SPERRY2005

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

1.3.148 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

1.3.149 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

1.3.150 THOMPSON2011

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

1.3.151 TOWNSON2007

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

1.3.152 TSAI2008

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

1.3.153 TSAO2012

Reason for exclusion	Non-systematic review

1.3.154 WARD2004

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

1.3.155 WATSON2008

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

1.3.156 WHITEHURST2006

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

1.3.157 WHITNEYTHOMAS1998

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

1.3.158 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

1.3.159 WOLFBERG1999

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

1.3.160 WONG1999

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

1.3.161 YAMAMOTO2008

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

1.3.162 ZAGER2010

Reason for exclusion	Non-systematic review

1.4 CHARACTERISTICS OF EXCLUDED QUANTITATIVE STUDIES

1.4.1 ALANBAR2010

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on relationship between perceived severity and treatment choices

1.4.2 ALKANDARI2010

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on maternal self-efficacy

1.4.3 ALLIK2006

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Paper focuses on health-related quality of life scores for parents of children with ASD

1.4.4 ALTIERE2009A

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on family dynamics and parental coping strategies

1.4.5 BAKERERICZEN2005

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

1.4.6 BARAKLEVY2010

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on the social and emotional adjustment of siblings

1.4.7 BARKER2011

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Only quantitative scales or statistical model - not experience of care

1.4.8 BARNARDBRAK2009

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Only quantitative scales or statistical model - not experience of care

1.4.9 BAUMINGER2003

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

1.4.10 BAYAT2007

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

1.4.11 BEADLEBROWN2009

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on quality of life for service users with autism

1.4.12 BENNETT2005

Reason for exclusion	Age of participants (mean ages 41-43 years) and no recollections of childhood experience

1.4.13 BILLSTEDT2011

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on quality of life for service users with autism

1.4.14 BOWKER2011

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

1.4.15 BROGAN2003

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

1.4.16 BROWN2006

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Paper focuses on family life experiences where there is a child with a developmental disorder and extrapolating to make any explicit recommendations for practice would be difficult

1.4.17 BROWN2011

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on the relationship between children's functioning and parents' perceived unmet needs and unmet need was described quantitatively rather than qualitatively

1.4.18 CAPPADOCIA2012

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on bullying, but not in relation to any particular service.

1.4.19 CAPPE2011

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on the relationship between cognitive and behavioural profiles and adjustment

1.4.20 CARDON2011

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on rates of assistive technology use rather than experience of using assistive technology

1.4.21 CARTER2011

Reason for exclusion	Sample included participants with intellectual disability and multiple disabilities without autism. However, even where disaggregated autism data could be extracted the focus was on predictors of paid work experience for service users with autism with no explicit implications for management, planning and/or delivery of care.

1.4.22 CEBULA2012

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on effectiveness in relations to sibling adjustment.

1.4.23 CHAMAK2011

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

1.4.24 CHAMBERLAIN2007

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

1.4.25 CHRISTON2010

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

1.4.26 COULTHARD1999

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on organised religon and personal belief and their relationship with health status

1.4.27 DARDENNES2011

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on relationship between parental beliefs about the causes of autism and treatment choices

1.4.28 DAVIES1996

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

1.4.29 DAVIES2009

Reason for exclusion	Sample included participants with intellectual disability without autism and not possible to extract disaggregated data for autism

1.4.30 DING2010

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

1.4.31 DIPIETRO2002

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

1.4.32 DOHERTY2000

Reason for exclusion	Age of participants (8-33 years; mean: 20 years) and no recollections of childhood experience

1.4.33 DUNN2001

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

1.4.34 EKAS2009

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on maternal religiosity, spirituality and socioemotional functioning

1.4.35 ENGSTROM2003

Reason for exclusion	Age of participants (18-49 years; mean: 30 years) and no recollections of childhood experience

1.4.36 ESCRIBANOHERNANDEZ2012

Reason for exclusion	Only 3% of sample have ASD

1.4.37 FALKMER2004

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

1.4.38 FITZGERALD2002

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

1.4.39 FOREST2004

Reason for exclusion	No useable data - Focus is on transition planning, but transition programme is not outlined

1.4.40 FROESE1999

Reason for exclusion	Mixed developmental disabilities population with only 4% of the sample with autism

1.4.41 FUJIWARA2011

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

1.4.42 GAU2012

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on parental adjustment, marital relationship, and family function

1.4.43 GHAZIUDDIN1995

Reason for exclusion	Focus is on the relation between coexisting depression and life events with no explicit implications for management, planning and/or delivery of care.

1.4.44 GILLETT2007

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

1.4.45 GLAUN1998

Reason for exclusion	Not autism-specific and autism data cannot be disaggregated

1.4.46 GOINKOCHEL2006

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

1.4.47 GOINKOCHEL2009

Reason for exclusion	Qualitative measures of perceived intervention effectiveness that were not relationship-focused, these focus primarily on parent/carer view of treatment efficacy on child

1.4.48 GRAETZ2010

Reason for exclusion	Age of participants (18-48 years) and no recollections of childhood experience

1.4.49 GREEFF2010

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on ways in which parents adapted to the diagnosis

1.4.50 GRIFFITH2010

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on child behaviour and maternal outcomes

1.4.51 HALL2011

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on relationship between child behaviour and parental stress and coping

1.4.52 HALL2012A

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on relationship between community support and coping strategies of carer and behaviour of children.

1.4.53 HALL2012B

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on relationship between community support and coping strategies of carer and behaviour of children.

1.4.54 HAMLYNWRIGHT2007

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on relationship between locus of control and parental anxiety and depression

1.4.55 HANSON2007

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

1.4.56 HARRINGTON2006

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

1.4.57 HASTINGS2001

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

1.4.58 HASTINGS2002

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on predictors of perceived self-efficacy amongst carers delivering EIBI

1.4.59 HAUSSLER1998

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

1.4.60 HAZELL2002

Reason for exclusion	Not autism-specific

1.4.61 HEIMAN2008

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on family environment and parental stress and ASD and LD comparison

1.4.62 HERMAN1995

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

1.4.63 HINTZEN2010

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

1.4.64 HOLST2009

Reason for exclusion	Age of participants (20-56 years) and no recollections of childhood experience

1.4.65 HOWLIN1997

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

1.4.66 HOWLIN1999

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

1.4.67 HUME2005

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 and the only rating of experience is perceived efficacy for child outcomes

1.4.68 JENNESCOUSSENS2006

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on quality of life for service users with autism

1.4.69 KAMINSKY2002

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

1.4.70 KAMPBECKER2010

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 health-related quality of life

1.4.71 KAMPBECKER2011

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 health-related quality of life

1.4.72 KASARI1999

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

1.4.73 KING2009

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on family beliefs about autism and coping

1.4.74 KNOTT2006

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

1.4.75 KOWALSKI2011

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

1.4.76 KUHN2006

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

1.4.77 LAM2010

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

1.4.78 LIN2011

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on cultural differences in social support and coping

1.4.79 LITTLE2002A

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

1.4.80 LITTLE2002B

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' stress and coping

1.4.81 LOCKE2010

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

1.4.82 LOUNDS2007

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on relationship between child behaviour and maternal outcomes

1.4.83 LUTHER2005

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

1.4.84 MACMULLIN2010

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on relationship between parents’ perceptions of their child’s educational experience and parental empowerment and mental health

1.4.85 MAGANA2006

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Paper is on experience of co-residence (i.e. family care-giving: relationship between parent and CYP with ASD) and the impact of race

1.4.86 MAK2010

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

1.4.87 MANDELL2007

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on predictors of parental support group participation

1.4.88 MANNING2011

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on adaptation and family functioning rather than on who may/may not be able to support this processes, and how.

1.4.89 MCCONACHIE2006

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

1.4.90 MCGRATH2009

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

1.4.91 MERCER2006

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

1.4.92 MICKELSON1999

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

1.4.93 MILSHTEIN2010

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

1.4.94 MONTALBANO2009

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

1.4.95 MONTES2007

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

1.4.96 MOORE2009

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

1.4.97 MOORE2011

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

1.4.98 MUGNO2007

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 parental quality of life

1.4.99 NESBITT2000

Reason for exclusion	No participant demographics or sample size reported

1.4.100 OBRUSNIKOVA2011

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on perceived barriers to after-school physical activity

1.4.101 OBRUSNIKOVA2012

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on perceived barriers to after-school physical activity

1.4.102 ORSMOND2006

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 mother-child relationship

1.4.103 ORSMOND2009

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

1.4.104 ORSMOND2011

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 use of leisure time/engagement with peers

1.4.105 PARSONS2009B

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

1.4.106 PARSONS2010

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

1.4.107 PERRY1997

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

1.4.108 PISULA2010

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

1.4.109 PITUCH2011

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on relationship between child outcomes and parent treatment priorities

1.4.110 POON2011

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

1.4.111 POTTIE2008

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on parental stress, coping strategies and well-being

1.4.112 REGEHR2009

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

1.4.113 RENTY2006B

Reason for exclusion	Age of participants (18-53 years) and no recollections of childhood experience

1.4.114 RESCH2012

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

1.4.115 RHOADES2007

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

1.4.116 RIVERS2003

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

1.4.117 RIZK2011

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on health-related quality of life for carers

1.4.118 RODGER2008

Reason for exclusion	Case study methodology

1.4.119 RODGER2011

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

1.4.120 ROEYERS1995

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on stress and coping strategies for siblings of children with autism

1.4.121 ROSS2006

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on adjustment and coping strategies for siblings of children with autism

1.4.122 SALDANA2009

Reason for exclusion	Age of participants (18-40 years) and no recollections of childhood experience

1.4.123 SAMIOS2008

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

1.4.124 SAMIOS2009

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

1.4.125 SARKADI2005

Reason for exclusion	Not autism-specific

1.4.126 SAWYER2010

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on relationship between time demands and maternal mental health

1.4.127 SCHIEVE2007

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

1.4.128 SCHRECK2006

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

1.4.129 SCHWICHTENBERG2007

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on predictors of maternal mental health problems

1.4.130 SENEL1996

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

1.4.131 SENEL2010

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 and the only rating of experience is perceived efficacy for child outcomes where an RCT approach would have been more appropriate

1.4.132 SHARPLEY1997

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

1.4.133 SHTAYERMMAN2007

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on relationship between aspergers and peer victimisation

1.4.134 SHTAYERMMAN2008

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on relationship between autism and suicidal ideation and comorbid disorders

1.4.135 SHTAYERMMAN2009

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on experience/perceptions of autism-related stigma,with a focus on relationships and social activities

1.4.136 SIMANTOV2011

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

1.4.137 SMITH2000

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 or perceived intervention effectiveness for child outcomes where an RCT would have been more appropriate

1.4.138 SMITH2010A

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

1.4.139 SOLISH2008

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on predictors of parental involvement in IBI

1.4.140 SRIVASTAVA2011

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on optimism-pessimism and maternal competence

1.4.141 STERZING2012

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on bullying, but not in relation to any particular service.

1.4.142 STOKES2005

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

1.4.143 SYMES2010

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

1.4.144 TALAYONGAN2000

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

1.4.145 TAYLOR2011

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on how the mother-child relationship is effected by the child leaving high school

1.4.146 TEHEE2009

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

1.4.147 THOMAS2007

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

1.4.148 TOBING2006

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

1.4.149 TODD2010

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

1.4.150 TUNALI2002

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

1.4.151 TWOY2007

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

1.4.152 TWYMAN2010

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

1.4.153 VANROEKEL2010

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

1.4.154 VIECILI2010

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

1.4.155 WACHTEL2008

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

1.4.156 WANG2009

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

1.4.157 WANG2011

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on predictors of parental stress and coping strategies

1.4.158 WANG2012

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on relationship between community support and coping strategies of carer and behaviour of children.

1.4.159 WESTLING1997

Reason for exclusion	Mixed mental health disorders population and only 2% of the sample have autism

1.4.160 WHITE2009

Reason for exclusion	Experience of autism with no explicit implications for management, planning and/or delivery of care. Focus is on relationship between anxiety, loneliness and social skills

1.4.161 WHITE2010A

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

1.4.162 WHITEHOUSE2009

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

1.4.163 WHITELAW2007

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

1.4.164 WONG2002

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

1.4.165 WOOD2009

Reason for exclusion	Case study methodology

1.4.166 YOUNG2009

Reason for exclusion	Focus is on relationship of US health insurance type to costs, accessibility, and use of services for children with autism, and is not directly applicable to the UK

1.4.167 YU2012

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

1.5 REFERENCES OF EXCLUDED STUDIES

Al Anbar NN, Dardennes RM, Prado-Netto A, Kaye K, Contejan Y. Treatment choices in autism spectrum disorder: the role of parental illness perceptions. Research in Developmental Disabilities. 2010;31:817-828.

Al-Kandari HY, Al-Qashan H. Maternal self-efficacy of mothers of children with intellectual developmental disabilities, down syndrome, and autism in Kuwait. Child and Adolescent Social Work Journal. 2010;27:21-39.

Alderson P, Goodey C. Autism in special and inclusive schools: 'There has to be a point to their being there'. Disability and Society. 1999;14:249-261.

Allen D, Evans C, Hider A, Hawkins S, Peckett H, Morgan H. Offending behaviour in adults with Asperger syndrome. Journal of Autism and Developmental Disorders. 2008; 38: 748-758.

Allik H, Larsson J-O, Smedje H. Health-related quality of life in parents of school-age children with Asperger syndrome or high-functioning autism. Health and Quality of Life Outcomes. 2006; 4:1.

Alqahtani MMJ. Understanding autism in Saudi Arabia: A qualitative analysis of the community and cultural context. Journal of Pediatric Neurology. 2012;10:15-22.

Altiere MJ, von Kluge S. Family functioning and coping behaviors in parents of children with autism. Journal of Child and Family Studies. 2009; 18: 83-92.

Ambikile JS, Outwater A. Challenges of caring for children with mental disorders: Experiences and views of caregivers attednign the outpatient clinic at Muhimbili National Hospital, Dae es Salaam - Tanzania. Child and Adolescent Psychiatry and Mental Health. 2012;6:16.

Ashby C. The trouble with normal: the struggle for meaningful access for middle school students with developmental disability labels. Disability and Society. 2010;25:345-358.

Avdi E, Griffin C, Brough S. Parents' constructions of professional knowledge, expertise and authority during assessment and diagnosis of their child for an autistic spectrum disorder. British Journal of Medical Psychology. 2000a;73:327-338.

Avdi E, Griffin C, Brough S. Parents' constructions of the 'problem' during assessment and diagnosis of their child for an autistic spectrum disorder. Journal of Health Psychology. 2000b;5:241-254.

Aylott J. Understanding and listening to people with autism. British Journal of Nursing. 2001; 10: 166-172.

Bachraz V, Grace R. Creating a different kind of normal: parent and child perspectives on sibling relationships when one Child in the family has autism spectrum disorder. Contemporary Issues in Early Childhood. 2009; 10: 317-330.

Bagby MS, Dickie VA, Baranek GT. How sensory experiences of children with and without autism affect family occupations. American Journal of Occupational Therapy. 2012;66:78-86.

Baker-Ericzén MJ, Brookman-Frazee L, Stahmer A. Stress levels and adaptability in parents of toddlers with and without autism spectrum disorders. Research and Practice for Persons with Severe Disabilities. 2005; 30: 194-204.

Barak-Levy Y, Goldstein E, Weinstock M. Adjustment characteristics of healthy siblings of children with autism. Journal of Family Studies. 2010;16:155-164.

Barker ET, Hartley ST, Seltzer MM, Floyd FJ, Greenberg JS, Orsmond GI. Trajectories of emotional well-being in mothers of adolescents and adults with autism. Developmental Psychology. 2011; 47: 551-561.

Barnard-Brak L, Davis T, Ivey JK, Thomson D. Student IEP participation and parental satisfaction among adolescents with autism. Journal on Developmental Disabilities. 2009; 15: 48-54.

Bauminger N, Shulman C. The development and maintenance of friendship in high-functioning children with autism: maternal perceptions. Autism. 2003;7:81-97

Bayat M. Evidence of resilience in families of children with autism. Journal of Intellectual Disability Research. 2007; 51: 702-714.

Beadle-Brown J, Murphy G, DiTerlizzi M. Quality of life for the camberwell cohort. Journal of Applied Research in Intellectual Disabilities.2009; 22: 380-390.

Benford P, Standen PJ. The internet: a comfortable communication medium for people with Asperger syndrome (AS) and high functioning autism (HFA)? Journal of Assistive Technologies. 2009; 3: 44-53.

Bennett HE, Wood CL, Julian Hare D. Providing care for adults with autistic spectrum disorders in learning disability services: needs-based or diagnosis-driven? Journal of Applied Research in Intellectual Disabilities. 2005; 18: 57-64.

Bilgin H, Kucuk L. Raising an autistic child: perspectives from Turkish mothers. Journal of Child and Adolescent Psychiatric Nursing. 2010;23:92-99.

Billington T. Working with autistic children and young people: sense, experience and the challenges for services, policies and practices. Disability and Society. 2006; 21: 1-13.

Billstedt E, Gillberg IC, Gillberg C. Aspects of quality of life in adults diagnosed with autism in childhood: a population-based study. Autism. 2011; 15: 7-20.

Bloch JS, Gardner M. Accessing a diagnosis for a child with an autism spectrum disorder: the burden is on the caregiver. American Journal for Nurse Practitioners. 2007;11:10-17.

Bloch JS, Weinstein JD. Families of young children with autism. Social Work in Mental Health. 2010; 8: 23-40.

Bowker A, D'Angelo NM, Hicks R, Wells K. Treatments for autism: parental choices and perceptions of change. Journal of Autism and Developmental Disorders. 2011;41:1373-1382.

Boström PK, Broberg M, Hwang P. Parents' descriptions and experiences of young children recently diagnosed with intellectual disability. Child: Care, Health and Development. 2009; 36: 93-100.

Brogan CA, Knussen C. The disclosure of a diagnosis of an autistic spectrum disorder: determinants of satisfaction in a sample of Scottish parents. Autism. 2003;7:31-46.

Brown RI, MacAdam–Crisp J, Wang M, Iarocci G. Family quality of life when there is a child with a developmental disability. Journal of Policy and Practice in Intellectual Disabilities. 2006; 3: 238-245.

Brown HK, Ouellette-Kuntz H, Hunter D, Kelley E, Cobigo V, Lam M. Beyond an autism diagnosis: children's functional independence and parents' unmet needs. Journal of Autism and Developmental Disorders. 2011; 41:1291-1302.

Browning J, Osborne LA, Reed P. A qualitative comparison of perceived stress and coping in adolescents with and without autistic spectrum disorders as they approach leaving school. British Journal of Special Education. 2009;36:36-43.

Brownlow C, O'Dell L. Representations of autism: implications for community healthcare practice. Community Practitioner. 2009; 82: 18-21.

Cappadocia, M.C., Weiss, J.A & Pepler, D. Bullying experiences among children and youth with autism spectrum disorders. Journal of Autism and Developmental Disorders. 2012; 42:266-277

Cappe E, Wolff M, Bobet R, Adrien J-L. Quality of life: a key variable to consider in the evaluation of adjustment in parents of children with autism spectrum disorders and in the development of relevant support and assistance programmes. Quality of Life Research. 2011;20:1279–1294.

Cardon TA, Wilcox J, Campbell PH. Caregiver perspectives about assistive technology use with their young children with autism spectrum disorders. Infants and Young Children. 2011;24:153-173.

Carlon S, Carter M, Stephenson J. A review of declared factors identified by parents of children with autism spectrum disorders (ASD) in making intervention decisions. Research in Autism Spectrum Disorders. 2012;7:369-381.

Carrington S, Graham L. Perceptions of school by two teenage boys with Asperger syndrome and their mothers: a qualitative study. Autism. 2001;5:37-48.

Carrington S, Templeton E, Papinczak T. Adolescents with Asperger syndrome and perceptions of friendship. Focus on Autism and Other Developmental Disabilities. 2003;18:211-218.

Carter EW, Austin D, Trainor AA. Factors associated with the early work experiences of adolescents with severe disabilities. Intellectual and Developmental Disabilities. 2011;49:233-247.

Carter I. Positive and negative experiences of parents involved in online self-help groups for autism. Journal on Developmental Disabilities. 2009;15:44-52.

Cebula, K.R. Applied behaviour analysis programs for autism: sibling psychosocial adjustment during and following intervention use. Journal of Autism and Developmental Disorders. 2012; 42:847-862.

Chamak B, Bonniau B, Oudaya L, Ehrenberg A. The autism diagnostic experiences of French parents. Autism. 2011;15:83-97.

Chamberlain B, Kasari C, Rotheram-Fuller E. Involvement or isolation? the social networks of children with autism in regular classrooms. Journal of Autism and Developmental Disorders. 2007;37:230-242.

Children in Scotland and Scottish Borders Council. Access all Areas: What Children and Young People Think about Accessibility, Inclusion and Additional Support at School. Edinburgh: Children in Scotland; 2007. Available from: http://www.childreninscotland.org.uk/docs/pubs/access_all_areas_v4.pdf.

Chong WH, Goh W, Tang HN, Chan WP, Choo S. Service practice evaluation of the early intervention programs for infants and young children in Singapore. Children's Health Care. 2012;41:281-301.

Christon LM, Mackintosh VH, Myers BJ. Use of complementary and alternative medicine (CAM) treatments by parents of children with autism spectrum disorders. 2010;4:249-259.

Church C, Alisanski S, Amanullah S. The social, behavioral, and academic experiences of children with Asperger syndrome. Focus on Autism and Other Developmental Disabilities. 2000;15:12-20.

Clavering EK. Enabling carers to care: processes of exclusion and support for parents of young disabled children. Benefits. 2007;15:33-44.

Corman MK. The positives of caregiving: mothers' experiences caregiving for a child with autism. Families in Society. 2009;90:439-445.

Coulthard P, Fitzgerald M. In God we trust? organised religion and personal beliefs as resources and coping strategies, and their implications for health in parents with a child on the autistic spectrum. Mental Health, Religion and Culture. 1999;2:19-33.

Dale E, Jahoda A, Knott F. Mothers' attributions following their child's diagnosis of autistic spectrum disorder: exploring links with maternal levels of stress, depression and expectations about their child's future. Autism. 2006; 10: 463-479.

Daly J. I Exist: The Message from Adults with Autism in Scotland. Glasgow: National Autistic Society; 2007. Available from: http://www.autism.org.uk/TDAA.

Daniel LS, Billingsley BS. What boys with an autism spectrum disorder say about establishing and maintaining friendships. Focus on Autism and Other Developmental Disabilities. 2010;25:220-229.

Dardennes RM, Al Anbar NN, Prado-Netto A, Kaye K, Contejean Y, Al Anbar NN. Treating the cause of illness rather than the symptoms: parental causal beliefs and treatment choices in autism spectrum disorder. Research in Developmental Disabilities. 2011;32:1137-1146.

Davies J. The role of the specialist for families with autistic children. Nursing Standard. 1996; 11:36-40.

Davies MD, Beamish W. Transitions from school for young adults with intellectual disability: parental perspectives on "life as an adjustment"." Journal of Intellectual and Developmental Disability. 2009;34:248-257.

DeGrace BW. The everyday occupation of families with children with autism. American Journal of Occupational Therapy. 2004;58:543-550.

Dellve L, Cernerud L, Hallberg LRM. Harmonizing dilemmas: siblings of children with DAMP and Asperger Syndrome's experiences of coping with their life situations. Scandinavian Journal of Caring Sciences. 2000; 14: 172-178.

de Santos R, Daly S. Improving inclusion: getting inclusive education right for children with autism. London: TreeHouse; 2008.

Dickie VA, Baranek GT, Schultz B, Watson LR, McComish CS. Parent reports of sensory experiences of preschool children with and without autism: a qualitative study. The American Journal of Occupational Therapy. 2009;63:172-181.

Ding Y, Yang L-Y, Salyers K, Harper H, Guo J-P, Liu H, et al. Assessing needs and challenges reported by caregivers and teachers of children with autism spectrum disorders in China. Journal of International Association of Special Education. 2010;11: 4-14.

Dipietro E, Luiselli JK, Campbell S, Cannon BO, Ellis JT, Taras M. A parent survey approach to evaluate public school education of children with autism/pervasive developmental disorder following center-based behavioral treatment. Special Services in the Schools. 2002;18:119-131.

Doherty K, Fitzgerald M, Matthews P. Services for autism in Ireland. The Irish Journal of Psychology. 2000;21:50-69.

Donnellan AM, Sabin LA, Majure LA. Facilitated communication: beyond the quandary to the questions. Topics in Language Disorders. 1992;12:69-82.

Dunn ME, Burbine T, Bowers CA, Tantleff-Dunn S. Moderators of stress in parents of children with autism. Community Mental Health Journal. 2001;37:39-52.

Dunstan E, Griffiths S. Sensory strategies: practical support to empower families. New Zealand Journal of Occupational Therapy. 2008;55:5-13.

Ekas NV, Whitman TL, Shivers C. Religiosity, spirituality, and socioemotional functioning in mothers of children with autism spectrum disorder. Journal of Autism and Developmental Disorders. 2009; 39: 706-719.

Elder JH, D'Alessandro T. Supporting families of children with autism spectrum disorders: questions parents ask and what nurses need to know. Pediatric Nursing. 2009;35:240-245.

Engström I, Ekström L, Emilsson B. Psychosocial functioning in a group of Swedish adults with Asperger syndrome or high-functioning autism. Autism. 2003;7:99-110.

Escribano-Hernández A, García-Garraus JM, Hernández-García I. Evaluation of satisfaction among relatives of mentally disabled patients who were users of a dental care protocol under general anaesthesia. Medicina Oral, Patologia Oral y Cirugia Bucal. 2012;17:e83-e88.

Falkmer T, Anund A, Sörensen G, Falkmer M. The transport mobility situation for children with autism spectrum disorders. Scandinavian Journal of Occupational Therapy. 2004;11:90-100.

Farrugia D. Exploring stigma: medical knowledge and the stigmatisation of parents of children diagnosed with autism spectrum disorder. Sociology of Health and Illness. 2009;31:1011-1027.

Fitzgerald M, Birkbeck G, Matthews P. Maternal burden in families with children with autistic spectrum disorder. The Irish Journal of Psychology. 2002;23:2-17.

Fleischmann A. The hero's story and autism. grounded theory study of websites for parents of children with autism. Autism. 2005; 9: 299-316.

Fletcher PC, Markoulakis R, Bryden PJ. The costs of caring for a child with an autism spectrum disorder. Issues in Comprehensive Pediatric Nursing. 2012;35:45-69.

Forest, E.J., Horner, R.H., Lewis-Palmer, T et al. Transitions for children with autism from preschool to kindergarten. Journal of Positive Behavior Interventions. 2004; 6: 103-112

Freedman RI, Boyer NC. The power to choose: supports for families caring for individuals with developmental disabilities. Health and Social Work. 2000;25:59-68.

Froese P, Richardson M, Romer LT, Swank M. Comparing opinions of people with developmental disabilities and significant persons in their lives using the individual supports identification system (ISIS). Disability and Society. 1999;14:831-843.

Fujiwara T, Okuyama M, Funahashi K. Factors influencing time lag between first parental concern and first visit to child psychiatric services in children with autism spectrum disorders in Japan. Research in Autism Spectrum Disorders. 2011;5:584-591.

Fullerton A, Coyne P. Developing skills and concepts for self-determination in young adults with autism. Focus on Autism and Other Developmental Disabilities. 1999;14:42-52.

Gau SS-F, Chou M-C, Chiang H-L, Lee J-C, Wong C-C, Chou W-J, et al. Parental adjustment, marital relationship, and family function in families of children with autism. Research in Autism Spectrum Disorders. 2012;6:263-270.

Ghaziuddin M, Alessi N, Greden JF. Life events and depression in children with pervasive developmental disorders. Journal of Autism and Developmental Disorders. 1995;25:495-502.

Gill J, Liamputtong P. Being the mother of a child with Asperger's syndrome: women's experiences of stigma. Health Care for Women International. 2011;32:708-722.

Gillett JN, LeBlanc LA. Parent-implemented natural language paradigm to increase language and play in children with autism. Research in Austism Spectrum Disorders. 2007;1:247-255.

Given J. Being heard: aiding public participation in decision making. Learning Disability Practice. 2011;14:26-30.

Glaun, D.E., Cole, K.E & Reddihough, D.S. Six month follow-up: the crucial test of multidisciplinary developmental assessment. Child: Care, Health and Development. 1998; 24: 457-472

Goin-Kochel RP, Mackintosh VH, Myers BJ. How many doctors does it take to make an autism spectrum diagnosis? Autism. 2006;10:439-451.

Goin-Kochel RP, Mackintosh VH, Myers BJ. Parental reports on the efficacy of treatments and therapies for their children with autism spectrum disorders. Research in Autism Spectrum Disorders. 2009; 3: 528-537.

Graetz JE. Autism grows up: opportunities for adults with autism. Disability and Society. 2010;25:33-47.

Gray DE. Lay conceptions of autism: parents' explanatory models. Medical Anthropology. 1995;16:99-118.

Gray DE. High functioning autistic children and the construction of "normal family life. Social Science and Medicine. 1997; 44: 1097-1106.

Gray DE. Accommodation, resistance and transcendence: three narratives of autism. Social Science and Medicine. 2001;53:1247–1257.

Gray DE. Ten years on: a longitudinal study of families of children with autism. Journal of Intellectual and Developmental Disability. 2002a; 27: 215-222.

Gray DE. 'Everybody just freezes. everybody is just embarrassed': felt and enacted stigma among parents of children with high functioning autism. Sociology of Health and Illness. 2002b;24:734-749.

Gray DE. Gender and coping: the parents of children with high functioning autism. Social Science and Medicine. 2003;56:631-642.

Gray DE. Coping over time: the parents of children with autism. Journal of Intellectual Disability Research. 2006; 50: 970-976.

Greeff AP, van der Walt K-J. Resilience in families with an autistic child. Education and Training in Autism and Developmental Disabilities. 2010;45:347-355.

Griffin E, Pollak D. Student experiences of neurodiversity in higher education: insights from the BRAINHE Project. Dyslexia.2009;15:23-41.

Griffith GM, Hastings RP, Nash S, Hill C. Using matched groups to explore child behavior problems and maternal well-being in children with Down syndrome and autism. Journal of Autism and Developmental Disorders. 2010; 40: 610-619.

Griffith GM, Totsika V, Nash S, Jones RSP, Hastings RP. "We are all there silently coping." the hidden experiences of parents of adults with Asperger syndrome. Journal of Intellectual and Developmental Disability. 2012;37:237-247.

Hall HR. The relationships among adaptive behaviors of children with autism, family support, parenting stress, and coping. Issues in Comprehensive Pediatric Nursing. 2011; 34: 4-25.

Hall HR. Families of children with autism: behaviors of children, community support and coping. Issues in Comprehensive Pediatric Nursing. 2012;35:111-132.

Hall, H.R & Graff, J.C. Maladaptive behaviours of children with autism: parent support, stress and coping. Issues in Comprehensive Pediatric Nursing, 2012; 35: 194-214.

Hall HR, Neely-Barnes SL, Graff JC, Kreck TE, Roberts RJ. Parental stress in families of children with a genetic disorder/disability and the resiliency model of family stress, adjustment, and adaptation. Issues in Comprehensive Pediatric Nursing. 2012;35:24-44.

Hamlyn-Wright S, Draghi-Lorenz R, Ellis J. Locus of control fails to mediate between stress and anxiety and depression in parents of children with a developmental disorder. Autism. 2007;11:489-501.

Hanson E, Kalish LA, Bunce E, Curtis C, McDaniel S, Ware J, et al. Use of complementary and alternative medicine among children diagnosed with autism spectrum disorder. Journal of Autism & Developmental Disorders. 2007;37:628-636.

Harrington JW, Rosen L, Garnecho A, Patrick PA. Parental perceptions and use of complementary and alternative medicine practices for children with autistic spectrum disorders in private practice. Journal of Developmental and Behavioral Pediatrics. 2006;27:S156-S161.

Hastings RP, Johnson E. Stress in UK families conducting intensive home-based behavioral intervention for their young child with autism. Journal of Autism and Developmental Disorders. 2001;31:327-336.

Hastings RP, Symes MD. Early intensive behavioral intervention for children with autism: parental therapeutic self-efficacy. Research in Developmental Disabilities. 2002;23:332-341.

Häussler A, Kurtz-Costes B. Child care for preschoolers with autism: an exploration of mothers' beliefs, decision-making, and knowledge. Early Childhood Research Quarterly. 1998;13:485-499.

Hazell PL, Tarren-Sweeney M, Vimpani GV, Keatinge D, Callan K. Children with disruptive behaviours II: clinical and community service needs. Journal of Paediatrics and Child Health. 2002;38:32-40.

Heiman T, Berger O. Parents of children with Asperger syndrome or with learning disabilities: family environment and social support. Research in Developmental Disabilities. 2008;29:289-300.

Herman SE, Thompson L. Families' perceptions of their resources for caring for children with developmental disabilities. Mental Retardation. 1995;33:73-83.

Hiebert-Murphy D, Trute B, Wright A. Patterns of entry to community-based services for families with children with developmental disabilities: implications for social work practice. Child and Family Social Work. 2008;13:423-432.

Hines M, Balandin S, Togher L. Communication and AAC in the lives of adults with autism: the stories of their older parents. Augmentative and Alternative Communication. 2011;27:256-266.

Hintzen A, Delespaul P, van Os J, Myin-Germeys I. Social needs in daily life in adults with pervasive developmental disorders. Psychiatry Research. 2010;179:75-80.

Holst Y, Nyman H, Larsson J-O. Predictors of patient satisfaction with the feedback after a neuropsychological assessment. The Open Psychiatry Journal. 2009;3:50-55

Howard B, Cohn E, Orsmond GI. Understanding and negotiating friendships: perspectives from an adolescent with Asperger syndrome. Autism. 2006; 10: 619-627.

Howlin P, Moorf A. Diagnosis in autism: a survey of over 1200 patients in the UK. Autism. 1997;1:135-162.

Howlin P, Asgharian A. The diagnosis of autism and Asperger syndrome: findings from a survey of 770 families. Developmental Medicine and Child Neurology. 1999;41:834-839.

Hume K, Bellini S, Pratt C. The usage and perceived outcomes of early intervention and early childhood programs for young children with autism spectrum disorder. Topics in Early Childhood Special Education. 2005;25:195-207.

Humphrey N, Symes W. Responses to bullying and use of social support among pupils with autism spectrum disorders (ASDs) in mainstream schools: a qualitative study. Journal of Research in Special Educational Needs. 2010;10:82-90.

Hurlburt RT, Happé F, Frith U. Sampling the form of inner experience in three adults with Asperger syndrome. Psychological Medicine. 1994;24:385-395.

Hurlbutt K, Chalmers L. Adults with autism speak out: perceptions of their life experiences. Focus on Autism and Other Developmental Disabilities. 2002; 17: 103-111.

Huws JC, Jones RSP. Diagnosis, disclosure, and having autism: an interpretative phenomenological analysis of the perceptions of young people with autism. Journal of Intellectual and Developmental Disability. 2008; 33: 99-107.

Jantz KM. Support groups for adults with Asperger syndrome. Focus on Autism and Other Developmental Disabilities. 2011;26:119-128.

Jennes-Coussens M, Magill-Evans J, Koning C. The quality of life of young men with Asperger syndrome. Autism. 2006; 10: 403-414.

Jones G. Parent and carer involvement in the commissioning of services for children and young people with autism spectrum disorder in the East Midlands. In: SEN Policy Options Group. Individual Budgets and Direct Payments: Issues, Challenges and Future Implications for the Strategic Management of SEN. Policy Paper 3, 6th series; 2008. Available from: http://www.docs.hss.ed.ac.uk/education/creid/NewsEvents/14_SENPolicyOptns_PP3.pdf.

Jordan R, Jones G. Educational Provision for Children with Autism in Scotland. Interchange No. 46. Edinburgh: Scottish Office Education and Industry Department; 1997.

Kaminsky L, Dewey D. Psychosocial adjustment in siblings of children with autism. Journal of Child Psychology and Psychiatry. 2002;43:225-232.

Kamp-Becker I, Schröder J, Remschmidt H, Bachmann CJ. Health-related quality of life in adolescents and young adults with high functioning autism-spectrum disorder. GMS Psycho-Social-Medicine. 2010; 7: 1-10.

Kamp-Becker I, Schröder J, Muehlan H, Remschmidt H, Becker K, Bachmann CJ. Health-related quality of life in children and adolescents with autism spectrum disorder. Zeitschrift fur Kinder-und Jugendpsychiatrie und Psychotherapie. 2011; 39: 123-131.

Kasari C, Freeman SFN, Bauminger N, Alkin MC. Parental perspectives on inclusion: effects of autism and down syndrome. Journal of Autism and Developmental Disorders. 1999; 29: 297-305.

Kayama M, Haight W. Cultural sensitivity in the delivery of disability services to children: a case study of Japanese education and socialization. Children and Youth Services Review. 2012; 34: 266-275.

Kelly B. 'Chocolate... makes you autism': impairment, disability and childhood identities. Disability and Society. 2005;20:261-275.

Kenny C, Buckley D, McDonnell AA. Group CBT for anxiety management in adults with Asperger syndrome. Good Autism Practice. 2008;9:9-14.

King GA, Zwaigenbaum L, King S, Baxter D, Rosenbaum P, Bates A. A qualitative investigation of changes in the belief systems of families of children with autism or down syndrome. Child: Care, Health and Development. 2006;32:353-369.

King G, Baxter D, Rosenbaum P, Zwaigenbaum L, Bates A. Belief systems of families of children with autism spectrum disorders or down syndrome. Focus on Autism and Other Developmental Disabilities. 2009;24:50-64.

King G, Zwaigenbaum L, Bates A, Baxter D, Rosenbaum P. Parent views of the positive contributions of elementary and high school-ages children with autism spectrum disorders and Down syndrome. Child: Care, Health and Development. 2012;38:817-828.

Knight A, Petrie P, Zuurmond M, Potts P. 'Mingling together': promoting the social inclusion of disabled children and young people during the school holidays. Child and Family Social Work. 2009;14:15-24.

Knott F, Dunlop A-W, Mackay T. Living with ASD: how do children and their parents assess their difficulties with social interaction and understanding? Autism. 2006;10:609-617.

Koh, M-S, Shin S, Yeo MH. The Learning Program for the Development of Autistic Children (LPDAC): parents' perspectives on the treatment outcomes. Journal of International Association of Special Education. 2010;11:92-100.

Kowalski RM, Fedina C. Cyber bullying in ADHD and Asperger Syndrome populations. Research in Autism Spectrum Disorders. 2011;5:1201-1208.

Krausz M, Meszaros J. The retrospective experiences of a mother of a child with autism. International Journal of Special Education. 2005; 20: 36-46.

Kuhn JC, Carter AS. Maternal self-efficacy and associated parenting cognitions among mothers of children with autism. American Journal of Orthopsychiatry. 2006;76:564-575.

Lam S-F, Wong BPH, Leung D, Ho D, Au-Yeung P. How parents perceive and feel about participation in community activities: the comparison between parents of preschoolers with and without autism spectrum disorders. Autism. 2010;14:359-377.

Langan M. Parental voices and controversies in autism. Disability and Society. 2011;26:193-205.

Larson E. Caregiving and autism: how does children's propensity for routinization influence participation in family activities? OTJR: Occupation, Participation and Health. 2006; 26: 69-79.

Lasser J, Corley K. Constructing normalcy: a qualitative study of parenting children with Asperger's disorder. Educational Psychology in Practice. 2008; 24: 335-346.

Lin L-Y, Orsmond GI, Coster WJ, Cohn ES. Families of adolescents and adults with autism spectrum disorders in Taiwan: the role of social support and coping in family adaptation and maternal well-being. Research in Autism Spectrum Disorders. 2011;5:144-156.

Little L. Middle-class mothers' perceptions of peer and sibling victimization among children with Asperger's syndrome and nonverbal learning disorders. Issues in Comprehensive Pediatric Nursing. 2002;25:43-57.

Little L. Differences in stress and coping for mothers and fathers of children with Asperger's syndrome and nonverbal learning disorders. Pediatric Nursing. 2002;28:565-570.

Little L, Clark RR. Wonders and worries of parenting a child with Asperger Syndrome and nonverbal learning disorder. MCN: The American Journal of Maternal/Child Nursing. 2006;31:39-44.

Locke J, Ishijima EH, Kasari C, London N. Loneliness, friendship quality and the social networks of adolescents with high-functioning autism in an inclusive school setting. Journal of Research in Special Educational Needs. 2010;10:74-81.

Lord P, Kinder K, Wilkin A, Atkinson M, Harland J. Evaluating the early impact of integrated children's services. Round 1 Final Report. Slough: NFER; 2008.

Lounds J, Seltzer MM, Greenberg JS, Shattuck PT. Transition and change in adolescents and young adults with autism: Longitudinal effects on maternal well-being. American Journal on Mental Retardation. 2007; 112: 401-417.

MacLeod A. The Birmingham community support scheme for adults with Asperger syndrome. Autism. 1999;3:177-192.

MacLeod A, Johnston P. Standing out and fitting in: a report on a support group for individuals with Asperger syndrome using a personal account. British Journal of Special Education. 2007; 34: 83-88.

Macleod A. 'Welcome to my first rant!': report on a participatory pilot project to develop the 'AS portal', an online peer support network for higher education students on the autism spectrum. Journal of Assistive Technologies. 2010;4:14-24.

MacMullin JA, Viecili MA, Cappadocia MC, Weiss JA. Parent empowerment and mental health: understanding parent perceptions of the educational experience. Journal on Developmental Disabilities. 2010;16:68-71.

Magana S, Ghosh S. Latina mothers caring for a son or daughter with autism or schizophrenia: similarities, differences, and the relationship between co-residency and maternal well-being. Journal of Family Social Work. 2010;13:227-250.

Magaña S, Smith MJ. Psychological distress and well-being of latina and non-latina white mothers of youth and adults with an autism spectrum disorder: cultural attitudes towards coresidence status. American Journal of Orthopsychiatry. 2006; 76: 346-357.

Mak WWS, Kwok YTY. Internalization of stigma for parents of children with autism spectrum disorder in Hong Kong. Social Science and Medicine. 2010;70:2045-2051

Makela NL, Birch PH, Friedman JM, Marra CA. Parental perceived value of a diagnosis for intellectual disability (ID): a qualitative comparison of families with and without a diagnosis for their child's ID. American Journal of Medical Genetics. 2009;149A:2393-2402.

Mandell DS, Salzer MS. Who joins support groups among parents of children with autism? Autism. 2007;11:111-122.

Manning MM, Wainwright L, Bennett J. The double ABCX model of adaptation in racially diverse families with a school-age child with autism. Journal of Autism and Developmental Disorders. 2011; 41: 320-331.

Margetts JK, Le Couteur A & Croom S. Families in a state of flux: the experience of grandparents in autism spectrum disorder. Child: Care, Health and Development. 2006;32:565-574.

Markoulakis R, Fletcher P, Bryden P. Seeing the glass half full: benefits to the lived experiences of female primary caregivers of children with autism. Clinical Nurse Specialist. 2012;26:48-56.

Marks SU, Schrader C, Longaker T, Levine M. Portraits of three adolescent students with Asperger's syndrome: personal stories and how they can inform practice. Journal of the Association for Persons with Severe Handicaps. 2000;25:3-17.

Martin N, Hendrickx S. Insights into intimacy from people with Asperger syndrome and their partners. Good Autism Practice. 2011;12:26-33.

Mascha K, Boucher J. Preliminary investigation of a qualitative method of examining siblings' experiences of living with a child with ASD. British Journal of Developmental Disabilities. 2006;52:19-28.

Matthews RA, Booth SM, Taylor CF, Martin T. A qualitative examination of the work-family interface: parents of children with autism spectrum disorder. Journal of Vocational Behavior. 2011;79:625-639.

McCabe H. Parent advocacy in the face of adversity: autism and families in the People's Republic of China. Focus on Autism and Other Developmental Disabilities. 2007;22:39-50.

McCabe H. Employment experiences, perspectives, and wishes of mothers of children with autism in the People's Republic of China.Journal of Applied Research in Intellectual Disabilities. 2010;23:122-131.

McConachie H, Robinson G. What services do young children with autism spectrum disorder receive? Child: Care, Health and Development. 2006;32:553-557.

McConkey R. Transitions and young people with autism spectrum disorders. Jordanstown: University of Ulster; 2010.

McGrath RJ, Laflamme DJ, Schwartz AP, Stransky M, Moeschler JB. Access to genetic counseling for children with autism, down syndrome, and intellectual disabilities. Pediatrics. 2009;124:S443-S449.

Meadan H, Stoner JB, Angell ME. Review of literature related to the social, emotional, and behavioral adjustment of siblings of individuals with autism spectrum disorder. Journal of Developmental and Physical Disabilities.2010; 22: 83-100.

Meadan H, Halle JW, Ebata AT. Families with children who have autism spectrum disorders: stress and support. Exceptional Children. 2010; 77: 7-36.

Medhurst B, Clay D. The Thomas Outreach Project (TOP): an early years intervention for children with an autistic spectrum disorder (ASD). Educational Psychology in Practice. 2008;24:69-78.

Mercer L, Creighton S, Holden JJA, Lewis MES. Parental perspectives on the causes of an autism spectrum disorder in their children. Journal of Genetic Counseling. 2006;15:41-50.
Mickelson KD, Wroble M, Helgeson VS. "Why my child?": parental attributions for children's special needs. Journal of Applied Social Psychology. 1999;29:1263-1292.

Milshtein S, Yirmiya N, Oppenheim D, Koren-Karie N, Levi S. Resolution of the diagnosis among parents of children with autism spectrum disorder: associations with child and parent characteristics. Journal of Autism and Developmental Disorders. 2010;40:89-99.

Montalbano R, Roccella M. The quality of life of children with pervasive developmental disorders. Minerva Pediatrica. 2009;61:361-370.

Montes G, Halterman JS. Psychological functioning and coping among mothers of children with autism: a population-based study. Pediatrics. 2007;119:e1040-e1046.

Moore K, McConkey R, Sines D, Cassidy A. Improving diagnostic and assessment services for children with autistic spectrum disorders. Early Child Development and Care. 1999;154:1-11.

Moore TR, Symons FJ. Adherence to behavioral and medical treatment recommendations by parents of children with autism spectrum disorders. Journal of Autism and Developmental Disorders. 2009;39:1173-1184.

Moore TR, Symons FJ. Adherence to treatment in a behavioral intervention curriculum for parents of children with autism spectrum disorder. Behavior Modification. 2011;35:570-594.

Moran H. A very personal assessment: using a personal construct psychology assessment technique (drawing the ideal self) with young people with ASD to explore the child's view of the self. Good Autism Practice. 2006;7:78-86.

Moyson T, Roeyers H. The overall quality of my life as a sibling is all right, but of course, it could always be better'. quality of life of siblings of children with intellectual disability: the siblings' perspectives. Journal of Intellectual Disability Research. 2012;56:87-101.

Müller E, Schuler A, Burton BA, Yates GB. Meeting the vocational support needs of individuals with Asperger Syndrome and other autism spectrum disabilities. Journal of Vocational Rehabilitation. 2003;18:163-175.

Müller E, Schuler A, Yates GB. Social challenges and supports from the perspective of individuals with Asperger syndrome and other autism spectrum disabilities. Autism. 2008;12:173-190.

Mugno D, Ruta L, D'Arrigo VG, Mazzone L. Impairment of quality of life in parents of children and adolescents with pervasive developmental disorder. Health and Quality of Life Outcomes. 2007; 5: 22.

Nally B, Houlton B, Ralph S. Researches in brief: the management of television and video by parents of children with autism. Autism. 2000;4:331–338.

National Autistic Society. "If I tell them how I feel then they'll understand.": adults with autism in their own words. London: The National Autistic Society; 2009.

Neely-Barnes SL, Graff JC, Roberts RJ, Hall HR, Hankins JS. "It's our job": qualitative study of family responses to ableism. Intellectual and Developmental Disabilities. 2010;48:245-258.

Neely-Barnes SL, Hall HR, Roberts RJ, Graff JC. Parenting a child with an autism spectrum disorder: public perceptions and parental conceptualizations. Journal of Family Social Work. 2011;14:208-225.

Nesbitt S. An evaluation of multi-agency service provision for children with autistic spectrum disorders. British Journal of Developmental Disabilities. 2000;46:43-50.

Norwich B, Kelly N. Pupils' views on inclusion: moderate learning difficulties and bullying in mainstream and special schools. British Educational Research Journal. 2004;30:43-65.

Nuehring ML, Sitlington PL. Transition as a vehicle: moving from high school to an adult vocational service provider. Journal of Disability Policy Studies. 2003;14:23-35.

O'Brien M. Ambiguous loss in families of children with autism spectrum disorders. Family Relations. 2007;56:135-146.

O'Brien I, Duffy A, Nicho H. Impact of childhood chronic illnesses on siblings: a literature review. British Journal of Nursing. 2009; 18: 1358-1365.

Obrusnikova I, Cavalier AR. Perceived barriers and facilitators of participation in after-school physical activity by children with autism spectrum disorders. Journal of Developmental and Physical Disability. 2010;23:195-211.

Obrusnikova I, Miccinello DL. Parent perceptions of factors influencing after-school physical activity of children with autism spectrum disorders. Adapted Physical Activity Quarterly. 2012;29:63-80.

Ogston PL, Mackintosh VH, Myers BJ. Hope and worry in mothers of children with an autism spectrum disorder or down syndrome. Research in Autism Spectrum Disorders. 2011;5:1378-1384.

Orme DM. A Qualitative examination of mothers' resolution or non-resolution of their childrens' disability of down syndrome or autism using a cognitive intervention. Qualitative Report. 2005;10:561-592.

Orsmond GI, Seltzer MM, Greenberg JS, Krauss MW. Mother-child relationship quality among adolescents and adults with autism. American Journal on Mental Retardation.2006; 111: 121-137.

Orsmond GI, Kuo H-Y, Seltzer MM. Siblings of individuals with an autism spectrum disorder: sibling relationships and wellbeing in adolescence and adulthood. Autism. 2009; 13: 59-80.

Orsmond GI, Kuo H-Y. The daily lives of adolescents with an autism spectrum disorder: Discretionary time use and activity partners. Autism. 2011; 15: 579-599.

Papageorgiou V, Kalyva E. Self-reported needs and expectations of parents of children with autism spectrum disorders who participate in support groups. Research in Autism Spectrum Disorders. 2010;4:653-660.

Parette P, Chuang S-JL, Huer MB. First-generation Chinese American families' attitudes regarding disabilities and educational interventions. Focus on Autism and Other Developmental Disabilities. 2004;19:114-123.

Parsons S, Leonard A, Mitchell P. Virtual environments for social skills training: comments from two adolescents with autistic spectrum disorder. Computers and Education. 2006;47:186-206.

Parsons S, Lewis A, Davison I, Ellins J, Robertson C. Satisfaction with educational provision for children with SEN or disabilities: a national postal survey of the views of parents in Great Britain. 2009;61:19-47.

Parsons S, Lewis A. The home-education of children with special needs or disabilities in the UK: views of parents from an online survey. International Journal of Inclusive Education. 2010;14:67-86.

Paterson P. How well do young offenders with Asperger syndrome cope in custody?: two prison case studies. British Journal of Learning Disabilities. 2008; 36: 54-58.

Pengelly S, Rogers P, Evans K. Space at home for families with a child with autistic spectrum disorder. British Journal of Occupational Therapy. 2009;72:378-383.

Perry A, Black A. A prospective study of out-of-home placement tendency in families of children with autism. Journal on Developmental Disabilities. 1997; 5: 1-23.

Phillips D. Asperger syndrome: from adolescence to adulthood. Catholic School Studies. 2003;76:10-14.

Pisula E, Kossakowska Z. Sense of coherence and coping with stress among mothers and fathers of children with autism. Journal of Autism and Developmental Disorders. 2010; 40: 1485-1494.

Pituch KA, Green VA, Didden R, Lang R, O’Reilly MF, Lancioni GE, et al. Parent reported treatment priorities for children with autism spectrum disorders. Research in Autism Spectrum Disorders. 2011;5:135-143.

Poon KK. The activities and participation of adolescents with autism spectrum disorders in Singapore: findings from an ICF-based instrument. Journal of Intellectual Disability Research. 2011;55:790-800.

Portway S, Johnson B. Asperger syndrome and the children who 'don't quite fit in'. Early Child Development and Care. 2003;173:435-443.

Portway SM, Johnson B. Do you know I have Asperger's syndrome? risks of a non-obvious disability. Health, Risk and Society. 2005;7:73-83.

Pottie CG, Ingram KM. Daily stress, coping, and well-being in parents of children With autism: a multilevel modeling approach. Journal of Family Psychology. 2008; 22: 855-864.

Preece D. Consultation with children with autistic spectrum disorders about their experience of short-term residential care. British Journal of Learning Disabilities. 2002;30:97-104.

Preece D. Effective short breaks services for families with children with autism spectrum disorders: how one local authority in the United Kingdom is working to meet the challenge. Practice: Social Work in Action. 2009b;21:159-174.

Punshon C, Skirrow P, Murphy G. The 'not guilty verdict': psychological reactions to a diagnosis of Asperger syndrome in adulthood. Autism. 2009;13:265-283.

Randall P. Autism: support work with families. Behavioural Social Work Review. 1995a;16:31-39.

Randall P. Autism: working with families. Practice. 1995b;7:11-20.

Read N, Schofield A. Autism: are mental health services failing children and parents? Journal of Family Health Care. 2010;20:120-124.

Reid B, Batten A. B is for bullied: the experiences of children with autism and their families. London: National Autistic Society; 2006.

Regehr K, Feldman M. Parent-selected interventions for infants at-risk for autism spectrum disorders and their affected siblings. Behavioral Interventions. 2009;24:237-248.

Renty JO, Roeyers H. Quality of life in high-functioning adults with autism spectrum disorder: the predictive value of disability and support characteristics. Autism. 2006;10:511-524.

Resch, J.A., Benz, M.R & Elliott, T.R. Evaluating a dynamic process model of well-being for parents of children with disabilities: a multi-method analysis. Rehabilitation Psychology. 2012; 57:61-72

Rhoades RA, Scarpa A, Salley B. The importance of physician knowledge of autism spectrum disorder: results of a parent survey. BMC Pediatrics. 2007;7:37.

Ridley J, Hunter S, Infusion Co-operative. "Go for it!": Supporting People with Learning Disabilities and/or Autistic Spectrum Disorders in Employment. Edinburgh: Scottish

Executive; 2005. Available from: http://www.scotland.gov.uk/Publications/2005/06/14102552/25532.

Rivers JW, Stoneman Z. Sibling relationships when a child has autism: marital stress and support coping. Journal of Autism and Developmental Disorders. 2003;33:383-394.

Rizk S, Pizur-Barnekow K, Darragh AR. Leisure and social participation and health-related quality of life in caregivers of children with autism. OTJR: Occupation, Participation and Health. 2011;31:164-171.

Robledo JA, Donnellan AM. Properties of supportive relationships from the perspective of academically successful individuals with autism. Intellectual and Developmental Disabilities. 2008;46:299-310.

Robledo J, Donnellan AM, Strandt-Conroy K. An exploration of sensory and movement differences from the perspective of individuals with autism. Frontiers in Integrative Neuroscience. 2012;6:107.

Rocque B. Mediating self-hood: exploring the construction and maintenance of identity by mothers of children labeled with autism spectrum disorder. Disability and Society. 2010;25:485-497.

Rodger S, Keen D, Braithwaite M, Cook S. Mothers satisfaction with a home based early intervention programme for children with ASD. Journal of Applied Research in Intellectual Disabilities. 2008;21:174-182.

Rodger S, Umaibalan V. The routines and rituals of families of typically developing children compared with families of children with autism spectrum disorder: an exploratory study. British Journal of Occupational Therapy. 2011;74:20-26.

Roeyers H, Mycke K. Siblings of a child with autism, with mental retardation and with a normal development. Child: Care, Health and Development. 1995;21:305-319.

Roper SO, Jackson JB. The ambiguities of out-of-home care: children with severe or profound disabilities. Family Relations. 2007;56:147-161.

Ross P, Cuskelly M. Adjustment, sibling problems and coping strategies of brothers and sisters of children with autistic spectrum disorder. Journal of Intellectual and Developmental Disability. 2006;31:77-86.

Ruef MB, Turnbull AP, Turnball HR, Poston D. Perspectives of five stakeholder groups: challenging behavior of individuals with mental retardation and/or autism. Journal of Positive Behavior Interventions. 1999;1:43-58.

Ruef MB, Turnbull AP. Stakeholder opinions on accessible informational products helpful in building positive, practical solutions to behavioral challenges of individuals with mental retardation and/or autism. Education and Training in Mental Retardation and Developmental Disabilities. 2001;36:441-456.

Ruef MB, Turnbull AP. The perspectives of individuals with cognitive disabilities and/or autism on their lives and their problem behavior. Research and Practice for Persons with Severe Disabilities. 2002;27:125-140.

Ryan S. "I used to worry about what other people thought but now I just think ... well I don't care": shifting accounts of learning difficulties in public places. Health and Place. 2008; 14: 730-739.

Ryan S. 'Meltdowns', surveillance and managing emotions; going out with children with autism. Health and Place. 2010; 16: 868-875.

Sage KD, Jegatheesan B. Perceptions of siblings with autism and relationships with them: European American and Asian American siblings draw and tell. Journal of Intellectual and Developmental Disability. 2010;35:92-103.

Saldaña D, Álvarez RM, Lobatón S, Lopez AM, Moreno M, Rojano M. Objective and subjective quality of life in adults with autism spectrum disorders in southern Spain. Autism. 2009;13:303-316.

Samios C, Pakenham KI, Sofronoff K. The nature of sense making in parenting a child with Asperger syndrome. Research in Autism Spectrum Disorders. 2008;2:516-532.

Samios C, Pakenham KI, Sofronoff K. The nature of benefit finding in parents of a child with Asperger syndrome. Research in Autism Spectrum Disorders. 2009; 3: 358-374.

Sarkadi A, Bremberg S. Socially unbiased parenting support on the internet: a cross-sectional study of users of a large Swedish parenting website. Child: Care, Health and Development. 2005; 31: 43-52.

Sawyer MG, Bittman M, La Greca AM, Crettenden AD, Harchak TF, Martin J. Time demands of caring for children with autism: what are the implications for maternal mental health? Journal of Autism and Developmental Disorders. 2010;40:620-628

Schaaf RC, Toth-Cohen S, Johnson SL, Outten G, Benevides TW. The everyday routines of children with autism: examining the impact of sensory processing difficulties on the family. Autism. 2011;15:373-389.

Schieve LA, Blumberg SJ, Rice C, Visser SN, Boyle C. The relationship between autism and parenting stress. Pediatrics. 2007; 119: S114-S121.

Schreck KA, Williams K. Food preferences and factors influencing food selectivity for children with autism spectrum disorders. Research in Developmental Disabilities. 2006;27:353-363.

Schwichtenberg A, Poehlmann J. Applied behaviour analysis: does intervention intensity relate to family stressors and maternal well-being? Journal of Intellectual Disability Research. 2007;51:598-605.

Scorgie K, Wilgosh L. Reflections on an uncommon journey: a follow-up study of life management of six mothers of children with diverse disabilities. International Journal of Special Education. 2008; 23: 103-114.

Scottish Executive. Make my day! the same as you? National Implementation Group: report of the Day Services Sub Group. Edinburgh: Scottisj Executive; 2006.

Şenel HG, Akkök F. Stress levels and attitudes of normal siblings of children with disabilities. International Journal for the Advancement of Counselling. 1996;18:61-68.

Şenel HG. Parents' views and experiences about complementary and alternative medicine treatments for their children with autistic spectrum disorder. Journal of Autism and Developmental Disorder. 2010;40:494-503.

Shaked M, Bilu Y. Grappling with affliction: autism in the Jewish ultraorthodox community in Israel. Culture, Medicine and Psychiatry. 2006;30:1-27.

Sharpe DL, Baker DL. Financial issues associated with having a child with autism. Journal of Family and Economic Issues. 2007;28:247-264.

Sharpley CF, Bitsika V, Efremidis B. Influence of gender, parental health, and perceived expertise of assistance upon stress, anxiety, and depression among parents of children with autism. Journal of Intellectual and Developmental Disability. 1997;22:19-28.

Shtayermman O. Peer victimization in adolescents and young adults diagnosed with Asperger's Syndrome: a link to depressive symptomatology, anxiety symptomatology and suicidal ideation. Issues in Comprehensive Pediatric Nursing. 2007; 30: 87-107.

Shtayermman O. Suicidal ideation and comorbid disorders in adolescents and young adults diagnosed with Asperger's syndrome: a population at risk. Journal of Human Behavior in the Social Environment. 2008; 18: 301-328.

Shtayermman O. An exploratory study of the stigma associated with a diagnosis of Asperger's syndrome: the mental health impact on the adolescents and young adults diagnosed with a disability with a social nature. Journal of Human Behavior in the Social Environment. 2009; 19: 298-313.

Shu B-C, Hsieh H-C, Hsieh S-C, Li S-M. Toward an understanding of mothering: the care giving process of mothers with autistic children. Journal of Nursing Research. 2001;9:203-213.

Siman-Tov A, Kaniel S. Stress and personal resource as predictors of the adjustment of parents to autistic children: a multivariate model. Journal of Autism and Developmental Disorders. 2011; 41: 879-890.

Sivberg B. Parents' detection of early signs in their children having an autistic spectrum disorder. Journal of Pediatric Nursing. 2003;18:433-439.

Skills for Care. Getting it right for people with autism: the research behind the 'autism skills and knowledge list'. Bristol: Skills for Care; 2011.

Smith C. Using social stories with children with autistic spectrum disorders: an evaluation. Good Autism Practice. 2001;2:16-25.

Smith LE, Hong J, Seltzer MM, Greenberg JS, Almeida DM, Bishop SL. Daily experiences among mothers of adolescents and adults with autism spectrum disorder. Journal of Autism and Developmental Disorders. 2010;40:167-178.

Smith LO, Elder JH. Siblings and family environments of persons with autism spectrum disorder: a review of the literature. Journal of Child and Adolescent Psychiatric Nursing. 2010; 23: 189-195.

Smith T, Antolovich M. Parental perceptions of supplemental interventions received by young children with autism in intensive behavior analytic treatment. Behavioral Interventions. 2000;15:83-97.

Solish A, Perry A. Parents' involvement in their children's behavioral intervention programs: parent and therapist perspectives. Research in Autism Spectrum Disorders. 2008;2:728-738.

Sperry LA, Mesibov GB. Perceptions of social challenges of adults with autism spectrum disorder. Autism. 2005;9:362-376.

Srivastava S, Mukhopadhyay A. Optimism-pessimism and emotional competence measures of parents of children with symptoms of autism. Indian Journal of Community Psychology. 2011;7:130-138.

Stefanatou A. Use of drawings in children with pervasive developmental disorder during hospitalization: a developmental perspective. Journal of Child Health Care. 2008;12:268-283.

Sterzing, P.R., Shattuck, P.T., Narendorf, S.C et al. Bullying involvement and autism spectrum disorders. Archives of Pediatric and Adolescent Medicine. 2012; 166:1058-1064.

Stokes MA, Kaur A. High-functioning autism and sexuality: s parental perspective. Autism. 2005;9:266-289.

Symes W, Humphrey N. Peer-group indicators of social inclusion among pupils with autistic spectrum disorders (ASD) in mainstream secondary schools: a comparative study. School Psychology International. 2010;31:478-494.

Talay-Ongan A, Wood K. Unusual sensory sensitivities in autism: a possible crossroads. International Journal of Disability, Development and Education. 2000;47:201-212.

Tanaka K, Uchiyama T, Endo F. Informing children about their sibling's diagnosis of autism spectrum disorder: an initial investiagtion into current practices. Research in Autism Spectrum Disorders. 2011;5:1421-1429.

Taylor JL, Seltzer MM. Changes in the mother-child relationship during the transition to adulthood for youth with autism spectrum disorders. Journal of Autism and Developmental Disorders. 2011;41:1397-1410.

Tehee E, Honan R, Hevey D. Factors contributing to stress in parents of individuals with autistic spectrum disorders. Journal of Applied Research in Intellectual Disabilities. 2009;22:34-42.

Thomas KC, Morrissey JP, McLaurin C. Use of autism-related services by families and children. Journal of Autism and Developmental Disorders. 2007;37:818-829.

Thompson D, Emira M. 'They say every child matters, but they don't': an investigation into parental and carer perceptions of access to leisure facilities and respite care for children and young people with autistic spectrum disorder (ASD) or attention deficit, hyperactivity disorder (ADHD). Disability and Society. 2011;26:65-78.

Tobing LE, Glenwick DS. Predictors and moderators of psychological distress in mothers of children with pervasive developmental disorders. Journal of Family Social Work. 2006;10:1-22.

Todd S, Bromley J, Ioannou K, Harrison J, Mellor C, Taylor E, et al. Using group-based parent training interventions with parents of children with disabilities: a description of process, content and outcomes in clinical practice. Child and Adolescent Mental Health. 2010;15:171-175.

Townson L, Macauley S, Harkness E, Docherty A, Dias J, Eardley M, et al. Research project on advocacy and autism. Disability and Society. 2007;22:523-536.

Tsai W-C, Tsai J-L, Shyu Y-IL. Integrating the nurturer-trainer roles: parental and behavior/symptom management processes for mothers of children with autism. Social Science and Medicine. 2008;67:1798-1806.

Tsao L, Davenport R, Schmiege C. Supporting siblings of children with autism spectrum disorders. Early Childhood Education Journal. 2012;40:47-54.

Tunali B, Power TG. Coping by redefinition: cognitive appraisals in mothers of children with autism and children without autism. Journal of Autism and Developmental Disorders. 2002;32:25-34.

Twoy R, Connolly PM, Novak JM. Coping strategies used by parents of children with autism. Journal of the American Academy of Nurse Practitioners. 2007;19:251-260.

Twyman KA, Saylor CF, Saia D, Macias MM, Taylor LLA, Spratt E. Bullying and ostracism experiences in children with special health care needs. Journal of Developmental and Behavioral Pediatrics. 2010;31:1-8.

van Roekel E, Scholte RHJ, Didden R. Bullying among adolescents with autism spectrum disorders: prevalence and perception. Journal of Autism and Developmental Disorders. 2010;40:63-73.

Viecili MA, Weiss JA, Lunsky Y, Shupak S. The relationship between social acceptance, problem behaviours, and social skills as perceived by youth with autism spectrum disorders. Journal on Developmental Disabilities. 2010;16:72-75.

Wachtel K, Carter AS. Reaction to diagnosis and parenting styles among mothers of young children with ASDs. Autism. 2008;12:575-594.

Wang P, Michaels CA. Chinese families of children with severe disabilities: family needs and available support. Research and Practice for Persons with Severe Disabilities. 2009;34:21-32.

Wang P, Michaels CA, Day MS. Stresses and coping strategies of Chinese families with children with autism and other developmental disabilities. Journal of Autism and Developmental Disorders. 2011;41:783-795.

Wang, J., Zhou, X., Xia, W et al. Parent-reported health care expenditures associated with autism spectrum disorders in Heilongjiang province, China. BMC Health Services Research. 2012; 12: 7

Ward L. Learning difficulties. Research Matters. 2004;Special issue:29-36.

Watson SL. "Something you have to do" - why do parents of children with developmental disabilities seek a differential diagnosis? Developmental Disabilities Bulletin. 2008;36:168-198.

Westling DL. What parents of young children with mental disabilities want: the views of one community. Focus on Autism and Other Developmental Disabilities. 1997;12:67-78.

White SW, Roberson-Nay R. Anxiety, social deficits, and loneliness in youth with autism spectrum disorders. Journal of Autism and Developmental Disorders. 2009;39:1006-1013.

White SE, Weiss JA. Services for adults and adolescents with ASD in Ontario - parent and professional perspectives. Journal on Developmental Disabilities. 2010;16:34-39.

Whitehouse AJO, Durkin K, Jaquet E, Ziatas K. Friendship, loneliness and depression in adolescents with Asperger's Syndrome. Journal of Adolescence. 2009; 32: 309-322.

Whitehurst T. The impact of building design on children with autistic spectrum disorders. Good Autism Practice. 2006;7:31-38.

Whitelaw C, Flett P, Amor DJ. Recurrence risk in autism spectrum disorder: a study of parental knowledge. Journal of Paediatrics and Child Health. 2007;43:752-754.

Whitney-Thomas J, Shaw D, Honey K, Butterworth J. Building a future: a study of student participation in person-centered planning. Journal of the Association for Persons with Severe Handicaps. 1998;23:119-133.

Winter-Messiers MA. From tarantulas to toilet brushes: understanding the special interest areas of children and youth with Asperger syndrome. Remedial and Special Education. 2007;28:140-152.

Wolfberg PJ, Zercher C, Lieber J, Capell K, Matias S, Hanson M, et al. "Can I play with you?" peer culture in inclusive preschool programs. Journal of the Association for Persons with Severe Handicaps. 1999;24:69-81.

Wong DKP. Struggling in the mainstream: the case of Hong Kong. International Journal of Disability, Development and Education. 2002;49:79-94.

Wong D, Pearson V, Ip F, Lo E. A slippery road to equality: Hong Kong's experience of unplanned integrated education. Disability and Society. 1999;14:771-789.

Yamamoto Y, Nihei Y. Difficulties in adjusting to college life experienced by students with pervasive developmental disorders: Comparison with schizophrenic students. Tohoku Psychologica Folia. 2008;67:1-5.

Young A, Ruble L, McGrew J. Public vs. private insurance: cost, use, accessibility, and outcomes of services for children with autism spectrum disorders. Research in Autism Spectrum Disorders. 2009;3:1023-1033.

Yu, C.K., Fan, T & Li, W. Diagnostic characteristics of care receivers with intellectual disabilities and the difficulty and burden experienced by family caregivers. Asia Pacific Journal of Counselling and Psychotherapy. 2012; 3:202-211

Zager D, Alpern CS. College-based inclusion programming for transition-age students with autism. Focus on Autism and Other Developmental Disabilities. 2010;25:151-157.