APPENDIX 14A:

CLINICAL EVIDENCE – STUDY CHARACTERISTICS TABLES: EXPERIENCE OF CARE

1.1 CHARACTERISTICS OF INCLUDED STUDIES

Study ID	**BEMPORAD1979**
Bibliographic reference	Bemporad, J. R. (1979) Adult recollections of a formerly autistic child. *Journal of Autism and Developmental Disorders*, *9*, 179–197.
Methods	**Sampling strategy:** not reported. **Data collection method:** participant was seen for a 2-hour interview with and without his parents present; his mother was seen for an extended interview at another time. Subsequently, there were numerous telephone calls with the participant, the family and the author regarding possible therapy arrangements, requests for practical advice and updating of current status. Lastly, past records from various institutions were made available for the purpose of writing this report. **Data analysis method:** not reported. **Country:** US.
Participants	**Diagnosis:** autism (diagnosed at 4 years by Dr Leo Kanner). **Coexisting conditions:** not reported. **N =** 1 (case study). **Age:** 31 years. **Sex:** male. **Ethnicity:** not reported. **IQ:** not reported.
Outcomes	**Key research question/aim:** not reported.
Focus of the study	Service user experience of autism
Results	Emerging themes: • Awareness/insight: Jerry blamed his current isolated condition on the evils of modern society and went on long digressions describing how current girls do not want to date 'nice guys' but are only attracted to 'weirdos and hippies'. There was an obvious awareness on his part that he was different from other people, but there was also an equally strong need to deny this difference and to blame his painful state on external factors. He also blamed much of his social isolation on his stuttering • Desire for relationships but social difficulties: Jerry did seem to reach out for some social contact, but his efforts were consistently unsuccessful. He was overly sensitive to being rejected by others, a response he would easily provoke due to his lack of social awareness. • Difficulties with sibling relationship: participant described difficulties with his brother, who would lose patience with Jerry's inappropriate behaviour. • Experience of residential services: at 18 years old, Jerry voluntarily admitted himself to a state hospital, but soon signed himself out because he could not comply with the daily patient routine. This was repeated with three more hospitals; each time, he found fault with the staff, other patients or some aspect of hospital life that he felt was intolerable.

Limitations	1. No detail given on data analysis techniques. 2. Not first-hand personal account, but narrative told through the author. 3. Ethical issues not adequately considered. 4. No rationale given for sampling strategy or research approach. 5. The age of the study may threaten the generalisability of findings.
Notes	Study concerned with an autistic adults' recollections of childhood, but data only extracted for descriptions of later life (from late adolescence onwards).

Study ID	**BLACHER2010**
Bibliographic reference	Blacher, J., Kraemer, B. R. & Howell, E. J. (2010) Family expectations and transition experiences for young adults with severe disabilities: does syndrome matter? *Advances in Mental Health and Learning Disabilities*, *4*, 3–16.
Methods	**Sampling strategy:** opportunity sampling. Participants were recruited for an ongoing longitudinal project through Southern California Regional Centers, agencies that provided case management services to individuals with learning disability and their families. Staff mailed letters of invitation to families who had sons or daughters between 18 and 26 years of age with moderate to severe learning disability. Recruitment continued until the sample criterion of 300 families was obtained. Families received honoraria for their participation. **Data collection method:** in-home interviews conducted in the preferred language of the family (English or Spanish). Interviews were conducted in teams of two and typically lasted 2 to 3 hours. **Data analysis method:** quantitative analysis of Likert scale responses. **Country:** US.
Participants	**Diagnosis:** parents of young adults with autism (diagnoses given by service agencies in California that specialise in identifying and serving individuals with a learning disability. Most of these young adults had had the diagnosis since early childhood). **Coexisting conditions:** young adults with autism had a coexisting learning disability. **N =** 30. **Age:** ranges not reported (mean age of parent: 53 years; mean age of adult with autism: 23 years). **Sex:** sex of family member not reported; 70% of young adults with autism were male. **Ethnicity:** not reported. **IQ:** not reported (but with a moderate to severe level of learning disability).
Outcomes	**Key research question/aim:** three central questions were addressed: Do parent expectations and actual post-school outcomes vary by diagnostic group?; Do parental knowledge of, and satisfaction in, transition planning differ by diagnostic group?; Do parental worries about transition planning vary by diagnostic group?
Focus of the study	Carer experience of autism and experience of services
Results	• Parent expectations and post-school outcomes: parents were

	asked whether they would like their sons and daughters with severe learning disabilities to work in the future. This item was presented on a five-point Likert scale with 5 being ‘strongly agree’ and 1 being ‘strongly disagree’. In parents of young adults with autism, 83.3% strongly agreed or agreed that they would like their son or daughter with autism to work in the future. This was contrasted against current vocational outcomes for exited young adults with autism: 8.7% were working in the community, 69.5% were in workshop/day programme, and 21.7% were at home and not working. Parents were also asked whether they could see their autistic son or daughter moving out of the family home: 43.3% responded ‘never’, 16.7% ‘occasionally’, 10% ‘seriously considered’, and 30% ‘young adult out of home/waitlist’. This was contrasted with the current living situation of young adults with autism in the sample where 73.9% were living in the family home and 26.1% in a group home. • Parent transition knowledge and satisfaction: parents were asked to indicate whether or not they were informed about various adult services. For each service (residential, vocational, day activity programmes, recreation activities, health and financial services) more than 70% of the parents of autistic young adults responded that they were informed. When asked about their level of satisfaction with their involvement in the transition planning process, parents of young adults with autism were slightly, though not significantly, less satisfied with their level of involvement (73.3% satisfied with involvement) than parents of young adults with other developmental disabilities (for example, 84.9% of parents of young adults with unspecified learning disability were satisfied with involvement). However, parents of young adults with autism wanted increased involvement in transition planning (36.7% of parents of young adults with autism, compared with 15.8% of parents of young adults with cerebral palsy, wanted much more involvement). • Parent worries during transition: to assess how much parents worried about various aspects of transition, they were asked to rate their worries about aspects of transition on a five-point Likert scale (with 1 being ‘never worry’ and 5 being ‘often worry’. For parents of young adults with autism, most worry was expressed about transition planning and employment/vocational options relative to living options, social activities or family involvement/attachment. Finally, to assess how parents being worried during the period of transition affected more distal aspects of family life, mothers were asked to report on how worrying about transition issues affected their own daily life and well-being as well as that of their family. Mothers of young adults with autism reported a significantly greater impact of worrying about their son/daughter’s transition on both their own personal daily life and well-being (58.6%), and the well-being of the family in general (44.8%) than parents of young adults with other developmental disabilities (for instance, parents of young adults with cerebral palsy had scores of 19% and 11.6%, respectively).
Limitations	1. Only quantitative data collected from interviews with parents of

	young adults with autism. 2. Not clear whether this study had approval from an ethics committee.
Notes	Data are also reported for parents of young adults with Down's syndrome, cerebral palsy and an undifferentiated learning disability. However, those data are not extracted here except where a direct comparison was made with the group with autism.

Study ID	**CEDERLUND2010**
Bibliographic reference	Cederlund, M., Hagberg, B. & Gillberg, C. (2010) Asperger syndrome in adolescent and young adult males. Interview, self- and parent assessment of social, emotional, and cognitive problems. *Research in Developmental Disabilities*, *31*, 287–298.
Methods	**Sampling strategy:** opportunity sampling. Medical records of 100 clinical cases of males with Asperger's syndrome, diagnosed according to the Gillberg and Gillberg criteria at least 5 years prior to the present study, were searched for information on background and associated factors. These 100 males (and their parents) were approached for inclusion in the follow-up study; 76 of the families agreed to participate in this in-depth study. **Data collection method:** diagnostic interviews and questionnaires including the ASDI – parent and teenage/adult versions, Leiter-R-Questionnaires, Beck Depression Inventory, Dysexecutive Syndrome Questionnaire, Wechsler Adult Intelligence Scale – 3rd version (WAIS-III), and Global Assessment of Functioning scale. **Data analysis method:** quantitative analysis of scale responses. **Country:** Sweden.
Participants	**Diagnosis:** Asperger's syndrome. **Coexisting conditions:** not reported. **N =** 76. **Age:** 16 to 36 years (mean 21.8 years). **Sex:** Asperger's syndrome group: 76 male, 0 female. **Ethnicity:** not reported. **IQ:** mean 103.8 (WAIS-III).
Outcomes	**Key research question/aim:** to investigate: how young adult males with Asperger's syndrome look upon themselves in relation to their clinically diagnosed problems; to what extent they agree with their parents on these core features of their diagnosis; and whether or not they recognise other psychological/cognitive problems not specifically included in the diagnostic algorithm for Asperger's syndrome.
Focus of the study	Service user and carer experience of autism
Results	• Individuals with Asperger's syndrome showed more desire for relationships than thought by parents or had less insight into their social difficulties: when self- and parent agreement on the different items of the ASDI were compared, 'No interest in seeking friends' was the item with the lowest agreement (39%). The other poor-agreement items across self- and parent scores, and where parents invariably scored 'more abnormal', were the

	items ‘understanding social cues’ (41%), ‘peer interaction’ (47%) and ‘narrow interest’ (48%). • Evidence for increased incidence of depression in individuals with autism: the mean Beck Depression Index (N = 71) score was 7.2, which was higher compared with population studies on Swedish adolescent boys (Olsson & von Knorring, 1997, score 4.2). The items with the highest number of participants scoring definitely pathological (a score of 2 or 3 on an individual item) were ‘work inhibition’, ‘sense of failure’ and ‘pessimism’. Altogether, N = 62 (88%) individuals scored within the range of ‘no depression’ (0 to 15), N = 6 (8%) had ‘dysphoria’, N = 2 (3%) had ‘depression’ and N = 1 (1%) had ‘severe depression’.
Limitations	1. A qualitative approach may have been more appropriate to addressing the key research aims. 2. Twelve per cent of the sample (N = 7) no longer met diagnostic criteria for ASD.
Notes	• Sixty-six individuals had a complete follow-up; that is, both the male with Asperger’s syndrome and his parent(s) participated. In a further ten individuals either the male (N = 5) with Asperger’s syndrome or his parent(s) (N = 5) participated. • This study was approved by the Medical Ethical Committee of the University of Gothenburg.

Study ID	**CESARONI1991**
Bibliographic reference	Cesaroni, L. & Garber, M. (1991) Exploring the experience of autism through firsthand accounts. *Journal of Autism and Developmental Disorders*, *21*, 303–313.
Methods	**Sampling strategy:** convenience sample. Initial contact made at a conference on high-functioning individuals with autism. **Data collection method:** data collected through telephone interviews and the collection of letters, essays and poems. Closer personal observation was not possible because the participant lived in a different region. Contact with the participant was maintained over a 6-month period. **Data analysis method:** not explicit – what is presented is a summary of the recorded and transcribed interviews, letters, poems and art work. The participant read the final interpretation of his experience for accuracy and there was a last interview or telephone contact to insure a shared meaning. **Country:** Canada.
Participants	**Diagnosis:** autism (high-functioning autism). **Coexisting conditions:** not reported. **N =** 1 (paper also reports on a 13-year-old boy, but those data are not extracted here). **Age:** 27 years old. **Sex:** male. **Ethnicity:** not reported. **IQ:** not reported.
Outcomes	**Key research question/aim:** not reported.

Focus of the study	Service user experience of autism
Results	Personal account summarised into five key areas: 1. Sensory processing: touching described as an area of difficulty. Being touched described as not necessarily painful but intense, and therefore it could be overwhelming and confusing. 2. Memory: Jim speculates that his memory is probably different from most people not so much because of the amount of information he can remember but because of how he can process it. At times, Jim is able to remember a great amount of detail, understand what it means and bring it into an appropriate context. Other times, he has the same recall of detail but is unable to process it coherently. 1. Stereotypical behaviours: stereotypical behaviours are described as involuntary. Jim describes learning to control these behaviours but states that the more 'normal' his behaviour appears, the more guarded and anxious he is. Changes in the environment are described as very traumatic unless they are adequately prepared for in advance. 2. Social interaction and empathy: despite a growing awareness of being different from his peers Jim, described a strong desire to develop interpersonal relationships during adolescence. However, he describes how his difficulties in judging the depth or sincerity of friendship led to him experiencing abuse from a co-worker. 3. Empathy: Jim feels that it is highly unfair to suggest that autistic people lack empathy and are unable to take other's perspectives. Jim describes how he has exerted many efforts to understand and interpret non-autistic individuals and their behaviours, as well as to reflect on his own behaviours and experiences and this effort illustrates awareness, motivation and interest in others.
Limitations	1. Data analysis method is not explained in sufficient detail. 2. More of a summary than a structured thematic analysis. 3. Case study methodology, which may raise generalisability questions.
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Study ID	**CLARKE2008**
Bibliographic reference	Clarke, J. & van Amerom, G. (2008) Asperger's syndrome: differences between parents' understanding and those diagnosed. *Social Work in Health Care*, *46*, 85–106.
Methods	**Sampling strategy:** convenience sampling. **Data collection method:** data taken from websites or blogs written by people who identify themselves as having Asperger's syndrome. Google search conducted using the search term 'asperger blogs', resulting in 619,000 hits. The selected sample of service user experience data was taken from the first 30 blogs written from a service users' perspective. **Data analysis method:** qualitative content analysis (Altheide, 1996) of blogs by both authors (no detail given as to whether this coding was independent). **Country:** researchers based in Canada, but country of origin for data

	was not reported.
Participants	**Diagnosis:** autism (Asperger's syndrome), but self-identified. **Coexisting conditions:** not reported. **N =** 30. **Age:** range and mean not reported; data incomplete (data available for N = 15; of these, 7% were aged 1 to 10 years, 40% were 11 to 20 years, 27% were 21 to 30 years and 27% were over 30 years). **Sex:** data incomplete (data available for N = 23; of these 9 male, 14 female). **Ethnicity:** not reported. **IQ:** not reported.
Outcomes	**Key research question/aim:** to investigate the portrayal of the salient issues with regard to dealing with the diagnosis/identity from the perspective of individuals with Asperger's syndrome.
Focus of the study	Service user experience of autism
Results	Emerging themes: • Self-pride and acceptance: for example, understanding that differences are shared by other individuals with Asperger's syndrome and not experienced alone; celebration of difference, not just acceptance; role as advocates; strength developed as a result of dealing with autism. • Positive role of the internet: for example, as a means of support; as a source of information; as a means of addressing stigma • Authors refer to disabling environments – but this could also be conceptualised as stigmatisation because participants discuss negative experiences with the medicalised conceptualisation of autism, that is autism being described as a 'disorder'. • Opposition to conventional language – this may also be categorised under stigmatisation because participants discuss the negative experience of terms such as 'epidemic' and 'devastating' (in association with autism). However, the positive experience of adopting a special language is also described, for example 'aspies', 'neuro-typicals' and 'curebies'.
Limitations	1. The demographic information for participants is not detailed enough and is incomplete. 2. The diagnosis of Asperger's syndrome is not validated and is based on self-report. 3. Ethical issues with consent.
Notes	This paper also reports on carer experience. However, those data are not extracted as the age of the offspring with autism is not reported.

Study ID	**GRAETZ2010**
Bibliographic reference	Graetz, J. E. (2010) Autism grows up: opportunities for adults with autism. *Disability and Society*, *25*, 33–47.
Methods	**Sampling strategy:** opportunity sampling. Participants were caregivers in the Midwest US supporting a family member/individual with autism who either responded to an investigator-developed survey posted on the internet or to a mailed survey. Two hundred surveys were mailed, of which 92 (46%) were

	returned. Fifty-seven surveys were retrieved from websites, but only 51 met the criteria. **Data collection method:** the survey used consisted of 52 questions designed to elicit information from caregivers supporting an adult (aged 18 years and over) with autism. It was based on the *Family Needs Survey* (McGrew *et al.*, 1989) and *A Collaborative Survey of Families with Children who have Disabilities* (Stuefen, 2001). Additional questions pertaining to the opportunities available to the family member were developed by the researcher and were based on questions from Gray's (1998) study of autism and the family. **Data analysis method:** quantitative analysis of the Likert-scale responses in the survey and qualitative analysis was used to interpret the open-ended responses. **Country:** US.
Participants	**Diagnosis:** parents of adults with autism. **Coexisting conditions:** not applicable. **N =** 143. **Age:** age of carer not reported; age of family member with autism 18 to 48 years (mean 22.5 years). **Sex:** sex of carer not reported; family member with autism: 112 male, 31 female. **Ethnicity:** not reported. **IQ:** not reported (but for family member with autism, 84% were somewhat/greatly affected in terms of intellectual functioning).
Outcomes	**Key research question/aim:** exploring the needs of families supporting an adult with autism and the opportunities afforded them in socialisation, employment and residential living.
Focus of the study	Service user experience of services
Results	• Family and social support: participants were asked about their level of satisfaction with their state services. 72% of respondents either 'disagreed' or 'strongly disagreed' when asked if there were adequate services in their state for families supporting an adult with autism. Respondents caring for a family member with significant intellectual impairment (68%, N = 97) were especially dissatisfied with services in the state. Finding respite care for the family member appeared more problematic for families. More than half (58%, N = 82) felt it a problem to obtain a respite provider, while only 24% (N = 34) actually used respite providers. With regard to difficulties working with systems/agencies, 83% (N = 112) of respondents wrote a negative comment regarding services. Comments regarding respite care highlighted the difficulties: 'I have no idea where to begin... we want to take a short vacation but there is no one to watch her... she functions at a 36 month level... who will watch her?' Although the topic of access to medical care was not addressed in the survey, nearly half of caregivers (45%, N = 64) stated concerns about this issue. Participants stated that: 'There are no doctors and dentists who understand autism and dealing with adults'. • Opportunities for socialisation: participants were asked about the socialisation opportunities for their family member with autism.

	Although 54% (N = 77) of the family members had daily interactions with non-family individuals, 31% (N = 44) of the caregivers felt that they never had opportunities for the family member to make a friend with a non-disabled individual. 41% of family members 'never' or only 'once a month' had the opportunity to experience recreation away from home. Of these, 40% demonstrated severe intellectual deficits. Some caregivers noted that their family member was very social but was not accepted in the community: 'Our son is social... but there is a lack of understanding and compassion from the non-disabled... for that reason we do not push socialization' and: '...when people hear the word 'autism' they think of *Rainman*... people need more information'. • Opportunities for employment: the majority of comments (90%) stated a specific fear related to employment. These fears included: (1) a lack of support and a lack of friends; (2) a lack of job opportunities; (3) fears about future employment once the caregiver was no longer able to care for the family member. Acknowledging the difficulty many of their family members would have in the workplace, caregivers stated what it would be necessary to have supports in place to make any employment successful: 'Our son's behavior would interfere with employment opportunities... he can be loud... invade others' space' In addition, caregivers felt that the attitude of the employer and other coworkers would also affect job success: 'There is a need to have an understanding boss' and: 'My concern is that there are job coaches available for some length of time... why can a person potentially stay on welfare for the rest of their lives... but developmentally disabled adults have very few job options'. • Opportunities for residential living: while the majority of adults with autism continued to live in the natural home (81%), caregivers expressed concern that the family member required 24 hour support and had frequent medical/health issues. Although they may be in the natural home now, 77% reported that they felt the family member would never have the opportunity to live out of home. The majority of written responses reflected concerns regarding the lack of residential opportunities in the future: 'What will I do when I can no longer care for him? My son needs reminders every day to do the simple things... who will remind him?' Others were concerned about the financial burden of finding out of home placement: 'It will be too expensive for my son to live away from home... the mental transition itself is daunting... not to mention finding people as dedicated to his care as I am'.
Limitations	1. Ethical issues are not adequately considered. 2. The qualitative data analysis techniques are not described in

	sufficient detail.
Notes	Participants were informed that they would remain anonymous.

Study ID	**HARE2004**
Bibliographic reference	Hare, D. J., Pratt, C., Burton, M., *et al.* (2004) The health and social care needs of family carers supporting adults with autism spectrum disorders. *Autism*, *8*, 425–444.
Methods	**Sampling strategy:** opportunity sampling. Databases of the Manchester Learning Disability Partnership and the NAS were used to identify adults who had a firm diagnosis of ASD and were living with their families. Families were invited to opt into the study. **Data collection method:** a structured interview schedule was developed from previous research examining the needs of families with children with autism (Bromley *et al.*, 2004). Families were interviewed at home for 1 to 2 hours. In addition to the information gathered from the structured interviews, a research journal was kept to record the researcher's observations and additional qualitative information from the interviews (which could not fit into the pre-coded interview structure). **Data analysis method:** the questionnaire data were analysed using SPSS-PS (v 10.1). The statistical analysis was supplemented by exploration of the qualitative data through identification of recurrent themes by the researcher. This analysis was checked by the field supervisor for the defensibility of the conclusions that were derived. **Country:** UK.
Participants	**Diagnosis:** carers of individuals with autism. **Coexisting conditions:** of those with autism: N = 3 had epilepsy; N = 1 had cerebral palsy; N = 1 had anxiety disorder; and N = 4 had depression. **N =** 26. **Age:** age of carers not reported; age of individuals with autism: range not reported (mean 27 years). **Sex:** 77% of interviewees female; individuals with autism: 22 male , 4 female. **Ethnicity:** carers: not reported; individuals with autism: white N = 17; African-Caribbean N = 5; Asian N = 3; African N = 1. **IQ:** not reported.
Outcomes	**Key research question/aim:** two main research aims. First, to explore the current support and service provision available to, and used by, families supporting adults with autism. Second, to examine the relationship between the level of support and the psychological wellbeing of the principal family carer, in this case the mother of the adult with autism.
Focus of the study	Carer experience of services
Results	• Family support: the majority of participants had very little support compared with parents looking after children with autism where support is available from grandparents (Bromley *et al.*, 2004). Within the immediate family, partners (N = 8) and, for a few participants, their parents (N = 2) and

	relatives (N = 1) were rated as 'extremely helpful'. The other support that was classed as 'extremely helpful' tended to be formal support from colleges, GPs and other professionals. The majority of respondents had no support from social groups, religion, parents' groups, coworkers or other parents and relied on support from statutory agencies, college and day services, and their own children. Professional support was not received by 11 of the families, but was rated useful when it was used. Although it appeared that a majority of respondents said that friends were 'not available', it transpired that this was often to avoid burdening friends with worries and concerns. • Unmet needs: the main unmet needs were for breaks from caring, planning for the future and information on available services. With regard to needing a break, several participants suggested that this could mean a few hours in the evening, not necessarily overnight respite. • Advantages of caring for somebody with autism: nine (25%) participants reported there were no advantages to living with somebody with autism, saying that it was a 'duty from God' or that 'he is just our son, he has come with autism and that's that'. Others discussed the new qualities acquired by living with somebody with autism, reporting they had developed greater understanding and ability to empathise with other parents with adult children with disabilities. Also they reported that they had become more patient and tolerant, and could appreciate other people's good qualities more. One participant talked about the benefits of unconditional love, giving everything and receiving nothing back. Several parents talked about happiness they had gained from their family member with autism. Parents talked of how their son or daughter could be very affectionate, stroking their faces and being very loveable. The fun they had together was also discussed, such as singing, playing guitars, laughing and joking. Many parents talked about the reward they felt when their family member learnt a new skill or achieved a set goal. Other advantages were not worrying about the person with autism having to get a good job, getting married or getting into trouble. • Contact with services and allied resources: awareness of services was very high, particularly for NHS and social services, but uptake was low. Resources such as parents' groups and national support groups were not well utilised, with parents often stating they had used these when the family member with autism was a child. • Helpful services: a total of 21 parents could identify a service that had been particularly helpful, 14 cited social services, one education and five 'other' (Aspirations, Citizens' Advice Bureau, independent daycare, Independent Living Fund and the NAS). The reasons why these services were helpful were largely attributed to the staff and management of the day services and to practical help from social workers (form filling, and so on). • Unhelpful services: 16 participants could identify an unhelpful service, including 47% social services, 42% health and 29% 'other' (support staff privately contracted with monies from the

	Independent Living Fund and service commissioners). Problems primarily related to services being unreliable and causing confusion and distress for themselves and the person with autism. In particular, they complained of carers not turning up, and waiting for staff who did not recognise the importance of routine and predictability for people with autism. Participants whose family members were living away from home were concerned about the staff turnover at the residential homes. • Transition to adulthood: none reported any autism-specific information/support being received and only ten people had been to a health and social services transition planning meeting. Participants found it hard to say what would have improved the transition to adult services because the majority of respondents were unaware of any formal transition process. A difference was found in the experiences of transition for younger adults with autism (that is, 25 years) who were more likely to have attended transition meetings and for the process to have been positive. Some parents felt that the process of transition was slow and were worried about whether their son or daughter would receive a suitable day service, particularly with regard to the 13 people with autism who either did not go to college, had left due to behavioural problems or were in the final year. Since leaving school, all of the people with autism had used various types of day service, predominantly colleges, day centres and respite care, but also including one instance each of residential college and psychiatric hospital. Fourteen judged the services to have been appropriate, with a local statutory sector autism-specific day service (Pope, 1998) receiving much praise. Other services were considered to be inappropriate on the grounds of being too small, being understimulating, lack of opportunity to learn new skills and staff not being knowledgeable about autism. The participants had a low awareness of autism-specific interventions, with the exception of TEACCH. Few were aware of social skills training, but thought that their son/daughter would benefit. • Restricted lives: the majority of participants expressed some form of restriction on their lives, predominantly the limitations to their social lives, describing their circumstances as 'having no life', being 'grounded for 20 years', 'feel like a prisoner' or 'can't live a normal life'. Restrictions on where the families could live were also significant in the interviews. One parent said that they lived near a day service, but would not choose to live there otherwise. Safety concerns also affected where families were living. One family avoided living on main roads because their son had no concept of danger or 'road sense'; other participants emphasised the need for privacy and quietness. While several parents said they would be unable to cope without support from their partner, others believed there had been a detrimental effect on their relationships. One parent said she felt she did not know her partner anymore because they spend the majority of their time caring for the family member with autism. With regard to the impact on their other children, one respondent said they would have used any support for siblings had it been available and that one of the main reasons the family member with autism was

	taken into care was the effect it was having on the other siblings. • Experience of services: a varied response, ranging from positive experiences to a 'fight' or 'battle', having to 'reach crisis point' before help was received, or 'who shouts the loudest' receives help. Some families felt that they had very little help from the services, particularly at the transition to adult services, which one parent described as being 'cut off into the wilderness'. The need for autism-specific day care was a theme raised repeatedly by the majority of families, together with more intervention (specifically speech therapy) in the day centres to enable their son/daughter to develop and live more independently. The need for more 'training' in autism for staff and carers was also raised by families. Access to emergency care was also regarded as very important, in particular for families whose family member with autism could become aggressive and physically violent. It was apparent that a mistrust of services, particularly social services, still prevailed. Particular difficulties were noted for families of adults with Asperger's syndrome, for whom there were very few opportunities or activities. This proved problematic for those people with Asperger's syndrome receiving inappropriate day care, which, when grouped with people with learning disabilities, could result in reported feelings of grandeur. Some parents expressed the similar view that their family member with Asperger's syndrome was not like 'the others with autism'. • The future: the majority of participants expressed concern about the future of their son/daughter. Several participants became distressed when talking about the future and were extremely worried about what would happen to their son/daughter when they were too old or too sick to care for them. The main concerns that parents had were that their son/daughter might be abused in care, services would not be suitable and nobody would stand up for them.
Limitations	1. Ethical issues are not adequately considered. 2. The qualitative data analysis techniques are not described in sufficient detail.
Notes	In total, 25 adults with confirmed ASD known to the Manchester Learning Disability Partnership together with 20 adults identified on the NAS database were contacted. Two of these people and three others were living in residential care and were included, because families still had substantial contact. Forty-eight families were contacted.

Study ID	**HURLBUTT2002**
Bibliographic reference	Hurlbutt, K. & Chalmers, L. (2002) Adults with autism speak out: perceptions of their life experiences. *Focus on Autism and Other Developmental Disabilities*, *17*, 103–111.
Methods	**Sampling strategy:** convenience sample. Individuals with autism were initially recruited at The Autism Society of America's annual conference. **Data collection method:** participants were interviewed at the

	conference with participants being asked two open-ended questions: Please tell me about your life?; How has autism affected your life? Other questions were asked in response to participants' responses or for clarification. Over the next 9 months following the conference, contact continued via telephone and email. Each participant also shared copies of various articles, stories and essays they had written over the years. Relevant information was highlighted, and the researchers took notes from these writings. **Data analysis method:** thematic analysis was conducted in the interviews and on writings. **Country:** US.
Participants	**Diagnosis:** autism (high-functioning autism). **Coexisting conditions:** not reported. **N =** 3. **Age:** 31 to 61 years (mean 42.3 years). **Sex:** 2 male, 1 female. **Ethnicity:** not reported. **IQ:** not reported, but high functioning.
Outcomes	**Key research question/aim:** investigate and describe the perceptions of life experiences of adults with autism.
Focus of the study	Service user experience of autism
Results	Four themes emerged from the data: • High-functioning adults with autism identify with their own unique culture; for instance, they viewed their role as advocates. Issues of accepting themselves as autistic were also described, for instance individuals spoke about how they used to want to fit in and be 'normal'; however, they realised that they could not be 'normal' and still be themselves at the same time. Moreover, some participants describe moving beyond acceptance of autism to seeing characteristics of people with autism as more desirable. • Support systems contributed to their feelings of self-worth. All three participants often spoke highly of the support systems in their lives and how much they valued them. High-functioning adults with autism believe that positive family involvement and support helps individuals with autism develop skills necessary to be as successful as possible as adults. • They had strong opinions about what could make a difference in the lives of people with autism. For instance, group living arrangements and activities were described as dehumanising, and participants expressed negative feelings toward group living arrangements, especially institutions and large-group situations. All three participants believed that efforts need to be made to provide supports necessary for individuals with autism to live in the community. The need for training of group-home staff is also described with one participant pointing out that 'ordinary workers aren't at autism conferences'. Unemployment and underemployment were also identified as real problems for people with autism. All three participants spoke at great length about the problems they have had in obtaining and maintaining successful

	employment. Participants spoke of the problems they experienced with employers and difficulties completing assigned job duties. They also addressed the issue of finding a job commensurate with their ability levels and education/ training. One participant liked the idea of a job mentor. Participants expressed negative feelings about the Lovaas approach and applied behavioural analysis, and felt that behaviour issues needed to be addressed individually and positively. Individuals with autism also expressed a need for support in developing social skills. Participants described frustration in trying to learn social skills, especially as they relate to dating, and social skills groups were described as a valuable opportunity for making friends and peer support. • The overall concluding theme is that high-functioning adults with autism want to be considered experts on, have opinions on and be consulted on issues related to autism.
Limitations	1. Transcripts were not double coded. 2. Insufficient justification for sampling strategy is provided. 3. Ethical approval was not acquired for this study and ethical issues are not adequately considered.
Notes	–

Study ID	**HUWS2008**
Bibliographic reference	Huws, J. C. & Jones, R. S. P. (2008) Diagnosis, disclosure, and having autism: an interpretative phenomenological analysis of the perceptions of young people with autism. *Journal of Intellectual and Developmental Disability*, *33*, 99–107.
Methods	**Sampling strategy:** purposive sampling by a psychologist who knew the potential participants (the researchers did not know participants) who were students at a college for young people with autism. **Data collection method:** semi-structured individual interview by the first author conducted according to a schedule which comprised three open-ended questions designed to encourage participants to talk about their own perceptions of autism: What is autism?; What does autism mean to you?; If you were asked to explain your autism to someone else who had never heard of it, what would you say? **Data analysis method:** interpretative phenomenological analysis (Smith, 1996; Smith *et al.*, 1999) was used in this study to analyse data. **Country:** UK.
Participants	**Diagnosis:** autism (Asperger's syndrome or autism) based on psychologist identification. **Coexisting conditions:** not reported. **N =** 9. **Age:** 16 to 21 years (mean not reported). **Sex:** 6 male, 3 female. **Ethnicity:** not reported. **IQ:** not reported.
Outcomes	**Key research question/aim:** service users perceptions of autism and diagnosis experiences.

Focus of the study	Service user experience of autism
Results	- Diagnosis as providing explanations by allowing participants with autism to retrospectively understand previous life events. - Negative aspects of labelling discussed in terms of anger with the label and its negative connotations but also positive aspects of labelling in terms of allowing access to autism services. - Experience of autism-specific facility given and described as improving behaviour and providing the opportunity to make friends. - Experience of information and support – accounts given of the active avoidance of information about autism.
Limitations	Diagnosis of autism not confirmed for the study
Notes	–

Study ID	**JENNESCOUSSEN2006**
Bibliographic reference	Jennes-Coussens, M., Magill-Evans, J. & Koning, C. (2006) The quality of life of young men with Asperger syndrome: a brief report. *Autism*, *10*, 403–414.
Methods	**Sampling strategy:** opportunity sampling. Participants were recruited from the Koning and Magill-Evans (2001) sample of 29 adolescents with a diagnosis of Asperger's syndrome. **Data collection method:** two self-administered mailed questionnaires (WHOQOL – Brief Version [The Group, WHOQOL, 1998] and Perceived Support Network Inventory [Orritt *et al.*, 1985]) and a semi-structured interview (which addressed level of independence, leisure activities and social relationships) that lasted 30 to 130 minutes and was largely conducted in-home (N = 6 participants lived in remote areas, so telephone interviews were conducted). To limit bias, all interviews were recorded. A research assistant who was unfamiliar with Asperger's syndrome randomly rated four (16%) interviews. Inter-rater reliability using double coding of the information obtained during the interviews was r = 0.97. **Data analysis method:** quantitative data analysis using SPSS (v 11.0). **Country:** Canada.
Participants	**Diagnosis:** DSM-IV Asperger's syndrome (diagnosed by four paediatric psychiatrist and diagnosis verified by the referring psychiatrist completing the Ehlers & Gillberg [1993] checklist for screening of Asperger's syndrome on each participant). **Coexisting conditions:** not reported (boys diagnosed with psychosis at any time were excluded). **N =** 12 with Asperger's syndrome; N = 13 without Asperger's syndrome (matched on age and Wechsler Intelligence Scale for Children – 3rd edition [WISC-III] vocabulary test scores). **Age:** no range reported (means: Asperger's syndrome group mean 20.3 years; without Asperger's syndrome group mean 20.5 years). **Sex:** 25 male, 0 female. **Ethnicity**: majority were reported as white. **IQ:** not reported.
Outcomes	**Key research question/aim:** to compare the quality of life of young

	men with and without Asperger's syndrome; examine differences in the perceived support network; and describe independence, friendship and dating relationships, and leisure activities.
Focus of the study	Service user experience of autism
Results	• Quality of life scores: young men with Asperger's syndrome rated their quality of life lower than did young men without Asperger's syndrome. Scores were significantly lower for the social domain and for physical health (if unequal variances assumed). • Social support scores: total Perceived Support Network Inventory scores and the overall quality of life item on the WHOQOL were correlated suggesting that viewing one's social network as supportive was associated with greater overall quality of life.
Limitations	No qualitative analysis of interview data.
Notes	The Health Research Ethics Board approved the study and all participants gave consent.

Study ID	**JONES2001**
Bibliographic reference	Jones, R. S. P., Zahl, A. & Huws, J. C. (2001) First-hand accounts of emotional experiences in autism: a qualitative analysis. *Disability and Society*, *16*, 393–401.
Methods	**Sampling strategy:** convenience sampling. **Data collection method:** data were collected from websites of individuals with autism who described their emotional experiences and their experiences with autism in general. After initial services on the internet, approximately 25 sites were found containing information from potential subjects. The inclusion criterion was that the internet page had to be written solely by a person with autism without any help from others. **Data analysis method:** thematic analysis approach adopted where the first-hand accounts were re-read and studied to see if any common codes related to emotion were found; if a code appeared in three or more accounts, it was categorised as a theme. **Country**: researchers are based in UK, but country of origin for accounts not reported.
Participants	**Diagnosis:** autism (high-functioning autism), but this is based on self-identification. **Coexisting conditions:** not reported. **N =** 5 (but data only extracted for N = 2 because no age reported for the other three participants). **Age:** for the two participants for whom data were extracted, one was described as 'middle-aged' and one as 18 years old. **Sex:** 1 male, 1 female. **Ethnicity:** not reported. **IQ:** not reported (but participants describe themselves as high-functioning).
Outcomes	**Key research question/aim:** emotional experiences of individuals with autism.
Focus of the study	Service user experience of autism

Results	• A sense of alienation emerged as core theme: participants describe themselves as feeling different and of not belonging prior to diagnosis. However, following diagnosis there is evidence for a change in feelings with participants being able to understand their condition and relate to others with a similar diagnosis. • A sense of frustration is also described, particularly with the social and language problems, and difficulties with social interaction described in terms of sensory-perceptual overload. • Depression: participants describe feelings of depression caused by not being able to understand why they are different. • Stigma: the reactions of other people are described as causing the autistic person to feel constantly under scrutiny.
Limitations	1. Impossible to verify inclusion criteria, that is that people with autism had developed these sites alone. 2. Ethical issues with consent. 3. Very little demographic information about participants and data could only be included from two participants as it was not clear whether the other three accounts described are from adults. 4. No independent verification of diagnosis.
Notes	–

Study ID	**KRAUSS2005**
Bibliographic reference	Krauss, M. W., Seltzer, M. M. & Jacobson, H. T. (2005) Adults with autism living at home or in non-family settings: positive and negative aspects of residential status. *Journal of Intellectual Disability Research*, *49*, 111–124.
Methods	**Sampling strategy:** convenience sample, which was a subsample of an ongoing (four-wave) longitudinal study. Families participating in the ongoing study were recruited via agencies, schools, diagnostic clinics, and the media. **Data collection method:** open-ended questions in a self-administered questionnaire followed by an in-home interview were used to collect qualitative data. Mothers were asked to write responses to the following two questions: What are some positive things about having your son or daughter live (at home/away from home)?; What are some negative things about having your son or daughter live (at home/away from home)? **Data analysis method:** the written comments from mothers to the open-ended questions were transcribed verbatim, read by the first and third authors to identify major themes and then subcategories within the major themes, before being coded by major theme and subcategory. **Country:** US.
Participants	**Diagnosis:** mothers of adults with autism. **Coexisting conditions:** not applicable. **N =** 135 (N = 49 co-residing; N = 86 living apart mainly in a community residential programme or a semi-independent living setting). **Age:** range not reported (mean age of mother: 61.1 years; mean age of

	son/daughter with autism: 31.9 years). **Sex:** 0 male, 135 female. **Ethnicity:** not reported. **IQ:** not reported.
Outcomes	**Key research question/aim:** how do mothers describe the positive and negative aspects of their son or daughter's current residential setting?
Focus of the study	Carer experience of organisation and delivery of care (settings)
Results	• Positive aspects of the child living at home included benefits for the family (for instance, son/daughter keeps us company/is fun to be around [46.9%]); benefits for son/daughter (for instance, that they are getting good care at home and are secure [40.8%]); and benefits for the parent (peace of mind [34.7%]). • Negative aspects of the child living at home included problems for the family (for instance, dealing with son/daughter's behaviour [40.8%]); problems for son/daughter (residing at home does not challenge son/daughter [8.2%]; isolation/lack of friends and social life [6.1%]; and not enough services [6.1%]); and problems for parent (for instance, constant caregiving/cannot leave son/daughter alone [40.8%]). • Positive aspects of the child living outside the home included benefits for the family (for instance, a calmer, more typical family life [26.7%]); benefits for the child (for instance, learning new skills/growing more independent/confident [54.7%]; and living a structured, ordered life with better programme-based services/activities [43%]); and benefits for the parent (for instance, more free time/freedom [18.6%]; and less stress/fatigue [17.4%]). • However, negative aspects of the child living outside the home included problems with the programme (for instance, staff not well trained [20.9%]; concerns about quality of care and the programme [18.6%]); problems for son/daughter (for instance, safety concerns [12.8%]; and grooming/personal appearance concerns [11.6%]); and problems for the parent (for instance, missing son/daughter [23.3%]; and worried/guilt [17.4%]).
Limitations	Ethical issues are not adequately considered
Notes	This paper also reports quantitative data from the questionnaire. However, those data are not extracted here.

Study ID	**KRAUSZ2005**
Bibliographic reference	Krausz, M. & Meszaros, J. (2005) The retrospective experiences of a mother of a child with autism. *International Journal of Special Education*, *20*, 36–46.
Methods	**Sampling strategy:** not reported. **Data collection method:** information collected from two initial and one follow-up in-depth semi-structured interviews. The semi-structured interview questions focused on diagnosis, understanding autism, support networks, schooling, changes in family life and expectations.

	Data analysis method: discourse analysis (Marshall, 1994) and a narrative approach (Clandinin & Conelly, 1999; Connelly & Clandinin, 1990; Polkinghorne, 1988) was used to analyse interview transcripts. **Country:** not reported.
Participants	**Diagnosis:** mother of young adult with autism. **Coexisting conditions:** not applicable. **N =** 1 (case study). **Age:** mother: 53 years; child with autism: 19 years. **Sex:** female. **Ethnicity:** not reported. **IQ:** not reported.
Outcomes	**Key research question/aim:** the purpose of this single case study was to record and understand the stages and characteristics of parental adaptation to a child with autism, and to form implications that could be learned from the participant's experiences.
Focus of the study	Carer experience of autism
Results	• The theme of fruitless sacrifices: this mother indicated her frustration that, despite all of her 'suffering' and her efforts as a mother, autism still exists and the struggle of parents of children with autism remains the same. • Mother as advocate: Linda has learned to believe that people with 'handicaps' have just as many rights as anybody else. Since her son is unable to speak for himself, she feels that it is her job as his mother to express his needs and fight for his rights. She has become an advocate for her son. • Experiences of organisation and delivery of care: Linda is happy with her son's living arrangements (group home). However, she describes how she felt forced to make this decision prematurely to the lack of an appropriate before and after-school programme and she still feels angry about being forced into a situation without being mentally prepared. • Experiences of therapeutic intervention: Linda is especially happy with her son's current school where teachers are willing to change the programme to suit the student instead of trying to plug him/her into an established programme. • Mother as teacher: Linda has shifted her focus from teaching her son practical skills to teaching him how to enjoy a variety of leisure activities. • Stigmatisation: Linda sometimes feels stigmatised. • Experience of mental health problems: Linda describes the toll of living for years under tremendous anxiety and stress, and how she sought psychiatric help. • Maturation as a parent: Linda describes how she has learnt to be a more patient person through caring for her son.
Limitations	1. The sampling strategy is not reported. 2. Ethical considerations are not adequately addressed. 3. The transcripts are not double-coded.
Notes	Paper reports on qualitative case study that talks about the first 18 years of parenting a child with autism. However, those data are not extracted here because the experiences of parenting an adult with

	autism are being looked at. Therefore, only data relevant to current experiences are extracted from this study.

Study ID	**LAU2011**
Bibliographic reference	Lau, W. & Peterson, C. C. (2011) Adults and children with Asperger syndrome: exploring adult attachment style, marital satisfaction and satisfaction with parenthood. *Research in Autism Spectrum Disorders*, *5*, 392–399.
Methods	**Sampling strategy:** convenience sampling. Recruitment details for the clinical group are not reported. Non-clinical participants were recruited via personal contacts, staff and student email, and research participant pools at a major university. **Data collection method:** two questionnaires were used for data collection (Quality Marriage Index [Norton, 1983] and a parenthood satisfaction scale [Johnston & Mash, 1989]). **Data analysis method:** quantitative data analysis. **Country:** Australia.
Participants	**Diagnosis:** DSM-IV Asperger's syndrome (and non-clinical group matched on age, gender and total numbers of offspring in their families). **Coexisting conditions:** not reported. **N =** 157 (N = 75 non-clinical group; N = 82 clinical group [of which N = 22 self and child have Asperger's syndrome; N = 11 spouse and child have Asperger's syndrome; N = 49 only child has Asperger's syndrome]). **Age:** 29 to 71 years (mean not reported). **Sex:** 37 male, 120 female. **Ethnicity:** not reported. **IQ:** not reported.
Outcomes	**Key research question/aim:** to what extent are relationship satisfaction and the emotional experiences associated with marriage and parenthood different for adults with Asperger's syndrome, and/or for their spouses, as compared with the feelings and the experiences of other couples without autism?
Focus of the study	Service user and carer experience of autism
Results	• Marital satisfaction: scores for the global marital satisfaction item on the Marital Satisfaction Index did not differ significantly across groups, suggesting that marriage was equally satisfying to respondents overall irrespective of whether they, their spouse, their offspring or no one in the household had a diagnosis of Asperger's syndrome. However, on the six-item total satisfaction score there was a statistically significant difference across groups. Neurotypicals with a spouse and a child with Asperger's syndrome scored significantly lower than the non-clinical control group parents. Those who had a spouse and child with Asperger's syndrome did not differ significantly from those with a child with Asperger's syndrome, suggesting that it was the child's and not the spouse's diagnosis that made the difference. Furthermore, respondents with Asperger's syndrome who also had a child with Asperger's syndrome had total satisfaction

	scores that equalled the other two groups with a child with Asperger's syndrome, further indicating that parental Asperger's syndrome status did not contribute over and above the child's to total satisfaction scores. Finally, on the composite index of divorce cognitions there were no statistically significant differences between groups. In summary, these results reveal that the husband's or wife's Asperger's syndrome status had little impact upon any aspect of marital quality. • Parenthood satisfaction: non-clinical control group parents gained significantly more satisfaction from parenthood than respondents with a child with Asperger's syndrome. However, clinical groups did not differ significantly from each other.
Limitations	A qualitative approach to this research question would have been interesting
Notes	Data were also reported for adult attachment style. However, those data were not extracted.

Study ID	**MACLEOD2007**
Bibliographic reference	MacLeod, A. & Johnston, P. (2007) 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*, *34*, 83–88.
Methods	**Sampling strategy:** purposive (first-hand personal account). **Data collection method:** a former member of a discussion and support group for individuals with autism was given open-ended questions in written form and provided written responses about her diagnosis and her experiences of the group. Questions included: How did you get your diagnosis?; How did you feel about receiving your diagnosis?; Why did you join in the discussion group?; What did you expect before you joined?; What was it like to meet other people with Asperger's syndrome?; What was the best thing about the group for you?; What was the thing you liked least?; What would you say to others thinking of joining a group like this? **Data analysis method:** excerpts from Paula's original transcripts are provided, as are commentary and conclusions. However, no further detail is given about data analysis or techniques for extracting themes. **Country:** not reported.
Participants	**Diagnosis:** autism (Asperger's syndrome). **Coexisting conditions:** not reported. **N =** 1 (case study). **Age:** at entry into the group: 52 years old. **Sex:** female. **Ethnicity:** not reported. **IQ:** not reported, but described in personal account as being in the top 5 to 10% of the country.
Outcomes	**Key research question/aim:** to use a personal account to examine the experiences of a discussion and support group for individuals with autism.
Focus of the study	Service user experiences of therapeutic intervention
Results	• The predominant emerging theme is the experience of the

	discussion and support group as providing positive experiences of peer support and a sense of belonging. - Describes the experience of actively seeking diagnosis to explain difficulties. - Suicidal feelings on receiving diagnosis are described. - The feeling of being different from other people and of experiencing stigma in the form of hostile reactions particularly in the workplace are also described.
Limitations	1. An explicit thematic analysis technique is not described. 2. Case study methodology may limit generalisation. 3. Experiences of this participant may not be representative of other participants as this personal account from a middle-aged woman, whereas the group (like most aimed at adults with autism) was primarily attended by 18- to 35-year-old males.
Notes	–

Study ID	**MAGANA2006**
Bibliographic reference	Magana, S. & Smith, M. J. (2006) 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*, *76*, 346–357.
Methods	**Sampling strategy:** convenience sample. Participants included in this analysis were a subsample from an ongoing (four-wave) longitudinal study of 433 adults or adolescents with autism. Participation in the study was voluntary and families were recruited through agencies, schools, diagnostic clinics and the media. **Data collection method:** open-ended questions from self-administered questionnaires. **Data analysis method:** content analysis of the two open-ended questions used the procedure outlined by Skinner and colleagues (1999) and involved double coding of questionnaires. **Country:** US.
Participants	**Diagnosis:** mothers of adults with autism. **Coexisting conditions:** not applicable. **N =** 108. **Age:** range not reported (mean age of mother: 44.8 and 48.8 years for Latino and non-Latino white sample, respectively; mean age of child with autism: 17.88 and 17.99 years for Latino and non-Latino white sample, respectively). **Sex:** 0 male, 108 female. **Ethnicity:** Latino sample N = 20; non-Latino white sample N = 88. **IQ:** not reported.
Outcomes	**Key research question/aim:** to explore how mothers experienced co-residing with their son or daughter with autism, and potential cultural differences in these experiences between Latina and non-Latina white mothers.
Focus of the study	Carer experience of organisation and delivery of care (settings)
Results	The content analysis revealed a number of themes that highlight mothers' perceptions about living at home with their son or daughter

	with autism. Many of these themes were common between Latina and non-Latina white mothers. For instance, both groups included family cohesion and peace of mind as positive aspects of living with their son or daughter. However, a theme that was articulated more by Latina mothers was the natural role of the mother as a positive aspect. There were several themes that were articulated by non-Latina white mothers and not by Latina mothers; for instance, including positive characteristics of the child and personal growth of the family or caregivers in their list of positive things about living with their child. Differences between the two groups were most striking for the list of negative things about living with a child with autism, with 75% of Latina mothers compared with 7.1% of the non-Latina white mothers answering 'nothing' to this question. Of those that cited negative aspects, both groups of mothers referred to limitations on activities of family members, being stressed by their son or daughter's behaviours, or a general strain on the family. Themes that emerged for non-Latina white mothers but not for Latina mothers were financial strain and being stressed from providing instrumental support.
Limitations	1. Validity of group comparisons given large differences in sample size. 2. Only one method of data collection used. 3. Ethical issues are not adequately considered. 4. These responses were not the result of in-depth interviews, but were short responses to open-ended questions.
Notes	Quantitative data from questionnaires is also reported in this paper. However, only qualitative data from open-ended questionnaire questions are extracted here.

Study ID	**ORSMOND2007**
Bibliographic reference	Orsmond, G. I. & Seltzer, M. M. (2007) Siblings of individuals with autism or Down syndrome: effects on adult lives. *Journal of Intellectual Disability Research*, *51*, 682–696.
Methods	**Sampling strategy:** opportunity sampling. Participants were part of separate, but linked, longitudinal studies of family caregiving (Krauss & Seltzer, 1999; Seltzer *et al.*, 2003). D**ata collection method:** data were collected via a mailed questionnaire. **Data analysis method:** quantitative analysis of questionnaire data. **Country:** US.
Participants	**Diagnosis:** siblings of individuals with autism or Down's syndrome Coexisting conditions: not applicable. **N =** 154 (N = 77 adults who had a brother or sister with autism and N = 77 adults who had a brother or sister with Down's syndrome, matched on age and gender). **Age:** siblings 21 to 56 years (mean age of siblings: 38.2 years; mean age of brother or sister with autism or Down's syndrome: autism group and Down's syndrome group, 34.9 years and 31.8 years, respectively). **Sex:** siblings 58.4% male; brother or sister with autism 72.7% male, brother or sister with Down's syndrome 67.5% male.

	Ethnicity: not reported. **IQ:** not reported (but for brother or sister with autism 89.6% had a learning disability and for brother or sister with Down's syndrome 100% had a learning disability).
Outcomes	**Key research question/aim:** examine whether the type of disability (autism or Down's syndrome) has a differential effect on the sibling relationship during adulthood, and explore whether the same factors are associated with positive as well as negative aspects of the sibling relationship for adults with a brother or sister with autism and Down's syndrome.
Focus of the study	Sibling experience of autism
Results	• Siblings with a brother or sister with Down's syndrome had more frequent contact with their brother or sister than those whose sibling had autism. They saw their brother or sister in person and spoke with him or her on the telephone significantly more frequently than did siblings with a brother or sister with autism. • Siblings of individuals with Down's syndrome reported significantly higher levels of positive affect in their relationship with their brother or sister than siblings of individuals with autism. • Siblings with a brother or sister with autism were significantly more likely to report that their relationship with their mother or father had been impacted than those with a brother or sister with Down's syndrome. • Data on the valence of effects reported by siblings of individuals with autism indicated that the majority of siblings who felt that their relationship with their mother had been affected stated that it had been affected in mainly positive (42.6%) or both positive and negative (42.6%) ways. Only 14.8% of siblings felt that the impacts had been mainly negative. Similarly, of the siblings who reported that their relationship with their father had been affected, 44.7% reported mainly positive effects, 31.9% reported both positive and negative effects, and 23.4% reported mainly negative effects. • Siblings with a brother or sister with autism were significantly more pessimistic about their brother or sister's future than siblings with a brother or sister with Down's syndrome.
Limitations	Qualitative approach may have been informative
Notes	–

Study ID	**ORSMOND2009**
Bibliographic reference	Orsmond, G. I., Kuo, H.-Y. & Seltzer, M. M. (2009) Siblings of individuals with an autism spectrum disorder: sibling relationships and wellbeing in adolescence and adulthood. *Autism*, *13*, 59–80.
Methods	**Sampling strategy:** opportunity sampling. Siblings were recruited from families of 406 adolescents and adults with autism participating in an ongoing longitudinal study (Lounds *et al.*, 2007; Seltzer *et al.*, 2003). Families were recruited via state-supported agencies, schools and diagnostic clinics that provided services to individuals with

	learning and developmental disabilities. Participants were also recruited through newspaper advertisements and television news interviews about the study. **Data collection method:** adult siblings completed a mailed packet of questionnaires, while adolescent siblings participated in a 45-minute telephone interview followed by a brief mailed packet of questionnaires. **Data analysis method:** quantitative analysis of questionnaire data. **Country:** US.
Participants	**Diagnosis:** siblings of adults with autism. **Coexisting conditions:** not applicable. **N =** 198 (N = 56 adolescent siblings and N = 142 adult siblings). **Age:** ranges not reported (means: adolescent sibling respondent: 16 years, brother/sister with autism of adolescent sibling: 19.5 years; adult sibling respondent: 31.9 years, brother/sister with autism of adult sibling: 29.1 years). **Sex:** adolescent sibling respondents 64.3% female, brother/sister with autism of adolescent sibling 28.6% female, adult sibling respondent 59.9% female, and brother/sister with autism of adult sibling 28.9% female. **Ethnicity:** not reported. **IQ:** not reported.
Outcomes	**Key research question/aim:** four research questions were posed: Do adolescent siblings of individuals with autism differ from adult siblings with respect to engagement in shared activities and reported positive affect in the sibling relationship?; Do adolescent siblings of individuals with autism differ from adult siblings in psychological wellbeing, coping and social support?; How does gender influence the relationship and wellbeing of adolescent and adult siblings?; and How do the characteristics of the brother or sister with autism (for example age, behaviour problems), family characteristics (for example family size) and sibling resources (for example coping, support and psychological wellbeing) predict engagement in shared activities and positive affect in the sibling relationship?
Focus of the study	Sibling experience of autism
Results	• Adolescent siblings of adults with autism engaged in more shared activities than adult siblings. • Adolescent siblings reported greater social support, greater use of emotion-focused coping strategies and less use of problem-focused coping than adult siblings. • In adulthood, females with a sister with autism reported the most positive affect in the sibling relationship and men with a sister with autism the least. • Adolescent siblings engaged in more shared activities and reported more positive affect in their sibling relationship when their sibling with autism had fewer behaviour problems; greater use of problem-focused coping buffered the negative effects of behaviour problems on sibling engagement. • For adult siblings, more shared activities were observed when the siblings with autism were younger in age and had fewer behaviour problems; greater positive affect in sibling relationships was predicted by greater parental support.

Limitations	Qualitative analysis may have been informative, particularly analysis of the interview with adolescent siblings which was not reported.
Notes	–

Study ID	**PUNSHON2009**
Bibliographic reference	Punshon, C., Skirrow, P. & Murphy, G. (2009) The 'not guilty verdict': psychological reactions to a diagnosis of Asperger syndrome in adulthood. *Autism*, *13*, 265–283.
Methods	**Sampling strategy:** convenience sample. Eleven users of the local service for adults with Asperger's syndrome were approached and asked to participate in the study. Sample identified through caseloads of local professionals as willing and able to participate. Specific exclusion criteria were applied if individuals had received a diagnosis prior to their 18th birthday, were actively psychotic, had a learning disability or were currently involved in forensic services. **Data collection method:** semi-structured individual interviews. **Data analysis method:** interpretative phenomenological analysis. (Smith *et al.*, 1999) approach to data collection and analysis. **Country:** UK.
Participants	**Diagnosis:** autism (Asperger's syndrome) formally diagnosed by the multidisciplinary team at a local service for adults with Asperger's syndrome using the DISCO (Wing, 2003), based on Gillberg's (1991) criteria. **Coexisting conditions:** not reported. **N =** 10. **Age:** at diagnosis: 21 to 44 years (median: 35 years); current age: 22 to 45 years (median: 31 years). **Sex:** 7 male, 3 female. **Ethnicity:** not reported. **IQ:** not reported.
Outcomes	**Key research question/aim:** to identify what are the experiences of adults with Asperger's syndrome relating to their diagnosis; whether these experiences can be accounted for using stage and/or cognitive models of adjustment to diagnosis; and how services might help individuals negotiate the diagnostic process and adjust to their diagnosis.
Focus of the study	Service user experience of autism and experience of services
Results	Six superordinate themes emerged from analysis of the data: • Negative life experiences: feeling not accepted and that they did not fit in with peers. • Experience of services (pre-diagnosis): being misdiagnosed with another mental health problem was common and this often led to failed interventions and reinforced feelings of not fitting in and being different and blamed for difficulties, and delayed diagnosis, and for some individuals misdiagnosis led to a lack of trust in services and anxiety over current diagnosis. Participants also described feeling that some clinicians did not have the knowledge or expertise to diagnose Asperger's syndrome.

	• Beliefs about symptoms of Asperger's syndrome: participants describe feeling different to other people. Most of the participants expressed a desire to be 'normal' and similar to others and some tried to mask autistic difficulties; however, this masking led to worsening symptoms and increased stress levels. • Identity formation: many participants had experiences of bullying or criticism from other people and participants spoke of struggling with a variety of mental health problems such as anxiety, depression and self-harm. • Effect of diagnosis on beliefs: diagnosis provided some participants with a framework to explain their difficulties to themselves and society, offered an explanation for previous experiences, and led to positive reactions such as elation and relief. A minority of participants viewed Asperger's syndrome as an advantage over their non-autistic peers. Receiving a diagnosis also allowed individuals to access services and support that they had not previously received, and for several participants one of the most valued aspects of support was meeting other people with autism, making friends and feeling as though they 'fitted in' with peers. However, negative reactions to diagnosis were also described and included frustration that there is no cure and feelings of loss and anger. • Effect of societal beliefs of Asperger's syndrome: participants described a need for further information and learning about autism for friends and families as a lack of understanding about what autism was and how it affected the individual was described. Participants also expressed frustration at the lack of societal understanding and the media portrayal of autism.
Limitations	None reported
Notes	–

Study ID	**ROBLEDO2008**
Bibliographic reference	Robledo, J. A. & Donnellan, A. M. (2008) Properties of supportive relationships from the perspective of academically successful individuals with autism. *Intellectual and Developmental Disabilities*, *46*, 299–310.
Methods	**Sampling strategy:** purposive sampling was used to select specific individuals with autism who met the criteria for the study of having a diagnosis of autism by a medical, psychological or educational agency not connected to the researchers using one of the DSM versions or state and/or federal guidelines under the Individuals with Disabilities Education Act, and entrance into and experience in post-secondary education, either at a university, community college or technical school. Four of the five participants with autism were approached about the study at professional conferences and the second author referred the final participant. **Data collection method:** participants were asked to define supportive

	relationships for themselves. The only criterion for selection was that the person with autism had known the individual for more than 6 months. Participants with autism identified 17 supportive relationships to be discussed during interviews. Of these supporters, 15 were female and two male (a father and stepfather). Seven were relatives, all parents or step-parents. The other ten supporters had at one time or another been paid support staff. A semi-structured interview was used to collect data about these relationships. These interviews used a guide that focused on three major areas: description of each relationship, ways in which the relationship was supportive, and the role of communication in the supportive relationship. As the interviews progressed, these guides evolved and expanded according to concepts that emerged during earlier interviews (Charmaz, 2001; Strauss, 1987). Documents and other materials were also collected from participants and used as data such as published articles or chapters, documentaries or other video recordings, conference presentation handouts and/or transcripts, schoolwork, and other miscellaneous documents. Finally, nine of the 17 dyads were directly observed with observation periods ranging from 1 to 4 hours and interactions video recorded. **Data analysis method:** data were analysed throughout the data collection process using the constant comparative method (Glaser & Strauss, 1967). Theoretical sampling also ensured that participants continued to play a role in the analysis of data because throughout the data collection and analysis process, the researchers checked back with participants in order to fill in gaps and further discuss emerging concepts and theories (Glaser & Strauss, 1967). **Country:** US.
Participants	**Diagnosis:** DSM autism. **Coexisting conditions:** not reported. **N =** 5. **Age:** 20 to 32 years (mean 26.8 years). **Sex:** 3 male, 2 female. **Ethnicity:** white N = 5. **IQ:** not reported, but academically successful.
Outcomes	**Key research question/aim**: to explore and describe properties of supportive relationships identified by individuals with autism.
Focus of the study	Service user experience of support for individuals with autism
Results	Six essential properties of supportive relationships emerged from the data: • Trust: participants identified trust as an important property of their supportive relationships. For developing trust support during bad times was highlighted as an important element. Participants highlighted how violations of trust by one supporter could have a negative impact on the ability to trust future supporters. Transitions to new supporters were described as a serious challenge. • Intimate connection: participants described the importance of establishing a bond with supporters based on mutual support and reciprocity. • Shared vision of independence: the ultimate goal of support for all of the relationships explored was independence.

	Participants spoke about their desire to constantly push themselves and be pushed by their supporters towards greater independence. Frustration with being 'oversupported' was described and a preferred model was described where individuals with autism were allowed to try things independently even if this involved making mistakes, and then be provided with support only when required. • The presumption of confidence: participants with autism spoke of the importance of their supporters presuming that they are competent human beings. Participants shared a common desire to be treated like a regular person who may need some extra supports and accommodation – a person with thoughts, emotions, a sense of humour and a personality. • Understanding: participants with autism desired to be seen beyond their label and the stereotypes associated with this label. They did not want their supporters to understand 'a person with autism'; instead, they wanted them to understand and know them as an individual. • Communication: participants indicated that supporting and understanding their communication was an important property of their successful supportive relationships.
Limitations	1. If double coding was adopted it is not described. 2. Ethical issues are not considered. 3. No rationale/justification given for sampling strategy.
Notes	–

Study ID	**RYAN2009**
Bibliographic reference	Ryan, S. & Runswick Cole, K. (2009) From advocate to activist? mapping the experiences of mothers of children on the autism spectrum. *Journal of Applied Research in Intellectual Disabilities*, 22, 43–53.
Methods	**Sampling strategy:** convenience sample. This sample was taken from a broader study that included people on the autism spectrum; however, the analysis discussed here focuses on mothers of children with autism. The sample was recruited in different ways including support groups, newsletters, online communities, special schools and local authority parent coordinators. A maximum variation approach (Coyne, 1997) was taken to incorporate a range of participants of different ages, ethnicity, social class, geographical location, the ability/disability of the child with autism and the number of siblings within the family. **Data collection method:** two-part interviews were used to collect data. First, parents were asked an open-ended question: 'Can you tell me about your experiences with your son/daughter?'. This question prompted lengthy uninterrupted narratives. The second part of the interview was based upon a semi-structured interview guide, which included questions such as: What sort of impact do you think these experiences have had on you?; Have you had any involvement with support groups?; Can you describe your dealings with health

	professionals? **Data analysis method:** interviews were recorded and transcribed in full. The interviews were analysed electronically using a thematic approach with the organisational support of NVivo software. A constant comparative method was used to develop and refine the theoretical categories (Morgan, 1993; Seale, 1999). **Country:** UK.
Participants	**Diagnosis:** mothers of adults with autism. **Coexisting conditions:** children with autism had coexisting conditions including ADHD, Tourette's syndrome, dyspraxia, dyslexia and epilepsy. **N =** 36 (data extracted for N = 2). **Age:** children aged 3 to 53 years (data extracted for two adults, aged 23 and 53 years). **Sex:** 100% female. **Ethnicity:** not reported. **IQ:** not reported.
Outcomes	**Key research question/aim:** not reported.
Focus of the study	Carer experience of autism
Results	Emerging themes included: • Mother as advocate: parents described being protective of children over a long period of time and fighting on their behalf. • Role of mother in raising public awareness of autism: one mother described regularly writing to newspapers and local politicians to question the way in which the media present autism. Another described how her support group have set up and run Asperger courses and she goes to talk to mental health teams, schools, colleges and social care departments to raise awareness.
Limitations	1. Research question/aim is not reported. 2. Transcripts were not double coded. 3. Ethical issues are not adequately considered.
Notes	Data were reported in this paper for mothers of children aged 3 to 53 years. However, data were only extracted for mothers of adults with autism.

Study ID	**RYAN2010**
Bibliographic reference	Ryan, S. (2010) 'Meltdowns', surveillance and managing emotions: going out with children with autism. *Health and Place*, *16*, 868–875.
Methods	**Sampling strategy:** convenience sample. This sample was taken from a broader study that included people on the autism spectrum; however, the analysis discussed here focused upon mothers of children with autism. The sample was recruited in different ways including support groups, newsletters, online communities, special schools and local authority parent coordinators. A maximum variation approach (Coyne, 1997) was taken to incorporate a range of participants of different ages, ethnicity, social class, geographical location, the ability/disability of the child with autism and the number of siblings within the family. **Data collection method:** two-part in-depth interviews conducted

	largely at participants homes were used to collect data. First, parents were asked an open-ended question: 'Can you tell me about your experiences with your son/daughter?'. This question prompted lengthy uninterrupted narratives. The second part of the interview was based upon a semi-structured interview guide, which included questions such as: 'What sort of impact do you think these experiences have had on you?', 'Can you describe your dealings with health professionals?' Given previous research, difficulties associated with going out was an anticipated theme and most parents spontaneously discussed their going out experiences in the first part of the interview. Those participants who did not either discussed going out when asked to talk about their everyday lives and two participants were directly asked: 'Can you tell me about your experiences of going out in public with your son/daughter?' Participants were not explicitly asked about how they felt going out in public places. **Data analysis method:** interviews were recorded and transcribed in full. The interviews were analysed electronically using a thematic approach with the organisational support of NVivo software. A constant comparative method was used to develop and refine the theoretical categories (Seale, 1999). **Country:** UK.
Participants	**Diagnosis:** mothers of adults with autism. **Coexisting conditions:** not reported. **N =** 48 (but data only extracted for N = 3 participants). **Age:** children aged 3 to 53 years, but data only extracted for adults (18-year-old and two 28-year-olds). **Sex:** 2 female, 1 male. **Ethnicity:** not reported for data extracted. **IQ:** not reported.
Outcomes	**Key research question/aim:** not reported.
Focus of the study	Carer experience of autism
Results	Emerging themes included: • Stigmatisation, with the majority of parents describing experiencing looks, stares or glares when out in public with their son or daughter with autism. Parents described how this experience articulated a spoiled identity in that they felt that people thought they were poor parents. One of the strategies several parents used to resolve this was to disclose their children's autism either directly or indirectly. For instance, one mother describes how she talks to her son in public in such a way that people around realise that something is not quite as it should be. However, another parent talked about his reluctance to label his son autistic, though the concern was particularly focused on not wanting to disclose autism in front of his son.
Limitations	1. Research question/aim is not reported. 2. Transcripts were not double coded. 3. Ethical issues are not adequately considered.
Notes	Data were reported in this paper for parents of children aged 3 to 53 years. However, data were only extracted for parents of adults with autism.

Study ID	**SELTZER2001**
Bibliographic reference	Seltzer, M. M., Krauss, M. W., Orsmond, G. I., *et al.* (2001) Families of adolescents and adults with autism: uncharted territory. *International Review of Research in Mental Retardation*, *23*, 267–294.
Methods	**Sampling strategy:** opportunity sampling. Data taken from a longitudinal study of aging families of adults with a learning disability (Krauss & Seltzer, 1999; Seltzer & Kraus, 1989 and 1994). **Data collection method:** multiple interviews conducted with the mothers of adults with autism. **Data analysis method:** quantitative and qualitative data were analysed from the interviews. The authors present two case studies of adults with autism and their aging families and then compare the small subgroup of adults with autism in the sample with adults with Down's syndrome in the longitudinal study (N = 120). **Country:** US.
Participants	**Diagnosis:** mothers of adults with autism. **Coexisting conditions:** not applicable. **N =** 13. **Age:** in 1988 when study began individuals with autism were 25 to 40 years old (mean 31 years) and their mothers ranged from 58 to 70 years old (mean 62 years) **Sex:** individuals with autism: 8 male, 5 female; parents of individuals with autism: 0 male, 13 female. **Ethnicity:** not reported. **IQ:** not reported.
Outcomes	**Key research question/aim:** not reported.
Focus of the study	Carer experience of autism
Results	• Case study of Donald described changing satisfaction with services, for example when study began mother very dissatisfied with the services provided by the advocates and felt they should try and do more to improve Donald's skills. Whereas in 1996, Donald's mother felt that he was learning more from the advocates than in the past: 'I can't say enough about them. This agency has done so much for Donald. It's been a whole new life for him. They have done wonders!' • Adults with autism compared with adults with Down's syndrome: the mothers of adults with autism were much more likely to feel as if they were 'walking on eggshells' around their adult child than mothers of adults with Down's syndrome, and to feel that their son or daughter's behaviour problems often 'came out of nowhere'. The particular problematic behaviours that differentiated the two groups were being hurtful to self, socially offensive and withdrawn – all of which were higher in adults with autism than in those with Down's syndrome. Indeed, over 80% of the sample of adults with autism were characterised by their mothers as being withdrawn, whereas only 20% of the adults with Down's syndrome behaved in this way. • Adults with autism were less likely to be seen by their mothers as being 'good company' (60%) than their counterparts with Down's

	syndrome (94%). - Although both the adults with autism and the adults with Down's syndrome received five or six discrete services, there were three types of services more likely to be received by the adults with autism: psychological services, occupational therapy and non-vocational day services (that is, day activity or day habilitation services rather than sheltered or supported employment). Their parents also perceived a higher level of unmet need for physical and occupational therapy, as contrasted with the perceptions of the parents of adults with Down's syndrome. Thus, parents of adults with autism may perceive a continuing need for therapeutic intervention well into adulthood. - Mothers of adults with autism versus Down's syndrome: mothers were similar in their level of global well-being, as indicated by their self-rated health, level of depressive symptoms, size of social support network, overall life satisfaction and positive psychological well-being. The two groups of mothers were found to differ in two measures of role-specific well-being: the mothers of the adults with autism were more pessimistic about their son or daughter's future and had a less emotionally close relationship with their son or daughter than did mothers of adults with Down's syndrome. - Siblings of adults with autism versus Down's syndrome: siblings of adults with autism felt less close emotionally to their brother or sister than siblings of adults with Down's syndrome. They were also less likely to participate together in social activities, such as going out for a meal, shopping or running errands, participating in a recreational activity, going out to visit relatives or friends, and going to doctors' appointments.
Limitations	A qualitative approach may have allowed greater insight into the carer experience of autism
Notes	–

Study ID	**SHTAYERMMAN2007**
Bibliographic reference	Shtayermman, O. (2007) 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*, *30*, 87–107.
Methods	**Sampling strategy:** the study included two samples. The first used snowball sampling, starting with parents of adolescents or young adults diagnosed with Asperger's syndrome who participated in a 2002 qualitative study. The second consisted of a volunteer sample of parents who visited one of the following websites: Asperger's Syndrome Parent Education Network; Advocates for Individuals with High Functioning Autism, Asperger's Syndrome and Other Pervasive Developmental Disorders; and the National Alliance for Autism Research. **Data collection method:** self-administered mail questionnaire and a web-based questionnaire. **Data analysis method:** quantitative analysis of questionnaire data.

	Country: US.
Participants	**Diagnosis:** Asperger's syndrome. **Coexisting conditions:** 66.7% of participants had additional psychiatric diagnoses. **N =** 10. **Age:** range not reported (mean 19.7 years). **Sex:** 9 male, 1 female. **Ethnicity**: white N = 10. **IQ:** not reported.
Outcomes	**Key research question/aim:** exploratory study to examine the level of peer victimisation, depressive symptomatology, anxiety symptomatology, and level of suicidal ideation among adolescents and young adults diagnosed with Asperger's syndrome
Focus of the study	Service user experience of autism
Results	• Fifty per cent (N = 5) of participants had clinically significant suicidal ideation. 20% met the diagnostic criteria for major depressive disorder and 30% met the diagnostic criteria for generalized anxiety disorder. • There was a strong negative correlation between level of suicidal ideation and severity of Asperger's syndrome symptomatology • There was a strong negative correlation between the severity of Asperger's syndrome symptomatology and current age. • There was also a strong positive correlation between current age and: degree of total peer victimisation; overt victimisation; and relational victimisation. • Prosocial behaviour was strongly and negatively correlated with age. • Severity of Asperger's syndrome symptomatology was strongly negatively correlated with degree of total degree of peer victimisation, relational victimisation, and overt victimisation and strongly and positively correlated with prosocial behaviour.
Limitations	A qualitative approach may have allowed greater insight
Notes	The institutional review board at Fordham University approved this study, and informed consents were obtained from each parent and each adolescent or young adult participating in the study. Same population as SHTAYERMMAN2009.

Study ID	**SHTAYERMMAN2009**
Bibliographic reference	Shtayermman, O. (2009) 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*, *19*, 298–313.
Methods	**Sampling strategy:** the study included two samples. The first sample used snowball sampling, starting with parents of adolescents or young adults diagnosed with Asperger's syndrome who participated in a 2002 qualitative study. The second sample consisted of a volunteer sample of parents who visited one of the following websites: Asperger's Syndrome Parent Education Network;

	Advocates for Individuals with High Functioning Autism, Asperger's Syndrome and Other Pervasive Developmental Disorders; and the National Alliance for Autism Research. **Data collection method:** self-administered mailed questionnaire and a web-based questionnaire. **Data analysis method:** quantitative analysis of questionnaire data. **Country:** US.
Participants	**Diagnosis:** Asperger's syndrome. **Coexisting conditions:** 66.7% of participants had additional psychiatric diagnoses. **N =** 10. **Age:** 15 to 24 years (mean 19.7 years). **Sex:** 9 male, 1 female. **Ethnicity:** white N = 10. **IQ:** not reported.
Outcomes	**Key research question/aim:** exploratory study to examine how adolescents and young adults with Asperger's syndrome perceived their diagnosis and whether they felt stigmatised.
Focus of the study	Service user experience of autism
Results	Asperger's syndrome symptomatology was strongly and negatively correlated with level of stigma
Limitations	A qualitative approach may have allowed greater insight
Notes	*Same population as SHTAYERMMAN2007.*

Study ID	**SHU2006**
Bibliographic reference	Shu, B.-C., Lo, L.-H., Lin, L.-L., *et al.* (2006) Process of self-identity transformation in women with autistic adolescent. *Journal of Nursing Research*, *14*, 55–64.
Methods	**Sampling strategy:** Convenience sample. This sample was drawn from a previous study in which autistic children were recruited from the Autism Societies of Tainan and Kaohsiung cities – volunteer support organisations for parents with autistic children. Mothers of autistic children who had no history of hypertension, diabetes or other chronic diseases, were aged 25 to 55 years and had an autistic child aged 13 to 21 years old were included in the present study. **Data collection method:** in-depth interviews with mothers of autistic adolescents were used to collect data. Each mother was interviewed at home, by an experienced psychiatric nurse, and interviewed one to four times, with each interview lasting 60 to 90 minutes. Interviews were focused to review the relationship between mothers and their autistic adolescents. All interviews were tape recorded, transcribed and reviewed prior to each subsequent interview. **Data analysis method:** applied grounded theory was used to analyse study data. Transcribed interviews were coded using an interactive process following the constant-comparative procedures described by Lincoln and Guba (1985). Two randomly selected interviews were coded by two researchers using the coding scheme and level of agreement was 95%. **Country:** Taiwan.

Participants	**Diagnosis:** mothers of autistic adolescents. **Coexisting conditions:** not applicable. **N =** 8. **Age:** age of mothers: 41 to 52 years (mean 46.6 years); age of children: 13 to 21 years (mean 17.8 years). **Sex:** children: 100% male. **Ethnicity:** not reported. **IQ:** not reported.
Outcomes	**Key research question/aim:** to better understand the condition of mothers caring for adolescent children with autism.
Focus of the study	Carer experience of autism
Results	Emerging themes: • Life-long parenting of autistic child: parents described the long-term nature of caring for autistic children, meaning that the daily activities and meaning of life for mothers of autistic children were closely tied with their children. Parents also expressed concerns about what would happen to their child when they died. • Impact of autism on family relationships: mothers described conflicts between themselves and their husbands in terms of child-rearing attitudes; for instance, one mother felt that her husband blamed her for overprotecting and spoiling their son. Parents also described conflict in other family relationships; for instance, one mother described how her mother-in-law said that it is the mothers fault if a boy is undisciplined. • Impact of autism on the carer: mothers described how their social life is limited due to family responsibilities. • Experience of support: parents described how support from external sources can help to inspire self-awareness. For instance, one mother described how attending lessons in a women's association allowed her the opportunity to make friends.
Limitations	1. Relationship between researcher and participant not adequately described. 2. More details could be given on how themes were identified from the data. 3. Only two interviews (12% of data) were double coded. 4. Ethical issues are not adequately considered. 5. More detail could be given about content of interviews, for instance, was it semi-structured?
Notes	–

Study ID	**SMITH2010**
Bibliographic reference	Smith, L. E., Hong, J., Seltzer, M. M., *et al.* (2010) Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *40*, 167–178.
Methods	**Sampling strategy:** opportunity sampling. Mothers of individuals with autism were drawn from the study on adolescents and adults with autism (Seltzer *et al.*, 2003; Shattuck *et al.*, 2007), which recruited participants via agencies, schools, diagnostic clinics and media

	announcements. A non-clinical control group was drawn from the National Survey of Midlife in the US (Brim *et al.*, 2004; Gruenewald *et al.*, 2008). **Data collection method:** daily diary study – participants were interviewed by telephone for 15 to 25 minutes each evening for a period of 8 days. The daily interview included questions about daily experiences in the previous 24 hours. Questions focused on time use, daily stressors, positive events, mood and physical symptoms. **Data analysis method:** quantitative analysis of interview data. **Country:** US.
Participants	**Diagnosis:** mothers of adolescents and adults with autism. **Coexisting conditions:** not applicable. **N =** 96 (compared against a non-clinical group N = 230). **Age:** child age range not reported (mean 22.4 years); mother age range not reported (mean 54.4 years). **Sex:** child: 23% female. **Ethnicity:** 92% white. **IQ:** not reported.
Outcomes	**Key research question/aim:** three primary aims: Compared mothers of a son or daughter with autism to mothers of children without disabilities on four outcomes reflecting daily psychological, physical, and economic well-being: (a) negative affect, (b) positive affect, (c) fatigue and (d) work intrusions; examined differences in the daily experiences of both groups of mothers in terms of their (a) time use, (b) stressful events, (c) positive events, and (d) giving and receiving emotional support; evaluated the impact of daily time use, stressful events, positive events, giving and receiving support, and parenting a child with autism on maternal well-being.
Focus of the study	Carer experience of autism
Results	• Positive and negative affect: mothers of adolescents and adults with autism reported significantly lower levels of positive affect averaged across days than the comparison sample. Mothers with a son or daughter with autism also reported significantly higher levels of negative affect averaged across days in comparison with mothers without a child with a disability. • Fatigue and work intrusions: mothers who had a son or daughter with autism reported significantly more days when they felt fatigued and more days with work intrusions across the 8-day period than did comparison mothers. They experienced fatigue on 50% of days, twice the number of the comparison group. Nineteen per cent of mothers of adolescents and adult children with autism reported fatigue on all 8 days whereas only 3% of comparison mothers did. Mothers of individuals with autism also reported having work intrusions on 22% of days in contrast with 8% of days for comparison mothers. • Stressful events: mothers with a son or daughter with autism reported having arguments on twice as many days as mothers in the comparison group (25% of days versus 13% of days). • Positive events and exchange of support: mothers of a son or daughter with autism did not differ from mothers in the comparison group in terms of the percent of days during which they experienced positive interactions or did volunteer work.

Limitations	A qualitative approach may have allowed greater insight
Notes	–

Study ID	**SPERRY2005**
Bibliographic reference	Sperry, L. A. & Mesibov, G. B. (2005) Perceptions of social challenges of adults with autism spectrum disorder. *Autism*, *9*, 362–376.
Methods	**Sampling strategy:** criterion-based sampling (Goetz & LeCompte, 1984), which establishes certain criteria that must be met before the participant can be included. Participants were selected based on participation as a social group member with a diagnosis of ASD. Division TEACCH sent out 60 letters of invitation to participants of their social skills groups. Nineteen letters were returned and 19 individuals participated in the discussions. **Data collection method:** focus group interviewing (as described by Brotherson, 1994). Participants were seen in groups and asked to write down a question they had about getting along with people. When all the questions were written they were read one at a time by the investigator, and the group were encouraged to generate possible solutions for each question. **Data analysis method:** the qualitative method of focus group interviewing was used. This method serves as a vehicle to gather data and insights through the facilitation and interaction of group discussion (Krueger, 1988; Morgan, 1988). **Country:** US.
Participants	**Diagnosis:** autism. **Coexisting conditions:** not reported. **N =** 18. **Age:** 22 to 49 years (mean 34 years). **Sex:** 0 male, 18 female. **Ethnicity:** white N = 16; African-American N = 1; Jewish-American N = 1. **IQ:** not reported.
Outcomes	**Key research question/aim:** to examine perceptions of social challenges by adults with autism.
Focus of the study	Service user experience of autism
Results	Four emergent themes: 1. Relationships at work: refers to how participants were able to interact with their co-workers (for example, by following directions, taking turns and following a schedule, and having a sense of humour) and how they were able to resolve conflict in the workplace (for example, through compromising, talking to the job coach or writing down feelings). 2. Developing and maintaining personal relationships: refers to questions about the skills necessary to initiate and sustain interpersonal interactions (includes concrete and rule-governed strategies). 3. Appropriate behaviour around members of the opposite sex: refers to the skills necessary to approach a member of the opposite sex, define limits and initiate relationships.

	4. Personal perspectives on having autism: refers to the metacognitive process of recognising the challenges and advantages of having autism. Some participants viewed their diagnosis as a means to access supports and services. Others saw their diagnosis as an obstacle that challenged their social interactions.
Limitations	1. The all-female sample may threaten the generalisability of findings. 2. Ethical issues are not adequately discussed.
Notes	One participant dropped out of the study. However, reasons are not reported.

1.2 CHARACTERISTICS OF EXCLUDED STUDIES

AKSOY2008

Reason for exclusion	Mean age <18 years old.

ALTIERE2009A

Reason for exclusion	Mean age <18 years old.

ALTIERE2009B

Reason for exclusion	Mean age <18 years old.

AVDI2000

Reason for exclusion	Mean age <18 years old.

BAKER2011A

Reason for exclusion	Focused on predictive value of participant characteristics rather than experience of care.

BAKER2011B

Reason for exclusion	Focused on predictive value of participant characteristics rather than experience of care.

BARKER2011

Reason for exclusion	Focus on predictive value of participant characteristics rather than experience of care.

BARNHILL2007

Reason for exclusion	Review of experimental studies and not qualitative studies examining first-hand personal accounts or descriptions of subjective experiences.

BAUMINGER2003

Reason for exclusion	Mean age <18 years old.

BENDRIX2007

Reason for exclusion	Mean age <18 years old.

BENJAK2009

Reason for exclusion	Focused on predictive value of participant characteristics rather than experience of care.

BENSON2006

Reason for exclusion	Mean age <18 years old.

BILGIN2010

Reason for exclusion	Mean age <18 years old.

BILLSTEDT2011

Reason for exclusion	Focused on predictive value of participant characteristics and prevalence estimates rather than experience of care.

BOYD2002

Reason for exclusion	Review of studies focused on predictive value of participant characteristics rather than experience of care.

BRAIDEN2010

Reason for exclusion	Mean age <18 years old.

BREWIN2008

Reason for exclusion	Mean age <18 years old.

BROGAN2003

Reason for exclusion	Mean age <18 years old.

BROMLEY2004

Reason for exclusion	Focused on predictive value of participant characteristics rather than experience of care.

BROWN2006

Reason for exclusion	Mean age <18 years old.

CAMARENA2009

Reason for exclusion	Mean age <18 years old.

CARRINGTON2003A

Reason for exclusion	Mean age <18 years old.

CARRINGTON2003B

Reason for exclusion	Mean age <18 years old.

CHAMAK2008

Reason for exclusion	Not primary data.

COLE2000

Reason for exclusion	Data are not autism-specific.

CORMAN2009

Reason for exclusion	Mean age <18 years old.

DALE2006

Reason for exclusion	Mean age <18 years old.

DEGRACE2004

Reason for exclusion	Mean age <18 years old.

DUNN2001

Reason for exclusion	Focused on predictive value of participant characteristics rather than experience of care.

ELDER2001

Reason for exclusion	Mean age <18 years old.

ELKINS2003

Reason for exclusion	Mean age <18 years old.

FARRUGIA2009

Reason for exclusion	Participants aged 5 to 23 years, and adult and child data cannot be separated.

FIRAT2002

Reason for exclusion	Mean age <18 years old.

FLEISCHMANN2004

Reason for exclusion	Age not reported, but described as children.

FROESE1999

Reason for exclusion	Data are not autism-specific.

GLASBERG2000

Reason for exclusion	Age of autistic siblings not reported and mean age of non-autistic siblings <18 years old.

GLENNON2001

Reason for exclusion	Not first-hand personal account or description of subjective experiences.

GRAY1993

Reason for exclusion	Age not reported, but described as children.

GRAY2001

Reason for exclusion	Mean age <18 years old.

GRAY2002A

Reason for exclusion	Mean age <18 years old.

GRAY2002B

Reason for exclusion	Mean age <18 years old.

GRAY2003

Reason for exclusion	Mean age <18 years old.

GRAY2006

Reason for exclusion	Mean age <18 years old.

GREEN2007

Reason for exclusion	Mean age <18 years old.

GRIFFITH2010

Reason for exclusion	Mean age <18 years old.

HAMLYNWRIGHT2007

Reason for exclusion	Mean age <18 years old.

HARRINGTON2006

Reason for exclusion	Mean age <18 years old.

HARTLEY2011

Reason for exclusion	Focused on predictive value of participant characteristics rather than experience of care.

HASTINGS2007

Reason for exclusion	Focused on predictive value of participant characteristics rather than experience of care.

HILLMAN2007

Reason for exclusion	Participant characteristics are not reported for the studies reviewed so not possible to ascertain age of participants. However, autistic participants are described as children.

HOLROYD1975

Reason for exclusion	Mean age <18 years old.

HOWARD2006

Reason for exclusion	Mean age <18 years old.

HUTTON2005

Reason for exclusion	Mean age <18 years old.

HUWS2001

Reason for exclusion	Age of participants is not reported.

JEGATHEESAN2010

Reason for exclusion	Mean age <18 years old.

JONES2003

Reason for exclusion	No participant characteristics reported.

KEENAN2010

Reason for exclusion	Mean age <18 years old.

KING2006

Reason for exclusion	Age not reported, but described as children.

KNOTT2006

Reason for exclusion	Mean age <18 years old.

KONSTANTAREAS2006

Reason for exclusion	Focused on predictive value of participant characteristics rather than experience of care.

KOWALSKI2011

Reason for exclusion	Mean age <18 years old.

KRING2010

Reason for exclusion	Focused on predictive value of participant characteristics rather than experience of care.

KUHN2006

Reason for exclusion	Focused on predictive value of participant characteristics rather than experience of care.

LARSON2010

Reason for exclusion	Mean age <18 years old.

LASGAARD2010

Reason for exclusion	Mean age <18 years old.

LASSER2008

Reason for exclusion	Mean age <18 years old.

LIN2008

Reason for exclusion	Mean age <18 years old.

LIPTAK2006

Reason for exclusion	Mean age <18 years old.

LITTLE2002A

Reason for exclusion	Mean age <18 years old.

LITTLE2002B

Reason for exclusion	Mean age <18 years old.

LOUNDS2007

Reason for exclusion	Focused on predictive value of participant characteristics rather than experience of care.

LUONG2009

Reason for exclusion	Mean age <18 years old.

LUTHER2005

Reason for exclusion	Mean age <18 years old.

MACKS2007

Reason for exclusion	Age not reported, but described as children.

MAGANA2010

Reason for exclusion	Mean age <18 years old.

MAK2007

Reason for exclusion	Focused on predictive value of participant characteristics rather than experience of care.

MANCIL2009

Reason for exclusion	Mean age <18 years old.

MANDELL2005

Reason for exclusion	Review of experimental studies and not qualitative studies examining first-hand personal accounts or descriptions of subjective experiences.

MANSELL2004

Reason for exclusion	Mean age <18 years old.

MARGETTS2006

Reason for exclusion	Mean age <18 years old.

MARSHALL2010

Reason for exclusion	Mean age <18 years old.

MASCHA2006

Reason for exclusion	Mean age <18 years old.

MCCABE2008

Reason for exclusion	Mean age <18 years old.

MEADAN2010

Reason for exclusion	Mean age <18 years old.

MEIRSSCHAUT2010

Reason for exclusion	Mean age <18 years old.

MIDENCE1999

Reason for exclusion	Mean age <18 years old.

MINNES2009

Reason for exclusion	Mean age <18 years old.

MIYAHARA2008

Reason for exclusion	Age not reported.

MUGNO2007

Reason for exclusion	Mean age <18 years old.

MYERS2009

Reason for exclusion	Mean age <18 years old.

NEELYBARNES2010

Reason for exclusion	Mean age <18 years old.

NEWSOME2000

Reason for exclusion	Mean age <18 years old.

NICHOLS2010

Reason for exclusion	Mean age <18 years old.

ORSMOND2004

Reason for exclusion	Focused on predictive value of participant characteristics rather than experience of care.

ORSMOND2006

Reason for exclusion	Focused on predictive value of participant characteristics rather than experience of care.

ORSMOND2007B

Reason for exclusion	Focused on predictive value of participant characteristics rather than experience of care.

ORSMOND2007C

Reason for exclusion	Review with no useable data.

PAKENHAM2004

Reason for exclusion	Focused on predictive value of participant characteristics rather than experience of care.

PAPAGEORGIOU2010

Reason for exclusion	Mean age <18 years old.

PARSONS2009

Reason for exclusion	Mean age <18 years old.

PETALAS2009

Reason for exclusion	Mean age <18 years old.

PHELPS2009

Reason for exclusion	Mean age <18 years old.

PILLING2007

Reason for exclusion	Mean age <18 years old.

PILOWSKY2004

Reason for exclusion	Mean age <18 years old.

PORTWAY2003

Reason for exclusion	Focused on school experiences.

PREECE2002

Reason for exclusion	Mean age <18 years old.

RAO2009

Reason for exclusion	Mean age <18 years old.

ROSS2006

Reason for exclusion	Mean age <18 years old.

ROSSETTI2008

Reason for exclusion	Data collection using facilitated communication.

RUSS2010

Reason for exclusion	Mean age <18 years old.

SABIH2008

Reason for exclusion	Mean age <18 years old.

SAGE2010

Reason for exclusion	Mean age <18 years old.

SALDANA2009

Reason for exclusion	Focused on predictive value of participant characteristics rather than experience of care.

SAMIOS2009

Reason for exclusion	Focused on predictive value of participant characteristics rather than experience of care.

SAWYER2010

Reason for exclusion	Focused on predictive value of participant characteristics rather than experience of care.

SCHALL2000

Reason for exclusion	Study methodology not reported.

SCHUNTERMANN2007

Reason for exclusion	Review with no useable data.

SHARPE2007

Reason for exclusion	Focused on predictive value of participant characteristics rather than experience of care.

SHTAYERMMAN2008

Reason for exclusion	Focused on prevalence rather than experience of care.

SHU2000

Reason for exclusion	Mean age <18 years old.

SHU2001

Reason for exclusion	Mean age <18 years old.

SHU2009

Reason for exclusion	Age not reported.

SIKLOS2007

Reason for exclusion	Mean age <18 years old.

SIROTA2010

Reason for exclusion	Mean age <18 years old.

SIVBERG2002A

Reason for exclusion	Mean age <18 years old.

SIVBERG2002B

Reason for exclusion	Focused on predictive value of participant characteristics rather than experience of care.

SMITH2008

Reason for exclusion	Mean age <18 years old.

SMITH2010B

Reason for exclusion	Review with no useable data.

SPANN2003

Reason for exclusion	Mean age <18 years old.

SPERRY1998

Reason for exclusion	Study methodology not reported.

STARR2006

Reason for exclusion	Mean age <18 years old.

STONER2006

Reason for exclusion	Mean age <18 years old.

THOMPSON2011

Reason for exclusion	No age range specified, but any comments on age suggest school age; autism and ADHD data are also analysed together.

VANROEKEL2010

Reason for exclusion	Mean age <18 years old.

VERTE2003

Reason for exclusion	Mean age <18 years old.

VOLKMAR2006

Reason for exclusion	Review with no useable data.

WANG2011

Reason for exclusion	Mean age <18 years old.

WELTERLIN2007

Reason for exclusion	Review with no useable data.

WOLF1998

Reason for exclusion	Mean age <18 years old.

WOODGATE2008

Reason for exclusion	Mean age <18 years old.

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