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1.1 EXPERIENCE OF CARE

1.1.1 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 seen for a 2-hour interview with and without his parents present. In addition, his mother was seen for an extended interview at another time. Subsequently, there were numerous phone 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:** USA
Participants	**Diagnosis:** Autistic (diagnosed at the age of 4 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. • Difficutlies with sibling relationship: Participant described difficulties with his brother, who would lose patience with Jerry's inappropriate behaviour • Experience of residential services: At age 18, 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:** Opportuity 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. Regional Center 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 2-3 hours. **Data analysis method:** Quantitative analysis of Likert scale responses **Country:** USA
Participants	**Diagnosis:** Parents of young adults with autism (diagnoses given by service agencies in California that specialise in identifying and serving individuals with learning disability. Most of these young adults had has this diagnosis since early childhood) **Coexisting conditions:** Young adults with autism had coexisting intellectual 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 moderate to severe levels of intellectual disability)
Outcomes	**Key research question/aim:** Three central questions were addressed: Do parent expectations and actual post-school outcomes vary by diagnostic group?; Do parent knowledge of, and satisfaction in, transition planning differ by diagnostic group?; Do parent 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 5-point Likert scale with 5 being 'strongly agree' and 1 being 'strongly disagree'. 83.3% of parents of young adults with autism 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 and 8.7% were working in the community, 69.5% 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 and 43.3% of parents of young adults with autism responded 'never', 16.7% 'occasionally', 10% 'seriously considered', and 30% 'young adult out of home/wait list'. 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 (e.g. 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 to 15.8% of parents of young adults with cerebral palsy, wanted much more involvement) • Parent worries during transition: In order to assess how much parents worried about various facets if transition, they were asked to rate, on a 5-point Likert scale (with 1 being 'never worry' and 5 being 'often worry'), how much they worried about aspects of transition. 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, in order to assess how parent worried during the period of transition affected more distal aspects of family life, mother 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. Mother 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 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 is also reported for parents of young adults with Downs syndrome, cerebral palsy, and undifferentiated learning disability. However, that data is not extracted here except where a direct comparison was made with the autistic group

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 syndrome diagnosed according to the Gillberg and Gillberg criteria at least 5 years prior to the present study were searched for information concerning background and associated factors. These 100 males (and their parents) were approached for inclusion in the follow-up study, and 76 of the families agreed to participate in this in-depth study **Data collection method:** Diagnostic interviews and questionnaires including the Asperger Syndrome Diagnostic Interview (ASDI) - parent and teenage/adult versions, Leiter-R-Questionnaires, Beck Depression Inventory (BDI), Dysexecutive Syndrome Questionnaire (DEX), WAIS-III, and GAF-scale **Data analysis method:** Quantitative analysis of scale repsonses **Country:** Sweden
Participants	**Diagnosis:** Asperger syndrome **Coexisting conditions:** Not reported **N:** 76 **Age:** 16-36 years (mean: 21.8 years) **Sex:** Asperger syndrome group: Male: 76; Female: 0 **Ethnicity:** Not reported **IQ:** 103.8 (WAIS-III)
Outcomes	**Key research question/aim:** This study aimed to investigate: how young adult males with Asperger 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 syndrome
Focus of the study	Service user and carer experience of autism
Results	• Individuals with Asperger 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%). • This study also found evidence for increased incidence of depression in individuals with autism: The mean BDI (N=71) score was 7.2 which was higher compared to population studies on Swedish adolescent boys (Olsson & von Knorring, 1997, 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, 62 individuals (88%) scored within the range of "no depression" (0-15), 6 (8%) had "dysphoria", 2 (3%) had "depression", and 1 (1%) had "severe depression"
Limitations	1. A qualitative approach may have been more appropriate to addressing the key research aims 2. 12% of the sample (N=7) no longer met diagnostic criteria for ASD
Notes	• 66 individuals had a complete follow-up, i.e. both the male with Asperger syndrome and his parent(s) participated. In a further 10 individuals either the male (N=5) with Asperger 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 through 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 six month period **Data analysis method:** This is not explicit and rather 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 13-year-old boy but that data is 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 can 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 as 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 3. 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 4. 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. 5. Empathy: Jim feels that it is highly unfair to suggest that autistic people lack empathy are are unable to take other's perspectives. Jim describes how he has exerted many efforts to understand and interpret nonautistic 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
Notes	

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". This resulted 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 is not reported
Participants	**Diagnosis:** Autism (Asperger's syndrome) but self-identified **Coexisting conditions:** Not reported **N:** 30 **Age:** Range and mean not reported and data incomplete (data available for N=15 and of these 7% 1-10 years; 40% 11-20 years; 27% 21-30 years; and 27% over 30 years) **Sex:** Data incomplete (data available for N=23 and of these Male: 9; Female: 14) **Ethnicity:** Not reported **IQ:** Not reported
Outcomes	**Key research question/aim:** The purpose of the research was to investigate the portrayal of the salient issues in 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, e.g. understanding that differences shared by other individuals with Asperger's syndrome and not alone; celebration of difference not just acceptance; role as advocates; strength developed as a result of dealing with autism • positive role of the internet, e.g. as a means of support; as a source of information; as a means of addressing stigma • authors refer to disabling environments but this might also be conceptualised as stigmatisation as participants discuss negative experiences with the medialized conceptualization of autism, i.e. "disorder" • opposition to conventional language - this may also be categorised under stigmatisation as 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, e.g. 'aspies', 'neuro-typicals', '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, this data is 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 of the USA supporting a family member/individual with autism who either responded to an investigator developed survey posted on the internet or to a mailed survey. 200 surveys were mailed, of which 92 (46%) were returned. 57 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 (age 18 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 Grays'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:** USA
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 18-48 years (mean: 22.5 years) **Sex:** Sex of carer not reported; for family member with autism: Male: 112; Female: 31 **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:** This study was aimed at exploring the needs of families supporting an adult with autism and the opportunities afforded them in socialization, 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. Again, 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 respect 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 watcher her?"

Although the topic of access to medical care was not addressed in the survey, several 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 socialization: Participants were asked about the socialization 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 (MLDP) and The National Autistic Society (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 1-2 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 precoded 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:** Amongst the individuals 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: Male: 22; Female: 4 **Ethnicity:** Ethnicity of carers not reported; individuals with autism: White N=17; Afro-Carribean N=5; Asian N=3; African N=1 **IQ:** Not reported
Outcomes	**Key research question/aim:** This study had two main research aims. First, it was intended to explore the current support and service provision available to, and used by, families supporting adults with

	autism. The second aim of the study was 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 (cf. 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, 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 utilized,

	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, etc.) • Unhelpful serices: 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: Noone reported any autism-specific information/support being received and only 10 people had been to a health and social services transition planning meeting. Participants found ti hard to say what would have improved the transition to adult services as 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 (i.e. 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. This was particularly in regard to the 13 people with autism who either did not go to college, or 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. 14 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 considered that their son/daughter would benefit from such. • 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 stated that they resided near a day service, but otherwise would not choose to live there. Safety concerns also affected where families were living. One family avoided living on main roads, as their son had no concept of danger or 'road sense'; other participants emphasized needs 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 stated how she felt she did not know her partner any more 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: There was a varied response to service experiences, ranging from some families having positive experiences to families who described their experiences as 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. Having 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 syndrome, for whom there were very few opportunities or activities. This proved problematic for those people with Asperger 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 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, that services would not be suitable and that 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 ASDs known to the MLDP together with 20 adults identified on The National Autistic Society (NAS) database were contacted. Two of these people and three others were currently living in residential care and were included, since families still had substantial contact. 48 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 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? and how has autism affected your life? Other questions were asked in response to participants' responses or for clarification. Over the course of the next 9 months following the conference, correspondence with the participants continued via phone 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:** USA
Participants	**Diagnosis:** Autism (high-functioning autism) **Coexisting conditions:** Not reported **N:** 3 **Age:** 31-61 years (mean: 42.3 years) **Sex:** Male: 2; Female: 1 **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: 1. High-functioning adults with autism identify with their own unique culture, for instance, high-functioning adults with autism 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 2. 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 those supports. 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 3. They have 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 felt that group living could be dehumanising and 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". Unemployemnt 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 Lovaas and applied behaviour analysis (ABA) 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 describe frustration in trying to learn social skills, especially as they relate to dating, and social skills groups are described as a valuable opportunity for making friends and peer support 4. Overall conclusion theme 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

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: (1) What is autism?; (2) What does autism mean to you?; (3) 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 (IPA: 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:** 16-21 years (mean not reported) **Sex:** Male: 6; Female: 3 **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	1. 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 syndrome **Data collection method:** Two self-administered mailed questionnaires (WHOQOL-Brief Version [WHOQOL Group, 1998] and Perceived Support Network Inventory [PSNI; Orritt et al., 1985]) and a semi-structured interview (which addressed level of independence, leisure activities, and social relationships) which lasted 30-130 minutes and was largely conducted in-home (note for N=6

	participants lived in remote areas so phone interviews conducted). To limit bias, all interviews were recorded. A research assistant who was unfamiliar with Asperger syndrome randomly rated 4 (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 (version 11.0) **Country:** Canada
Participants	**Diagnosis:** DMS-IV Asperger syndrome (diagnosed by four paediatric psychiatrist and diagnosis verified by the referring psychiatrist completing the Ehlers & Gillberg [1993] checklist for screening of Asperger syndrome on each participant) **Coexisting conditions:** Not reported (boys diagnosed with psychosis at any time were excluded) **N:** 12 with Asperger syndrome; N=13 without Asperger syndrome (matched on age and WISC-III vocabulary test scores) **Age:** No range reported (means: Asperger syndrome group mean: 20.3 years; without Asperger syndrome group mean: 20.5 years) **Sex:** Male: 25; Female: 0 **Ethnicity:** Authors report that most participants were white **IQ:** Not reported
Outcomes	**Key research question/aim:** The key aims of this study were: to compare the quality of life of young men with and without Asperger 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 syndrome rated their quality of life lower than did young men without Asperger syndrome. Scores were significantly lower for the social domain and for physical health (if unequal variances assumed) • Social support scores: Total PSNI 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	1. 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 criteria was that the internet page had to be written solely by a person with autism without any outside help from others. **Data analysis method:** Thematic analysis approach adopted where the first-hand accounts were reread and studied to see if any common codes related to emotion were found and if a code appeared in three or more accounts then it was categorised as a theme **Country:** Researchers are based in UK, however, country of origin for accounts not reported
Participants	**Diagnosis:** Autism (high-functioning autism), however, this is based on self-identification **Coexisting conditions:** Not reported **N:** 5 (but data only extracted for N=2 as no age reported for the other three participants) **Age:** For the two participants for which data was extracted, one was described as 'middle-aged' and one as 18 years old **Sex:** For the two participants for which data was extracted, one was male and one was 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 category: 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 similiar 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, i.e. 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 is 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 who were 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 ere 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)? and 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 author to identify major themes and then subcategories within the major themes, and then coded by major theme and subcategory **Country:** USA
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:** Male: 0; Female: 135 **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%]). • However, 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 strictured, 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%]; and 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	1. Ethical issues are not adequately considered
Notes	• This paper also reports quantitative data from the questionnaire. However, that data is 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 (Brune, 1990; Connelly & Clandinin, 1990; Clandinin & Conelly, 1999; 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:** Age of mother: 53 years; age of 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 a parent 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 emerged in that 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 • Stigmatization: Linda sometimes feels stigmatized • 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 which talks about the first 18 years of parentlng a child with autism. However, this data is not extracted here as we are interested in the experiences of parenting an adult with autism. 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 [QMI; Norton, 1983] and a parenthood satisfaction scale [Johnston & Mash, 1989]) **Data analysis method:** Quantitative data analysis **Country:** Australia
Participants	**Diagnosis:** DSM-IV Asperger 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 syndrome; N=11 spouse and child have Asperger syndrome; N=49 only child has Asperger syndrome]) **Age:** 29-71 years (mean not reported) **Sex:** Male: 37; Female: 120 **Ethnicity:** Not reported **IQ:** Not reported
Outcomes	**Key research question/aim:** A key research question was: To what extent are relationship satisfaction and the emotional experiences associated with marriage and parenthood different for adults with Asperger syndrome, and/or for their spouses, as compared with the feelings and the experiences of other couples without an autism spectrum disorder?
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 syndrome. However, on the 6-item total satisfaction score there was a statistically significant difference across groups. Neurotypicals with a spouse and a child with Asperger syndrome scored significantly lower than the non-clinical control group parents. Those who had a spouse and child with Asperger syndrome did not differ significantly from those with a child with Asperger syndrome, suggesting that it was the child's and not the spouse's diagnosis that made the difference. Furthermore, respondents with Asperger syndrome who also had a child with Asperger syndrome had total satisfaction scores that equalled the other two groups with a child with Asperger syndrome, further indicating that parental Asperger 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, surprisingly, that the husband's or wife's Asperger 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 syndrome. However, clinical groups did not differ significantly from each other.
Limitations	1. A qualitative approach to this research question would have been interesting
Notes	• Data were also reported for adult attachment style. However, this data was 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 syndrome?; What was the best thing about the group for you?; What was the thing you liked least?; and 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 is 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:** Age at entry into the group was 52 years old **Sex:** Female **Ethnicity:** Not reported **IQ:** Not reported but described in personal account as being top 5-10% in 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 in order 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 decsribed
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 (liej most aimed at adults with autism) is primarily attended by 18-35 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 (4-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, Rodriguez, and Bailey (1999) and involved double-coding of questionnaires **Country:** USA
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:** Male: 0; Female: 108 **Ethnicity:** Latino sample N=20; Non-Latino white sample N=88 **IQ:** Not reported
Outcomes	**Key research question/aim:** To explore how mother experienced coresiding 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 family is a natural setting and peace of mind as positive things about 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 to 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	ORSMOND2007A
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) **Data collection method:** Data was collected via a mailed questionnaire **Data analysis method:** Quantitative analysis of questionnaire data **Country:** USA
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 21-56 years (mean age of siblings: 38.2 years; mean age of brother or sister with autism or Down's syndrome: 34.9 years for autism group and 31.8 years for Down's syndrome group) **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 intellectual disability and for brother or sister with Down's syndrome 100% had intellectual 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 phone 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	1. 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, which provided services to individuals with intellectual 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 phone interview followed by a brief mailed packet of questionnaires **Data analysis method:** Quantitative analysis of questionnaire data **Country:** USA
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 suport?; 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 (e.g. age, behaviour problems), family characteristics (e.g. family size), and sibling resources (e.g. 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 did 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	1. 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. 11 users of the local service for adults with Asperger 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 an intellectual disability or were currently involved in forensic services. **Data collection method:** Semi-structured individual interviews **Data analysis method:** Interpretative phenomenological analysis (IPA: Smith et al., 1999) approach to data collection and analysis **Country:** UK
Participants	**Diagnosis:** Autism (Asperger syndrome) formally diagnosed by the multidisciplinary team at a local service for adults with Asperger syndrome using the DISCO (Wing, 2003), based on Gillberg's (1991) criteria **Coexisting conditions:** Not reported **N:** 10 **Age:** Age at diagnosis: 21-44 years (median: 35 years); Current age: 22-45 years (median: 31 years) **Sex:** Male: 7; Female: 3 **Ethnicity:** Not reported **IQ:** Not reported
Outcomes	**Key research question/aim:** To identify what are the experiences of adults with Asperger 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: 1. Negative life experiences: Feeling not accepted and that they did not fit in with peers 2. 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 syndrome. 3. Beliefs about symptoms of Asperger 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 4. 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 5. 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 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 6. Effect of societal beliefs of Asperger 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	
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 postsecondary 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 2 male (a father and stepfather). Seven were relatives, all parents or stepparents. The other 10 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 which focused on 3 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, 9 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 as 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, 1976; Glaser & Strauss, 1967) **Country:** USA
Participants	**Diagnosis:** DSM autism **Coexisting conditions:** Not reported **N:** 5 **Age:** 20-32 years (mean: 26.8 years) **Sex:** Male: 3; Female: 2 **Ethnicity:** White: 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: 1. 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. 2. Intimate connection: Participants described the importance of establishing a bond with supporters which was based on mutual support and reciprocity 3. 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 4. 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 accomodations - a person with thoughts, emotions, a sense of humour, and a personality. 5. 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 6. Communication: Participanst 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

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 which included people on the autism spectrum, however, the analysis discussed here focuses 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 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 like '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 organizational 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 (but data only extracted for 2 participants) **Age:** Children aged 3-53 years but data only extracted for adults (23 year old and 53 year old) **Sex:** 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 describes regularly writing to newspapers and local

	politicians to question the way in which the media present autism. While, another mother describes 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 in order 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 was reported in this paper for mothers of children aged 3-53 years old. 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 which included people on the autism spectrum, however, the analysis discussed here focuses 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 like '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 2 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 organizational 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 3 participants) **Age:** Children aged 3-53 years but data only extracted for adults (18 year old and two 28 year olds) **Sex:** Female:2; Male:1 **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: • Stigmatization 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 was reported in this paper for parents of children aged 3-53 years old. 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 longitudinal study of aging families of adults with intellectual disability (Krauss & Seltzer, 1999; Seltzer & Kraus, 1989, 1994) **Data collection method:** Multiple interviews conducted with the mothers of adults with autism **Data analysis method:** Quantitative and qualitative data was 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 syndrome in the longitudinal study (N=120) **Country:** USA
Participants	**Diagnosis:** Mothers of adults with autism **Coexisting conditions:** Not applicable **N:** 13 **Age:** In 1988 when study began individuals with autism were 25-40 years old (mean: 31 years) and their mothers ranged in age from 58-70 years (mean: 62 years)

	Sex: Individuals with autism: Male: 8; Female: 5; parents of individuals with autism: Male: 0; Female: 13 **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, e.g. 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 to adults with Down's syndrome: The mothers of adults with autism were much more likely feel as if they are "walking on eggshells" around their adult child than were mothers of adults with Down 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 higher in adults with autism than in those with Down syndrome. Indeed, over 80% of the sample of adults with autism were characterized by their mothers as being withdrawn, whereas only 20% of the adults with Down syndrome behaved in this way • Adults with autism were also less likely to be seen by their mothers as being "good company" (60%) than their counterparts with Down syndrome (94%) • Although both adults with autism and the adults with Down syndrome received about 5 or 6 discrete services, there were 3 types of services more likely to be received by the adults with autism: psychological services, occupational therapy, and nonvocational day services (i.e. 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 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 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 syndrome

	• Siblings of adults with autism versus Down syndrome: Siblings of adults with autism felt less close emotionally to their brother or sister than siblings of adults with Down 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	1. A qualitative approach may have allowed greater insight into the carer experience of autism

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 sample used snowball sampling, starting with parents of adolescents or young adults diagnosed with Asperger 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 mail questionnaire and a web-based questionnaire **Data analysis method:** Quantitative analysis of questionnaire data **Country:** USA
Participants	**Diagnosis:** Asperger syndrome **Coexisting conditions:** 66.7% of participants had additional psychiatric diagnoses **N:** 10 **Age:** Range not reported (mean: 19.7 years) **Sex:** Male: 9; Female: 1 **Ethnicity:** White N: 10 **IQ:** Not reported
Outcomes	**Key research question/aim:** Exploratory study to examine the level of peer victimization, 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	• 50% (N=5) 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 syndrome symptomatology • There was a strong negative correlation between the severity

	of Asperger syndrome symptomatology and current age • There was also a strong positive correlation between current age and: degree of total peer victimization; overt victimization; and relational victimization • Prosocial behaviour was strongly and negatively correlated with age • Severity of Asperger syndrome symptomatology was strongly negatively correlated with degree of total degree of peer victimization, relational victimization, and overt victimization and strongly and positively correlated with prosocial behaviour
Limitations	1. 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

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 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 mail questionnaire and a web-based questionnaire **Data analysis method:** Quantitative analysis of questionnaire data **Country:** USA
Participants	**Diagnosis:** Asperger syndrome **Coexisting conditions:** 66.7% of participants had additional psychiatric diagnoses **N:** 10 **Age:** 15-24 years (mean: 19.7 years) **Sex:** Male: 9; Female: 1 **Ethnicity:** White N: 10 **IQ:** Not reported
Outcomes	**Key research question/aim:** Exploratory study to examine how adolescents and young adults with Asoperger's syndrome perceived their diagnosis and whether they felt stigmatized
Focus of the study	Service user experience of autism
Results	• Asperger syndrome symptomatology was strongly and negatively correlated with level of stigma

Limitations	1. 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, who were aged 25-55 years and who had an autistic child aged 13-21 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 were interviewed 1-4 times with each interview lasting 60-90 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: 41-52 years (mean: 46.6 years); age of children: 13-21 years (mean: 17.8 years) **Sex:** Mothers: all female; children: all 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 describe 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 childrearing attitudes, for instance, one mother feels that her

	husband blames her for overprotecting and spoiling their son. Parents also describe conflict in other family relationships, for instance, one mother describes how her mother-in-law says that it's the mothers fault if a boy is undisciplined • Impact of autism on the carer: Mothers describe how their social life is limited due to family responsibilities • Experience of support: Parents describe how support from external sources can help to inspire self-awareness. For instance, one mother describes 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	SMITH2010A
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 (AAA; 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 (MIDUS I; Brim et al., 2004; Gruenewald et al., 2008) **Data collection method:** Daily diary study - participants were interviewed by telephone for 15-25 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:** USA
Participants	**Diagnosis:** Parents of adolescents and adults with autism **Coexisting conditions:** Not applicable **N:** 96 (compared against a non-clinical group N=230) **Age:** Age of child: Range not reported (mean: 22.4 years); Age of mother: Range not reported (mean: 54.4 years) **Sex:** Sex of child: 23% female; Sex of parent: 100% 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 relative to 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. 19% 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	1. 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. 19 letters were returned and 19 individuals participated in the discussions **Data collection method:** Focus group interviewing (as described by Brotherson, 1994) was the data collection method used. Participants were seen in groups and were asked to write down a question they had about getting along with people and 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 to analyse the collected information from the individuals with autism. This method serves as a vehicle to gather data and insights through the facilitation and interaction of group discussion (Krueger, 1988; Morgan, 1988) **Country:** USA
Participants	**Diagnosis:** Autism **Coexisting conditions:** Not reported **N:** 18 **Age:** 22-49 years (mean: 34 years) **Sex:** Male: 0; Female: 18 **Ethnicity:** White: 16; African-American: 1; Jewish-American: 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

1.1.2 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	Focus on predictive value of participant characteristics rather than experience of care

BAKER2011B

Reason for exclusion	Focus 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	Focus 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	Focus on predictive value of participant characteristics and prevalance 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	Focus 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 is 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	Focus 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 5-23 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	Not specific to autism

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	Focus on predictive value of participant characteristics rather than experience of care

HASTINGS2007

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

KOWALSKI2011

Reason for exclusion	Mean age <18 years old

KRING2010

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

KUHN2006

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

ORSMOND2006

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

ORSMOND2007B

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

ORSMOND2007C

Reason for exclusion	Review with no useable data

PAKENHAM2004

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

SAMIOS2009

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

SAWYER2010

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

SHTAYERMMAN2008

Reason for exclusion	Focus 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	Focus 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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1.2 CASE IDENTIFICATION INSTRUMENTS

1.2.1 Characteristics of included studies

Study ID	ALLISON2012
Bibliographic reference	Allison, C., Auyeung, B. & Baron-Cohen, S. (2012) Towards brief 'red flags' for autism screening: the short autism spectrum quotient and the short quantitative checklist in 1000 cases and 3000 controls. *Journal of the American Academy of Child and Adolescent Psychiatry, 51*, 202-212.
Clinical features and settings	**Recruitment:** Adults with autism recruited from as volunteers from www.autismresearchcentre.com Control data collected at the Cambridge Psychology website fro volunteers www.cambridgepsychology.com **Country:** UK
Participants	**N=** 1287 (Autism = 449; Controls = 838) **Age:** 32.93 (SD 12.20) - 35.62 (SD 13.04) across groups **Sex:** 569 M: 718 F **Ethnicity:** Not stated **Intellectual Ability:** Not stated
Study design	Cross-sectional
Target condition and reference standard(s)	Aspergers or high-functioning autism (AS/HFA) by DSM-IV **Coexiting Conditions:** None reported
Index and comparator tests	**1.Instrument** Autism-Spectrum Quotient (AQ) - 10 item version **2.Reference Standard** DSM-IV criteria **Assessors** **1.Instrument** Self-report **2.Reference Standard** Medic or clinical psychologist
Follow-up	
Index cut-off	6+
Limitations	• Analyses is retrospective and data on AQ was produced post-diagnosis. This might mean the participants were more aware of symptoms and hence answered as expected. • Method of data collection varied between groups (e.g. by post, online etc) • Diagnosis was not validated by the research team and only available data on diagnosis was utilised
Source of funding	Big Lottery Fund, the MRC, the Three Guineas Trust, the CLAHRC
Notes	10 most discriminating items of AQ were:- Attention to detail (Items 5 & 28); Attention Switching (Items 32 & 37); Communication (Items 27 & 31); Imagination (Items 20 & 41); Social (Items 36 & 45)

Study ID	BARONCOHEN2001
Bibliographic reference	Baron-Cohen, S., Wheelwright, S., Skinner, R., *et al*. (2001) The autism-spectrum quotient (AQ): evidence from asperger syndrome/high functioning autism, males and females, scientists and mathematicians. *Journal of Autism and Developmental Disorders, 31*, 5-17.
Clinical features and settings	**Recruitment:** Group 1 Recruited via National Autistic Society (UK), specialist clinics, and advertisements in news letters and WebPages Group 2 recruited from a random sample sent the AQ by post. Group 3 was a random sample of students sent the AQ Group 4 were winners of a Mathematics Olympiad **Country:** UK
Participants	**N=** Total N = 1088 Group 1 ? 58 adults with AS/HFA Group 2 ? 174 randomly selected adults Group 3 ? 840 Cambridge University Students Group 4 ? 16 winners of UK Mathematics Olympiad **Age:** Group 1 ? Mean age = 31.6 years; SD=11.8, range = 16.5 ? 58.3 Group 2 ? Mean age = 37 years, SD = 7.7, range = 18.1-60.0 Group 3 ? Mean age = 21 years, SD = 2.9, range = 17.6 ? 51.1 Group 4 ?Mean age = 17.4 years, SD = 1.0, range = 15.3 ? 18.7 **Sex:** Group 1: 45 M, 13 F Group 2: 76 M, 98 F Group 3: 454 M, 386 F Group 4: 15 M, 1 F **Ethnicity:** Mixed (not specified) **Intellectual Ability:** Group 1 ? Normal range N=15 randomly selected to come to the lab for intellectual assessment using the WAIS-R. Prorated IQ of at least 85 (normal range), mean = 106.5, SD = 8.0 Group 2 ? 15 randomly selected to come to the lab for intellectual assessment using the WAIS-R. IQ mean = 105.8, SD = 6.3 (not significantly different from group 1, p>.5) Group 3 ? Unclear Group 4 ? Unclear
Study design	Cross-sectional (Group 1 - unclear; Group 2/3 - randomly selected; Group 4 - participants in a pre-defined group)
Target condition and reference standard(s)	Aspergers or high-functioning autism (AS/HFA) by DSM-IV **Coexisting conditions:** None reported
Index and comparator tests	**1.Instrument** Autism-Spectrum Quotient (AQ) **2.Reference Standard** DSM-IV criteria **Assessors** **1.Instrument** Self-report **2.Reference Standard** Clinicians
Follow-up	
Index cut-off	32+
Limitations	False negative in controls could not be determined as the majority of

	questionnaires were completed anonymously
Source of funding	MRC, McDonnell-Pew Foundation, and Three Guineas Trust
Notes	

Study ID	BERUMENT1999
Bibliographic reference	Berument, S.K., Rutter, M., Lord, C., *et al*. (1999) Autism screening questionnaire: diagnostic validity. *British Journal of Psychiatry, 175*, 444-451.
Clinical features and settings	**Recruitment:** Postal questionnaire to individuals whom had participated in previous studies **Country:** UK
Participants	**N=**200 (160 = PDD, 40 = non-PDD diagnosis) **Age:** Ranged from 4-40 years across diagnosis. Mean ages for Autism = 23.08 (SD = 8.7), Atypical Autism = 7.03 (SD = 7.01), Asperger syndrome = 17.03 (SD = 4.09) **Sex:** Ratios: Autism 2.8 M: 1 F; other PDD 6.7 M: 1 F **Ethnicity:** Not stated **Intellectual Ability:** Although mental retardation was separated out, IQ ranged from 30 to > 70 across the groups (see paper for more detail) NOTE:- Non-PDD comprised of Conduct disorder (n=10), specific developmental disorder (n=7), mental retardation (n=15, other ?e.g. anxiety (n=8)
Study design	Cross-sectional (individuals had participated in previous studies)
Target condition and reference standard(s)	Diagnosis: ADI/ADI-R PDD:- Autism (n=83), Atypical Autism (n=49), Asperger's syndrome (n=16), Fragile X (n=7), Rett syndrome (n=5) **Coexisting conditions:** None reported
Index and comparator tests	**1.Instrument** Autism Screening Questionnaire(ASQ) **2.Reference Standard** ADI (n=77), ADI-R (n=123) ? measured several years before study **Assessors** **1.Instrument** Unclear - postal questionnaire so might have been parental or self-report **2.Reference Standard** Clinicians (?) NOTE@- ASQ Now named Social Communications Questionnaire (SCQ)
Follow-up	
Index cut-off	Cut-off 15+ (autism vs other diagnosis) Also suggest 22+ (autism vs. other PDDs)
Limitations	
Source of funding	Medical Research Council
Notes	

Study ID	BRUGHA2012
Bibliographic reference	Brugha, T.S., McManus, S., Smith, J., *et al*. (2012) Validating two survey methods for identifying cases of autism spectrum disorder among adults in the community. *Psychological Medicine, 42*, 647-656.
Clinical features and settings	**Recruitment:** Phase 1 data were obtained from a random probability sample of the general population, phase 2 were selected based on high levels of psychosis probability, ASD probability, borderline personality disorder probability and antisocial personality disorder probability **Country:** UK
Participants	**N=** Phase 1=7353; phase 2=618 **Age:** Mean ages not reported but all participants >16 years **Sex:** Not reported **Ethnicity:** Not reported **Intellectual Ability:** Not reported
Study design	Cohort
Target condition and reference standard(s)	**Diagnosis:** Autism **Coexisting conditions:** Potential psychosis, borderline personality disorder, and antisocial personality disorder
Index and comparator tests	**1.Instrument** Autism-Spectrum Quotient-20 item version (AQ-20) **2.Reference Standard** Autism Diagnostic Observation Schedule (ADOS) - Module 4 **Assessors** **1.Instrument** Self-reported postal questionnaire **2.Reference Standard** Research psychologists
Follow-up	Not reported
Cut-off	10
Limitations	AQ-20 tested in general population not in sample where suspicion of autism has already been raised
Source of funding	The National Health Service (NHS) Information Centre for Health and Social Care and the Department of Health, London UK; The National Institute for Health Research (NIHR) and the Department of Health Policy Research Programme, London, UK
Notes	

Study ID	KRAIJER2005
Bibliographic reference	Kraijer, D. & de Bildt A. (2005) The PDD-MRS: an instrument for identification of autism spectrum disorders in persons with mental retardation. *Journal of Autism and Developmental Disorders, 35*, 499-513.
Clinical features and settings	**Recruitment:** Residential institutions and day care centres **Country:** The Netherlands
Participants	**N=** 1230 (408 PDD, 696 non-PDD,126 doubtful PDD) **Age:** Range 2-80 years **Sex:** 719 M, 511 F. **Ethnicity:** Not stated **Intellectual Ability:** Mild to profound intellectual disability
Study design	
Target condition and reference standard(s)	**Diagnosis:** PDD with DSM-III-R **Coexisting conditions:** Mental retardation (mild to profound), additional congenital impairments, Downs syndrome , Fragile X)
Index and comparator tests	**1.Instrument** Pervasive Developmental Disorder in Mentally Retarded Persons (PDD-MRS) **2.Reference Standard** Reported diagnosis base on clinical classification and classification by means of scale **Assessors** **1.Instrument** Unclear **2.Reference Standard** Unclear
Follow-up	
Index cut-off	10+
Limitations	Sub-group analysis revealed poor sensitivity and specificity as well as misclassification rate for those with borderline intellectual functioning Additionally, poor specificity and overall misclassification rate for those who are blind/severe visual impairments
Source of funding	Not stated
Notes	

Study ID	KURITA2005
Bibliographic reference	Kurita, H., Koyama, T. & Osada H. (2005) Autism-spectrum quotient-Japanese version and its short forms for screening normally intelligent persons with pervasive developmental disorders. *Psychiatry and Clinical Neurosciences, 59*, 490-496.
Clinical features and settings	**Recruitment:** Outpatients at the Child Guidance Clinic affiliated with the National Welfare Foundation for Disabled Children **Country:** Japan
Participants	**N=** 240 (25 HPDD, 215 controls) **Age:** HPDD Mean = 24.2 years; Control Mean = 30.4 years **Sex:** 111 M, 130 F. **Ethnicity:** Japanese **Intellectual Ability:** Normal intelligence
Study design	Cross-sectional (Control Group = stratified two-way random sample; HFPDD group = unclear)
Target condition and reference standard(s)	**Diagnosis:** High functioning pervasive developmental disorder (HPDD) (n=13 Asperger syndrome, n=5 autistic disorder, n=7 PDD-NOS) with DSM-IV & ICD-10 (fro PDD-NOS) **Coexisting conditions:** None stated
Index and comparator tests	**1.Instrument** Autism-Spectrum Quotient (AQ) (Japanese version) **2.Reference Standard** DSM-IV clinical diagnosis **Assessors** **1.Instrument** Experienced Psychologist **2.Reference Standard** A team of clinicians
Follow-up	
Index cut-off	Different cut-offs evaluated 50 item AQ cut-off = 26 21 item AQ cut-off = 12 10 item AQ cut-off = 7
Limitations	
Source of funding	Not stated
Notes	

Study ID	VOLKMAR1988
Bibliographic reference	Volkmar, F.R., Cicchetti, D.V., Dykens, E., *et al*. (1988) An evaluation of the autism behavior checklist. *Journal of Autism and Developmental Disorders, 8*, 81-97.
Clinical features and settings	**Recruitment** Participants recruited from university-affiliated school for autistic individuals, a residential facility for mentally retarded and a clinic for children with developmental disabilities **Country:** Sweden
Participants	**N=** 157 (94 autistic, 63 non-autistic) **Age:** Mean age 19.72 years (SD 12.60) **Sex:** 121 M, 36 F. **Ethnicity:** Not stated **Intellectual Ability:** Mean IQ on Stanford Binet (for 147 participants) = 36.80 (SD 24.30). Sample included both profoundly retarded (n=47) and some with average scores (n=14)
Study design	
Target condition and reference standard(s)	**Diagnosis:** Infantile Autism with DSM-III Non-autistic group included mental retardation, atypical pervasive developmental disorder, language disorder, schizophrenia of childhood onset **Coexisting conditions:** None stated
Index and comparator tests	**1.Instrument** Autism Behavior Checklist (ABC) **2.Reference Standard** DSM-III clinical diagnosis (prior to scoring and analysis of ABC) **Assessors** **1.Instrument** Teachers & Parents **2.Reference Standard** Clinicians
Follow-up	
Index cut-off	57+
Limitations	
Source of funding	In part by William T. Grant Foundation, the John Merck Fund, MHCRC Grant 30929, CCRC Grant RR00125, NICHD Grant HD-03008, NIMH Grant MH00418, and Mr Leonard Berger
Notes	

Study ID	WAKABAYASHI2005
Bibliographic reference	Wakabayashi, A., Baron-Cohen, S., Wheelwright, S., *et al*. (2006) The autism-spectrum quotient (AQ) in Japan: a cross-cultural comparison. *Journal of Autism and Developmental Disorders, 36*, 263-270.
Clinical features and settings	**Recruitment:** HFA sample recruited via Japanese Autistic Society, specialist clinics and self-help groups Control Group randomly selected from general population and sent a postal questionnaire Students recruited from 5 universities in or near Tokyo **Country:** Japan
Participants	**N=** 1301 (Group 1: HFA = 57, Group 2: Control = 194, Group 3: Students = 1050 **Age:** Group 1 Mean age = 26.9 years (SD 7.88, range = 18-57) Group 2 Mean age = 33.6 years (SD 6.2, range 22-56) Group 3 Mean age = 20.3 (SD = 1.9, range = 18-41) **Sex:** Group 1 44 M, 13 F; Group 2 103 M, 91 F, Group 3 555 M, 495 F **Ethnicity:** Not stated **Intellectual Ability:** HFA group assumed to have IQ in normal range as had completed high school and some had a university degree
Study design	Cross-sectional (group 1 - unclear; group 2 - randomly, group 3 - unclear)
Target condition and reference standard(s)	**Diagnosis:** High Functioning Autism or Aspergers Syndrome (HFA) with DSM-IV **Coexisting conditions:** None stated
Index and comparator tests	**1.Instrument** Autism-Spectrum Quotient (AQ) **2.Reference Standard** DSM-IV clinical diagnosis **Assessors** **1.Instrument** Self-report **2.Reference Standard** Clinical Reports
Follow-up	
Index cut-off	33+
Limitations	
Source of funding	Medical Research Council
Notes	

Study ID	WOODBURYSMITH2005
Bibliographic reference	Woodbury-Smith, M.R., Robinson, J., Wheelwright, S., *et al.* (2005) Screening adults for Asperger syndrome using the AQ: a preliminary study of its diagnostic validity in clinical practice. *Journal of Autism and Developmental Disorders, 35*, 331-335.
Clinical features and settings	**Recruitment:** Cambridge Lifespan Asperger Syndrome Service **Country:** UK
Participants	**N=** 100 patient referrals **Age:** Median age = 32 years, range 18-69 **Sex:** 4:1 M/F ratio **Ethnicity:** Not stated **Intellectual Ability:** Not stated - but people with intellectual disabilities were excluded
Study design	cross-sectional (consecutive sample)
Target condition and reference standard(s)	**Diagnosis:** Asperger Syndrome or Autism with DSM-IV **Coexisting conditions:** None stated
Index and comparator tests	**1.Instrument** Autism-Spectrum Quotient **2.Reference Standard** DSM-IV clinical interview **Assessors** **1.Instrument** Self-report **2.Reference Standard** Two clinicians
Follow-up	
Index cut-off	26+
Limitations	Clinicians not blind to AQ score as AQ is used as part of clinical practice
Source of funding	The Three Guineas Trust supports the Cambridge Lifespan Asperger Syndrome. SBC and SW supported by Medical Research Council
Notes	

1.2.2 Characteristics of excluded studies

FERRITER2001

Reason for exclusion	No available data and the paper is a brief report with not enough information about the study. No access to full paper.

GARFIN1988

Reason for exclusion	No sensitivity and specificity data available.

MESIBOV1989

Reason for exclusion	No sensitivity and specificity data, reference standard is not adequate, age of sample (15.9 years) is outside the scope.

NYLANDER2001

Reason for exclusion	The sensitivity and specificity data in unreliable. Not all participants had a clear diagnosis.

1.2.3 References of excluded studies

Ferriter, M., Hare, D., Bendall, P., *et al*. (2001) Brief report: assessment of a screening tool for autistic spectrum disorders in adult population. *Journal of Autism and Developmental Disorders, 3*, 351-353.

Garfin, D. G. & McCallon, D. (1988) Validity and reliability of the childhood autism rating scale with autistic adolescents. *Journal of Autism and Developmental Disorders, 18*, 376-378.

Mesibov, G. B., Schopler, E., Schaffer, B., *et al*. (1989) Use of the childhood autism rating scale with autistic adolescents and adults. *Journal of American Academy of Child and Adolescent Psychiatry, 28*, 538-541.

Nylander, L. & Gillberg, C. (2001) Screening for autism spectrum disorders in adult psychiatric out-patients: a preliminary report. *Acta Psychiatrica Scandinavica, 103*, 428-434.

1.3 ASSESSMENT INSTRUMENTS

1.3.1 Characteristics of included studies

Study ID	BARONCOHEN2005
Bibliographic reference	Baron-Cohen, S., Wheelwright, S., Robinson, J., *et al*. (2005) The Adult Asperger Assessment (AAA): a diagnostic method. *Journal of Autism and Developmental Disorders, 35*, 807-819.
Clinical features and settings	**Recruitment:** Patients attending the Cambridge Lifespan Asperger Syndrome Service (CLASS) **Country:**UK
Participants	**N=** 42 **Age:** Mean 34.1 years (SD = 10.6 years) **Sex:** Ration = 9:1 M:F (28 M: 3 F) **Ethnicity:** **Intellectual Ability:** Normal range
Study design	Cross sectional
Target condition and reference standard(s)	**Diagnosis:** DSM-IV Asperger syndrome & High-Functioning Autism **Coexisting conditions:** None stated
Index and comparator tests	**1.Instrument** Adult Asperger Assessment (AAA) **2.Reference Standard** DSM-IV criteria **Assessors** **1.Instrument** Clinical psychologist or consultant psychiatrist & a clinician psychologist **2.Reference Standard** Clinical psychologist or consultant psychiatrist & a clinician psychologist
Follow-up	
Limitations	• Same assessors completed the AAA and DSM-IV criteria
Source of funding	Three Guineas Trust; Medical Research Council; Lifespan Healthcare NHS Trust; Cambridgeshire and Peterborough Mental Health Partnership NHS Trust
Notes	• Each patient accompanied by at least one parent as an informant • Patients also completed the Autism-Spectrum Quotient (AQ) and the Empathy Quotient (EQ)

Study ID	BRUGHA2012
Bibliographic reference	Brugha, T.S., McManus, S., Smith, J., *et al*. (2012) Validating two survey methods for identifying cases of autism spectrum disorder among adults in the community. *Psychological Medicine, 42*, 647-656.
Clinical features and settings	**Recruitment:** Participants were recruited from a cohort general population screening study using the AQ-20 **Country:** UK
Participants	**N=** 199 participants had both an ADOS score and a vignette assessment **Age:** Not reported but all participants >16 years **Sex:** Not reported **Ethnicity:** Not reported **Intellectual Ability:** Not reported, but assumption that IQ>70 as screened using self-report postal questionnaire (AQ-20)
Study design	Cohort
Target condition and reference standard(s)	**Diagnosis:** Autism (based on case vignette ratings) **Coexisting conditions:** Not reported
Index and comparator tests	**1.Instrument** Autism Diagnostic Observation Schedule (ADOS)-Module 4 **2.Reference Standard** Case vignette ratings **Assessors** **1.Instrument** Research psychologists **2.Reference Standard** Clinicians
Follow-up	Not reported
Limitations	Case vignette ratings are not gold standard for diagnosis
Source of funding	The National Health Service (NHS) Information Centre for Health and Social Care and the Department of Health, London, UK; The National Institute for Health Research (NIHR) and the Department of Health Policy Research Programme, London, UK
Notes	

Study ID	DZIOBEK2006
Bibliographic reference	Dziobek, I., Fleck, S., Kalbe, E., *et al*. (2006) Introducing MASC: a Movie for the Assessment of Social Cognition. *Journal of Autism and Developmental Disorders, 36*, 623-636.
Clinical features and settings	**Recruitment:** Asperger syndrome group from local support groups or referred by specialist clinician Matched control group from volunteers participating in ongoing studies of normal aging and dementia **Country:** USA
Participants	**N=** AS N = 21 (2 were excluded post diagnosis); Controls N = 20 **Age:** AS group: mean = 41.6 years (SD = 10.4, range = 25-62 years) Matched control group: mean = 39.9 (SD = 12.6 years) **Sex:** AS group: 19 = M, 2 = F Matched control group: 18 = M, 2 = F **Ethnicity:** Not stated **Intellectual Ability:** AS group = WAIS IQ Score of 122 (SD = 6.1, range = 111-134) Matched control group = WAIS IQ Score of 124 (SD = 6.3, range = 108-139)
Study design	Cross-sectional
Target condition and reference standard(s)	**Diagnosis:** DSM-IV Asperger syndrome **Coexisting conditions:** None stated
Index and comparator tests	**1.Instrument** Movie for the Assessment of Social Cognition (MASC) **2.Reference Standard** DSM-IV diagnosis; 16/19 also had the ADI-R as parental informants were available (assessed from taped interview) **Assessors** **1.Instrument** Trained tester **2.Reference Standard** One psychiatrist and two psychologists
Follow-up	
Limitations	
Source of funding	Not stated
Notes	• Participants underwent medical, neurologic, psychiatric and neurological examinations to exclude any with conditions that could significantly impact of functional ability • Autism-Spectrum Quotient (AQ), Reading the Mind in the Eyes Test, and a basic emotion recognition task were also administered • An extensive neurological test battery was administered to assess memory, attention and executive functions

Study ID	GILLBERG2001
Bibliographic reference	Gillberg, C., Gillberg, C., Rastam, M., *et al*. (2001) The Asperger Syndrome (and High Functioning Autism) Diagnostic Interview (ASDI): a preliminary study of a new structured clinical interview. *Autism, 5*, 57-66.
Clinical features and settings	**Recruitment:** Unclear **Country:** Sweden
Participants	**N=** 24 **Age:** 6 – 55 years **Sex:** 18 = M, 6= F. **Ethnicity:** Not stated **Intellectual Ability:** Not stated
Study design	Cross-sectional
Target condition and reference standard(s)	**Diagnosis:** DSM-IV Asperger syndrome **Coexisting conditions:** N = 17 with neuropsychiatric disorder
Index and comparator tests	**1.Instrument** Asperger Syndrome (and High Functioning Autism) Diagnostic Interview (ASDI) **2.Reference Standard** DSM-IV diagnosis **Assessors** **1.Instrument** Two expert neuropsychiatrists (one scoring ASDI and the other observing) **2.Reference Standard** Two neuropsychiatrists or one neuropsychiatrist and one neuropsychologist
Follow-up	
Limitations	
Source of funding	Swedish Medical Research Council (grant no. K2000-21X-11251-06C) State grants under the LUA agreement
Notes	

Study ID	LORD1997
Bibliographic reference	Lord, C., Pickles, A., McLennan, J., *et al*. (1997) Diagnosing autism: analyses of data from the Autism Diagnostic Interview. *Journal of Autism and Developmental Disorders, 27*, 501-517.
Clinical features and settings	**Recruitment:** Data & referrals from eight sites (Institute of Psychiatry, University of London; Greensboro-High Point TEACH Center; John Hopkins University; Glenrose Hospital, Edmonton, Alberta; INSERM research team, France; University of Pittsburgh Clinic for Social Dysfunction; Emory University **Country:** USA, UK, France
Participants	**N=**330 **Age:** Nonverbal participants mean age = 14.5 years (SD = 7.2, range = 3-37 years) Verbal participants mean age = 21.4 years (SD = 6.9, range = 12-40 years) **Sex:** Not stated **Ethnicity:** Not stated **Intellectual Ability:** Nonverbal group IQ = 56 (SD = 17.9; range = 39-84) Verbal group IQ = 94.8 (SD = 14.3, range = 80-144)
Study design	Cross sectional
Target condition and reference standard(s)	**Diagnosis:** DSM-III-R Autism, PDD-NOS **Coexisting conditions:** None stated
Index and comparator tests	**1.Instrument** Autism Diagnostic Interview (ADI) **2.Reference Standard** DSM-III-R diagnostic criteria **Assessors** **1.Instrument Unknown** – scores on the instrument obtained from records **2.Reference Standard** Clinical judgement of principle investigator/ senior research associates
Follow-up	
Limitations	• Scores on the ADI were obtained by unknown raters
Source of funding	National Institute of Mental Health K05 MH01196, MH19726 Grant from the John D. And Catherine T. MacArthur Foundation in association with the DSM-IV Field Trials to the first author
Notes	

Study ID	LORD2000
Bibliographic reference	Lord, C., Risi, S., Lambrecht, L., *et al*. (2000) The Autism Diagnostic Observation Schedule-Generic: a standard measure of social and communication deficits associated with the spectrum of autism. *Journal of Autism and Developmental Disorders, 30*, 205-223.
Clinical features and settings	**Recruitment:** Referrals to the Developmental Disorders Clinic, University of Chicago **Country:** USA & UK
Participants	**N=** 45 (20 participants used in reliability analyses) **Age:** Autism group = 18.65 years (SD = 7.79); PDDNOS group = 21.59 years (SD = 8.56); Nonspectrum group = 19.11 years (SD = 6.27) **Sex:** 37 M, 8 F **Ethnicity:** Not stated **Intellectual Ability:** Verbal IQ:- Autism group = 99.94 (22.29); PDDNOS group = 105.5 (21.46); Nonspectrum group = 99.73 (26.69) Nonverbal IQ:- Autism group = 94.06 (28.22); PDDNOS group = 105.21 (21.82); Nonspectrum group = 103.8 (27.48)
Study design	Cross-sectional
Target condition and reference standard(s)	**Diagnosis:** Autism using Autism Diagnostic Observation Schedule-Generic (ADOS-G) **Coexisting conditions:** None stated
Index and comparator tests	**1.Instrument** Autism Diagnostic Observation Schedule-Generic (ADOS-G) – Module 4 **2.Reference Standard** Clinical Interview (included use of the ADI-R) **Assessors** **1.Instrument** Twelve experienced examiners **2.Reference Standard** Clinical psychologist and clinical psychiatrist
Follow-up	
Limitations	
Source of funding	Not stated
Notes	• Assessment conducted live and via videotape

Study ID	MATSON2007A
Bibliographic reference	Matson, J. L., Boisjoli, J. A., Gonzalez, M. L., *et al*. (2007) Norms and cut off scores for the autism spectrum disorders diagnosis for adults (ASD-DA) with intellectual disability. *Research in Autism Spectrum Disorders, 1*, 330-338.
Clinical features and settings	**Recruitment:** Residents from two developmental centres located in the Southeastern region of the United States **Country:** USA
Participants	**N=** 232 **Age:** 20-80 years **Sex:** Not stated **Ethnicity:** Not stated **Intellectual Ability:** Intellectual disability:- Profound N = 176; Severe N = 33; Moderate N = 12; Mild N = 1; Unspecified N = 10
Study design	Cross sectional
Target condition and reference standard(s)	**Diagnosis:** DSM-IV/ICD-10 ASD **Coexisting conditions:** With/without intellectual disabilities (profound to mild)
Index and comparator tests	**1.Instrument** Autism Spectrum Disorders Diagnosis for Adults with intellectual disability (ASD-DA) **2.Reference Standard** DSM-IV/ICD-10 diagnosis criteria list of symptoms **Assessors** **1.Instrument** Clinical psychology doctorate students **2.Reference Standard** Clinical psychology doctorate students
Follow-up	
Limitations	
Source of funding	Not stated
Notes	

Study ID	MATSON2007B
Bibliographic reference	Matson, J. L. & Wilkins, J. (2007) Reliability and factor structure of the Autism Spectrum Disorders – Diagnosis Scale for Intellectually Disabled Adults (ASD-DA). *Journal of Developmental and Physical Disabilities, 19*, 565-577.
Clinical features and settings	**Recruitment:** Residents from two developmental centres in central or south Louisiana **Country:** USA
Participants	**N=** 192 **Age:** Autism group mean age = 48.4 years (SD=10.9, range = 20 – 78 years) Control group mean age = 53.9 years (SD=13.5, range = 27 – 88 years) **Sex:** 109 M, 83 F **Ethnicity:** Percent Caucasian:- Autism group = 72%; Control group = 72.9% **Intellectual Ability:** Intellectual disability:- Profound N = 142; Severe N = 28; Moderate N = 13; Mild N = 1 Percent profound intellectual disability:- Autism group = 88.8%; Control group = 52.9%
Study design	Cross sectional
Target condition and reference standard(s)	**Diagnosis:** ASD (Autism or PDD-NOS) **Coexisting conditions:** Intellectual disabilities
Index and comparator tests	**1.Instrument** Autism Spectrum Disorders – Diagnosis Scale for Intellectually Disabled Adults (ASD-DA) **2.Reference Standard** DSM-IV-TR and ICD-10 diagnostic criteria **Assessors** **1.Instrument** PhD students in Clinical Psychology **2.Reference Standard** PhD students in Clinical Psychology
Follow-up	
Limitations	
Source of funding	Not stated
Notes	

Study ID	MATSON2008
Bibliographic reference	Matson, J. L., Wilkins, J., Boisjoli, J. A., *et al*. (2008) The validity of the autism spectrum disorders-diagnosis for intellectually disabled adults (ASD-DA). *Research in Developmental Disabilities, 29*, 537-546.
Clinical features and settings	**Recruitment:** Residents of developmental centres **Country:** USA
Participants	**N=**307 **Age:** Mean age = 55 years, range = 16-88 years **Sex:** 168M, 139F **Ethnicity:** Percentage of Caucasians Autism Group 78.2%; Control group 76% **Intellectual Ability:** N=235 profound LDs, N=40 severe LDs, N=16 moderate LDs, N=2 mild LDs, N=14 unspecified LDs
Study design	Cross sectional
Target condition and reference standard(s)	**Diagnosis:** DSM-IV-TR or ICD-10 ASD **Coexisting conditions:** Anxiety disorders, depressive disorder, pica, stereotypic movement disorder
Index and comparator tests	**1.Instrument** Autism Spectrum Disorders-diagnosis for intellectually Disabled Adults (ASD-DA) **2.Reference Standard** DSM-IV-TR or ICD-10 clinical diagnosis **Assessors** **1.Instrument** PhD level clinical psychology student **2.Reference Standard** PhD level clinical psychology student
Follow-up	
Limitations	
Source of funding	Not stated
Notes	• Direct care staff were interviewed not adults with autism

Study ID	RITVO2008
Bibliographic reference	Ritvo, R. A., Ritvo, E. R., Guthrie, D., *et al*. (2008) A scale to assist the diagnosis of autism and asperger's disorder in adults (RAADS): a pilot study. *Journal of Autism and Developmental Disorders, 38*, 213-223.
Clinical features and settings	**Recruitment:** Patients known to clinicians, national autism and Asperger's Disorder support group, referrals from autism diagnostic clinics, volunteers for advertisements on websites for adults with Asperger's Disorder **Country:** USA
Participants	**N=** 94 **Age:** Mean age = 38 years **Sex:** 47 M, 47 F **Ethnicity:** Not stated **Intellectual Ability:** 17% high school education; 83% college education
Study design	Cross sectional
Target condition and reference standard(s)	**Diagnosis:** Aspergers syndrome or autistic disorder **Coexisting conditions:** None stated
Index and comparator tests	**1.Instrument** Ritvo Autism and Asperger's Diagnostic Scale (RAADS) **2.Reference Standard** DSM-IV-TR clinical diagnosis **Assessors** **1.Instrument** Self-completed **2.Reference Standard** Two psychiatrists
Follow-up	
Limitations	• Clinicians not blind to participants prior diagnosis
Source of funding	Not stated
Notes	

Study ID	RITVO2011
Bibliographic reference	Ritvo, R. A., Ritvo, E. R., Gutherie, D., *et al.* (2011) The Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-R): a scale to assist the diagnosis of autism spectrum disorder in adults: an international validation study. *Journal of Autism and Developmental Disorders, 41*, 1076-1089.
Clinical features and settings	**Recruitment:** From nine English speaking centres on three continents **Country:** English speaking countries
Participants	**N=** 779 **Age:** Mean age 30.81 – 42.04 across diagnostic groups **Sex:** 394 M, 386 F **Ethnicity:** Not stated **Intellectual Ability:** IQ of 80 and above
Study design	Cross sectional
Target condition and reference standard(s)	**Diagnosis:** DSM-IV-TR ASD (Asperger's syndrome or autistic disorder) **Coexisting conditions:** None stated
Index and comparator tests	**1.Instrument** Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-R) **2.Reference Standard** DSM-IV-TR Clinical diagnosis **Assessors** **1.Instrument** Self-completed **2.Reference Standard** Psychiatrist or licensed psychologist
Follow-up	
Limitations	
Source of funding	Not stated
Notes	

1.3.2 Characteristics of excluded studies

BOLTE2008

Reason for exclusion	Validated in children

BUITELAAR1999

Reason for exclusion	8.7% of the sample were adults

CAPONE2005

Reason for exclusion	Validated in children

GARFIN1988

Reason for exclusion	Validated in children

HELLINGS2005

Reason for exclusion	Validated in children

LECAVALIER2006

Reason for exclusion	Validated in children

LECONTEUR1989

Reason for exclusion	Validated in children

PROSSER1998

Reason for exclusion	16% of the sample diagnosed with Autism which is too low

READING2007

Reason for exclusion	Validated in children

ROJAHN2001

Reason for exclusion	4.4% with autism which is too low

STURMEY1995

Reason for exclusion	Psychometric data not provided

1.3.3 References of excluded studies

Bolte, S., Poustka, F. & Constantino, J. N. (2008) Assessing autistic traits: cross-cultural validation of the social responsiveness scale (SRS). *Autism Research, 1*, 354-363.

Buitelaar, J. K., Van der Gaag, R., Klin, A., *et al*. (1999) Exploring the boundaries of pervasive developmental disorder not otherwise specified: analyses of data from the DSM-IV autistic disorder field trial. *Journal of Autism and Devlopmental Disorders, 29*, 33-43.

Capone, G. T., Grados, M. A., Kaufmann, W. E., *et al*. (2005) Down syndrome and comorbid autism-spectrum disorder: characterization using the aberrant behavior checklist. *American Journal of Medical Genetics, 134A*, 373-380.

Garfin, D. G. & McCallon, D. (1988) Validity and reliability of the childhood autism rating scale with autistic adolescents. *Journal of Autism and Developmental Disorders, 18*, 376-378.

Hellings, J. A., Nickel, E. J., Weckbaugh, M., *et al*. (2005) The overt aggression scale for rating aggression in outpatient youth with autistic disorder: preliminary findings. *Journal of Neuropsychiatry and Clinical Neurosciences, 17*, 29-35.

Lecavalier, L. & Aman, M. G. (2006) Validity of the autism diagnostic interview-revised. *American Journal of Mental Retardation, 111*, 199-215.

Le Couteur, A. & Rutter, M. (1989) Autism diagnostic interview: a standardized investigator-based instrument. *Journal of Autism and Devlopmental Disorders, 19*, 363-387.

Prosser, H., Moss, S., Costello, H., *et al*. (1998) Reliability and validity of the mini PAS-ADD for assessing psychiatric disorders in adults with intellectual disability. *Journal of Intellectual Disability Research, 42*, 264-272.

Reading, S. & Richie, C. (2007) Documenting changes in communication behaviours using a structured observation system. *Child Language Teaching and Therapy, 23*, 181-200.

Rojahn, J., Matson, J. L., Lott, D., *et al*. (2001) The behaviour problems inventory: an instrument for the assessment of self-injury, stereotyped behaviour, and aggression/destruction in individuals with developmental disabilities. *Journal of Autism and Developmental Disorders, 31*, 577-588.

Sturmey, P., Burcham, K. J. & Perkins, T. S. (1995) The reiss screen for maladaptive behaviour: its reliability and internal consistencies. *Journal of Intellectual Disability Research, 39*, 191-195.

1.4 PSYCHOSOCIAL INTERVENTIONS

1.4.1 Characteristics of included studies

Study ID	BATHAEE2001
Bibliographic reference	Bat-haee, M.A. (2001) A longitudinal study of active treatment of adaptive skills of individuals with profound mental retardation. *Psychological Reports, 89*, 345-354.
Methods	**Allocation:** Not applicable - no control group **Matching:** Not applicable - no control group **Blindness:** Non-blind **Setting:** Residential **Raters:** Psychologists **Country:** USA
Participants	**Diagnosis:** Intellectual disability (DSM-IV) **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Slosson Intelligence Test **N:** 59 for first 5 year comparison, 51 for next 5 year comparison **Age:** 32-75 years (mean: 44.4 years) **Sex:** For first 5 year comparison: Male: 14; Female: 45; for second five year comparison: Male:12; Female: 39 **Ethnicity:** Not reported **IQ:** Mental age = 2-17 months **Inclusion criteria:** Adults with intellectual disabilities living in group homes
Interventions	1. Active treatment (N=59 or N=51) **Duration:** **Intervention:** 10 years **Follow-up:** 10 years
Outcomes	Data on participants' adaptive skills were taken from their records and were done using the Behaviour Maturity Checklist II-1978 which examines six general areas of adaptive skills (dressing, grooming, eating, toileting, language, and social interaction). Data were extracted for the toileting subscale.
Study Design	Observational (before-and-after study)
Source of funding	Not reported
Limitations	1. No control group 2. Little detail given about nature of intervention 3. Efficacy data cannot be extracted
Notes	• This is longitudinal 10-year study examining changes in a number of adaptive skills over consecutive 5-year periods. Data is extracted for toileting over both periods as this adaptive skill continues to improve.

Study ID	BENSON1986
Bibliographic references	Benson, B.A., Rice, C.J. & Miranti, S.V. (1986) Effects of anger management training with mentally retarded adults in group treatment. *Journal of Consulting and Clinical Psychology, 54*, 728-729.
Methods	**Allocation:** Not applicable - no control group **Matching:** Not applicable - no control group **Blindness:** Non-blind **Setting:** Community **Raters:** Self-report, 2 students were trained to rate role-play responses, and two supervisors from subject's vocational training centre **Country:** USA
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** Not given **Qualifying Diagnostic Assessment:** Level of intellectual functioning taken from training centre records and based on the American Association on Mental Deficiency system **N:** 54 **Age:** 17-57 years (mean: 32 years) **Sex:** Male: 37; Female: 17 **Ethnicity:** Black N=28, white N=23, Hispanic N=3 **IQ:** Not reported, mildly or moderately mentally retarded **Inclusion criteria:** Participants were from vocational training centres for the developmentally disabled and acknowledged that losing their temper at work was a problem
Interventions	1. CBT anger management training, including a relaxation group, self-instruction group, problem solving condition, and a combined condition beginning with relaxation training, followed by self-instruction, and then by problem solving (N=54) **Duration:** **Intervention:** 12 weekly 90-minute sessions **Follow-up:** 19 weeks
Outcomes	The primary outcome was anger management. Outcome measures were a self-report Anger Inventory (AI), a Conflict Situations Test (CST) which provides mean aggression scores for Think and Do responses separately, ratings of videotaped role-plays of anger-arousing situations, and supervisor ratings on an aggressive behaviour rating scale. Data were extracted for aggressive gestures on the videotaped roleplay test.
Study Design	Observational (before-and-after)
Source of funding	Not reported
Limitations	1. No control group 2. Sample sizes in the different CBT groups do not allow for comparison 3. Efficacy data could not be extracted
Notes	• Data extracted for the gestures dimension of the videotaped roleplay test. Results suggestive of significant pre-to-post-test difference but difference not maintained at follow-up 4-5 weeks later

Study ID	BOTSFORD2004
Bibliographic reference	Botsford, A.L. & Rule, D. (2004) Evaluation of a group intervention to assist aging parents with permanency planning for an adult offspring with special needs. *Social Work, 49*, 423-431.
Methods	**Allocation:** Randomised **Matching:** Matched on age and marital status **Blindness:** Non-blind **Setting:** Not reported **Raters:** Graduate student **Country:** USA
Participants	**Diagnosis:** ASD **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Not reported **N:** 27 **Age:** Mothers: 49-82 years (mean: 64.2); Children: 23-49 years (mean: 33.7) **Sex:** Male: 0; Female: 27 **Ethnicity:** White N=26 **IQ:** Not reported **Inclusion criteria:** To participate in the study mothers had to have a son or daughter who was at least 23 years old, their offspring were identified as having intellectual disability, the offspring lived with the mother, and the mother had not made appreciable permanency plans for the offspring.
Interventions	1. Psychoeducational permanency planning group intervention (N=13) which provided opportunities for parents to express concerns about future of their offspring, increase participants' awareness and knowledge about options and resources, identify obstacles to planning, strengthen relationships with professionals, and problem solve on specific planning issues and concerns. Group sessions included both parent discussion and interaction, and speakers on residential, financial and legal resources followed by group discussion. 2. Control group (N=14) **Duration:** **Intervention:** 6 weeks **Follow-up:** 6 weeks
Outcomes	Primary outcome was mothers' awareness and knowledge of planning issues including knowledge and awareness about planning, competence and confidence to plan, appraisals of the planning process, intermediate planning behaviours, and residential and legal planning. Interviews with mothers were coded using standardized (including Heller & Factor's [1991] Community Resources Scale) and original scales and variables were clustered into the five categories listed previously.
Study Design	RCT
Source of funding	Not reported
Limitations	1. Non-blind allocation, administration and assessment 2. Randomization methods uinclear

	3. Small sample size 4. Group N not clear, assumed N=13 in experimental and N=14 in control but not clear that this assumption is correct 5. Not clear that control group received care apart from intervention 6. Indirect as extrapolating from adults with intellectual disability 7. Relatively short duration of follow-up
Notes	• One mother terminated participation because of her daughter's medical crisis

Study ID	ELLIOTT1991
Bibliographic reference	Elliott, R.O. Jr., Hall, K.L. & Soper, H.V. (1991) Analog language teaching versus natural language teaching: generalization and retention of language learning for adults with autism and mental retardation. *Journal of Autism and Developmental Disorders, 21*, 433-447.
Methods	**Allocation:** Non-randomised **Matching:** Matched according to vocabulary scores. Groups did not significantly differ in mental age equivalents, chronological ages, and total duration of stays in residential treatment facilities **Blindness:** Blind observers for 40/120 assessments to score rater reliability **Setting:** Residential **Raters:** Trained evaluators **Country:** USA
Participants	**Diagnosis:** ASD **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** DSM-III-R **N:** 23 **Age:** 17-37 years (mean: 26 years) **Sex:** Male: 19; Female: 4 **Ethnicity:** Not reported **IQ:** Not reported - severe to profound cognitive delays, average estimated mental age equivalent = 3.3 years (range 1.7-5.1) **Inclusion criteria:** Clients of residential treatment program with autism and severe to profound cognitive delays. All participants were in good health. None had significant sensory or motor disabilities or displayed behaviours likely to preclude regular attendance at scheduled training sessions
Interventions	1. Analog language teaching which attempts to evoke imitative responses through use of successive trials (N=23, but halved for data analysis as this is a crossover study) 2. Natural language teaching which allows participant to select items which determine order of presentation (N=23, but halved for data analysis as this is a crossover study) **Duration:** **Intervention:** 1 month for each intervention **Follow-up:** 3 months
Outcomes	Number of nouns generalized
Study Design	Quasi-experimental (crossover)

Source of funding	Not reported
Limitations	1. Small sample size 2. No waiting-list or attention-placebo control group 3. Study designed to compare two ABA techniques and not to examine the overall efficacy of ABA training for language acquisition
Notes	

Study ID	ERGUNERTEKINALP2004
Bibliographic reference	Ergüner-Tekinalp, B. & Akkök, F. (2004) The effects of a coping skills training program on the coping skills, hopelessness, and stress levels of mothers of children with autism. *International Journal for the Advancement of Counselling, 26*, 257-269.
Methods	**Allocation:** Non-randomised **Matching:** No matching **Blindness:** Non-blind **Setting:** Education **Raters:** Self-completed questionnaires **Country:** Turkey
Participants	**Diagnosis:** ASD **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Not reported **N:** 20 **Age:** Mothers: 29-52 years (means: experimental group: 42.4; control group: 39.1); Children: 11-19 years (means: experimental group: 15.2 years; control group: 14) **Sex:** Male: 0; Female: 20 **Ethnicity:** Not reported **IQ:** Not reported **Inclusion criteria:** Not reported
Interventions	1. Coping skills training programme (N=10) consisting of eight group sessions which used techniques of instruction, discussion, sharing and application of techniques and covered understanding stress and coping, general coping strategies, problem solving, relaxation training, positive thinking, and social support. 2. Control group (N=10). After completion of experimental training program the control group were provided with written information about skills and techniques used in the program. **Duration:** **Intervention:** 4 weeks (twice-weekly 1.5 hour sessions) **Follow-up:** 4 weeks
Outcomes	Primary outcomes were parental stress as measured by The Questionnaire on Resources and Stress (QRS; Holroyd, 1987); parental coping skills as measured by The Coping Skills Strategy Indicator (CSI; Amirkhan, 1990); and parental depression (as measured by the Beck Hopelessness Scale (BHS; Beck et al., 1974)
Study Design	Quasi-experimental (parallel groups)
Source of funding	Not reported

Limitations	1. Group allocation not randomised 2. Efficacy data cannot be extracted 3. Small sample size 4. Short duration of follow-up
Notes	

Study ID	FELDMAN1999
Bibliographic reference	Feldman, M.A., Ducharme, J.M. & Case, L. (1999) Using self-instructional pictorial manuals to teach child-care skills to mothers with intellectual disabilities. *Behavior Modification, 23*, 480-497.
Methods	**Allocation:** Not applicable - no control group **Matching:** Not applicable - no control group **Blindness:** Non-blind **Setting:** Community **Raters:** Not reported **Country:** Canada
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** WAIS-R **N:** 10 **Age:** 19-39 years (mean: 28 years) **Sex:** Male: 0; Female: 10 **Ethnicity:** Not reported **IQ:** 71-76 (mean: 73.8) **Inclusion criteria:** Not reported
Interventions	1. Self-instructional pictorial manuals to teach child-care skills (N=10) **Duration:** **Intervention:** Until mothers reached training criterion of 80% or higher for 2 sessions **Follow-up:** 3 years
Outcomes	Target child-care behaviour checklist
Study Design	Observational (before-and-after)
Source of funding	Ontario Mental Health Foundation and the Ontario Ministry of Community and Social Services Research Grants Program
Limitations	1. Small sample size 2. No control group 3. Duration of intervention not reported 4. Efficacy data cannot be extracted
Notes	

Study ID	GARCIAVILLAMISAR2000
Bibliographic reference	García-Villamisar, D., Ross, D. & Wehman, P. (2000) Clinical differential analysis of persons with autism in a work setting: a follow-up study. *Journal of Vocational Rehabilitation, 14*, 183-185.
Methods	**Allocation:** Non-randomised **Matching:** Matched on age, total score on Childhood Autism Rating Scale (CARS), and degree of intelligence **Blindness:** Non-blind **Setting:** Community for supported work group **Raters:** First author conducted interviews with caretakers, therapists, and families **Country:** Spain & Germany
Participants	**Diagnosis:** DSM IV ASD **Coexisting conditions:** N=22 epilepsy **Qualifying Diagnostic Assessment:** Not reported **N:** 51 **Age:** Range not reported (means: sheltered workshop group mean: 21.07 years; supported work group mean: 21.64 years) **Sex:** Male: 39; Female: 12 **Ethnicity:** Not reported **IQ:** Range not reported (means: sheltered workshop group mean: 55.52; supported work group mean: 57.41; as assessed with the IQ Leiter) **Inclusion criteria:** Supported employment subjects selected on the following criteria: sheltered workshops enrolment prior to participation in supported work program; diagnosis of autism; no severe behaviour problems; acceptable professional and vocational abilities; informed consent
Interventions	1. Sheltered workshop group (N=25) 2. Supported work group (all jobs in the community, predominantly in service sector and included food services, waiters, recycling and delivery, retail, gardening, industrial laundry, agriculture and cattle-raising; all subjects worked 15-30 hours per week; job coach assigned to each worker) (N=26) **Duration:** **Intervention:** Average length of community employment was 30 months **Follow-up:** 3 years (1996-1999)
Outcomes	Primary outcome was autistic behaviours as measured by the Childhood Autism Rating Scale (CARS)
Study Design	Quasi-experimental (parallel groups)
Source of funding	Not reported
Limitations	1. Figures in text and tables do not add up with regards to sample size of the group. The sample sizes reported in the demographic table are extracted as these are corroborated by follow-up study. 2. No inclusion criteria reported for sheltered workshop group
Notes	

Study ID	GARCIAVILLAMISAR2002
Bibliographic reference	García-Villamisar, D., Wehman, P. & Diaz Navarro, M. (2002) Changes in the quality of autistic people's life that work in supported and sheltered employment. a 5-year follow-up study. *Journal of Vocational Rehabilitation, 17*, 309-312.
Methods	**Allocation:** Non-randomised **Matching:** Matched on age, total score on Childhood Autism Rating Scale (CARS), and degree of intelligence **Blindness:** Non-blind **Setting:** Community for supported work group **Raters:** First author conducted interviews with caretakers, therapists, and families **Country:** Spain & Germany
Participants	**Diagnosis:** DSM IV ASD **Coexisting conditions:** N=22 epilepsy **Qualifying Diagnostic Assessment:** Not reported **N:** 51 **Age:** Range not reported (means: sheltered workshop group mean: 21.07 years; supported work group mean: 21.64 years) **Sex:** Male: 39; Female: 12 **Ethnicity:** Not reported **IQ:** Range not reported (means: sheltered workshop group mean: 55.52; supported work group mean: 57.41; as assessed with the IQ Leiter) **Inclusion criteria:** Supported employment subjects selected on the following criteria: sheltered workshops enrolment prior to participation in supported work program; diagnosis of autism; no severe behaviour problems; acceptable professional and vocational abilities; informed consent
Interventions	1. Sheltered workshop group (N=25) 2. Supported work group (all jobs in the community, predominantly in service sector and included food services, waiters, recycling and delivery, retail, gardening, industrial laundry, agriculture and cattle-raising; all subjects worked 15-30 hours per week; job coach assigned to each worker) (N=26) **Duration:** **Intervention:** Average length of community employment was 30 months **Follow-up:** 3 years (1996-1999)
Outcomes	Primary outcome was quality of life as measured by the Quality of Life Survey (QLS; Sinnot-Oswald et al., 1991)
Study Design	Quasi-experimental (parallel groups)
Source of funding	Horizon Program of European Union and Cosejer ía de Asuntos Sociales de la Comunidad Autónoma de Madrid (Spain)
Limitations	1. Figures in text and tables do not add up with regards to sample size of the group. The sample sizes reported in the demographic table are extracted
Notes	• Follow-up from GARCIAVILLAMISAR2000 but different outcome data reported and extracted

Study ID	GARCIAVILLAMISAR2007
Bibliographic reference	García-Villamisar, D. & Hughes, C. (2007) Supported employment improves cognitive performance in adults with autism. *Journal of Intellectual Disability Research, 51*, 142-150.
Methods	**Allocation:** Random selection but not allocation **Matching:** No matching **Blindness:** Non-blind **Setting:** Supported work was in the community **Raters:** Computer-administered testing **Country:** Spain
Participants	**Diagnosis:** DSM-IV ASD **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Childhood Autism Rating Scale (CARS) >30 **N:** 44 **Age:** Range not reported (means: supported work group mean: 25.52 years; no supported work group mean: 24.32 years) **Sex:** Male: 32; Female: 12 **Ethnicity:** Not reported **IQ:** Range not reported (means: supported work group mean: 80.81; no supported work mean: 82.42; as assessed by the British Picture Vocabulary Scale) **Inclusion criteria:** Supported employment participants selected according to the following criteria: sheltered workshops enrolment prior to the participation in the supported work program (minimum 2 years); no previous participation in other supported employment programs; diagnosis of autism; no severe behavioural problems; acceptable professional and vocational abilities; informed consent; and all participants required to score above the 35th percentile point on the Standard Progressive Matrices (SPM)
Interventions	1. Supported work group (all jobs were in the community and predominantly in the service sector including food services, waiters, recycling and delivery, retail, gardening, industrial laundry, agriculture and cattle raising; participants worked an average of 20 hours per week; job coach assigned to each worker) (N=22?) 2. Waiting list control group (N=22?) **Duration:** **Intervention:** Mean length of supported employment was 30 months **Follow-up:** Mean length of supported employment was 30 months
Outcomes	Primary outcome was executive functioning and memory performance as assessed by a battery of neuropsychological tests from the Cambridge Neuropsychological Tests: Automated Battery (CANTAB). Data for a measure of executive functioning, the 'Stockings of Cambridge' (SOC) Planning task was selected for analysis. This task is a computerized version of the Tower of London Planning Task.
Study Design	Quasi-experimental (parallel groups)
Source of funding	Fondo Social Europeo and Consejería de Asuntos Sociales de la Comunidad Autónoma de Madrid
Limitations	1. Sample sizes for each group not reported. Data was extracted on the

	basis of an equal sample size in each group but obviously this assumption may be invalid 2. No inclusion criteria reported for the waiting list controls
Notes	• Data for Planning task 'Stockings of Cambridge', average planning time extracted

Study ID	GARCIAVILLAMISAR2010
Bibliographic reference	García-Villamsiar, D.A. & Dattilo, J. (2010) Effects of a leisure programme on quality of life and stress of individuals with ASD. *Journal of Intellectual Disability Research, 54*, 611-619.
Methods	**Allocation:** Randomised **Matching:** No matching **Blindness:** Blind outcome assessment **Setting:** Residential and community **Raters:** Team of therapists blind to objectives of research **Country:** Spain
Participants	**Diagnosis:** ASD (N=2 Asperger syndrome) **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Clinically diagnosed by a psychiatrist or clinical psychologist with several years of experience in assessment of autism and related conditions **N:** 71 **Age:** 17-39 years (means: experimental mean: 31.49 years; control mean: 30.06 years) **Sex:** Male: 41; Female: 30 **Ethnicity:** Not reported **IQ:** Not reported **Inclusion/exclusion criteria:** All participants were screened to exclude comorbid psychiatric illness (e.g. schizophrenia, major depression) and neurological disorders that might influence brain function (e.g. epilepsy)
Interventions	1. Leisure program (N=37), consisted of a group recreation context from 17:00-19:00 (2 hours) each day (5 days/week) for participants to interact with media, engage in exercise, play games and do crafts, attend events and participate in other recreation activities. The criteria for activity selection included those activities that were understandable, reactive, comfortable, and active 2. Waiting list control group (N=34) **Duration:** **Intervention:** One year **Follow-up:** One year
Outcomes	The primary outcome was quality of life as measured by the Quality of Life Questionnaire-Spanish version (QOL) (Scaholck & Keith, 1993; Caballo et al., 2005)
Study Design	RCT
Source of funding	Not reported
Limitations	1. No attention-placebo condition

Study ID	GARCIAVILLAMISAR2011
Bibliographic reference	García-Villamisar, D. & Dattilo, J. (2011) Social and clinical effects of a leisure program on adults with autism spectrum disorder. *Research in Autism Spectrum Disorders, 5*, 246-253.
Methods	**Allocation:** Randomised **Matching:** Participants were matched according to age and gender **Blindness:** Blind outcome assessment **Setting:** Residential **Raters:** Team of therapists blind to objectives of research **Country:** Spain
Participants	**Diagnosis:** ASD **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Clinically diagnosed by a psychiatrist or clinical psychologist with several years of experience in assessment of autism and related conditions **N:** 40 **Age:** 24-38 years (means: experimental group mean: 32.05 years; control group mean: 31.75 years) **Sex:** Male: 24; Female: 16 **Ethnicity:** Not reported **IQ:** Not reported **Inclusion criteria:** All participants were screened to exclude comorbid psychiatric illness (e.g. schizophrenia, major depression) and neurological disorders that might influence brain function (e.g. epilepsy)
Interventions	1. Leisure program (N=20), consisted of a group recreation context from 17:00-19:00 (2 hours) each day (5 days/week) for participants to interact with media, engage in exercise, play games and do crafts, attend events and participate in other recreation activities. The criteria for activity selection included those activities that were understandable, reactive, comfortable, and active 2. Waiting list control group (N=20) **Duration:** **Intervention:** One year **Follow-up:** One year
Outcomes	The primary outcome of interest was recognition of emotion as assessed by The Facial Discrimination Battery (FDB)-Spanish version (GarcÍa-Villamisar et al., 2010)
Study Design	RCT
Source of funding	Grant from the Real Patronato para la Discapacidad, Ministerior de Sanidad y Cosumo, Government of Spain; and Asociación Nuevo Horizonte, Madrid, Spain
Limitations	1. No attention-placebo control group
Notes	

Study ID	GOLAN2006
Bibliographic reference	Golan, O. & Baron-Cohen, S. (2006) Systemizing empathy: teaching adults with Asperger syndrome or high-functioning autism to recognize complex emotions using interactive multimedia. *Development and Psychopathology, 18*, 591-617.
Methods	**Allocation:** Randomised **Matching:** Matched on age, verbal and performance IQ, handedness, and gender **Blindness:** Assistants and participants blind to group, but not investigator **Setting:** Community **Raters:** Computer-based assessments which the first author and 3 trained assistants helped participants through **Country:** UK
Participants	**Diagnosis:** ASD (Asperger syndrome and high-functioning autism) **Coexisting conditions:** 5 participants in each group had another psychiatric diagnosis, such as depression or ADHD **Qualifying Diagnostic Assessment:** Autism Spectrum Quotient (AQ) **N:** 41 (data was also reported for a typical control group N=28 but that data is not extracted here) **Age:** 17-52 years (means: experimental group mean: 30.5 years; control group mean: 30.9 years) **Sex:** Male: 31; Female: 10 **Ethnicity:** Not reported **IQ:** 80-140 (means: experimental group mean VIQ: 108.3 and mean PIQ: 112; control group mean VIQ: 109.7 and mean PIQ: 115.3) **Inclusion criteria:** Participants had not participated in any related intervention during the least 3 months and had no plans for engaging in another intervention while the study was ongoing. Participants were also required to complete a minimum of 10 hours intervention training.
Interventions	1. Software home users group (N=19), training with Mind Reading which is an interactive guide to emotions and mental states 2. Control group (N=22), completed pre- and post-assessments but with no intervention **Duration:** **Intervention:** 2 hours per week over a period of 10 weeks (and a minimum of 10 hours) **Follow-up:** 15 weeks
Outcomes	Primary outcome was emotion recognition as assessed by the recognition of complex emotions in faces and voices measured using The Cambridge Mindreading (CAM) Face-Voice Battery, the Reading of the Mind in the Eyes task (revised, adult version), and Reading the Mind in Film task which tests for holistic distant generalization. Data was extracted for the CAM face task
Study Design	RCT
Source of funding	National Alliance for Autism Research, the Corob Charitable Trust, the Cambridge Overseas Trust, B'nai and B'rith Leo Baeck scholarships, Shirley Foundation, MRC, and the Three Guineas Trust
Limitations	1. Generalization to real-life social situations needs to be examined

Notes	• The randomised trial comparing adults with autism in experimental and no-treatment control groups (experiment 1) was followed by a non-randomised trial which compared adults with autism in the experimental group to an alternative-treatment control group (experiment 2). However, data was not extracted for experiment 2.

Study ID	HARRIS1984
Bibliographic reference	Harris, M.B. & Bloom, S.R. (1984) A pilot investigation of a behavioral weight control program with mentally retarded adolescents and adults: effects on weight, fitness, and knowledge of nutritional and behavioral principles. *Rehabilitation Psychology, 29*, 177-182.
Methods	**Allocation:** Non-randomised **Matching:** No matching **Blindness:** Non-blind **Setting:** Community **Raters:** Not reported **Country:** USA
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Not reported **N:** 21 **Age:** Range not reported (mean: 25.3 years) **Sex:** Male: 4; Female: 17 **Ethnicity:** Not reported **IQ:** Range not reported (mean=52.5) **Inclusion criteria:** Not reported
Interventions	1. Behavioural weight control program (N=10) 2. Dropouts from the program after attending 0-4 meetings (N=11) **Duration:** **Intervention:** 7 weekly meetings **Follow-up:** 26 weeks
Outcomes	Primary outcome was weight loss
Study Design	Quasi-experimental (parallel groups)
Source of funding	Not reported
Limitations	1. Potential bias in group allocation 2. Small sample sizes
Notes	

Study ID	HERBRECHT2009
Bibliographic reference	Herbrecht, E., Poustka, F., Birnkammer, S., *et al.* (2009) Pilot evaluation of the frankfurt social skills training for children and adolescents with autism spectrum disorder. *European Child and Adolescent Psychiatry, 18*, 327-335.
Methods	**Allocation:** Not applicable - no control group **Matching:** Not applicable - no control group **Blindness:** Non-blind **Setting:** Community **Raters:** Non-blind experts; blind experts; parent ratings (teachers also rated but missing data). **Country:** Germany
Participants	**Diagnosis:** ICD-10 ASD **Coexisting conditions:** 3 participants were medicated for obsessive compulsive symptoms, 2 for impulsive and aggressive behaviour, and 1 for hyperactivity. **Qualifying Diagnostic Assessment:** ADOS and ADI-R **N:** 17 **Age:** 9-20 years (mean: 14.7 years) **Sex:** Male: 15; Female: 2 **Ethnicity:** Not reported **IQ:** Range not reported (mean: 93.4) **Inclusion criteria:** Referred outpatients of department of child & adolescent psychiatry; clinical diagnosis of ASD; no functional language and severe co morbid organic health problems (e.g. Fragile X, tuberous sclerosis, intractable epilepsy); IQ>70.
Interventions	1.Frankfurt social skills training (KONTAKT) N=17, social skills groups focused on learning to initiate social overtures, conversation skills, understanding social rules and relationships, identification and interpretation of verbal and non-verbal social signals, problem-solving, coping strategies and improvement of self-confidence. Techniques include teaching of rules, social interaction games, role play, and group discussion. **Duration:** **Intervention:** Weekly 1 hour social skills training sessions for children and 1.5 hour bi-weekly sessions for adolescents for period of 5 months. **Follow-up:** 11 months
Outcomes	Primary outcome was social interaction as measured using a battery of assessments as follows: expert ratings on the Diagnostic Checklist for Pervasive Developmental Disorders (DCL), the Checklist for Group Behaviours (CGB), and the Global Assessment of Functioning Scale (GAS); a blind-expert video rating; parent ratings collected with a modified version of the Parent Interview for Autism (PIA-CV-mini), Social Competence Scale (SKS), and the Family Burden Questionnaire (FaBel). Data were extracted for the blind-expert video rating as this was the only blinded outcome assessment.
Study Design	Observational (before-and-after)
Source of funding	Not reported
Limitations	1. Small sample

	2. No control group 3. Efficacy data could not be extracted
Notes	

Study ID	HILLIER2007
Bibliographic reference	Hillier, A., Fish, T., Cloppert, P., *et al*. (2007) Outcomes of a social and vocational skills support group for adolescents and young adults on the autism spectrum. *Focus on Autism and Other Developmental Disabilities, 22*, 107-115.
Methods	**Allocation:** Not applicable - no control group **Matching:** Not applicable - no control group **Blindness:** Non-blind **Setting:** Community **Raters:** Self-report and 2 trained observers **Country:** USA
Participants	**Diagnosis:** ASD **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Gilliam Asperger's Disorder Scale **N:** 13 **Age:** 18-23 years (mean: 19 years) **Sex:** Male: 11; Female: 2 **Ethnicity:** Not reported **IQ:** 2 participants did not complete due to low verbal skills, for N=11 IQ was 81-141 (mean: 108.08) **Inclusion criteria:** Prior diagnosis of ASD, aged between 18 and 30 years, and commitment to attend sessions
Interventions	1.Aspirations social skills group (N=13), overall aims of the program were to foster understanding of a range of social and vocational issues, to enhance insight and awareness, and to provide social opportunities for group members. **Duration:** **Intervention:** Weekly 1 hour meetings for 8 weeks **Follow-up:** 8 weeks (after completing the program group members attended monthly reunions but no data for these)
Outcomes	Primary outcome was social skills as assessed by self-report measures as follows: modified version of The Index of Peer Relations (IPR) which questions how participants view and evaluate persons in their peer group and whether they are accepted and liked by their peer group; The Autism Quotient (AQ); The Empathy Quotient (EQ); and structured observations by trained observers to determine whether frequency of participants' contributions to the group increased. Data extracted for the EQ.
Study Design	Observational (before-and-after)
Source of funding	Not reported
Limitations	1. Small sample size 2. No control group 3. No data from monthly reunion meetings

Study ID	HOWLIN1999
Bibliographic reference	Howlin, P. & Yates, P. (1999) The potential effectiveness of social skills groups for adults with autism. *Autism, 3*, 299-307.
Methods	**Allocation:** Not applicable - no control group **Matching:** Not applicable - no control group **Blindness:** Non-blind **Setting:** Community **Raters:** Family and participants themselves (checklist); unknown raters (video of conversation). **Country:** UK
Participants	**Diagnosis:** ASD **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Not reported **N:** 10 **Age:** 19-44 years (mean: 28.4 years) **Sex:** Male: 10; Female: 0 **Ethnicity:** Not reported **IQ:** Non-verbal IQ 86-138 (mean: 109) **Inclusion criteria:** Diagnosis of autism or Asperger syndrome; previously attended Maudsley Hospital for diagnosis or treatment; attended an initial 2-day course on social problems and skills; registered interest in attending a social skills group on a regular basis
Interventions	1.Social skills group (N=10) focused on major issues raised by group members and core features of conversational ability. Techniques included role-play, team activities, structured games, and feedback based on behavioural observations **Duration:** **Intervention:** Monthly 2.5 hour sessions over the course of a year **Follow-up:** One year
Outcomes	Primary outcome was social interaction as measured by: checklist of social skills problem areas sent to families and participants themselves; changes in personal life/living situation of participants over the course of the year of intervention; and changes in conversational ability assessed through before and after ratings of video recording of simulated social activities: a party scenario and a job enquiry scenario. Data extracted for the changes in conversational style during the 'party' scenario.
Study Design	Observational (before-and-after)
Source of funding	Not reported
Limitations	1. No control group 2. Small sample size 3. Question of generalization of improvements to naturalistic settings 4. Assessment methods for improvements in social functioning lack any formal assessment of reliability or validity
Notes	

Study ID	HOWLIN2005
Bibliographic reference	Howlin, P., Alcock, J. & Burkin, C. (2005) An 8 year follow-up of a specialist supported employment service for high-ability adults with autism or Asperger syndrome. *Autism, 9*, 533-549.
Methods	**Allocation:** Not applicable - no control group **Matching:** Not applicable - no control group **Blindness:** Not applicable - no control group **Setting:** Not reported **Raters:** Not applicable - objective measure of number of job placements **Country:** UK
Participants	**Diagnosis:** ASD (diagnosis made by either a psychiatrist or psychologist) **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Approximately 20% had diagnosis confirmed by ADI **N:** 89 **Age:** 18-56 years (mean: 31.4 years) **Sex:** Male: 72; Female: 17 **Ethnicity:** Not reported **IQ:** 60-139 (mean: 110.7) as measured by Raven non-verbal IQ **Inclusion criteria:** Clients registered with the scheme between 2002 and 2003 who completed assessments used in original study
Interventions	1. Supported employment group (N=89) **Duration:** **Intervention:** One year **Follow-up:** One year
Outcomes	Primary outcome was job placements
Study Design	Observational (before-and-after study)
Source of funding	Not reported
Limitations	1. No control group 2. Efficacy data cannot be extracted
Notes	• Narrative 7-8 year follow-up data reported for MAWHOOD1999 but this is not extracted here. See notes section of MAWHOOD1999.

Study ID	KHEMKA2000
Bibliographic reference	Khemka, I. (2000) Increasing independent decision-making skills of women with mental retardation in simulated interpersonal situations of abuse. *American Journal on Mental Retardation, 105*, 387-401.
Methods	**Allocation:** Randomised **Matching:** No matching **Blindness:** Non-blind **Setting:** Community **Raters:** Not reported **Country:** USA
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Not reported **N:** 45 **Age:** Range not reported (mean: 35.8 years) **Sex:** Male: 0; Female: 45 **Ethnicity:** Not reported **IQ:** Range not reported (mean: 60.89) **Inclusion criteria:** Participants were women with mild and moderate mental retardation from a large non-profit agency for adults with developmental disabilities and mental retardation. Participant IQ, as provided by agency records, was used as a screening criterion in order to select participants who had adequate communication and language skills required for the decision-making tasks
Interventions	1. Self-directed decision-making training (N=12) which combined instruction on cognitive and motivational aspects of decision-making 2. Control (N=12) Study also reports data for a decision-making training condition (N=12), however, that data is not extracted **Duration:** **Intervention:** 10 training sessions spread over several weeks **Follow-up:** 10 training sessions
Outcomes	Decision-making in response to hypothetical situations of abuse was evaluated using a Social Interpersonal Decision-Making Video Scale where participants watched video vignettes and were assessed on their ability to recommend a decision for the key decision maker. The Self Social Interpersonal Decision Making Scale was also used where participants were presented with vignettes representing situations of interpersonal conflicts and sexual, physical or verbal abuse and asked what they would do in that situation. Finally, the Nowicki-Strickland Internal-External Scale was used to assess participants' perception of their locus of control. Data were extracted for the Self Social Interpersonal Decision Making Scale.
Study Design	RCT
Source of funding	Not reported
Limitations	1. Small sample sizes 2. No follow-up to examine long-term retention of treatment effects 3. Assessment methods lack any formal assessment of reliability or validity
Notes	• N=9 dropouts, N=8 due prior to randomisation due to

	scheduling difficulties and/or unwillingness to continue participation and N=1 randomly excluded to balance sample sizes across groups

Study ID	KHEMKA2005
Bibliographic reference	Khemka, I., Hickson, L. & Reynolds, G. (2005) Evaluation of a decision-making curriculum designed to empower women with mental retardation to resist abuse. *American Journal of Mental Retardation, 110*, 193-204.
Methods	**Allocation:** Randomised **Matching:** Matched on decision making screening measure **Blindness:** Non-blind **Setting:** Community **Raters:** 2 independent raters **Country:** USA
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** WAIS or Stanford-Binet **N:** 36 **Age:** Range not reported (mean: 34 years) **Sex:** Male: 0; Female: 36 **Ethnicity:** 33.3% white, 50% African American, 16.7% Hispanic **IQ:** Range not reported (mean: 55.92) **Inclusion criteria:** Participants were required to be female, have an IQ of between 35 and 75, be aged 22-55 years, and live with natural/foster family or on own
Interventions	1. Effective Strategy-Based Curriculum for Abuse Prevention and Empowerment (ESCAPE) group (N=18) 2. Treatment as usual group (N=18) **Duration:** **Intervention:** 40-50min sessions once or twice a week over a 6-12 week period **Follow-up:** 12 weeks
Outcomes	The primary outcome was anti-victimization skills as assessed by the following measures: The Decision-Making Video Scale was used to measure decision-making skills in response to 12 hypothetical social interpersonal decision-making vignettes; Knowledge of Abuse Concepts Scale was used as a cognitive measure of knowledge of abuse concepts, the Empowerment Scale was used to assess perceptions of control and self-efficacy; the Stress Management Survey measured self-reported stress; and the Self Decision-Making Scale measured participants' ability to suggest self-protective decisions in response to simulated interpersonal situations involving different scenarios of sexual, physical, and verbal abuse. Data for the Decision-Making Video Scale was extracted.
Study Design	RCT
Source of funding	Grant from the Joseph P. Kennedy, Jr. Foundation
Limitations	1. Small sample size

	2. High risk of attrition bias
Notes	• Data extracted for intention-to-treat sample

Study ID	KING1999
Bibliographic reference	King, N., Lancaster, N., Wynne, G., *et al*. (1999) Cognitive-behavioural anger management training for adults with mild intellectual disability. *Scandinavian Journal of Behaviour Therapy, 28*, 19-22.
Methods	**Allocation:** Not applicable – no control group **Matching:** Not applicable – no control group **Blindness:** Non-blind **Setting:** Community **Raters:** Self-report and caregiver report **Country:** Australia
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** N=3 cerebral palsy **Qualifying Diagnostic Assessment:** Not reported **N:** 11 **Age:** 17-48 years (mean: 29.5 years) **Sex:** Male: 7; Female: 4 **Ethnicity:** Not reported **IQ:** Not reported – mild intellectual disabilities **Inclusion criteria:** Participants were referred because of anger problems, all participants confirmed that they had an anger control problem and expressed a desire to change their behaviour. Participants demonstrating psychotic behaviour were excluded.
Interventions	1. Cognitive-behavioural anger management training program (N=11) **Duration:** **Intervention:** 15 90-min weekly sessions **Follow-up:** 27 weeks
Outcomes	The primary outcome was anger management, as assessed using self-report measures including the Anger Inventory for Mentally Retarded Adults, and the Coopersmith Self-esteem Inventory; and caregiver reports including Anger Inventory-Caregiver Report and Developmental Behaviour Checklist. Data is extracted for the Anger Inventory.
Study Design	Observational (before-and-after)
Source of funding	Not reported
Limitations	1. Small sample size 2. No control group 3. No correction applied for multiple statistical comparisons
Notes	

Study ID	LAUGESON2009
Bibliographic reference	Laugeson, E.A., Frankel, F., Mogil, C., *et al*. (2009) Parent-assisted social skills training to improve friendships in teens with autism spectrum disorders. *Journal of Autism & Developmental Disorders, 39*, 596-606.
Methods	**Allocation:** Randomised **Matching:** No matching **Blindness:** Non-blind **Setting:** Community **Raters:** Self- and parent-report **Country:** USA
Participants	**Diagnosis:** ASD **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Not reported **N:** 33 **Age:** 13-17 years (mean: 14.6 years) **Sex:** Male: 28; Female: 5 **Ethnicity:** Caucasian N:14, Hispanic/Latino N:6, African American **N:**3, Asian N:4, Middle-Eastern N:3, mixed ethnicities N:3 **IQ:** Range not reported (means: Treatment group mean VIQ=96, delayed treatment control mean VIQ=88.3 (KBIT-2)) **Inclusion criteria:** Participants were aged between 13 and 17 years, had social problems as reported by their parents, had a diagnosis of ASD, was fluent in English, had a parent or family member who was fluent in English, had a VIQ>70, had no history of major mental illness, and had no hearing, visual, or physical impairments which precluded participation in outdoor sports activities
Interventions	1. PEERS intervention group (N=17), with parents and teens attending separate concurrent sessions that instructed them on key elements about making and keeping friends 2. Delayed treatment group (N=16) **Duration:** **Intervention:** 12 90-min sessions delivered once a week over course of 12 weeks **Follow-up:** 24 weeks
Outcomes	The primary outcome was social interaction as measured by the parent-rated Social Skills Rating Scale (SSRS), and self-report scales as follows: The Quality of Play Questionnaire (QPQ), Test of Adolescent Social Skills Knowledge (TASSK), and Friendship Quality Scale (FQS). This study also collected data for teacher-report SSRS, however, sample sizes were not sufficient for analysis. Data was extracted for the Test of Adolescent Social Skills Knowledge
Study Design	RCT
Source of funding	NIH Training Grant T32-MH17140 and NIMH Grant 1U54MH068172
Limitations	1. Small sample size 2. Generalizability to real social situations needs to be examined
Notes	

Study ID	LEE1977
Bibliographic reference	Lee, D.Y. (1977) Evaluation of a group counseling program designed to enhance social adjustment of mentally retarded adults. *Journal of Counseling Psychology, 24*, 318-323.
Methods	**Allocation:** Randomised **Matching:** No matching **Blindness:** Non-blind **Setting:** Residential **Raters:** Key worker and fellow residents **Country:** Canada
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Peabody Picture Vocabulary Test **N:** 48 **Age:** 20-64 years (median: 37 years) **Sex:** Male: 22; Female: 26 **Ethnicity:** Not reported **IQ:** 12-87 (mean: 47) **Inclusion criteria:** Participants were mentally retarded residents of institution. Those residents under heavy medication during the time of this study and those severely handicapped in speech and hearing were excluded.
Interventions	1. Social adjustment training (N=20) 2. Treatment as usual (N=24) **Duration:** **Intervention:** 1 hour session 3 times a week for 10 weeks. Upon completion of the program the entire 15 sessions were repeated. **Follow-up:** 10 weeks
Outcomes	The outcome of interest was challenging behaviour as assessed by Part 2 of the AAMD Adaptive Behavior Scale (Nihira et al., 1974). The study also reports on the effects of social learning on social interaction. However, as this is an intellectual disabilities population we are only extrapolating for challenging behaviour outcomes.
Study Design	RCT
Source of funding	Not reported
Limitations	1. Small sample size 2. High risk for attrition bias
Notes	• N=4 dropped out of experimental group because of medical reasons or transfer to other institution

Study ID	LINDSAY2004
Bibliographic reference	Lindsay, W.R., Allan, R., Parry, C., *et al*. (2004) Anger and aggression in people with intellectual disabilities: treatment and follow-up of consecutive referrals and a waiting list comparison. *Clinical Psychology and Psychotherapy, 11*, 255-264.
Methods	**Allocation:** Non-randomised **Matching:** No matching **Blindness:** Non-blind **Setting:** Outpatient **Raters:** Self-report and blind raters for role-play videotapes **Country:** UK
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** WAIS-III **N:** 47 **Age:** Range not reported (means: Treatment group mean: 28.4 years; control group mean: 23.9 years) **Sex:** Male: 33; Female: 14 **Ethnicity:** Not reported **IQ:** Range not reported (means: Treatment group mean: 65.4; control group mean: 66.2) **Inclusion criteria:** Individuals who were known to the service and were now living in the community were referred back for reasons of aggression and destructive behaviour
Interventions	1. CBT for anger management (N=33) 2. Control group (N=14) **Duration:** **Intervention:** 9 months (around 40 sessions) **Follow-up:** 9 months
Outcomes	The primary outcome was anger management as measured by the Dundee Provocation Inventory (DPI) which measures anger related to frustration, disappointment, jealousy, embarrassment, anger towards self, and direct assault; ratings of role-plays which included 2 situations that were considered to be generally anger provoking and 1 that was specific to the participant involved; and self-reports of anger where participants completed an anger inventory on how they felt during each day. Data for the DPI were extracted
Study Design	Quasi-experimental (parallel groups)
Source of funding	Not reported
Limitations	1. Significant differences between control and experimental groups in age and gender 2. Significant baseline differences between groups 3. Discrepancy between sample sizes in experimental and control groups
Notes	• The treatment group was followed up to 30 months but with diminishing sample size and no data for control group. Data not extracted here for follow-ups.

Study ID	MATSON1981
Bibliographic reference	Matson, J.L., DiLorenzo, T.M. & Esveldt-Dawson, K. (1981) Independence training as a method of enhancing self-help skills acquisition of the mentally retarded. *Behaviour Research and Therapy, 19*, 399-405.
Methods	**Allocation:** Randomised **Matching:** No matching **Blindness:** Non-blind **Setting:** Residential **Raters:** Two psychiatric aides pretrained to a criterion of 90%+ reliability on rating showering skills **Country:** USA
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Stanford-Binet Intelligence Test and the American Association for Mental Deficiency Adaptive Behaviour Scale **N:** 72 **Age:** 21-55 years (mean: 32.2 years) **Sex:** Male: 46; Female: 26 **Ethnicity:** Not reported **IQ:** Not reported - moderate to severe intellectual disability **Inclusion criteria:** All participants were residents at a state institute for the mentally retarded. All residents in both groups were ambulatory and possessed the necessary motor skills and manual dexterity to participate in independent personal showering. Also, the residents had acquired a number of appropriate self-help skills prior to the beginning of the study, including self-toileting and independent dressing and feeding
Interventions	1. Independence training (N=36) 2. No-treatment control group (N=36) **Duration:** **Intervention:** 4 months **Follow-up:** 7 months
Outcomes	The primary outcome was activities of daily living, in this case, showering. The target behaviour, showering, was broken down into 27 task-analyzed steps and rated using a task-specific checklist
Study Design	RCT
Source of funding	Not reported
Limitations	1. Drug dosages were changed periodically throughout the study 2. Generalizability of findings 3. The task-specific checklist lacks formal assessments of reliability and validity
Notes	

Study ID	MAWHOOD1999
Bibliographic reference	Mawhood, L. & Howlin, P. (1999) The outcome of a supported employment scheme for high functioning adults with autism or asperger syndrome. *Autism, 3*, 229–254.
Methods	**Allocation:** Non-randomised **Matching:** No matching **Blindness:** Non-blind **Setting:** Not reported **Raters:** Self-report **Country:** UK
Participants	**Diagnosis:** ASD (formal diagnosis made by psychiatrist or psychologist; N=41 Asperger syndrome; N=6 autism; N=3 ASD) **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Not reported **N:** 50 **Age:** 18-55 years (means: supported work group mean: 31.1 years; control group mean: 28 years) **Sex:** Male: 47; Female: 3 **Ethnicity:** Not reported **IQ:** 66-128 (means: supported work mean: 98.8; control group mean: 97.7; as assessed by WAIS) **Inclusion criteria:** For supported work group: a formal diagnosis of autism or Asperger syndrome; IQ of 70 or above on either the performance or the verbal scale of the WAIS; actively seeking work (i.e. not registered simply because of parents' wishes or other pressures); able to travel independently and prepared to work within the Greater London area; capable of eventually managing employment with minimal support; no additional psychiatric or physical problems that would adversely affect employability. For control group: lived in metropolitan areas outside Greater London but otherwise met all eligibility criteria; all were actively seeking employment and none was receiving treatment for psychiatric or other problems that might have affected their ability to work; none of the cities in which the control group lived were in areas of high unemployment
Interventions	1. Supported group (support workers responsible for job finding and job preparation and guidance provided on full-time basis for first 2-4 weeks of employment) (N=30) 2. Control group (N=20) **Duration:** **Intervention:** 5-24 months (mean: 17 months) **Follow-up:** 24 months
Outcomes	Outcomes of interest were job placements, participant satisfaction (measured with a questionnaire based on that developed by Bass & Drewett, 1998) and self-esteem (measured with the Rosenberg Self-Esteem Inventory). Data could only be extracted for the number of job placements.
Study Design	Quasi-experimental (parallel groups)
Source of funding	Nuffield Foundation; Department of Employment; and The National Autistic Society

Limitations	
Notes	• Psychometric data are based on N=29 as one individual did not complete all assessments • By the end of the evaluation period N=5 no longer registered with scheme: N=1 moved out of the London area; N=1 failure to respond to letters and telephone calls; N=1 decided no longer wished to look for work; N=1 enrolled on full time course; and N=1 who had obtained permanent contract suddenly left job and declined further involvement • Follow-up 7-8 years later (HOWLIN2005) found that 13/19 who had found employment during the pilot project remained in permanent jobs

Study ID	MAZZUCCHELLI2001
Bibliographic reference	Mazzucchelli, T.G. (2001) Feel safe: a pilot study of a protective behaviours programme for people with intellectual disability. *Journal of Intellectual and Developmental Disability, 26*, 115-126.
Methods	**Allocation:** Non-randomised **Matching:** No matching **Blindness:** Non-blind **Setting:** Community **Raters:** Self-report and carer-report scales **Country:** Australia
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Not reported **N:** 20 **Age:** Range not reported (means: Experimental group mean: 31 years; control group mean: 37 years) **Sex:** Male: 5; Female: 15 **Ethnicity:** Not reported **IQ:** Range not reported (means: Experimental group mean: 56.3; control group mean: 60.3) **Inclusion criteria:** Clients that staff and carers felt would benefit from the programme were nominated and offered a time to attend a group, those who said they would be able to attend made up the experiential group and those who could not make that time made up the waiting list control group
Interventions	1. Feel Safe program to increase personal safety skills (N=10) 2. Waiting list control group (N=10) - participants who could not make the allocated time slots for treatment **Duration:** **Intervention:** One 3-hour session a week over 4 weeks **Follow-up:** 9 weeks
Outcomes	The primary outcome was anti-victimization skills. The Feel Safe Questionnaire (FSQ) was used to assess knowledge of the Feel Safe sessions, including: early warning signs (body feelings), empowerment and relaxation, the right to feel safe, emergencies, linking safety with

	adventurousness, networking, persistence expectation, and problem solving. The Protective Behaviour Skills Evaluation (PBSE) was used to obtain a measure of the degree to which participants actually applied protective behaviour strategies and concepts. Finally, Comprehensive Quality of Life Scale Intellectual Disability - Fourth Edition (ComQol-ID4) was used. Data was extracted for the PBSE.
Study Design	Quasi-experimental (parallel groups)
Source of funding	Not reported
Limitations	1. Potential bias in group allocation 2. Small sample size
Notes	

Study ID	MYLES1996A
Bibliographic reference	Myles, B.S., Simpson, R.L. & Smith, S.M. (1996) Collateral behavioral and social effects of using facilitated communication with individuals with autism. *Focus on Autism and Other Developmental Disabilities, 11*, 163-169.
Methods	**Allocation:** Not applicable - no control group **Matching:** Not applicable - no control group **Blindness:** Not applicable - no control group **Setting:** Educational **Raters:** Graduate research assistants **Country:** USA
Participants	**Diagnosis:** DSM-IV ASD **Coexisting conditions:** Moderate-to-severe intellectual disability **Qualifying Diagnostic Assessment:** Not reported **N:** 12 **Age:** 12-28 years (mean: 19.4 years) **Sex:** Male: 9; Female: 3 **Ethnicity:** White N: 9; African-American N:3 **IQ:** Not reported but intellectual disabilities **Inclusion/exclusion criteria:** Not reported
Interventions	1. Faciltated communication (N=12) in the classroom with the teacher acting as facilitator **Duration:** **Intervention:** 4 days per week for 14 weeks **Follow-up:** 17 weeks (including 3-week baseline observation period)
Outcomes	The primary outcome was the frequency of seven behaviours and social interaction outcomes as measured at baseline, during the intervention, and in the final few weeks of the intervention. These targeted behaviours included requesting, getting attention, protesting, giving information, expressing feelings, interacting socially, and non-focused response.
Study design	Observational (before-and-after study)
Source of funding	Grant No. H023A20093 from the US Department of Education, Office of Special Education Research, Division of Innovation and Development

Limitations	1. No control group 2. Efficacy data could not be extracted 3. Small sample size
Notes	• Participants were on concurrent medications during the study including flurazepam (N=1); thorazine (N=1); carbamazepine (N=2); klonopin (N=1); lithium (N=2); congentin (N=1); haldo (N=1); tegretol (N=1); lorazepam (N=1); depakote (N=2); benadryl (N=1); lamicta (N=1); dilantin (N=2); namictal (N=1); zoloft (N=1)

Study ID	POLIRSTOK2003
Bibliographic reference	Polirstok, S.R., Dana, L., Buono, S., *et al*. (2003) Improving functional communication skills in adolescents and young adults with severe autism using gentle teaching and positive approaches. *Topics in Language Disorders, 23*, 146-153.
Methods	**Allocation:** Not applicable - no control group **Matching:** Not applicable - no control group **Blindness:** Non-blind **Setting:** Residential **Raters:** Psychologist **Country:** Italy
Participants	**Diagnosis:** Intellectual disability & >50% of group had diagnoses of autism or related autistic features **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** WAIS **N:** 18 **Age:** 16-38 years (mean not reported) **Sex:** Male: 0; Female: 18 **Ethnicity:** Not reported **IQ:** Not reported (mental age: 12-25 months) **Inclusion criteria:** Not reported
Interventions	1. Intensive Habilitation Program (N=18) targeting 4 main areas of preoccupational skills, occupational skills, psychomotor skills, and functional communication skills **Duration:** **Intervention:** One year of training **Follow-up:** 18 months
Outcomes	The primary measure was communication as measured by the Vineland Adaptive Behaviour Scale (VABS) with subscale of communication. Data extracted for expressive language.
Study Design	Observational (before-and-after)
Source of funding	Grant provided by the Italian Ministry of Education
Limitations	1. Small sample size 2. No control group 3. Limited description of methodology
Notes	

Study ID	ROSE2005
Bibliographic reference	Rose, J., Loftus, M., Flint, B., *et al*. (2005) Factors associated with the efficacy of a group intervention for anger in people with intellectual disabilities. *British Journal of Clinical Psychology, 44*, 305-317.
Methods	**Allocation:** Non-randomised **Matching:** No matching **Blindness:** Non-blind **Setting:** Community **Raters:** Self-report **Country:** Ireland
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Not reported **N:** 60 (N=38 for data extracted) **Age:** 17-60 years (means: CBT group mean: 36 years; additional stakeholder involvement group mean: 35 years; waiting list control mean: 33 years) **Sex:** Male: 30; Female: 30 **Ethnicity:** Not reported **IQ:** Not reported – borderline, mild, or moderate intellectual disability **Inclusion criteria:** Participants were from 3 work centres run by the same organization, all participants were recorded on clinical files as having borderline, mild, or moderate intellectual disability
Interventions	1. Psychoeducational anti-bullying intervention with a cognitive behavioural orientation (N=20) 2. Waiting list control group (N=18) Data was also reported for an additional group (N=22) which involved the same intervention but with additional involvement of community stakeholders. However, the data for this group is not extracted here. **Duration:** **Intervention:** 10 sessions **Follow-up:** 3 months
Outcomes	The primary outcome was anti-victimization skills as measured by self-reports of bullying behaviour and victimization, obtained using a modified version of the Bullying Questionnaire designed and produced by Mencap (1999), participants were asked to report whether they had experienced bullying in the past 3 months. A second question using the same format was devised to obtain self-report information on bullying behaviour. Dichotomous data for bullying victimization rates were extracted.
Study Design	Quasi-experimental (parallel groups)
Source of funding	Not reported
Limitations	1. Small sample sizes 2. More directly measured outcomes (i.e. in addition to self-reports of bullying) are needed including independent observation of incidents of bullying 3. Generalization of effects outside of the work centre environment needs to be explored
Notes	

Study ID	RUSSELL2009
Bibliographic reference	Russell, A.J., Mataix-Cols, D., Anson, M.A.W., *et al*. (2009) Psychological treatment for obsessive-compulsive disorder in people with autism spectrum disorders - a pilot study. *Psychotherapy and Psychosomatics, 78*, 59-61.
Methods	**Allocation:** Non-randomised **Matching:** No matching **Blindness:** Non-blind **Setting:** Outpatient **Raters:** Not reported **Country:** UK
Participants	**Diagnosis:** ICD-10 ASD **Coexisting conditions:** OCD. 50% of the CBT group and 42% of the treatment as usual group had additional psychopathology and the majority of additional diagnoses were of recurrent uni-polar depression or anxiety disorder **Qualifying Diagnostic Assessment:** ADI (in 67% of cases), ADOS (in 13% of cases) **N:** 24 **Age:** Range not reported (means: Treatment as usual group mean: 32.1 years; CBT group mean: 23.8 years) **Sex:** Male: 21; Female: 3 **Ethnicity:** Not reported **IQ:** Range not reported (means: Mean VIQ: 100.3; mean PIQ: 95.5 (WAIS-III)) **Inclusion criteria:** High-functioning adults with autism and co-morbid OCD who were referred to specialist autism clinic
Interventions	1. CBT for OCD, comprising exposure and response prevention and cognitive appraisal of OCD-related beliefs (N=12) 2. Treatment as usual (N=12) **Duration:** **Intervention:** 10-50 (mean=27.5) treatment sessions **Follow-up:** Mean of 15.9 months
Outcomes	The primary outcome was treatment effects on co-existing conditions, in this case OCD, as measured by the Yale-Brown Obsessive Compulsive Scale (YBOCS) severity scale. OCD symptoms were carefully distinguished from the repetitive phenomena typically seen in autism.
Study Design	Quasi-experimental (parallel groups)
Source of funding	South London and Maudsley NHS Foundation Trust
Limitations	1. The treatment as usual group were significantly older than the CBT group 2. Small sample size 3. Changes in medication were introduced at mid-treatment in some cases 4. In 50% of the CBT cases, the YBOCS was completed by the treating therapist 5. The CBT group had severer OCD symptoms at baseline, and the treatment effects may simply reflect a regression to the mean
Notes	

Study ID	TAYLOR2005
Bibliographic reference	Taylor, J.L., Novaco, R.W., Gillmer, B.T., *et al.* (2005) Individual cognitive-behavioural anger treatment for people with mild-borderline intellectual disabilities and histories of aggression: a controlled trial. *British Journal of Clinical Psychology*, 44, 367-382.
Methods	**Allocation:** Non-randomised **Matching:** No matching **Blindness:** Non-blind **Setting:** Inpatient forensic **Raters:** Self- and staff-reporters **Country:** UK
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** WAIS-R **N:** 36 **Age:** Range not reported (means: Treatment group mean: 29.4 years; control group mean: 29.9 years) **Sex:** Male: 36; Female: 0 **Ethnicity:** Not reported **IQ:** Range not reported (means: Treatment group mean: 67.1; control group mean: 70.7) **Inclusion criteria:** Male 18-60 years; FIQ 55-80; detained under sections of the Mental Health Act 1983; self-report total score ≧90 on the Novaco Anger Scale (NAS); self-report total score ≧55 on the Provocation Inventory (PI); no active (uncontrolled) Axis I mental disorder (DSM-IV); no presence of epilepsy that was judged to be intrinsic to the patient's anger/aggression problems; no plans for discharge or transfer during the 6-month period from the beginning of treatment
Interventions	1. CBT anger treatment guided by treatment manual of Taylor and Novaco (1999, 2005) (N=16) 2. Routine care control group (N=20) **Duration:** **Intervention:** 18 sessions consisting of 6-week psychoeducational preparatory phase, followed by 12-week treatment phase **Follow-up:** 4 months
Outcomes	The primary outcome was anger management. To measure anger disposition the Novaco Anger Scale (NAS) and the Anger Expression (AX) scale of the Spielberger State-Trait Anger Expression Inventory (STAXI) was used. The Provocation Inventory (PI) was used to measure disposition to anger reactivity across a range of potentially anger-provoking situations. The Anger Control subscale of the Anger Expression (AX) was used as an index of participants' capacity to regulate their anger. Finally, the Ward Anger Rating Scale (WARS) was used to rate the patients' behaviour during the previous 7 days. Data for the PI were extracted.
Study Design	Quasi-experimental (parallel groups)
Source of funding	Not reported
Limitations	1. Small sample size
Notes	

Study ID	TSE2007
Bibliographic reference	Tse, J., Strulovitch, J., Tagalakis, V., *et al*. (2007) Social skills training for adolescents with Asperger syndrome and high-functioning autism. *Journal of Autism and Developmental Disorders, 37*, 1960–1968.
Methods	**Allocation:** Not applicable - no control group **Matching:** Not applicable - no control group **Blindness:** Non-blind **Setting:** Outpatient **Raters:** Parent-report **Country:** Canada
Participants	**Diagnosis:** ASD **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Not reported **N:** 46 **Age:** 13-18 years (mean: 14.6 years) **Sex:** Male: 28; Female: 18 **Ethnicity:** Not reported **IQ:** Not reported **Inclusion criteria:** Adolescents were 13-18 years old and referred to the group from psychiatry and community clinics across the McGill University network, participants had a diagnosis of ASD, adequate language skills for participation in activities, and able to talk about their interests and to verbalize some goals for participation
Interventions	1. Social skills group (N=46) which combined psychoeducational and experiential methods of teaching social skills, with emphasis on learning through role play **Duration:** **Intervention:** 1-1.5 hour meetings held weekly for 12 weeks **Follow-up:** 12 weeks
Outcomes	The primary outcome was social interaction as measured by the parent-completed Social Responsiveness Scale (SRS) which measured children's social competence, and the Nisonger Child Behaviour Rating Form (N-CBRF) positive social subscale. Data were extracted for the SRS. A secondary outcome was challenging behaviour as measured by the Aberrant Behaviour Checklist (ABC) Irritability subscale and the Nisonger Child Behaviour Rating Form (N-CBRF) problem behaviour subscale. Data was extracted for ABC Irritability.
Study Design	Observational (before-and-after)
Source of funding	Not reported
Limitations	1. Small sample size 2. No control group 3. Incomplete data sets
Notes	

Study ID	WEBB2004
Bibliographic reference	Webb, B.J., Miller, S.P., Pierce, T.B., *et al.* (2004) Effects of social skill instruction for high-functioning adolescents with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities, 19*, 53-62.
Methods	**Allocation:** Not applicable - no control group **Matching:** Not applicable - no control group **Blindness:** Non-blind **Setting:** Community **Raters:** Parent-rated scale **Country:** USA
Participants	**Diagnosis:** ASD **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Not reported **N:** 10 **Age:** 12-17 years (mean: 14.8 years) **Sex:** Male: 10; Female: 0 **Ethnicity:** White N: 9; Asian N: 1 **IQ:** 81-132 (mean: 100.5) **Inclusion criteria:** Participants needed to have current educational eligibility for an autism program, be aged 12-18 years, have receptive and expressive language ability >70 standard score s measured within last 3 years, be currently attending a general education classroom for at least 1 lesson a day, have a deficit in social skills, and have parental agreement to transport the child to and from sessions twice a week for the 10 week project
Interventions	1. SCORE social skills intervention (N=10) **Duration:** **Intervention:** 13 1-hour sessions twice a week for 6.5 weeks **Follow-up:** 10 weeks
Outcomes	The primary outcome was social interaction as assessed by role-play behavioural observations and the parent-completed Social Skills Rating System (SSRS) which was used as an index of parental perception of changes in the social skills of the participants. Data was extracted for the SSRS.
Study Design	Observational (before-and-after)
Source of funding	Not reported
Limitations	1. Small sample size 2. No control group
Notes	

1.4.2 Characteristics of excluded studies

ALANSARI1996

Reason for exclusion	This paper was from the intellectual disability sift but only 63% of sample had intellectual disabilities and all had co-morbid psychiatric diagnoses

APPLE2005

Reason for exclusion	Sample size was less than 10 per arm

ATTWOOD2004

Reason for exclusion	Descriptive paper

AZRIN1973

Reason for exclusion	Sample size is less than 10 per arm

BANZETT1991

Reason for exclusion	Sample size was less than 10 per arm

BARLOW2006

Reason for exclusion	Mean age <15 years

BARLOW2008

Reason for exclusion	Mean age <15 years

BAUMINGER2002

Reason for exclusion	Mean age <15 years

BEAUMONT2008

Reason for exclusion	Mean age <15 years

BIZARRA2009

Reason for exclusion	This paper was from the intellectual disabilities sift but only 44% of the study sample had intellectual disability

BOLTE2002

Reason for exclusion	Sample size was less than 10 per arm

BRODERICK2002

Reason for exclusion	Sample size was less than 10 per arm

CARROLL1978

Reason for exclusion	Sample size was less than 10 per arm

CARTER2005

Reason for exclusion	Sample size (N=5 with autism)

CHALFANT2007

Reason for exclusion	Mean age <15 years

CRAIG2006

Reason for exclusion	Sample size was less than 10 per arm

DAVIS1991

Reason for exclusion	Mean age <15 years

DIXON1998

Reason for exclusion	Sample size was less than 10 per arm

DIXON2001

Reason for exclusion	Sample size was less than 10 per arm

DUNLAP1984

Reason for exclusion	Sample size was less than 10 per arm

EBERLIN1993

Reason for exclusion	Data could not be extracted as no statistical analysis is reported

EIKESETH2005

Reason for exclusion	Mean age <15 years

ELDEVIK2006

Reason for exclusion	Mean age <15 years

EPP2008

Reason for exclusion	No details given as to diagnosis of sample so cannot ascertain whether this is an autistic population

FARR2010

Reason for exclusion	Sample size was less than 10 per arm

FAYYAD2010

Reason for exclusion	Mean age <15 years

FELDMAN1992

Reason for exclusion	Data could not be extracted as no statistical analysis reported

FELDMAN2002

Reason for exclusion	Mean age <15 years

FIELD2001

Reason for exclusion	Mean age <15 years

FRANKEL2010

Reason for exclusion	Mean age <15 years

FRIMAN1994

Reason for exclusion	Letter to editor - no useable data

GEURTS2008

Reason for exclusion	Mean age <15 years

GHEZZI2007

Reason for exclusion	Descriptive paper

GREENBERG2008

Reason for exclusion	Mean age <15 years

GUTSTEIN2007

Reason for exclusion	Mean age <15 years

HARCHIK1990

Reason for exclusion	Sample size was less than 10 per arm

HAYS2007

Reason for exclusion	Descriptive paper

HIGBEE2002

Reason for exclusion	Sample size was less than 10 per arm

HUDSON1982

Reason for exclusion	Mean age <15 years

HUDSON2003

Reason for exclusion	Mean age <15 years

ISRAEL1993

Reason for exclusion	Data could not be extracted as no statistical analysis reported

KASHIMA1988

Reason for exclusion	Mean age <15 years

KAZDIN1993

Reason for exclusion	Not primary data

KEEL1997

Reason for exclusion	Data could not be extracted

KEELING2007

Reason for exclusion	Sample size and co-morbidity: intellectual disabilities population was small (N=11) and 3 had acquired brain injury

KENT1994

Reason for exclusion	Data could not be extracted as no statistical analysis reported

KIRKHAM1993

Reason for exclusion	Mean age <15 years

KOEGEL1988

Reason for exclusion	Sample size was less than 10 per arm

KRATOCHWILL2003

Reason for exclusion	Mean age <15 years

LAUD2009

Reason for exclusion	Mean age <15 years

LEGOFF2004

Reason for exclusion	Mean age <15 years

LEGOFF2006

Reason for exclusion	Mean age <15 years

LEUNG2003

Reason for exclusion	Mean age <15 years

LIM2007

Reason for exclusion	Mean age <15 years

LLEWELLYN2003

Reason for exclusion	Sample size was less than 10 per arm for statistical analysis as a cross-over design was used

LOVAAS1973

Reason for exclusion	Mean age <15 years

LOVELAND1991

Reason for exclusion	Sample size is less than 10 per arm for post-hoc tests for intervention efficacy

LUND1992

Reason for exclusion	Sample size was less than 10 per arm

MARTIN2003

Reason for exclusion	Mean age <15 years

MATSON1980A

Reason for exclusion	Data could not be extracted as ANOVA is 2x2x3

MATSON1980B

Reason for exclusion	Data could not be extracted as ANOVA is 2x3

MATSON1982

Reason for exclusion	Data could not be extracted as ANOVA is 3x1

MATSON1998

Reason for exclusion	Data could not be extracted as ANOVA is 2x2

MATSUMOTO2007

Reason for exclusion	Mean age <15 years

MAZURYK1978

Reason for exclusion	Mean age <15 years

MCCARRAN1990

Reason for exclusion	Sample size is less than ten participants per arm

MCCUBBIN1988

Reason for exclusion	Data could not be extracted as no measure of variability was reported

MCCLANNAHAN2002

Reason for exclusion	Data could not be extracted

MCGARRY1979

Reason for exclusion	Data could not be extracted as no statistical analysis reported

MCGREGOR1998

Reason for exclusion	Mean age <15 years

MCGREGOR1999

Reason for exclusion	Sample size was less than 10 per arm

MESIBOV1984

Reason for exclusion	Data could not be extracted

MESIBOV1990

Reason for exclusion	Data from MESIBOV1984

MEYER1987

Reason for exclusion	Sample size was less than 10 per arm

MICHIE1998

Reason for exclusion	Data could not be extracted

MILLER1973

Reason for exclusion	Mean age <15 years

MORAWSKA2007

Reason for exclusion	Mean age <15 years

MYLES1996B

Reason for exclusion	Duplicate data from MYLES1996A

NAJDOWSKI2010

Reason for exclusion	Sample size is less than ten participants per arm

NELSON1980

Reason for exclusion	Mean age <15 years

NIKOPOULOS2007

Reason for exclusion	Sample size was less than 10 per arm

NIND1996

Reason for exclusion	Sample size was less than 10 per arm

NIND1999

Reason for exclusion	Descriptive paper

NORVELL1989

Reason for exclusion	Sample size was less than 10 per arm

OCONNOR1996

Reason for exclusion	Descriptive paper

ODELL1977

Reason for exclusion	Descriptive paper

ONEILL2002

Reason for exclusion	Sample size is less than ten participants per arm

PASSERINO2008

Reason for exclusion	Sample size was less than 10 per arm

PEARSON1999

Reason for exclusion	Mean age <15 years

RIVERS2010

Reason for exclusion	Mean age <15 years

ROEYERS1996

Reason for exclusion	Mean age <15 years

ROSE2000

Reason for exclusion	Over-lapping (but smaller) data set with ROSE2005

ROSE2009

Reason for exclusion	Mean age <15 years

ROSSITER1998

Reason for exclusion	Sample size was less than 10 per arm

ROTATORI1979

Reason for exclusion	Sample size was less than 10 per arm

ROUTH1995

Reason for exclusion	Mean age <15 years

RUSSELL1999

Reason for exclusion	Mean age <15 years

SALLOWS2005

Reason for exclusion	Mean age <15 years

SCHALLER2005

Reason for exclusion	Data could not be extracted

SCHREIBMAN1991

Reason for exclusion	Sample size is less than ten participants per arm and mean age <15 years

SCHULTZ1992

Reason for exclusion	Mean age <15 years

SEUNG2006

Reason for exclusion	Mean age <15 years

SHORT1984

Reason for exclusion	Mean age <15 years

SILVER2001

Reason for exclusion	Data could not be extracted

SMITH1994

Reason for exclusion	Data could not be extracted as no statistical analysis is reported

SMITH2005

Reason for exclusion	Mean age <15 years

SOFRONOFF2004

Reason for exclusion	Mean age <15 years

SOFRONOFF2007

Reason for exclusion	Mean age <15 years

SPACCARELLI1992

Reason for exclusion	Mean age <15 years

STEELEMCCARRAN1990

Reason for exclusion	Sample size was less than 10 per arm

STRAIN2000

Reason for exclusion	Sample size was less than 10 per arm

TAANILA1998

Reason for exclusion	Mean age <15 years

TANAKA2010

Reason for exclusion	Mean age <15 years

TAVORMINA1975

Reason for exclusion	Mean age <15 years

TAYLOR2008

Reason for exclusion	Mean age <15 years

TAYLOR2009

Reason for exclusion	Data could not be extracted as 3x1 ANOVA

THOMPSON1996

Reason for exclusion	Mean age <15 years

THORELL2009

Reason for exclusion	Mean age <15 years

TO2000

Reason for exclusion	Data could not be extracted as no measure of variance reported

TRACE1977

Reason for exclusion	Sample size was less than 10 per arm

TYSON1991

Reason for exclusion	Data could not be extracted as no statistical analysis reported

USLU2006

Reason for exclusion	Mean age <15 years

VANOORSOUW2009

Reason for exclusion	Mean age <15 years

VARMA1992

Reason for exclusion	Mean age <15 years

WACHTEL2006

Reason for exclusion	Sample size was less than 10 per arm

WAGNER1975

Reason for exclusion	Descriptive paper

WEBSTERSTRATTON1994

Reason for exclusion	Mean age <15 years

WEINBLATT2008

Reason for exclusion	Mean age <15 years

WELLMAN2002

Reason for exclusion	Mean age <15 years

WHITTINGHAM2009

Reason for exclusion	Mean age <15 years

WILLIAMS1989

Reason for exclusion	Mean age <15 years

WILLIAMS2005

Reason for exclusion	Mean age <15 years

WOLFE2009

Reason for exclusion	Case studies

WONG2006

Reason for exclusion	Mean age <15 years

ZINGALE2008

Reason for exclusion	Mean age <15 years

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1.5 BIOMEDICAL INTERVENTIONS

1.5.1 Characteristics of included studies

Study ID	BELSITO2001
Bibliographic reference	Belsito, K.M., Law, P.A., Kirk, K.S., *et al*. (2001) Lamotrigine therapy for autistic disorder: a randomized, double-blind, placebo-controlled trial. *Journal of Autism and Developmental Disorders, 31*, 175-181.
Methods	**Allocation:** Randomised **Matching:** No matching **Blindness:** Double-blind **Setting:** Not reported **Raters:** Caregiver-report and clinician-rated **Country:** USA
Participants	**Diagnosis:** ASD **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** ADI-R **N:** 35 **Age:** 3-11 years (mean: 5.8 years) **Sex:** Male: 33; Female: 2 **Ethnicity:** Caucasian: N=22 **IQ:** Not reported **Inclusion criteria:** Children with a primary diagnosis of ASD **Exclusion criteria:** Children with autistic disorder associated with comorbid medical etiologies, such as fragile X syndrome or metabolic disorders were excluded. Children with severe or profound mental retardation in whom a definitive diagnosis of autism could not be made were excluded. No participants were taking concurrent medications for at least 1 month before entering the trial
Interventions	1. Lamotrigine (mean: 5mg/kg per day, administered twice daily) (N=14) 2. Placebo (N=14) **Duration:** **Intervention:** 12 weeks **Follow-up:** 18 weeks
Outcomes	Primary outcomes were autistic behaviours as measured by the Autism Behaviour Checklist (AUBC; Krug et al., 1993), the Pre-Linguistic Autism Diagnostic Observation Schedule (PL-ADOS; DiLavore et al., 1995); and the Childhood Autism Rating Scale (CARS; Schopler et al., 1988). Other outcomes included challenging behaviour as measured by the Aberrant Behaviour Checklist (ABC; Aman et al., 1985), and adaptive behaviour as measured by the Vineland Adaptive Behaviour Scales (VABS; Sparrow et al., 1984).
Study Design	RCT
Source of funding	GlaxoWellcome
Limitations	1. Narrative reporting of results does not allow for extraction of data to calculate effect sizes.
Notes	• The trial ended with a 4-week drug-free period but data not extracted for this

	• A total of 7 participants dropped out; N=5 from experimental group and N=2 from placebo group • Intention-to-treat analysis was not performed • The mean number of reported side effects for lamotrigine was 0.63 and for placebo 0.69. Insomnia and hyperactivity were the most frequently reported side effects.

Study ID	BUITELAAR1992
Bibliographic reference	Buitelaar, J.K., van Engeland, H., de Kogel, K., *et al*. (1992) The adrenocorticotrophic hormone (4-9) analog ORG 2766 benefits autistic children: Report on a second controlled clinical trial. *Journal of the American Academy of Child and Adolescent Psychiatry, 31*, 1149-1156.
Methods	**Allocation:** Randomised **Matching:** Treatment order groups matched by IQ and age **Blindness:** Double-blind **Setting:** Outpatient **Raters:** Parent-, teacher-, and clinician-rated scales. No details given about raters of behavioural observation **Country:** The Netherlands
Participants	**Diagnosis:** DSM-II-R ASD (autistic disorder) **Coexisting conditions:** N=2 convulsive disorder; N=1 congenital thyroid aplasia **Qualifying Diagnostic Assessment:** Diagnosis made independently by 2 child psychiatrists on the basis of extensive diagnostic evaluations which included review of previous records, a parent interview, a child psychiatric observation and a complete medical diagnostic workup. Subjects additionally characterized by scores on the Childhood Autism Rating Scale (CARS). **N:** 21 **Age:** 5-15 years (mean: 10 years) **Sex:** Male: 17; Female: 4 **Ethnicity**: Not reported **IQ:** Range and mean not reported (N=4 in IQ range 22-40; N=4 in IQ range 40-55; N=3 in IQ range 55-70; N=10 in IQ range 70-85) **Inclusion criteria:** Not reported
Interventions	1. ACTH (ORG 2766; oral tablets 40mg/day) (N=21, but sample size halved for analysis as crossover study) 2. Placebo (oral tablets) (N=21, but sample size halved for analysis as crossover study) **Duration:** **Intervention:** 8 weeks per intervention **Follow-up:** 36 weeks
Outcomes	Primary outcomes were challenging behaviour as measured by behaviour checklist ratings (Aberrant Behaviour Checklist (ABC; Aman et al., 1985); General Assessment Parents Scale (GAP) designed for this study) and behaviour observation (playroom sessions); and symptom severity/improvement as measured by the Clinical Global

	Impressions Scale (CGI)
Study Design	RCT (crossover)
Source of funding	Tablets of ORG 2766 and placebo tablets supplied by Organon International B.V.
Limitations	1. Small sample size 2. Data could not be extracted for ABC scales
Notes	• Data could not be extracted for ABC-teacher ratings as data was only available for 15 subjects and hence sample size is less than 10 per arm as this is a crossover study • N=2 on antiepileptic medication (sodium valproate and ethosuximide), N=1 received thyroid substitution therapy. The dosage remained fixed throughout the study.

Study ID	BUITELAAR1996
Bibliographic reference	Buitelaar, J.K., Dekker, M.E.M., van Ree, J.M., *et al*. (1996) A controlled trial with ORG 2766, an ACTH-(4-9) analog, in 50 relatively able children with autism. *European Neuropsychopharmacology, 6*, 13-19.
Methods	**Allocation:** Randomised **Matching:** No matching **Blindness:** Double-blind **Setting:** Outpatient **Raters:** Parent-, teacher-, and clinician-rated scales. Rater details not reported for the behaviour observation. **Country:** The Netherlands
Participants	**Diagnosis:** DSM-IIIR ASD **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Diagnosis made independently by 2 child psychiatrists on the basis of extensive diagnostic evaluations which included review of previous records, a parent interview, a child psychiatric observation and a complete medical diagnostic workup. Subjects additionally characterized by scores on the Childhood Autism Rating Scale (CARS). **N:** 47 **Age:** 5-17 years (means: experimental group mean: 9.7 years; control group mean: 10.6 years) **Sex:** Male: 32; Female: 15 **Ethnicity:** Not reported **IQ:** Range not reported (means: experimental group mean: 79.9; control group mean: 77.2) **Inclusion/exclusion criteria:** Diagnosis of autistic disorder according to DSM-IIIR criteria; PIQ >60 on WISC-R; aged 7-15 years; and no concurrent treatment with psychotropic medication.
Interventions	1. ACTH (ORG 2766; oral tablets 40mg once daily) (N=29) 2. Placebo (oral tablets) (N=18) **Duration:** **Intervention:** 6 weeks

	Follow-up: 6 weeks
Outcomes	Primary outcomes of interest, and for which data was available, were challenging behaviour as measured by the parent- and teacher-completed Aberrant Behaviour Checklist (ABC; Aman et al., 1985), and symptom severity/improvement as measured by the investigator-rated Clinical Global Impressions Scale (CGI; NIMH, 1985)
Study Design	RCT
Source of funding	Tablets of ORG 2766 and placebo tablets provided by Organon International B.V.
Limitations	1. There was a trend for participants in experimental group to be younger and to have higher CARS scores than subjects treated with placebo 2. Randomisation methods unclear. Authors state "The subjects were in principle randomized" 3. Uneven sample sizes
Notes	• N=50 children with ASD were included in the study but N=3 dropped out (N=1 ORG2766; N=2 placebo) due to an increase in anxiety, nervousness, and irritability after they had ingested the tablets. As demographic characteristics are only reported for the 47 completers, the N is given as 47 above • Data could not be extracted for the playroom behaviour observation as more subjects dropped out in the placebo group resulting in sample size of less than 10 per arm and potential attrition bias • There was no systematic difference in the number or distress of side effects. Side effects associated with ORG2766 included headache (N=2), increase in aggression and oppositional behaviour (N=2), increase in anxiety (N=1) and emotional lability (N=1). Side effects associated with placebo were increase in anxiety (N=3) and an increase in stereotypies (N=1). • Continuous data extracted for CGI as reported. • Dichotomous data extracted for ABC Social withdrawal subscale with responders classified as participants showing reliable improvement on the ABC social withdrawal scale either at home or at school or in both contexts (reliable change (RC) approach, Jacobson & Truax, 1991, used) and extracted as reported

Study ID	CHEZ2000
Bibliographic reference	Chez, M.G., Buchanan, C.P., Bagan, B.T., *et al*. (2000) Secretin and autism: a two-part clinical investigation. *Journal of Autism and Developmental Disorders, 30*, 87-94.
Methods	**Allocation:** Randomised **Matching:** No matching **Blindness:** Double-blind **Setting:** Not reported **Raters:** Parent-rated scale **Country:** USA
Participants	**Diagnosis:** ASD **Coexisting conditions:** GI problems (N=9); past abnormal EEG (N=10) **Qualifying Diagnostic Assessment:** Not reported **N:** 25 **Age:** Range not reported (mean: 6 years) **Sex:** Male: 22; Female: 3 **Ethnicity:** Not reported **IQ:** Not reported **Inclusion criteria:** Not reported
Interventions	1. Secretin (intravenous injection, single dose 2 IU/kg) (N=25, but sample size halved for analysis as this is a crossover study) 2. Placebo (normal saline, intravenous injection, single dose) (N=25, but sample size halved for analysis as this is a crossover study) **Duration:** **Intervention:** Single dose **Follow-up:** 8 weeks
Outcomes	Primary outcome was autistic behaviours as measured by a modified parent-completed version of the Childhood Autism Rating Scale (CARS)
Study Design	RCT (crossover)
Source of funding	Not reported
Limitations	1. Small sample size
Notes	• This double-blind placebo controlled trial was preceded by an open-label trial of secretin, however, data is not extracted for that phase • 1 participant dropped out

Study ID	CHEZ2002
Bibliographic reference	Chez, M.G., Buchanan, C.P., Aimonovitch, M.C., *et al*. (2002) Micronutrients versus standard medication management in autism: a naturalistic case-control study. *Journal of Child and Adolescent Psychopharmacology, 17*, 833-837.
Methods	**Allocation:** Randomised **Matching:** No matching **Blindness:** Double-blind **Setting:** Not reported **Raters:** Parent-rated and clinician-rated scales **Country:** USA
Participants	**Diagnosis:** DSM-IV-R ASD **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Not reported **N:** 31 **Age:** 3-12 years (mean: 7.45 years) **Sex:** Male: 21; Female: 10 **Ethnicity:** Not reported **IQ:** Not reported **Inclusion criteria:** Children aged 3-12 years with a prior diagnosis of ASD (DSM-IV-R)
Interventions	1.L-Carnosine (powder to be mixed with food or drink; dose: 400mg twice daily) (N=14) 2. Placebo (identical in powdered appearance) (N=17) **Duration:** **Intervention:** 8 weeks **Follow-up:** 8 weeks
Outcomes	Primary outcome was autistic behaviours as measured by the Childhood Autism Rating Scale (CARS) and the Gilliam Autism Rating Scale (GARS). Secondary outcome was clinical global impression improvement scale
Study Design	RCT
Source of funding	Not reported
Limitations	1. Significant difference between groups in baseline scores on the Communication subscale of the Gilliam Autism Rating Scale
Notes	• Data not extracted for GARS scores due to baseline group differences

Study ID	CHEZ2003
Bibliographic reference	Chez, M.G., Buchanan, T.M., Becker, M., *et al*. (2003) Donepezil hydrochloride: a double-blind study in autistic children. *Journal of Pediatric Neurology, 1*, 83-88.
Methods	**Allocation:** Randomised **Matching:** No matching **Blindness:** Double-blind **Setting:** Not reported **Raters:** Parent-rated scale **Country:** USA
Participants	**Diagnosis:** DSM-IV ASD (N=13 autistic disorder; N=27 PDD-NOS; N=3 Landau-Kleffner syndrome) **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Diagnosis confirmed by a pediatric neurologist after completing a comprehensive neurological evaluation and also by a clinical interview with a clinical psychologist **N:** 43 **Age:** 2-10 years (mean: 6.8 years) **Sex:** Male: 35; Female: 8 **Ethnicity:** Not reported **IQ:** Not reported **Inclusion criteria:** Males or females aged 2-10 with prior DSM-IV diagnosis of ASD **Exclusion criteria:** Concomitant neurological syndrome or disease in which neurological compromise is a feature (e.g. neurofibromatosis)
Interventions	1. Donepezil hydrochloride (capsule sprinkle form for oral administration; dose 1.25-2.5mg/day) 2. Placebo (identical in appearance capsule sprinkle form) **Duration:** **Intervention:** 6 weeks **Follow-up:** 6 weeks
Outcomes	Primary outcome was autistic behaviours as assessed by a modified parental rating report version of the Childhood Autism Rating Scale (CARS)
Study Design	RCT
Source of funding	Not reported
Limitations	1. Potential attrition bias
Notes	• The double-blind placebo-controlled phase was followed by a 6 week open-label extension. However, data for that phase is not extracted here. • Included patients with abnormal EEG • Patients were maintained on the medications that they had initiated prior to study start: N=32 anticonvulsants (divalproex sodium, valproic acid or lamotrigine); N=6 corticosteroids (pulse-dose prednisone or prednisolone); N=8 CNS stimulants (dextroamphetamine/amphetamine or methylphenidate); N=7 antidepressants (fluoxetine hydrochloride or paroxetine); N=4 antipsychotics (risperidone); and N=9 alpha adrenergic blocking agents (clonidine)

	• 9 patients dropped out of the study: 6 from experimental and 3 from control. N=2 on donepezil hydrochloride discontinued due to diarrhoea or stomach cramping and N=4 due to increased irritability accompanied by increased screaming and vocalizations. N=3 in placebo group dropped out due to failure to attend post-test appointment

Study ID	CHEZ2007
Bibliographic reference	Chez, M.G., Burton, Q., Dowling, T., *et al*. (2007) Memantine as adjunctive therapy in children diagnosed with autistic spectrum disorders: an observation of initial clinical response and maintenance tolerability. *Journal of Child Neurology*, *22*, 574-579.
Methods	**Allocation:** Not applicable - no control group **Matching:** Not applicable - no control group **Blindness:** Not applicable - no control group **Setting:** Not reported **Raters:** Clinician-rated scale **Country:** USA
Participants	**Diagnosis:** DSM-IV ASD (N=105 autism; N=46 PDD-NOS) **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Clinical observation by primary author **N:** 151 **Age:** 2-26 years (mean: 9.3 years) **Sex:** Male: 129; Female: 22 **Ethnicity:** Not reported **IQ:** Not reported **Exclusion criteria:** Children excluded if any underlying genetic disorders such as Fragile X or Rett syndrome, and none had known brain malformations or known metabolic disorders such as aminoacidurias or degenerative diseases; concomitant lamotrigine not allowed as it may inhibit glutamate; and patients with active clinical seizures excluded
Interventions	1. Memantine (once or twice daily taken whole or crushed; final dose 2.5-30mg/day, mean: 12.67mg/day) (N=151) **Duration:** **Intervention:** 1-20 months (mean: 9.27 months) **Follow-up:** 1-20 months (mean: 9.27 months)
Outcomes	Primary outcomes of interest were the core ASC symptom of communication and challenging behaviour. Both of these outcomes were measured with the Clinical Global Impression Improvement scale, CGI-I language was based on both receptive skills and expressive utterances and CGI-I behaviour was based on cognitive improvement as well as increased social interest or efforts
Study Design	Observational (before-and-after)
Source of funding	Not reported
Limitations	1. Efficacy data cannot be extracted

Notes	• Participants with an abnormal baseline EEG were not excluded • Concurrent medications included SSRIs (N=20 fluoxetine; N=11 citralopram; N=6 sertraline; N=2 fluvoxamine; N=6 escitralopram; N=3 others); atypical antipsychotics (N=31 risperidone; N=5 aripipazole; N=17 quitiepine; N=2 olazepine; N=3 ziprazidone); stimulants (N=20 amphetamine salts; N=22 methylphidate products); atomoxetine (N=5); alpha-adrenergic antagonists (N=14 clonidine; N=19 tizanidine; N=4 guanfasine); lithium (N=5); cholinesterase inhibitors (N=15 donezepil; N=9 rivastigmine; N=2 galantamine); and antiepileptic drugs (N=77 valproic acid; N=1 topiramate; N=1 levetiracitam). All patients on concurrent medication were kept as stable as possible and were not given memantine unless they were already stable on other medications for at least 8 weeks

Study ID	COOK1992
Bibliographic reference	Cook, E.H. Jr., Rowlett, R., Jselskis, C., *et al*. (1992) Fluoxetine treatment of children and adults with autistic disorder and mental retardation. *Journal of the American Academy of Child and Adolescent Psychiatry, 31*, 739-745.
Methods	**Allocation:** Not applicable - no control group **Matching:** Not applicable - no control group **Blindness:** Open-label **Setting:** Outpatient **Raters:** Treating clinician **Country:** USA
Participants	**Diagnosis:** DSM-III-R ASD (autistic disorder) **Coexisting conditions:** Intellectual disabilities (profound N=3; severe N=7; moderate N=3; mild N=6, borderline N=2); OCD (N=3); impulse control disorder not otherwise specified (NOS) with self-injurious behaviour (SIB) (N=6); impulse control disorder NOS without SIB (N=5); cyclothymia (N=1); bipolar disorder NOS (N=1); eating disorder (N=1) **Qualifying Diagnostic Assessment:** Not reported **N:** 23 **Age:** 7-28 years (mean: 15.9 years) **Sex:** Male: 18; Female: 5 **Ethnicity:** Not reported **IQ:** Not reported but with intellectual disabilities Inclusion criteria: Consecutive series of patients treated with fluoxetine by child and adolescent psychiatrists at the Unversity of Chicago in an outpatient setting between 1988 and 1990.
Interventions	1. Fluoxetine (oral, dose range from 20mg every other day to 80mg/day) **Duration:** **Intervention:** 11-426 days (mean: 189 days) **Follow-up:** 11-426 days (mean: 189 days)
Outcomes	The primary outcome was symptom severity/improvement as assessed by the Clinical Global Impressions (CGI) scale. Two subscales

	were used. The first was an overall rating of severity of illness and therapeutic efficacy. The second was a rating limited to perseverations, compulsions, or rituals depending on the individual's particular difficulties
Study Design	Observational (before-and-after study)
Source of funding	Harris Center for Developmental Studies; NIMH Child and Adolescent Mental Health Academic Award MH00822
Limitations	1. Coexisting psychiatric conditions may threaten generalizability of findings 2. No control group and efficacy data cannot be extracted 3. Small sample size 4. Question of indirectness as adolescent sample
Notes	• A group with intellectual disabilities and without autism were also studied, however, data is not extracted for this group • Concomitant psychotropic medication included neuroleptics (N=8); carbamazepine (N=1); lithium carbonate (N=2); clonidine and alprazolam (N=1); and methylphenidate (N=1) • 6/23 participants had side effects that significantly interfered with function or outweighed therapeutic effects. Side effects included hyperactivity, insomnia, elated affect, decreased appetite, behavioural problems, and maculopapular rash

Study ID	DOSMAN2007
Bibliographic reference	Dosman, C.F., Brian, J.A., Drmic, I.E., *et al*. (2007) Children with autism: effect of iron supplementation on sleep and ferritin. *Pediatric Neurology, 36*, 152-158.
Methods	**Allocation:** Not applicable - no control group **Matching:** Not applicable - no control group **Blindness:** Open-label **Setting:** Not reported **Raters:** Parent-rated and clinician-rated scales **Country:** Canada
Participants	**Diagnosis:** ASD **Coexisting conditions:** Majority of sample had restless sleep (occurring on average once or twice per week) **Qualifying Diagnostic Assessment:** ADI-R, ADOS, and clinical evaluation **N:** 33 **Age:** 2-10 years (mean: 6.5 years) **Sex:** Male: 27; Female: 6 **Ethnicity:** Not reported **IQ:** Not reported **Exclusion criteria:** Currently receiving iron supplementation
Interventions	1. Iron supplement (oral preparation 6mg elemental iron/kg/day N=23; or if anticipated that oral preparations would not be accepted sprinkles 2 sachets total of 60mg/day N=10) (N=33) **Duration:** **Intervention:** 8 weeks

	Follow-up: 8 weeks
Outcomes	Primary outcome was sleep patterns as assessed by two parent-report questionnaires (Sleep Disturbance Scale for Children, Bruni et al. 1996; and Periodic Leg Movements during Sleep scale of Chervin & Hedger, 2001). Secondary outcome was challenging behaviour as measured by a modified Clinical Global Impressions Scale to measure the frequency of irritability (CGI-Irritability)
Study Design	Observational (before-and-after)
Source of funding	Trainee's Start-Up Fund, The Hospital for Sick Children, Toronto, Ontario, Canada
Limitations	1. High attrition rate
Notes	• 43 participants were originally enrolled in the study but data was not reported for participants who withdrew. N=3 refused to take iron preparation; N=2 refused venipuncture; N=2 side effects; N=3 unrelated to procedures • Data reported for ferretin levels but not extracted here

Study ID	DUNNGEIER2000
Bibliographic reference	Dunn-Geier, J., Ho, H.H., Auersperg, E., *et al.* (2000) Effect of secretin on children with autism: a randomized controlled trial. *Developmental Medicine and Child Neurology, 42*, 796-802.
Methods	**Allocation:** Randomised **Matching:** No matching **Blindness:** Double-blind **Setting:** Not reported **Raters:** Parent- and clinician-rated scales **Country:** Canada
Participants	**Diagnosis:** DSM-IV ASD **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Childhood Autism Rating Scale (CARS) **N:** 95 **Age:** 2-7 years (mean: 5.1 years) **Sex:** Male: 88; Female: 7 **Ethnicity:** White: N=75 **IQ:** Not reported **Inclusion criteria:** A diagnosis of autism based on behavioural observation of the child and semistructured interview with the parent (defined as a score of ≥30 on the Childhood Autism Rating Scale, Schopker et al., 1988); a score of ≥6 on the DSM-IV diagnostic criteria for autism; clinical judgement by a developmental pediatrician and registered psychologist experienced in the field of autism **Exclusion criteria:** A recognizable neurological or genetic disorder (e.g. infantile spasms, Rett syndrome, Fragile X syndrome, Tourette syndrome, tuberous sclerosis, phenylketonuria, or neurofibromatosis), a pancreatic or liver disorder, or an allergy to lidocaine or prilocaine; if secretin had been used previously, if there had been any treatment initiated or changed within the 2 months immediately before

	enrolment, or if any treatment was planned to begin within the 3 weeks after injection (including drugs, supplements, dietary changes, and behavioural therapy
Interventions	1. Secretin (single dose injection of 2 CU/kg to a maximum of 75 CU) (N=47) 2. Placebo (single dose injection) (N=48) **Duration:** **Intervention:** Single dose **Follow-up:** 3 weeks
Outcomes	Primary outcomes were autistic behaviours (as measured by the Childhood Autism Rating Scale (CARS) and the Autism Behaviour Checklist, Krug et al., 1993), core autistic symptom of communication (as measured by the Preschool Language Scale-3 (PLS-3), Zimmerman et al., 1992), and side effects (as measured by parent-completed GI symptoms questionnaire and a treatment behaviour/side-effect rating scale designed for this study)
Study Design	RCT
Source of funding	Financial contribution from Children at Risk, Ottawa; and grants from the Children's Hospital of Eastern Ontario Research Institute and the PA Woodward's Foundation
Limitations	1. Short duration of follow-up 2. Data could not be extracted for CARS, ABC, or side effect measures
Notes	Treatment groups significantly different in baseline PLS-3 scores, however, this was controlled for in statistical analysis

Study ID	ERICKSON2007
Bibliographic reference	Erickson, C.A., Posey, D.J., Stigler, K.A., *et al.* (2007) A retrospective study of memantine in children and adolescents with pervasive developmental disorders. *Psychopharmacology, 191*, 141-147.
Methods	**Allocation:** Not applicable - no control group **Matching:** Not applicable - no control group **Blindness:** Not applicable - no control group **Setting:** Outpatient **Raters:** Clinician-rated scale **Country:** USA
Participants	**Diagnosis:** DSM-IV-TR ASD (N=13 autistic disorder; N=3 Asperger's disorder; N=2 PDD-NOS) **Coexisting conditions:** N=11(61%) comorbid mental retardation **Qualifying Diagnostic Assessment:** Not reported **N:** 18 **Age:** 6-19 years (mean: 11.4 years) **Sex:** Not reported **Ethnicity:** Not reported **IQ:** Not reported **Inclusion criteria:** Individuals included were all patients meeting DSM-IV-TR criteria for a PDD who received treatment with memantine. In all cases, memantine was used targeting social impairment (including impaired social use of language) and/or

	inattention/hyperactivity
Interventions	1. Memantine (2.5-20mg/day; mean: 10.1mg/day) (N=18) **Duration:** **Intervention:** 1.5-56 weeks (mean: 19.3 weeks) **Follow-up:** 1.5-56 weeks (mean: 19.3 weeks)
Outcomes	Primary outcome was symptom improvement/severity and as part of routine care the treating physician completed the Clinical Global Impressions-Severity subscale (CGI-S) and CGI-Improvement subscale (CGI-I) (Guy, 1976)
Study Design	Observational (case series)
Source of funding	National Institute of Mental Health (K23 MH68627), a Daniel X. Freedman Psychiatric Research Fellowship, and the Department of Housing and Urban Development (B-01-SP-IN-0200)
Limitations	1. Efficacy data cannot be extracted 2. Small sample size
Notes	• N=13 participants receiving concomitant medications had the doses of these medications held constant during the trial • Challenging behaviour as assessed by the Aberrant Behaviour Checklist (ABC) but this was only for six patients and as such is not extracted as it does not meet the sample size eligibility criterion. • Target symptoms identified as the reason for prescribing memantine included social withdrawal (N=11); inattention (N=8); communication impairment (N=10); and irritability (N=5). Most patients had more than one target symptom. • Overall, adverse effects during treatment were reported in N=7 including irritability (N=4); rash (N=1); emesis (N=1); increased seizure frequency (N=1); and excessive sedation

Study ID	EVANGELIOU2003
Bibliographic reference	Evangeliou, A., Vlachonikolis, I., Mihailidou, H., *et al*. (2003) Application of a ketogenic diet in children with autistic behavior: pilot study. *Journal of Child Neurology, 18*, 113-118.
Methods	**Allocation:** Not applicable - no control group **Matching:** Not applicable - no control group **Blindness:** Not applicable - no control group **Setting:** Not reported **Raters:** Clinician-rated scale **Country:** Greece
Participants	**Diagnosis:** ASD **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Childhood Autism Rating Scale (CARS) **N:** 30 **Age:** 4-10 years (median: 7 years) **Sex:** Male: 16; Female: 14 **Ethnicity:** Not reported **IQ:** Not reported **Inclusion criteria:** Not reported
Interventions	1. Ketogenic diet (The recommended diet was the John Radcliffe diet, which distributes daily energy intake as follows: 30% of energy as medium-chain triglyceride oil, 30% as fresh cream, 11% as saturated fat, 19% as carbohydrates, and 10% as protein. Participants also received vitamin and mineral supplements according to the recommended daily allowances for age) (N=30) **Duration:** **Intervention:** 6 months (with continuous administration for 4 weeks at a time, interrupted by 2-week intervals that were diet free) **Follow-up:** 6 months
Outcomes	Primary outcome was autistic behaviour as measured by the Childhood Autism Rating Scale (CARS; Schopler et al, 1980)
Study Design	Observational (before-and-after)
Source of funding	Not reported
Limitations	1. High attrition rate, only 18 participants completed the diet for a 6 month period
Notes	• All participants were concurrently treated with haloperidol. The participants were treated with haloperidol at least 6 months before the initiation of a ketogenic diet without having any changes in the CARS. During and 6 months before and after the diet, no behavioural treatments were given

Study ID	GAGIANO2005
Bibliographic reference	Gagiano, C., Read, S., Thorpe, L., *et al*. (2006) Short- and long-term efficacy and safety of risperidone in adults with disruptive behaviour disorders. *Psychopharmacology, 179*, 629-636.
Methods	**Allocation:** Randomised **Matching:** No matching **Blindness:** Double-blind **Setting:** Not reported **Raters:** Clinician-rated **Country:** Canada, UK, and South Africa
Participants	**Diagnosis:** DSM-IV intellectual disability **Coexisting conditions:** Conduct disorder, N=44; Disruptive behaviour disorder, N=13; Intermittent explosive disorder, N=11; Oppositional defiant disorder. N=5; and Antisocial personality disorder, N=4. **Qualifying Diagnostic Assessment:** IQ measured at screening using the Wechsler or Stanford-Binet IQ tests **N:** 77 **Age:** 18-59 years (mean not reported) **Sex:** Male: 47; Female: 30 **Ethnicity:** Not reported **IQ:** 35-83 (mean not reported) **Inclusion/exclusion criteria:** Participants aged 18-65 years and had a DSM-IV Axis I diagnosis of conduct disorder, oppositional defiant disorder, antisocial personality disorder, disruptive behaviour disorder, or intermittent explosive disorder. Participants also had to have a DSM-IV Axis II diagnosis of borderline intellectual functioning, or mild or moderate mental retardation, which represents an IQ range of 35-84. Participants were excluded if they had a diagnosis of schizophrenia and other psychotic disorders or pervasive developmental disorder; head injury as a cause of mental impairment (except for birth trauma); seizure disorder requiring medication; clinically relevant abnormal laboratory values outside the normal range; serious or progressive illnesses (including but not restricted to liver or renal insufficiency; cardiac, vascular, gastrointestinal, pulmonary, or endocrine disturbances; or HIV infection); history of tardive dyskinesia or neuroleptic malignant syndrome; or a known hypersensitivity to antipsychotics. Participants who had previously received risperidone for conduct disorder for more than 3 weeks and those who had received risperidone for fewer than 3 weeks and did not respond were also excluded.
Interventions	1. Risperidone (oral tablets, 1-4mg/day with a mean dose of 1.45/day) (N=39) 2. Placebo (oral tablets) (N=38) **Duration:** **Intervention:** 4 weeks **Follow-up:** 52 weeks (open-label continuation)
Outcomes	Primary outcome was symptom severity/improvement (as measured by the Clinical Global Impressions (CGI) Scale, Guy, 1976)
Study Design	RCT
Source of funding	Johnson & Johnson Pharmaceutical Research & Development

Limitations	1. Data for challenging behaviour outcome (ABC scores) could not be extracted
Notes	• Four participants in each group discontinued the study prematurely. No participant discontinued because of adverse events. Two in the placebo group and 1 in the risperidone group withdrew because of insufficient response • Allowable psychotropic medications other than risperidone included antidepressants, lithium, carbamazepine, and valproic acid. Anticholinergic medication was discontinued at study entry. Limited use of sedative and hypnotic medication was allowed. Concomitant use of medications for medical disorders was also allowed. • 25/38 of participants in the placebo group, and 21/39 participants in the risperidone group received concomitant medication • After double-blind RCT participants could enter open-label treatment with risperidone for 48 weeks

Study ID	HAESSLER2007
Bibliographic reference	Haessler, F., Glaser, T., Beneke, M., *et al*. (2007) Zuclopenthixol in adults with intellectual disabilities and aggressive behaviours: discontinuation study. *British Journal of Psychiatry, 190*, 447-448.
Methods	**Allocation:** Randomised **Matching:** No matching **Blindness:** Double-blind **Setting:** Predominantly residential **Raters:** Clinician-rated scale **Country:** Germany
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Not reported **N:** 39 **Age:** 18-50 years (mean not reported) **Sex:** Not reported **Ethnicity:** Not reported **IQ:** 30-70 (mean not reported) **Inclusion/exclusion criteria:** All participants scored below 39 on the Disability Assessment Schedule (Holmes et al., 1982). Exclusion criteria were the presence of a diagnosed neurological disorder (without epilepsy), psychotic disorder, infantile cerebral palsy, hypersensitivity to zuclopenthixol and cardiac abnormalities. Female participants who were sexually active and did not use an effective form of birth control were also excluded.
Interventions	1. Zuclopenthixol (2-20mg/day, mean=11.4mg/day) (N=19) 2. Placebo (N=20) **Duration:** **Intervention:** Up to 12 weeks (discontinuation period) **Follow-up:** 18 weeks

Outcomes	Primary outcome was the challenging behaviour, aggression (as measured by the Modified Overt Aggression Scale (MOAS), Yudofsky et al., 1986). The outcome measure was dichotomous with participants rated as responders or non-responders. Patients with a deterioration of at least 3 points in MOAS sum scores at 2 subsequent visits when compared with their state at randomisation were designated as non-responders. All patients without deterioration were considered to be responders.
Study Design	RCT
Source of funding	Study medication and placebos provided by Bayer Vital GmbH
Limitations	-Low dosages of zuclopenthixol (6-18mg, mean 11.4mg) might be responsible for the relatively high relapse rates in the continuation (zuclopenthixol) subgroup -Small sample sizes
Notes	• Concomitant use of other antipsychotics was not permitted throughout the study. Use of consistent doses of anticonvulsants as well as lithium, medication for extrapyramidal symptoms and benzodiazepines as an anti-epileptic escape medication was permitted. • Psychotropic adjunctive medications given after randomisation (N=7) were equally distributed between the groups and involved the prescription of one benzodiazepine drug in each group. • This was a double-blind placebo controlled withdrawal study including responders from an open-label 6-week treatment with zuclopenthixol • The psychopharmacological mechanism of zuclopenthixol differs slightly from the dopaminergic-serotonergic impact of risperidone • The number of adverse events and possible symptoms of withdrawal, such as nausea, insomnia, and diarrhoea, were recorded and did not differ between the groups

Study ID	HANDEN2006
Bibliographic reference	Handen, B.L. & Hardan, A.Y. (2006) Open-label, prospective trial of olanzapine in adolescents with subaverage intelligence and disruptive behavioral disorders. *Journal of the American Academy of Child and Adolescent Psychiatry, 45*, 928-935.
Methods	**Allocation:** Not applicable - no control group **Matching:** Not applicable - no control group **Blindness:** Open-label **Setting:** Outpatient **Raters:** Primary caregiver-report **Country:** USA
Participants	**Diagnosis:** Intellectual disability and disruptive behaviours **Coexisting conditions:** N=11 disruptive behaviour disorder (DBD); N=12 attention-deficit/hyperactivity disorder; (ADHD) N=2 oppositional defiant disorder (ODD); N=1 stereotypic movement

	disorder; N=1 anxiety disorder; N=1 conduct disorder (CD); N=1 impulse control disorder **Qualifying Diagnostic Assessment:** Not reported **N:** 16 **Age:** 13-17 years (mean: 14.7 years) **Sex:** Male: 10; Female: 6 **Ethnicity:** Not reported **IQ:** 36-79 (mean: 55) based on the most recently available test (typically conducted by the participant's school districts) Inclusion/exclusion criteria: Inclusion criteria included a minimum score at or above the 85th percentile for age and gender on the Irritability subscale of the Aberrant Behaviour Checklist (ABC). Axis I diagnoses included ADHD, ODD, CD, and DBD. Participants were excluded from the study if they had a diagnosis of schizophrenia or other psychotic disorder; ASD; mood disorder, bipolar disorder, or depressive disorder. Participants with an unstable seizure disorder (seizure within past 3 months), who were medically unstable or had significant medical or neurologic illness, were also excluded. Individuals who had been prescribed olanzapine for >3 weeks at >15mg/day were also excluded. Participants were allowed to continue any concomitant therapies with the exception of typical and atypical antipsychotics. For participants prescribed concomitant medications, stable doses of these medications were required for a minimum of 4 weeks before entering the study. In addition, no changes in dosing of concomitant therapies were allowed during the course of the study.
Interventions	1. Olanzapine (2.5-20mg/day; mean dose 13.7mg/day) (N=16) **Duration:** **Intervention:** 8 weeks **Follow-up:** 8 weeks
Outcomes	Primary outcomes were challenging behaviour (as measured by the Aberrant Behaviour Checklist (ABC), Aman et al., 1985) and symptom severity/improvement (Clinical Global Impressions - Severity (CGI-S)
Study Design	Observational
Source of funding	Not reported
Limitations	1. No control group 2. Data could not be extracted to calculate effect sizes 3. Small sample size 4. Data could not be extracted for measures of adverse effects, for example, weight gain
Notes	• An intent-to-treat approach was used, with the last observation carried forward with missing data • An adjusted Bonferroni level of significance was used (p=0.0024) • N=4 subjects were terminated from the study prematurely because of significant side effects (N=2), worsening behaviour (N=2), or refusal to take medication (N=1)

Study ID	HARDAN2004
Bibliographic reference	Hardan, A.Y., Jou, R.J. & Handen, B.L. (2004) A retrospective assessment of topiramate in children and adolescents with pervasive developmental disorders. *Journal of Child and Adolescent Psychopharmacology, 14*, 426-432.
Methods	**Allocation:** Not applicable - no control group **Matching:** Not applicable - no control group **Blindness:** Open-label **Setting:** Outpatient **Raters:** Clinician-rated and parent-report **Country:** USA
Participants	**Diagnosis:** DSM-IV ASD (N=11 autistic disorder; N=2 Asperger's disorder; N=2 PDD-NOS) **Coexisting conditions:** **Qualifying Diagnostic Assessment:** All diagnoses made by board-certified child and adolescent psychiatrists with autism experience **N:** 15 **Age:** 8-18 years (mean: 14.7 years) **Sex:** Male: 12; Female: 3 **Ethnicity:** Not reported **IQ:** Not reported **Inclusion criteria:** Participants treated with topiramate after their behavioural symptoms failed to respond to psychosocial interventions and at least 2 psychoactive agents. The study subjects were consecutive patients treated with topiramate. Participants taking other psychotropic medications were included only if their medications were unchanged. Exclusion criteria: None of the participants had serious medical or neurological disorders disorders, including seizure disorder.
Interventions	1. Topiramate (mean dose: 235mg ± 88mg/day) (N=15) **Duration:** **Intervention:** 8-56 weeks (mean: 25 weeks) **Follow-up:** 8-56 weeks (mean: 25 weeks)
Outcomes	Primary outcome was challenging behaviour as measured by the Conners Parent Scale (CPS; Goyette et al., 1978), and symptom severity/improvement as measured by the Clinical Global Impressions (CGI) scale, Global Improvement item (CGI-GI; Guy, 1976).
Study Design	Observational (case series)
Source of funding	NIMH grant MH 64027
Limitations	1. No control group and open-label so cannot get a rigorous and unbiased test of treatment efficacy
Notes	• N=3 discontinued topiramate because of side effects, N=2 cognitive difficulties such as disorientation and speech problems, and N=1 skin rash • 8/15 participants were rated as treatment responders (based on CGI-GI)

Study ID	HELLINGS2005
Bibliographic reference	Hellings, J.A., Weckbaugh, M., Nickel, E.J., *et al*. (2005) A double-blind, placebo-controlled study of valproate for aggression in youth with pervasive developmental disorders. *Journal of Child and Adolescent Psychopharmacology, 15*, 682-692.
Methods	**Allocation:** Randomised **Matching:** No matching **Blindness:** Double-blind **Setting:** Outpatient **Raters:** Parent-report and clinician-rated **Country:** USA
Participants	**Diagnosis:** ADI and ADOS ASD (N=27 Autistic Disorder; N=1 PDD-NOS; N=2 Asperger's disorder) and aggression **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** ADI and ADOS **N:** 30 **Age:** 6-20 years (mean: 11.2 years) **Sex:** Male: 20; Female: 10 **Ethnicity:** Caucasian N: 27; African-American N: 2; Hispanic N: 1 **IQ:** 20-137 (mean: 54) **Inclusion criteria:** Age 6-20 years, significant aggression to self, others, or property at least three times per week, and the presence of a PDD. All co-morbid DSM-IV Axis I diagnoses, except Tourette's Disorder, were allowed. Exclusion criteria: Previous adequate valproate trial for any indication or clinical seizures within the past year. Other exclusion criteria were a history of degenerative neurological changes or metabolic disorders, Tourette's Disorder, a history of thrombocytopenia, hepatitis, pancreatitis, pregnancy, or polycystic ovarian syndrome. Concomitant psychotropic or anti-seizure medications were not allowed. Stimulant medications were required to be stopped the day before placebo run-in commenced.
Interventions	1. Valproate (20mg/kg/day) (N=16) 2. Placebo (N=14) **Duration:** **Intervention:** 8 weeks **Follow-up:** 8 weeks
Outcomes	Primary outcome was challenging behaviour as measured by the parent-rated Aberrant Behaviour Checklist-Community scale (ABC-C; Aman et al., 1995) and the Overt Aggression Scale (OAS; Yudofsky et al., 1986). In addition symptom severity/improvement was measured with the Clinical Global Impression (CGI) - Improvement subscale (CGI-I) as rated by the principal investigator.
Study Design	RCT
Source of funding	Grant from the National Institute of Mental Health (1K08MH01561-01), the National Institute of Child Health and Human Development (HD26927, HD02528), and an unrestricted $5000 grant from Abbott Pharmaceuticals.
Limitations	1. Small sample size 2. Heterogeneity of sample with large differences in aggression

	frequency and severity for different weeks during the 8-week period and large standard deviations reported for each of the measures 3. Placebo response problems
Notes	• N=3 in the experimental group and N=2 in the control group dropped out. N=1 discontinued due to skin rash. • An intent-to-treat analysis was performed. • Teacher-ratings were also collected but only parent-ratings were used in the data analysis and reported. • Dichotomous data extracted for side effects with 'any side effect present during the trial' rated as event • Multiple outcome measures so data extracted consistent with the previous literature with CARS scores extracted as a measure of autistic behaviours, and ABC Irritability as a measure of challenging behaviour.

Study ID	HELLINGS2006
Bibliographic reference	Hellings, J.A., Zarcone, J.R., Reese, R.M., *et al*. (2006) A crossover study of risperidone in children, adolescents and adults with mental retardation. *Journal of Autism and Developmental Disorders, 36*, 401-411.
Methods	**Allocation:** Randomised **Matching:** Not applicable - Crossover study **Blindness:** Double-blind **Setting:** Community **Raters:** Caregiver-report **Country:** USA
Participants	**Diagnosis:** ASD (90%): Intellectual disabilities (N=40), DSM-IV autism (N=28), PDD-NOS (N=8) **Coexisting conditions:** N=9 with epilepsy in remission for at least a year where dosages of antiseizure medications remained constant during the study **Qualifying Diagnostic Assessment:** WAIS-Revised, WISC-3rd ed., or Leiter International Performance Scale **N:** 40 **Age:** 8-56 years (mean: 22 years) **Sex:** Male: 23; Female: 17 **Ethnicity:** White N: 34, African American N: 3, Hispanic N: 1, Other **N:** 2 **IQ:** Not reported; 11 mild MR, 9 moderate MR, 11 severe MR, & 9 profound MR **Inclusion/exclusion criteria:** Aged 6-65 years, with intellectual disabilities (IQ<70), and at least 6 months' history of aggression, property destruction or self-injury, by caregiver report. In addition, baseline Irritability subscale scores rated on the Aberrant Behavior Checklist-Community (ABC-C) rating scale (Aman et al., 1985) were required to be above given norms for age, gender and setting as rated by the primary caregiver. Exclusion criteria were previous risperidone hypersensitivity, history of neuroleptic malignant syndrome, seizures within the past year, degenerative brain disease as assessed by history, and a problematic living situation such as lack of reliable

	caregiving. Prior treatment with risperidone was not an exclusion criterion.
Interventions	1. Low dose risperidone (liquid 1mg/day for children and adolescents; 2mg/day for adults) (N=39 but crossover so N=18 for analysis) 2. Placebo II (liquid) (N=33 but crossover so N=17 for analysis) High dose and placebo I interventions were also reported but not analysed here as the study found no difference between high and low doses of risperidone in behavioural outcomes but significantly more adverse effects of the high dose intervention and placebo I was used in the paper as a co-variate for analysis **Duration:** **Intervention:** 3-5 weeks per intervention **Follow-up:** 22 weeks (open-label continuation)
Outcomes	The primary outcome of interest was the challenging behaviour, irritability, as measured by the Aberrant Behaviour Checklist (ABC-C).
Study Design	RCT (crossover)
Source of funding	National Institute of Child Health and Human Development
Limitations	1. Rater blinding may have been compromised as participants received drug at predictable stages due to study design 2. Broad age range 3. IQ test was only performed if one had not been completed by participant in the last 3 years 4. No qualifying diagnostic assessment used 5. Adverse events, such as increased appetite and weight gain were narratively described but not statistically quantified.
Notes	12 participants did not complete the trial (N=6 due to side effects, N=3 due to insufficient response, N=1 due to development of seizure reoccurrence, N=2 were lost to follow-up)

Study ID	HOLLANDER2010
Bibliographic reference	Hollander, E., Chaplin, W., Soorya, L., *et al*. (2010) Divalproex sodium vs placebo for the treatment of irritability in children and adolescents with autism spectrum disorders. *Neuropsychopharmacology, 35*, 990-998.
Methods	**Allocation:** Randomised **Matching:** No matching **Blindness:** Double-blind **Setting:** Outpatient **Raters:** Blinded clinical psychologist **Country:** USA
Participants	**Diagnosis:** DSM-IV-TR ASD (N=23 autistic disorder; N=4 Asperger's syndrome) **Coexisting conditions**: Not reported **Qualifying Diagnostic Assessment:** ADI-R and ADOS-G **N:** 27 **Age:** 5-15 years (mean: 9.5 years) **Sex:** Male: 23; Female: 4

	Ethnicity: White N=8; Hispanic N=6; Black N=6; Asian N=3; Other N=2; More than one race N=2 **IQ:** 30-126 (mean: 63.3) **Inclusion criteria:** Participants were children 5-17 years, outpatients, who met DSM-IV-TR diagnostic criteria for autistic disorder, full diagnostic criteria on the ADI-R and autism spectrum criteria on the ADOS-G. Participants had to be at least moderately ill (CGI-Severity score of at least 4) to justify exposure to this medication. The population was also stratified for significant irritability/aggression difficulties at baseline, such that children had an Overt Agression Scale-Modified (OAS-M) score of at least 13 or an Aberrant Behaviour Checklist (ABC)-Irritability score of at least 18 (raw scores) to qualify. Exclusion criteria: Excluded sexually active and pregnant females and nursing mothers; subjects with overall adaptive behaviour scores below the age of 2 years on the Vineland Adaptive Behaviour Rating Scale; participants with active or unstable epilepsy, other Axis I disorders, unstable medical illness, genetic syndromes, or congenital infections associated with autism-like syndromes, prematurity; participants treated within the previous 30 days with any drug known to have a well-defined potential for toxicity or with any psychotropic drugs; participants with clinically significant abnormalities in laboratory tests or physical examination; subjects with a history of hypersensitivity or severe side effects associated with the use of divalproex sodium or other other ineffective previous therapeutic trial of divalproex sodium (serum levels within the range of 50-100µg/ml for 6 weeks); and participants who had begun any new non-medication treatments, such as diet, vitamins, and psychosocial therapy, within the previous 3 months.
Interventions	1. Divalproex sodium (valproate) (N=16) 2. Placebo (N=11) **Duration:** **Intervention:** 12 weeks **Follow-up:** 12 weeks
Outcomes	Primary outcome measures were challenging behaviour as measured by the Clinical Global Impression (CGI) scale focusing on irritability (CGI-I) and the irritability subscale of the Aberrant Behaviour Checklist (ABC). Secondary outcome measures of challenging behaviour included the Overt Aggression Scale-Modified (OAS-M). The core autistic symptom of repetitive behaviour was also assessed using the Child-Yale-Brown Obsessive-Compulsive Scale (CYBOCS).
Study Design	RCT
Source of funding	NNDS R21 NS4 3979-01, E Holander, PI. Active medication and placebo provided by Abbott Laboratories. Also, Grant Number MO1-RR00071 from the National Center for Research Resources (NCRR), a component of the National Institute of Health (NIH).
Limitations	1. The placebo group had a significantly higher mean full-scale IQ than the experimental group. IQ was used as a covariate and results were unchanged. However, this difference was not controlled for in the data extracted 2. Small sample size
Notes	• N=3 withdrew before week 12 (N=2 on divalproex sodium,

	N=1 on placebo). Only one participant in experimental group discontinued because of side effects. • Intent-to-treat approach to analysis used. • Dichotomous data extracted for CGI-Irritability with data extracted as reported for responders and non-responders. • No significant differences in weight gain between groups: Placebo weight gain=2.95lbs (3.37), experimental weight gain=3.02lbs (6.41).

Study ID	IZMETH1988
Bibliographic reference	Izmeth, M.G.A., Khan, S.Y., Kumarajeewa, D.I.S.C., *et al*. (1988) Zuclopenthixol decanoate in the management of behavioural disorders in mentally handicapped patients. *Pharmatherapeutica, 5*, 217-227.
Methods	**Allocation:** Randomised **Matching:** No matching **Blindness:** Double-blind **Setting:** Inpatient **Raters:** Clinicians **Country:** UK
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** Most patients had concurrent illness. The principal disorders were psychiatric (N=24) and epilepsy (N=29). The behavioural disorders ranged from antisocial behaviour to physical aggression. **Qualifying Diagnostic Assessment:** Not reported **N:** 113 **Age:** 18-56 years (experimental group mean: 30 years; control group mean: 32 years) **Sex:** Male: 67; Female: 45; Not recorded: 1 **Ethnicity:** Not reported **IQ:** 20-80 (experimental group mean: 51; control group mean: 48) **Inclusion/exclusion criteria:** Mentally handicapped patients with associated behavioural and/or psychiatric disorders, aged 18-60 years, and who had been receiving treatment with zuclopenthixol for at least 12 weeks were eligible for inclusion. Pregnancy or serious physical illness were exclusion criteria.
Interventions	1. Zuclopenthixol decanoate (intramuscular injection, mean dose: 119mg/week) (N=57) 2. Placebo (oily base only, mean dose: 129mg/week) (N=56) **Duration:** **Intervention:** 12 weeks **Follow-up:** 12 weeks
Outcomes	Primary outcomes were symptoms severity/improvement (as measured by the Clinical Global Impression (CGI) Scale; Guy, 1976) and challenging behaviour (as measured by the Nurse's Observation Scale for In-patient Evaluation (NOISE-30) and the Specific Behaviour Rating Scale (SBRS) which was designed for this study.

Study Design	RCT
Source of funding	Not reported
Limitations	1. No data could be extracted for CGI or SBRS outcome measures as all reporting narrative. The only quantitative value of treatment effects on final scores reported was for the irritability subscale of the NOISE-30 and even here only a significance level and not an exact p-value was reported ($p<0.05$) 2. Higher attrition rate in the placebo group
Notes	• Prior to the 12-week double-blind period when participants were randomly allocated to zuclopenthixol or placebo all participants had received zuclopenthixol in a 4-week open-label phase • No significant differences in sex, age, IQ, severity of handicap or accomodation between groups • N=20 in the zuclopenthixol group received anti-Parkinsonian drugs • N=29 participants with co-existent epilepsy were receiving anticonvulsant drug treatment (carbamazepine, sodium valproate, phenytoin, sulthiame or phenobarbitone); N=16 in zuclopenthixol group and N=13 in placebo • 18 participants were withdrawn because of behavioural deterioration: N=4 in zuclopenthixol; N=14 in placebo

Study ID	JAHROMI2009
Bibliographic reference	Jahromi, L.B., Kasari, C.L., McCracken, J.T., *et al*. (2009) Positive effects of methylphenidate on social communication and self-regulation in children with pervasive developmental disorders and hyperactivity. *Journal of Autism and Developmental Disorders, 39*, 395-404.
Methods	**Allocation:** Randomised **Matching:** No matching **Blindness:** Double blind **Setting:** Outpatient **Raters:** Blind raters for behavioural observation measures **Country:** USA
Participants	**Diagnosis:** DSM-IV ASD **Coexisting conditions:** Moderate to severe hyperactivity (SNAP-IV and CGI-Severity ratings) **Qualifying Diagnostic Assessment:** ADI-R **N:** 33 **Age:** 5-13 years (mean: 6.9 years) **Sex:** Male: 29; Female: 4 **Ethnicity:** Caucasian N: 23; African American N: 7; Asian N: 2; Hispanic N: 1 **IQ:** Not reported **Inclusion/exclusion criteria:** See RUPP2005. This study had an additional inclusion criterion of a mental age of <9 years as the social behavioural constructs and measures used would not be developmentally appropriate for older children

Interventions	1. Methylphenidate (oral capsules three times a day; given in low, medium, and high dosage levels of 0.125, 0.250, and 0.500 mg/kg per dose respectively) (N=33 but sample size was halved for analysis as crossover study and only data for the best dose was extracted) 2. Placebo (N=33 but sample size was halved for analysis as crossover study) **Duration:** **Intervention:** 4 weeks **Follow-up:** 5 weeks (includes a 1 week test-dose phase prior to 4 week crossover trial)
Outcomes	Primary outcome for this study was the core autistic symptom of social communication. This was assessed through observational ratings using a brief social communication measure, the Joint Attention Measure from the EScs (JAMES), this was derived from the Early Social Communication Scales (Mundy et al., 2003), and caregiver-child interactions including a competing demands task and a clean-up task
Study Design	RCT (crossover)
Source of funding	See RUPP2005
Limitations	1. Reduced sample size relative to RUPP2005 study 2. Duration of each intervention 3. Methylphenidate may help some of the core social and communication problems, however, this is not the target outcome of the drug and further research is needed as to whether methylphenidate helps these core problems enough to justify targeting them for treatment
Notes	• Secondary analysis of subset of data from RUPP2005 • Data extracted for joint attention initiations (measured with the JAMES) only

Study ID	KARSTEN1981
Bibliographic reference	Karsten, D., Kivimäki, T., Linna, S., -L., *et al*. (1981) Neuroleptic treatment of oligophrenic patients. A double-blind clinical multicentre trial of cis(Z)-clopenthixol and haloperidol. *Acta Psychiatrica Scandinavica, Suppl. 294*, 39-45.
Methods	**Allocation:** Randomised **Matching:** No matching **Blindness:** Double-blind **Setting:** Inpatient **Raters:** Psychiatrists and nursing staff **Country:** Finland
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Not reported **N:** 100 **Age:** Range not reported (mean age for cis(z)-clopenthixol group: 25 years; mean age for haloperidol group: 27 years) **Sex:** Male: 56; Female: 44 **Ethnicity:** Not reported

	IQ: Not reported **Inclusion/exclusion criteria:** The study included individuals with intellectual disabilities with symptoms like psychomotor excitation, agitation, and violence and who might benefit from the treatment of either cis(Z)-clopenthixol or haloperidol. Participants were excluded if they had concomitant serious somatic illness or pathological laboratory findings as well as pregnant or epileptic participants.
Interventions	1. Cis(z)-clopenthixol (available as 5 & 25mg tablets) (N=49) 2. Haloperidol (available as 1 & 4mg tablets) (N=49) **Duration:** **Intervention:** 12 weeks **Follow-up:** 12 weeks
Outcomes	Primary outcomes were symptom severity/improvement (as measured by the Clinical Global Impression (CGI), McGlasham, 1973, psychiatrists and nurses scale) and side effects (assessed with CGI)
Study Design	RCT
Source of funding	Not reported
Limitations	1. Range and mean for daily or final dosage not reported
Notes	• Identical placebo tablets were available as well. All participants were treated during the 12 weeks with both sets of tablets, only one set. however, contained active drug while the other set was placebo. • Two patients were withdrawn from the trial, one in each treatment group. Reasons for withdrawal not reported. • The most frequently encountered single side effects were extrapyramidal (especially parkinsonism) and anticholinergic • This study compares two antipsychotic drugs. For the statistical analysis of dichotomous data cis(z)-clopenthixol is treated as the experimental condition and haloperidol as the control condition • For data analysis for the symptom severity/improvement outcome the dichotomous data are entered as reported with improved as 'event' and unchanged or deteriorated as 'no event'. For the side effects analysis the data are calculated to produce dichotomous outcomes with no side effect rated as 'event' and all side effect categories (side effects interfering slightly with functioning, side effects interfering moderately with functioning, and side effects interfering markedly with functioning) summed to produce 'no event' total score

Study ID	KING2001
Bibliographic reference	King, B.H., Wright, D.M., Handen, B.L., *et al*. (2001) Double-blind, placebo-controlled study of amantadine hydrochloride in the treatment of children with autistic disorder. *Journal of the American Academy of Child and Adolescent Psychiatry, 40*, 658-665.
Methods	**Allocation:** Randomised **Matching:** No matching **Blindness:** Double-blind

	Setting: Not reported **Raters:** Parent-rated and clinician-rated scales **Country:** Not reported
Participants	**Diagnosis:** DSM-IV and ICD-10 ASD **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** ADI-R and ADOS-G **N:** 39 (intention-to-treat sample) **Age:** 5-15 years (mean: 7 years) **Sex:** Male: 34; Female: 5 **Ethnicity:** White: 75% in placebo and 79% in amantadine group **IQ:** Not reported **Inclusion criteria:** Diagnosis of autistic disorder according to DSM-IV and ICD-10 and the ADI-R and ADOS-G; composite age equivalent of >18 months on Vineland Adaptive Behaviour Scales; and Aberrant Behaviour Checklist-Community Version (ABC-CV) subscale scores for irritability and hyperactivity equal to or greater than age-adjusted 75th percentile **Exclusion criteria:** IQ<35 as measured on the Mullen Scales of Early Learning or the Differential Ability Scale
Interventions	1. Amantadine hydrochloride (Synnetrel syrup; 5mg/kg per day) (N=19) 2. Placebo (N=20) **Duration:** **Intervention:** 4 weeks **Follow-up:** 5 weeks (including 1 week placebo run-in)
Outcomes	Primary outcomes were challenging behaviour as measured by the parent-completed Aberrant Behaviour Checklist-Community Version (ABC-CV; Aman et al., 1985, 1995), and symptom severity/improvement as measured by the Clinical Global Impression (CGI) scale. Dichotomous outcome measures extracted for the ABC-CV. Responders categorised on the basis of a reduction of at least 25% in subscale scores for the ABC-CV for irritability and/or hyperactivity at the end of treatment.
Study Design	RCT
Source of funding	Cerebrus plc, Winnersh, UK
Limitations	1. Small sample size
Notes	• Some participants received psychopharmacological agents during the course of the study, or which SSRIs (e.g. fluoxetine and fluvoxamine) were the largest category with N=4 in experimental and N=6 in control group. • Data could not be extracted for the CGI • Similar numbers of patients in both active (N=14) and placebo (N=14) groups reported at least one side effect. The side effect reported most often was insomnia (N=4 active and N=2 placebo). N=2 in amantadine group reported to have somnolence. N=4 in placebo and N=2 in amantadine group reported difficult or antisocial behaviours

Study ID	KNIVSBERG2003
Bibliographic reference	Knivsberg, A-M., Reichelt, K-L., Høien, T., *et al*. (2003) Effect of dietary intervention on autistic behavior. *Focus on Autism and Other Developmental Disabilities, 18*, 247-256.
Methods	**Allocation:** Randomised **Matching:** Matched on age, cognitive level, and severity of autistic traits **Blindness:** Single-blind **Setting:** Not reported **Raters:** Parent-report and clinician-rated behavioural observation **Country:** Norway
Participants	**Diagnosis:** ASD **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Not reported **N:** 20 **Age:** Range not reported (means: experimental group mean: 7.5 years; control group mean: 7.2 years) **Sex:** Not reported **Ethnicity:** Not reported **IQ:** Range not reported (means: experimental group mean: 81; control group mean: 84.6, as measured by the Leiter International Performance Scale) **Inclusion criteria:** Not reported
Interventions	1. Gluten-free and casein-free diet group (a dietician visited the parents of the children in the diet group and gave the parents oral and written information about gluten-free and casein-free diets) (N=10) 2. Control group (N=10) **Duration:** **Intervention:** 1 year **Follow-up:** 1 year
Outcomes	Primary outcome was autistic behaviour as assessed by an observation scheme, the DIPAB (Diagnose of Psykotisk Adferd hos Børn [Diagnosis of Psychotic Behaviour in Children; Haracopos & Kelstrup, 1975]) which included items evaluating social isolation and bizarre behaviour
Study Design	RCT
Source of funding	County Council of Rogaland, Sigval and Nanki Bergensen's public trust, and the Sein Family Foundation
Limitations	1. Small sample size 2. No formal monitoring of dietary compliance
Notes	

Study ID	LEVY2003
Bibliographic reference	Levy, S.E., Souders, M.C., Wray, J., *et al*. (2003) Children with autistic spectrum disorders. I: comparison of placebo and single dose of human synthetic secretin. *Archives of Disease in Childhood, 88*, 731-736.
Methods	**Allocation:** Randomised **Matching:** No matching **Blindness:** Double-blind **Setting:** Not reported **Raters:** Parent- or clinician-rated scales **Country:** USA
Participants	**Diagnosis:** ASD **Coexisting conditions:** >50% gastrointestinal symptoms **Qualifying Diagnostic Assessment:** ADI-R **N:** 62 **Age:** 3-8 years (mean: 6 years) **Sex:** Male: 50; Female: 12 **Ethnicity:** Caucasian: 90.3% **IQ:** Not reported **Inclusion criteria:** Diagnosis of ASD **Exclusion criteria:** Significant hearing or vision loss; other neurological disorders, e.g. cerebral palsy, phenylketonuria, tuberous sclerosis, neurofibromatosis, seizure disorder; genetic disorder; prematurity (<32 weeks gestation); diagnosis of coeliac disease or other gastrointestinal disease associated with malabsorption; previous treatment with secretin; anaemia and plumbism (lead poisoning)
Interventions	1. Secretin (human synthetic secretin, single intravenous dose; 2 CU/kg to a maximum dose of 75 CU) (N=62, but N=31 for analysis as crossover study) 2. Placebo (N=62, but N=31 for analysis as crossover study) **Duration:** **Intervention:** Single dose **Follow-up:** 8 weeks
Outcomes	Primary outcome was autistic behaviours as measured by the Real Life Ritvo Behaviour Scale. Other outcomes included the core autistic symptom of communication (as measured by the Communication and Symbolic Behaviour Scale (CSBS) and challenging behaviour (as measured by the Global Behaviour Rating Scales (GBRS) developed for this study)
Study Design	RCT (crossover)
Source of funding	Maternal and Child Health Bureau, Grant No. 2T73 MC 00035 09, the General Clinical Research Center of The Children's Hospital of Philadelphia, NIH Grant No. RR00240, and Mental Retardation and Development Disabilities Research Center (MRDDRC) NIH Grant No. 3P30 HD26979-04S2. ChiRhoClin Corporation donated the secretin
Limitations	1. There was a significant difference between the groups in baseline CARS total score
Notes	Data not extracted for Teacher Global Behaviour Rating Scale as Parent Global Behaviour Rating Scale selected as the measure for challenging behaviour

Study ID	MARTINEAU1988
Bibliographic reference	Martineau, J., Barthelemy, C., Cheliakine, C., *et al*. (1988) Brief report: an open middle-term study of combined vitamin B6-magnesium in a subgroup of autistic children selected on their sensitivity to this treatment. *Journal of Autism and Developmental Disorders, 18*, 435-447.
Methods	**Allocation:** Not applicable - no control group **Matching:** Not applicable - no control group **Blindness:** Not applicable - no control group **Setting:** Not reported **Raters:** Nurse-rated scale **Country:** France
Participants	**Diagnosis:** DSM-III ASD **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Not reported **N:** 11 **Age:** 4-8 years (mean: 5.8 years) **Sex:** Male: 5; Female: 6 **Ethnicity:** Not reported **IQ:** 30-80 (mean: 50) **Inclusion/exclusion criteria:** All participants were in excellent physical health, audiologically intact, none had a history of gross neurological deficit, severe seizure disorder, endocrine or systematic disease
Interventions	1. Vitamin B6-magnesium (oral medication twice daily; 30mg/kg per day pyridoxine hydrochloride and 10mg/kg per day magnesium lactate) (N=11) **Duration:** **Intervention:** 8 weeks **Follow-up:** 14 weeks
Outcomes	Primary outcome was symptom severity/improvement as assessed by the Behaviour Summarized Evaluation (BSE)
Study Design	Observational (before-and-after)
Source of funding	Not reported
Limitations	1. Sample selected on basis of previous sensitivity to this treatment 2. Small sample size
Notes	No adverse reactions or side effects noted in any of the 11 participants during the study period

Study ID	MCDOUGLE1996
Bibliographic reference	McDougle, C.J., Naylor, S.T., Cohen, D.J., *et al*. (1996) A double-blind, placebo-controlled study of fluvoxamine in adults with autistic disorder. *Archives of General Psychiatry, 53*, 1001-1008.
Methods	**Allocation:** Randomised **Matching:** No matching **Blindness:** Double-blind **Setting:** Inpatient (N=9) and Outpatient (N=21) **Raters:** Clinician-rated scales **Country:** USA
Participants	**Diagnosis:** DSM-III-R & ICD-10 ASD (Autistic disorder) **Coexisting conditions:** N=1 fragile X syndrome, none of the other participants had a diagnosed genetic, metabolic or neurological cause for their syndrome **Qualifying Diagnostic Assessment:** ADI and ADOS **N:** 30 **Age:** 18-53 years (mean: 30.1 years) **Sex:** Male: 27; Female: 3 **Ethnicity:** Not reported **IQ:** 25-115 (mean: 79.9; as measured by WAIS-R for verbal and Leiter International Performance Scale for non-verbal participants) **Exclusion criteria:** Participants were excluded if they met DSM-III-R criteria for schizophrenia or had psychotic symptoms, if they had abused illicit substances within the previous 6 months, or if a notable medical condition, including seizure disorder, was identified. Women with positive serum pregnancy test results were excluded.
Interventions	1. Fluvoxamine maleate (200-300 mg/day; mean dose 276.7 mg/day) (N=15) 2. Placebo (200-300 mg/day; mean dose 283.3 mg/day) (N=15) **Duration:** **Intervention:** 12 weeks **Follow-up:** 12 weeks
Outcomes	Primary outcomes included the core autistic symptom of repetitive behaviour as measured by the Yale-Brown Obsessive Compulsive Scale (Y-BOCS); autistic behaviours as measured by the Ritvo-Freeman Real-Life Rating Scale; challenging behaviour (aggression) as measured by the Brown Aggression Scale (Brown et al., 1979); maladaptive behaviour as measured by the Vineland Adaptive Behaviour Scale; and symptom severity/improvement as measured by the Clinical Global Impressions (CGI) scale
Study Design	RCT
Source of funding	National Alliance for Research on Schizophrenia and Depression Young Investigator Award; the State of Connecticut Deaprtment of Mental Health and Addiction Services; The Korczak Foundation for Autism and Related Disorders; and grants M01 RR06022-33, P50 MH30929-18, HD 03008-27, and P01 MH25642 from the National Institutes of Health, Bethesda, Md. Fluvoxamine and financial support were provided by Solvay Pharmaceuticals, Marietta, Ga.
Limitations	1. Small sample size 2. Y-BOCS scale valid and reliable for assessing severity of obsessive-

	compulsive symptoms in individuals with OCD but reliability and validity for assessing repetitive thoughts in autism is unknown
Notes	• All participants completed the trial. Fluvoxamine was well tolerated with no medically significant adverse events. N=4 reported nausea (N=3 in experimental and N=1 in control group) during the first 2 weeks but they experienced tolerance and were able to continue. N=3 experienced moderate sedation (N=2 in experimental; N=1 in control group), which also resolved.

Study ID	MCDOUGLE1998A
Bibliographic reference	McDougle, C.J., Holmes, J.P., Carlson, D.C., et al. (1998) A double-blind, placebo-controlled study of risperidone in adults with autistic disorder and other pervasive developmental disorders. *Archives of General Psychiatry, 55*, 633-641.
Methods	**Allocation:** Randomised **Matching:** No matching **Blindness:** Double-blind **Setting:** Outpatient (N=24), inpatient (N=7) **Raters:** Board certified psychiatrists **Country:** USA
Participants	**Diagnosis:** DSM-IV ASD: autism (N=17), PDD-NOS (N=14) **Coexisting conditions:** None reported **Qualifying Diagnostic Assessment:** Autistic Diagnostic Interview and the Autism Diagnostic Observation Schedule **N:** 31 **Age:** 18-43 years (mean: 28.1 years) **Sex:** Male: 22; Female: 9 **Ethnicity:** White N: 24, African American N: 6, Hispanic N: 1 **IQ:** Range not reported (mean: 54.6 on WAIS-R or Leiter International Performance Scale) **Inclusion/exclusion criteria:** Yale-Brown Obsessive Compulsion Scale (Y-BOCS) compulsion subscale score of greater than 10, Self-Injurous Behaviour Questionnaire (SIB-Q) score of 25 or greater or a Ritvo-Freeman Real-Life Rating Scale overall score of 0.20 or greater, no diagnosis of schizophrenia, psychotic symptoms or identified significant acute medical condition
Interventions	1. Risperidone (oral capsules, mean dose 2.9mg/day) (N=15) 2. Placebo (oral capsules, mean dose 3.9mg/day) (N=16) **Duration:** **Intervention:** 12 weeks **Follow-up:** 24 weeks (open-label continuation)
Outcomes	Primary outcomes were: autistic behaviours (as measured by Ritvo-Freeman Real-life Rating Scale, Freeman et al. 1986); the core autistic symptom of repetitive behaviour (as measured by the Yale-Brown Obsessive Compulsive Scale (Y-BOCS), Goodman et al., 1989); symptom severity/improvement (as measured by the Clinical Global Impression (CGI) scale, Guy, 1976); and the challenging behaviour,

	aggression (as measured by the Self-Injurious Behaviour Questionnaire (SIB-Q)).
Study Design	RCT
Source of funding	Supported in part by grants from the Public Health Service, Young Investigator Award, Independent Investigator Award from the National Alliance for Research in Schizophrenia and Depression, Theodore and Vada Stanley Foundation Research Awards Program, State of Connecticut, Department of Mental Health and Addiction Services, National Institute of Mental Health, Rockville
Limitations	1. Relatively short duration of intervention and no longer-term post-intervention follow-up
Notes	Subjects had not taken any psychotropic drugs for at least 4 weeks before the trial

Study ID	MCDOUGLE1998B
Bibliographic reference	McDougle, C.J., Brodkin, E.S., Naylor, S.T., *et al*. (1998) Sertraline in adults with pervasive developmental disorders: a prospective open-label investigation. *Journal of Clinical Psychopharmacology, 18*, 62-66.
Methods	**Allocation:** Not applicable - no control group **Matching:** Not applicable - no control group **Blindness:** Open-label **Setting:** Outpatient (N=40) and inpatient (N=2) **Raters:** Clinician-rated scales **Country:** USA
Participants	**Diagnosis:** DSM-IV ASD (N=22 autistic disorder; N=6 Asperger's disorder; N=14 PDD-NOS) **Coexisting conditions:** Participants did not meet criteria for any other DSM-IV axis I or axis II disorder other than mental retardation (N=28) **Qualifying Diagnostic Assessment:** ADI & ADOS used to aid diagnosis **N:** 42 **Age:** 18-39 years (mean: 26.1 years) **Sex:** Male: 27; Female: 15 **Ethnicity:** White N: 36; black N: 5; Hispanic N: 1 **IQ:** 25-114 (mean: 60.5; as measured by the WAIS-R for verbal and the Leiter International Performance Scale for non-verbal participants) **Inclusion criteria:** Symptom severity entry screening criteria: a Yale-Brown Obsessive Compulsive Scale (Y-BOCS) score of >15 (verbal patients) or >7 (nonverbal patients); a Self-Injurious Behaviour Questionnaire (SIB-Q) score of 25 or greater; a Ritvo-Freeman Real-life Rating Scale overall score of 0.20 or greater; or a Vineland Maladaptive Behaviour Scale part 1 score of 14 or greater; or a Vineland Maladaptive Behaviour Scale part 2 score of 5 or greater. Exclusion criteria: Participants were excluded if they met DSM-IV criteria for a psychotic disorder or bipolar disorder or if a significant medical condition, including seizure disorder, was identified
Interventions	1. Sertraline (50-200 mg/day) (N=42) **Duration:**

	Intervention: 12 weeks **Follow-up:** 12 weeks
Outcomes	Primary outcomes included the core autistic symptom of repetitive behaviour as measured by the Yale-Brown Obsessive Compulsive Scale (Y-BOCS); autistic behaviours as measured by the Ritvo-Freeman Real-Life Rating Scale; maladaptive behaviour as measured by the Vineland Adaptive Behaviour Scale; and symptom severity/improvement as measured by the Clinical Global Impression scale (CGI) global improvement item score
Study Design	Observational (before-and-after study)
Source of funding	Educational grant from Pfizer Pharmaceuticals; MH-30929 from the National Institute of Mental Health; HD-03008 from the National Institute of Child Health and Human Development; an Independent Investigator Award from the National Alliance for Research on Schizophrenia and Depression; the Theodore and Vada Stanley Research Foundation; the State of Connecticut Department of Mental Health and Addiction Services; and a National Institute of Mental Health Research Unit on Pediatric Psychopharmacology grant to Indiana University
Limitations	1. No control group and efficacy data cannot be extracted 2. Small sample size 3. Y-BOCS scale valid and reliable for assessing severity of obsessive-compulsive symptoms in individuals with OCD but reliability and validity for assessing repetitive thoughts in autism is unknown
Notes	• Participants were psychotropic drug-free for at least 4 weeks before the start of the trial • 37/42 completed the trial and were included in the efficacy analysis. N=3 dropped out because of increased anxiety/agitation; N=1 because of a syncopal episode of undetermined cause; N=1 because of noncompliance • Side effects in the 37 completers included anorexia (N=1); headache (N=1); tinnitus (N=1); alopecia (N=1); weight gain (N=3); sedation (N=1); anxiety/agitation (N=2). No adverse cardiovascular, extrapyramidal, or proconvulsant effects were identified

Study ID	MCKENZIE1966
Bibliographic reference	McKenzie, M.E. & Roswell-Harris, D. (1966) A controlled trial of Prothipendyl (Tolnate) inmentally subnormal patients. *British Journal of Psychiatry, 112*, 95-100.
Methods	**Allocation:** Randomised **Matching:** No matching and an IQ difference between groups (experimental mean: 34.4 and control mean: 25.4) **Blindness:** Blinding of investigators and outcome assessor **Setting:** Inpatient **Raters:** Medical officer **Country:** UK
Participants	**Diagnosis:** Intellectual disabilities **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Not reported **N:** 40 **Age:** 14-42 years (mean age for males: 20.5 years; mean age for females: 26.2 years) **Sex:** Male: 20; Female: 20 **Ethnicity:** Not reported **IQ:** 19-58 as measured by Goodenough Draw-a-Man test (experimental group mean: 34.4; control group mean: 25.4) **Inclusion/exclusion criteria:** Each participant was given a complete physical examination to exclude intercurrent disease. All drugs except anticonvulsants were stopped for a month before commencement of the trial.
Interventions	1. Prothipendyl (oral tablets, 80mg (1 tablet) - 320mg (4 tablets) 6-hourly) (N=20) 2. Placebo (oral tablets) (N=19) **Duration:** **Intervention:** 16 weeks **Follow-up:** 16 weeks
Outcomes	Primary outcome was symptom severity/improvement as measured by clinical observation rating scale
Study Design	RCT
Source of funding	Smith Kline and French Laboratories Ltd. supplied the drug and placebo
Limitations	1. Pre-trial differences between experimental and control groups in IQ
Notes	• In the first week of the trial one participant was withdrawn at the request of her parents, the group to which she had been allocated is not explicitly reported, however, due to number discrepancies between groups the assumption was made that she had been allocated to the placebo group • IQ scores based on the 29 participants who were testable • Liver function was estimated in a random sample of 10 participants; a raised serum alkaline phosphatase level was found in several participants, and the start of the trial was postponed until the levels were within the normal range • Calculated dichotomous outcome for the clinical assessment with participants showing slight improvement, good improvement, very good improvement, or excellent

	improvement summed to provide 'event' score and participants showing no change or deterioration summed to provide 'no event' total score

Study ID	MEHLMADRONA2010
Bibliographic reference	Mehl-Madrona, L., Leung, B., Kennedy, C., *et al*. (2010) Micronutrients versus standard medication management in autism: a naturalistic case-control study. *Journal of Child and Adolescent Psychopharmacology, 20*, 95-103.
Methods	**Allocation:** Non-randomised **Matching:** Matched on age (within a year), sex, parental education and income, IQ (by category), and symptom severity as measured on the Clinical Global Impressions scale **Blindness:** Non-blind **Setting:** Not reported **Raters:** Parent-rated, teacher-rated, and clinician-rated scales **Country:** Hawaii
Participants	**Diagnosis:** DSM-IV ASD **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Clinical assessment based on interview, history, and questionnaires **N:** 88 **Age:** 2-28 years (means: experimental group mean: 8.4 years; control group mean: 9.4 years) **Sex:** Male: 68; Female: 20 **Ethnicity:** Caucasian: >80% **IQ:** Range not reported (means: experimental group mean: 88.8; control group mean: 91.3) **Inclusion criteria:** Presence of a complete set of outcome data for at least 3 months
Interventions	1. Micronutrient management (EMPowerplus formula consists of all 14 of the known vitamins, 16 dietary minerals, 3 amino acids, and 3 antioxidants) (N=44) 2. Medication management (N=44) **Duration:** **Intervention:** 3-98 months (means: experimental group mean: 24 months; control group mean: 18 months) **Follow-up:** 3-98 months (means: experimental group mean: 24 months; control group mean: 18 months)
Outcomes	Outcomes included autistic behaviours as measured by the Childhood Autism Rating Scale (CARS) and the Children's Psychiatric Rating Scale (CPRS; Fish, 1985); challenging behaviour as measured by the Aberrant Behaviour Checklist (ABC) and the Yale-Paris Self-Injurious Behaviour Scale (YAPA-SIB); and symptom severity/improvement as measured by the Clinical Global Impressions (CGI) severity scale
Study Design	Observational (case-control)
Source of funding	Richmond Foundation of Santa Barbara, California; Health Canada; Alberta Children's Hospital Foundation; and Janzen

Limitations	1. Not randomized
Notes	• Parents of 5 children could not afford to purchase any supplements, so they were prescribed prenatal formulas (covered by their health insurance plan) in does that approximated the micronutrient formula) • Data extracted for the CARS rather than the CPRS as a measure of autistic behaviours as it is a more widely used measure • Data extracted for the irritability subscale of the ABC as this is widely used as a measure of challenging behaviour • Data could not be extracted for YAPA-SIB) • The micronutrient group had 33 adverse events, compared to 214 in the medication group. In no case was an adverse event reported more often in the micronutrient group. Furthermore, the average weight gain was significantly less in the micronutrient group compared to the medication group ($p<0.0001$).

Study ID	MOUSAINBOSC2006
Bibliographic reference	Mousain-Bosc, M., Roche, M., Polge, A., *et al*. (2006) Improvement of neurobehavioral disorders in children supplemented with magnesium-vitamin B6. II. Pervasive developmental disorder-autism. *Magnesium Research, 19*, 53-62.
Methods	**Allocation:** Not applicable - no control group **Matching:** Not applicable - no control group **Blindness:** Not applicable - no control group **Setting:** Not reported **Raters:** Physician **Country:** France
Participants	**Diagnosis:** DSM-IV ASD **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** DSM-IV assessment **N:** 33 **Age:** 1-10 years (mean: 4 years) **Sex:** Male: 21; Female: 12 **Ethnicity:** Not reported **IQ:** Not reported **Inclusion criteria:** Not reported
Interventions	1. Magnesium-vitamin B6 (6mg/kg/day Mg; 0.6mg/kg/day vit. B6) **Duration:** **Intervention:** Mean: 8 months **Follow-up:** 24 months
Outcomes	Primary outcomes were core autistic symptoms (social interactions, communication, and stereotyped restricted behaviour) as assessed by DSM-IV evaluation
Study Design	Observational (before-and-after)
Source of funding	Sanofi-Aventis
Limitations	1. No control group 2. Exact p-values not reported

Notes	No other medical treatment was given before and during the Mg-B6 treatment period

Study ID	MUNASINGHE2010
Bibliographic reference	Munasinghe, S.A., Oliff, C., Finn, J., *et al.* (2010) Digestive enzyme supplementation for autism spectrum disorders: a double-blind randomized controlled trial. *Journal of Autism and Developmental Disorders, 40*, 1131-1138.
Methods	**Allocation:** Randomised **Matching:** No matching **Blindness:** Double-blind **Setting:** Not reported **Raters:** Parent-report scales **Country:** Australia
Participants	**Diagnosis:** DSM-IV ASD (N=38 Autistic disorder; N=5 PDD-NOS) **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Not reported **N:** 43 **Age:** 2-8 years (mean: 5.8 years) **Sex:** Male: 36; Female: 7 **Ethnicity:** Not reported **IQ:** Not reported **Inclusion criteria:** Children aged 3-8 years; resident in Perth metropolitan area; have Autistic disorder or PDD-NOS as established along the criteria of the APA and outlined in the DSM IV **Exclusion criteria:** Children should not have commenced on any new alternative therapy during the study period; children with significant hearing or vision loss, comorbid neurological disorders including phenylketonuria, tuberous sclerosis, neurofibromatosis, other identifiable metabolic disorders, genetic abnormalities and intractable seizure disorders and coeliac disease; children who were to have any new medical/surgical intervention carried out in the next 6 months were excluded; children who had a history of allergy to Aspergillus enzyme proteins or papaya or any known allergy to fungal proteins (from which the enzymes in Peptizyde™ are derived) and children with active stomach or duodenal ulcers, severe bowel inflammation (characterised by blood in stools), a history of haemophilia or other bleeding disorders, or within a week of scheduled surgery (contraindications as per manufacturer's guidelines) were also excluded.
Interventions	1. Proteolytic enzyme supplement (Peptizyde™; 1/2-9 capsules per day according to manufacturer's recommended dose) (N=43, but crossover study so sample size is halved for analysis) 2. Placebo (N=43, but crossover study so sample size is halved for analysis) **Duration:** **Intervention:** 3 months for each phase **Follow-up:** 6 months
Outcomes	Primary outcomes were the core autistic symptom of communication

	as measured by the vocabulary subscale of the Language Development Survey (LDS; Rescorla, 1989); challenging behaviour as measured by the parent-rated Global Behaviour Rating Scale (GBRS); and the coexisting gastrointestinal symptoms as measured by the Additional Rating Scale (ARS) which required parents to rate gastrointestinal symptoms
Study Design	RCT (crossover)
Source of funding	Supplement and placebo supplied by Houston Nutraceuticals
Limitations	1. Small sample size
Notes	• Behavioural intervention and other ongoing medical therapy which a child had been engaged in for the previous three months or more was continued without interruption during the study period • No serious adverse effects were noted by the investigating team during the 6 month study period. There is some suggestion of increased irritability and difficulties with engagement observed by parents and noted as reasons for discontinuation (N=3 in experimental group; N=1 in placebo group). However, the attrition rate was not high and for some of these participants problems continued post-cessation of the treatment.

Study ID	NICOLSON2006
Bibliographic reference	Nicolson, R., Craven-Thuss, B. & Smith, J. (2006) A prospective, open-label trial of galantamine in autistic disorder. *Journal of Child and Adolescent Psychopharmacology, 16*, 621-629.
Methods	**Allocation:** Not applicable - no control group **Matching:** Not applicable - no control group **Blindness:** Not applicable - no control group **Setting:** Not reported **Raters:** Parent-rated and clinician-rated scales **Country:** Canada
Participants	**Diagnosis:** DSM-IV ASD **Coexisting conditions:** N=7 coexisting mild or moderate intellectual disability **Qualifying Diagnostic Assessment:** ADI-R and clinical observation **N:** 13 **Age:** 4-17 years (mean: 8.8 years) **Sex:** Male: 10; Female: 3 **Ethnicity:** Not reported **IQ:** Not reported **Inclusion criteria:** Participants were required to be off of all psychotropic medications for at least 4 weeks prior to the start of treatment with galantamine **Exclusion criteria:** Individuals with a seizure disorder, a significant cardiac condition, or previous exposure to an acetylcholinesterase inhibitor were excluded from participating in this study
Interventions	1. Galantamine (2-24mg/day; mean final dose 18.4mg/day) (N=13)

	Duration: **Intervention:** 12 weeks **Follow-up:** 12 weeks
Outcomes	Primary outcomes were challenging behaviour as assessed by the Parent-completed Aberrant Behaviour Checklist (ABC) Irritability subscale and the long form of the Conners' Parent Rating Scale - Revised (Conners et al, 1998). Other outcomes were autistic behaviours as measured by the Children's Psychiatric Rating Scale (Fish, 1985) Autism factor, and symptom severity/improvement was assessed with the Clinical Global Impressions - Severity scale (CGI-S)
Study Design	Observational (before-and-after)
Source of funding	London Health Sciences Research, Inc.
Limitations	1. Efficacy data cannot be extracted 2. Small sample size
Notes	• Data extracted for the ABC rather than the Conners' Parent Rating Scale as a measure of challenging behaviour as this is the more widely used scale • N=3 participants dropped out of study, N=2 after 8 weeks due to worsening of target symptoms, and N=1 withdrew 1 week prior to end of trial due to headaches

Study ID	OWLEY2006
Bibliographic reference	Owley, T., Salt, J., Guter, S., *et al*. (2006) A prospective, open-label trial of memantine in the treatment of cognitive, behavioral, and memory dysfunction in pervasive developmental disorders. *Journal of Child and Adolescent Psychopharmacology, 16*, 517-524.
Methods	**Allocation:** Not applicable - no control group **Matching:** Not applicable - no control group **Blindness:** Not applicable - no control group **Setting:** Not reported **Raters:** Parent-rated and clinician-rated scales **Country:** USA
Participants	**Diagnosis:** DSM-IV ASD (N=10 autistic disorder; N=2 Asperger's disorder; N=2 PDD-NOS) **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** ADI-R and ADOS **N:** 14 **Age:** 3-12 years (mean: 7.8 years) **Sex:** Male: 14; Female: 0 **Ethnicity:** White N: 7; African American N: 4; Hispanic N: 3 **IQ:** Nonverbal IQ mean: 96.8 **Exclusion criteria:** Individuals were excluded if they had previously received memantine
Interventions	1. Memantine (5-20mg/day) (N=14) **Duration:** **Intervention:** 8 weeks **Follow-up:** 8 weeks

Outcomes	Primary outcomes were challenging behaviour as assessed by the parent-completed Aberrant Behaviour Checklist-Community Version (ABC-CV) Irritability subscale, and symptom severity/improvement as measured by the Clinical Global Impressions Scale - Severity (CGI-S)
Study Design	Observational (before-and-after)
Source of funding	The Autism Project (TAP) of Illinois; National Institute of Health grant K01 MH64539; National Institute of Mental Health grant U19 HD35482
Limitations	1. Efficacy data could not be extracted 2. Small sample size
Notes	• Participants could continue to take other medications, including psychotropic agents, but the doses of all medication were held stable throughout the study. N=4 on additional psychotropic medications (risperidone; aripiprazole; guanfacine; melatonin) • N=2 participants did not complete the study

Study ID	PAAVONEN2003
Bibliographic reference	Paavonen, E.J., Nieminen-von Wendt, T., Vanhala, R., *et al*. (2003) Effectiveness of melatonin in the treatment of sleep disturbances in children with asperger disorder. *Journal of Child and Adolescent Psychopharmacology, 13*, 83-95.
Methods	**Allocation:** Not applicable - no control group **Matching:** Not applicable - no control group **Blindness:** Not applicable - no control group **Setting:** Not reported **Raters:** Parent- and self-report **Country:** Finland
Participants	**Diagnosis:** DSM-IV ASD (Asperger disorder) **Coexisting conditions:** N=1 ADHD, N=4 asthma, N=3 overweight **Qualifying Diagnostic Assessment:** Not reported **N:** 15 **Age:** 6-17 years (mean: 10.3 years) **Sex:** Male: 13; Female: 2 **Ethnicity:** Not reported **IQ:** Not reported **Inclusion criteria:** Diagnosis of Asperger disorder and all children had severe sleep problems during the previous 3 months. Severe insomnia was defined as continuous problems with sleep initiation or maintenance, disturbing either the child or the family so that the child was constantly tired or had other symptoms that could be attributed to sleep deprivation. **Exclusion criteria:** Children with ongoing psychotropic medication or major psychiatric comorbidity were excluded
Interventions	1. Melatonin (3mg/day 30 minutes prior to bedtime) (N=15) **Duration:** **Intervention:** 2 weeks **Follow-up:** 5 weeks
Outcomes	The primary outcome was sleep patterns as measured by an actigraph which is a small piece of wrist-worn equipment used for collecting data

	relating to motor activity, a self-report sleep questionnaire (Children's Self Report Form for sleep problems; Owens et al., 2000) and a parent-report questionnaire (Sleep Disturbance Scale for Children; Bruni et al., 1996)
Study Design	Observational (before-and-after)
Source of funding	Academy of Finland, The Finnish Medical Foundation, Research Funds of Helsinki University Central Hospital, the Foundation for Pediatric Research, the Foundation of Children's Castle Hosptial, and the Finnish Sleep Research Society
Limitations	1. Data could not be extracted for self-report and parent-report questionnaires
Notes	Although no explicit criteria were used, all participants had sleep problems "every night" or "almost every night"

Study ID	POSEY2007
Bibliographic reference	Posey, D.J., Aman, M.G., McCracken, J.T., *et al*. (2007) Positive effects of methylphenidate on inattention and hyperactivity in pervasive developmental disorders: an analysis of secondary measures. *Biological Psychiatry, 61*, 538-544.
Methods	**Allocation:** Randomised **Matching:** No matching **Blindness:** Double-blind **Setting:** Outpatient **Raters:** Clinician-rated scale **Country:** USA
Participants	**Diagnosis:** DSM-IV ASD (N=47 autistic disorder; N=5 Asperger disorder; N=14 PDD-NOS) **Coexisting conditions:** Hyperactivity (Clinical Global Impressions scale & Swan et al. version IV ADHD scale) **Qualifying Diagnostic Assessment:** ADI-R **N:** 66 **Age:** 5-13 years (mean: 7.5 years) **Sex:** Male: 59; Female: 7 **Ethnicity:** White N: 48; Black or African American N: 9; Asian N:6; Hispanic or Latino N: 3 **IQ:** 16-135 (mean: 62.6) as assessed with the Slosson Intelligence Test **Inclusion/exclusion criteria:** See RUPP2005
Interventions	1. Methylphenidate (oral capsules three times a day; given in low, medium, and high dosage levels of 0.125, 0.250, and 0.500 mg/kg per dose respectively) (N=66 but sample sizes differed by measure due to data availability; sample size was halved for analysis as crossover study and only data for the best dose was extracted) 2. Placebo (N=66 but sample sizes differed by measure due to data availability; sample size was halved for analysis as crossover study) **Duration:** **Intervention:** 4 weeks **Follow-up:** 5 weeks (includes a 1 week test-dose phase prior to 4 week crossover trial)

Outcomes	The main outcome of interest for this secondary analysis of the RUPP2005 data was the core autistic symptom of repetitive behaviour as assessed by the Children's Yale-Brown Obsessive Compulsive Scales-PDD (CYBOCS-PDD)
Study Design	RCT (crossover)
Source of funding	See RUPP2005
Limitations	See RUPP2005
Notes	This was a secondary analysis of the data from RUPP2005

Study ID	READ2007
Bibliographic reference	Read, S.G. & Rendall, M. (2007) An open-label study of risperidone in the improvement of quality of life and treatment of symptoms of violent and self-injurious behaviour in adults with intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 20*, 256-264.
Methods	**Allocation:** Not applicable - no control group **Matching:** Not applicable - no control group **Blindness:** Open-label **Setting:** Outpatient **Raters:** Research nurse independent of investigator with caregiver-report **Country:** UK
Participants	**Diagnosis:** Intellectual disabilities **Coexisting conditions:** N=8 with ASD (33.3%); N=13 with epilepsy (54.2%); and N=11 with organic behaviour disorder (45.8%). **Qualifying Diagnostic Assessment:** Not reported **N:** 24 **Age:** 16-65 years (mean: 27.4 years) **Sex:** Male: 19; Female: 5 **Ethnicity:** White N: 19; Black N: 2; Asian N: 3 **IQ:** Not reported; N=18 (75%) with severe or profound intellectual disabilities **Inclusion/exclusion criteria:** Not reported
Interventions	1. Risperidone (oral tablet of 1, 3 or 4mg, or oral suspension of 1mg/mL; final dose 0.5-6mg/day, mean final dose: 2.92mg/day) (N=24) **Duration:** **Intervention:** 4-103 days (mean duration of treatment: 76.4 days) **Follow-up:** 76.4 days
Outcomes	Primary outcome was challenging behaviour (as measured by the Aberrant Behaviour Checklist (ABC), Aman et al., 1985). Secondary outcomes included symptom severity/improvement (as measured by the Clinical Global Improvement - severity scale (CGI-S)) and quality of life (as measured by a modified version of the Composite Autonomic Symptom Scale (COMPASS)).
Study Design	Observational
Source of funding	Not reported
Limitations	1. No control group 2. Data could not be extracted to calculate effect sizes

Notes	• No antipsychotic treatments other than risperidone were allowed during the trial; use of these was stopped at trial entry and there was no wash-out period • Doses of medication used to treat organic disorders were maintained constant • The primary efficacy variable was the change from baseline to final visit (last observation carried forward, LOCF) • N=3 discontinued the study: N=2 withdrew consent (at weeks 4 and 6); N=1 had abnormal electrocardiogram readings following screening and was therefore ineligible to continue • Increases in body weight were modest (P=0.061) and decreases in systolic blood pressure (p=0.191) and diastolic blood pressure (p=0.031) were not clinically significant

Study ID	REMINGTON2001
Bibliographic reference	Remington, G., Sloman, L., Konstantareas, M., *et al*. (2001) Clomipramine versus haloperidol in the treatment of autistic disorder: a double-blind, placebo-controlled, crossover study. *Journal of Clinical Psychopharmacology, 21*, 440-444.
Methods	**Allocation:** Randomised **Matching:** Not applicable - crossover study **Blindness:** Double-blind **Setting:** Outpatient **Raters:** Independently by two researchers **Country:** Canada
Participants	**Diagnosis:** DSM-IV ASD **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Diagnosis independently confirmed by two of the investigators who specialize in autistic disorder **N:** 36 **Age:** 10-36 years (mean: 16.3 years) **Sex:** Male: 30; Female: 6 **Ethnicity:** Not reported **IQ:** Not reported **Inclusion/exclusion criteria:** Evidence that haloperidol or clomipramine had not been used previously or, if so, that an adequate therapeutic trial was not completed
Interventions	1. Clomipramine (Oral capsules, final dose 100-150 mg/day, mean 123 mg/day) (N=36 but N=18 for analysis as crossover study) 2. Haloperidol (Oral capsules, final dose 1-1.5mg/day) (N=36 but N=18 for analysis as crossover study) 3. Placebo (Oral capsules) (N=36 but N=18 for analysis as crossover study) **Duration:** **Intervention:** 6 weeks per intervention **Follow-up:** 21 weeks
Outcomes	Primary outcome measures were: autistic behaviours (as measured by the Childhood Autism Rating Scale (CARS), Schopler et al., 1980); and

	side effects (as measured by the Dosage Treatment Emergent Symptom Scale (DOTES) as global measure of side effects and Extrapyramidal Symptom Rating Scale (ESRS) to specifically evaluated drug-induced EPS)
Study Design	RCT (crossover)
Source of funding	Ontario Mental Health Foundation
Limitations	1. Potential carryover effect due to crossover design and short duration of washout phase 2. Data reported did not allow calculation of effect size for ABC scores
Notes	• 12/32 participants completed the clomipramine trial (dropouts due to fatigue or lethargy (n=4), tremors (N=2), tachycardia (n=1), insomnia (n=1), diaphoresis (n=1), nausea or vomiting (n=1), decreased appetite (n=1), behavioural problems (n=8). N=1 categorised as side effects but dropped out because of previous electrocardiogram results • 23/33 participants completed the haloperidol trial (dropouts due to fatigue (n=5), dystonia (n=1), depression (n=1), behavioural problems (n=4) • 21/32 participants completed the placebo trial (dropouts due to behavioural problems (n=10), nosebleeds (n=1) • Benztropine (antiparkinsonian could be used as required throughout the study)

Study ID	RUPP2005
Bibliographic reference	Research Units on Pediatric Psychopharmacology (RUPP) Autism Network (2005) Randomized, controlled, crossover trial of methylphenidate in pervasive developmental disorders with hyperactivity. *Archives of General Psychiatry, 62*, 1266-1274.
Methods	**Allocation:** Randomised (with 2 exceptions, see notes) **Matching:** No matching **Blindness:** Double-blind **Setting:** Outpatient **Raters:** Parent-rated and teacher-rated **Country:** USA
Participants	**Diagnosis:** DSM-IV ASD (N=47 autistic disorder; N=5 Asperger disorder; N=14 PDD-NOS) **Coexisting conditions:** Hyperactivity (Clinical Global Impressions scale & Swan et al. version IV ADHD scale) **Qualifying Diagnostic Assessment:** ADI-R **N:** 66 **Age:** 5-13 years (mean: 7.5 years) **Sex:** Male: 59; Female: 7 **Ethnicity:** White N: 48; Black or African American N: 9; Asian N:6; Hispanic or Latino N: 3 **IQ:** 16-135 (mean: 62.6) as assessed with the Slosson Intelligence Test **Inclusion criteria:** Boys and girls aged 5-14 years, with a diagnosis of autistic disorder, Asperger disorder, or PDD-NOS based on the criteria set forth in the DSM-IV. All of the subjects had to have

	interfering symptoms of hyperactivity and/or impulsiveness that were present for at least 6 months and began prior to the age of 7 years. The severity was confirmed by a Clinical Global Impressions (CGI) severity subscale score of 4 or higher (rated "moderately ill" taking into account all of the symptoms) and a total score of 27 or higher (item mean 1.5 on a 0-3 metric) on both a parent-rated and teacher-rated Swanson, Nolan, and Pelham-version IV ADHD scale (items 1-18), with a score of at least 10 on the hyperactivity-impulsivity subscale; and mental age of at least 18 months as determined by IQ testing **Exclusion criteria:** Concurrent psychotropic medications for at least 1-3 weeks (1 week for stimulants and clonidine hydrochloride; 2 weeks for antidepressants except fluoxetine and citalopram hydrobromide; 3 weeks for fluoxetine, citalopram hydrobromide, or antipsychotics) prior to baseline visit; other neuropsychiatric disorders that might require alternative medical management; for subjects with a tic disorder, tic severity had to be mild or less on a CGI-severity subscale rating pertaining to tics only; significant medical condition, such as heart or liver disease, that could make treatment unsafe; for subjects with a seizure disorder, no seizures in the past 6 months and a stable anticonvulsant dose for at least a month; hypertension; treatment with an adequate trial of methylphenidate hydrochloride (0.4mg/kg per dose given at least twice daily for a minimum of 2 weeks) within the past 2 years; and history of severe adverse response to methylphenidate
Interventions	1. Methylphenidate (oral capsules three times a day; given in low, medium, and high dosage levels of 0.125, 0.250, and 0.500 mg/kg per dose respectively) (N=66 but sample sizes differed by measure due to data availability; sample size was halved for analysis as crossover study and only data for the best dose was extracted) 2. Placebo (N=66 but sample sizes differed by measure due to data availability; sample size was halved for analysis as crossover study) **Duration:** **Intervention:** 4 weeks **Follow-up:** 5 weeks (includes a 1 week test-dose phase prior to 4 week crossover trial)
Outcomes	The primary outcome was hyperactivity as measured by the hyperactivity subscale of the Aberrant Behaviour Checklist (ABC). A secondary outcome was symptom improvement as measured by the Clinical Global Impressions-improvement scale (CGI-S).
Study Design	RCT (crossover)
Source of funding	This study was supported by funds under contracts N01MH80011 (Dr Aman), N01MH70001 (Dr McDougle), N01MH70010 (Dr McCracken), and N01MH70009 (Dr Scahill) from the National Institute of Mental Health, Bethesda, Md; by garnts M01 RR00750 for Indiana University, M01RR00052 for John Hopkins University, M01 RR00034 for The Ohio State University, and M01 RR06022 for Yale University; from the General Clinical Reserach Centers, National Center for Research resources, National Institutes of Health, Bethesda; by grants K23 MH068627 (Dr Posey) and K24 MH001805 (Dr McCracken) from the National Institute of Mental Health; and by the Korczak Foundation, Amsterdam (Dr Scahill)

Limitations	1. One week of treatment of each dose may not be long enough to determine efficacy 2. High rate of discontinuation owing to adverse effects 3. Rate of adverse events may be an underestimate relative to clinical settings as subjects who had had a previous adverse response to methylphenidate were excluded 4. Possibility that test-dose phase could have influenced parent blinding
Notes	• This study continues with an 8-week open-label phase. However, data is not extracted for this phase here. • N=72 participated in the test-dose phase. N=6 had intolerable side effects with more than 1 dosage level and dropped out. N=16 of the remaining 66 subjects had intolerable adverse effects at the highest dose of methylphenidate, and they were randomised to a modified crossover phase that omitted the highest dose. • 2 exceptions to completely randomised design: (1) subjects who could not tolerate the high dosage level received the medium dose twice; and (2) the high dose could not follow the placebo so as to avoid an abrupt exposure to a high dose of methylphenidate that might cause adverse effects • Parent-rated and teacher-rated ABC hyperactivity subscales were reported. However, only data from the parent-rated scale was extracted as this is the more consistently reported scale in the literature • Data could not be extracted for the CGI-I or the overall response score which summed all the measures as results not reported for best dose which was selected as the intervention group of interest

Study ID	SINGH1992
Bibliographic reference	Singh, I. & Owino, J. E. (1992) A double-blind comparison of zuclopenithixol tablets with placebo in the treatment of mentally handicapped in-patients with associated behavioural disorders. *Journal of Intellectual Disability Research, 36*, 541-549.
Methods	**Allocation:** Randomised **Matching:** No matching but no major differences in patient characteristics and no significant difference in the patient distribution according to the severity of mental handicap. **Blindness:** Double-blind **Setting:** Inpatient **Raters:** Clinicians **Country:** UK
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** Physical disorders (N=21); epilepsy (N=15); psychiatric disorders (N=9) **Qualifying Diagnostic Assessment:** Not reported **N:** 52 **Age:** 33-60 years (means: 34 and 38 years in experimental and control

	groups respectively) **Sex:** Male: 28; Female: 24 **Ethnicity:** Not reported **IQ:** Not reported; mild intellectual disabilities (N=1); moderate intellectual disabilities (N=17); severe intellectual disabilities (N=34) **Inclusion/exclusion criteria:** Participants had intellectual disabilities, 16-65 years. Exclusion criteria were confirmed or possible pregnancy, severe concomitant diseases, or treatment with depot neuroleptics in the last 3 months.
Interventions	1. Zuclopenthixol (oral tablets, 10-150mg/day, modal dose 20mg/day) (N=27) 2. Placebo (equivalent number of oral tablets) (N=25) **Duration:** **Intervention:** 12 weeks (double-blind period), this followed on from 6-week open-label phase **Follow-up:** 18 weeks
Outcomes	Primary outcome measure was symptom severity/improvement (as measured by the Clinical Global Assessment (CGA) which was derived from the Clinical Global Impressions (Guy, 1986); The Behavioural Disorder Assessment; and a simplified UKU Side-effect Rating Scale (Lingjaerde et al., 1986))
Study Design	RCT
Source of funding	Not reported
Limitations	1. Higher attrition rate in placebo group
Notes	• This was a prospective study including a 6-week, open-label treatment phase in which all patients received zuclopenthixol dihydrochloride (10mg tablets) followed by a 12-week, randomised, placebo-controlled double-blind period using a parallel group design in which some participants discontinued active drug treatment and switched to placebo • Participants could receive the hypnotics nitrazepam and temazepam, anticonvulsants and the antiparkinson drug procyclidine. Antibiotics and other medication for somatic diseases were permitted • 41 participants were taking neuroleptic medication at trial entry; 12 participants in the zuclopenthixol group and 8 in the placebo group were receiving antiparkinson drugs at entry • 9 participants were excluded from the efficacy analysis either due to protocol violation (for example, receiving unpermitted additional medication), withdrawal from the single-blind phase, or receiving less than 2 weeks treatment in the double-blind phase • Of the 43 patients (zuclopenthixol N=24; placebo N=19) who remained eligible for efficacy analysis, 5 participants (all receiving placebo) were withdrawn from the study resulting in outcome data for zuclopenthixol N=24, placebo N=14 • No data could be extracted for Behavioural Disorder Assessment or UKU side-effect rating scale outcome measures as narrative description of results • Dichotomous data calculated for 'severity of behavioural disorder' on CGA with the number of participants causing

	fewer problems in management rated as 'events' and the number of participants remaining unchanged or causing more problems summed to create 'no events' total

Study ID	TYRER2008
Bibliographic reference	Tyrer, P., Oliver-Africano, P.C., Ahmed, Z., *et al*. (2008) Risperidone, haloperidol, and placebo in the treatment of aggressive challenging behaviour in patients with intellectual disability: a randomised controlled trial. *The Lancet, 371*, 57-63.
Methods	**Allocation:** Randomised **Matching:** No matching **Blindness:** Double-blind **Setting:** Community **Raters:** Keyworker-report and independent researcher **Country:** UK and Australia
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** N=14 (16%) had ASD **Qualifying Diagnostic Assessment:** Not reported **N:** 86 **Age:** 26-51 years (placebo group mean age: 43 years; Risperidone group mean age: 39 years; Haloperidol mean age: 37.5 years) **Sex:** Male: 53; Female: 33 **Ethnicity:** Not reported **IQ:** Not reported; N=1 borderline intellectual disability; N=30 mild intellectual disability; N=41 moderate intellectual disability; N=14 severe (profound) intellectual disability **Inclusion/exclusion criteria:** Individuals treated by services for intellectual disability (IQ<75) with all degrees of severity of intellectual disability, including those who had been given antipsychotic drugs in the past but no longer took them. Participants were required to have recent challenging behaviour and aggression (defined by at least two episodes of aggressive behaviour, with a total MOAS score of at least 4 in the past 7 days). Only those who had been previously diagnosed as having a psychosis were excluded. A possible ASD was not an exclusion criteria, provided that a clinical diagnosis of psychosis was absent. Patients who had taken depot antipsychotic drugs, or any other injected antipsychotic drug, within the past 3 months or continuous oral antipsychotic drugs within the past week, or those under a section of the Mental Health Act, 1983, (or the Queensland Mental Health Act, 2000 in the Australian group) at the time of assessment were excluded.
Interventions	1. Risperidone (oral tablets, 1mg-2mg/day) (N=29) 2. Haloperidol (oral tablets, 2.5mg-5mg/day) (N=28) 3. Placebo (oral tablets) (N=29) **Duration:** **Intervention:** 12 weeks **Follow-up:** 26 weeks (optional continuation)
Outcomes	The primary outcome was challenging behaviour (as measured by the Modified Overt Aggression Scale (MOAS), Sorgi et al., 1991; and the

	Aberrant Behaviour Checklist (community version) (ABC-C), Aman et al., 1985). Secondary outcomes included effect on carers (as measured by the uplift and burden scale, Pruchno, 1990), quality of life (as measured by the 40-item quality of life questionnaire, Schalock & Keith, 1993); side effects (as measured by the udvalg for kliniske undersogelser scale, Lingjaerde et al., 1987), and symptom severity/improvement (as measured by the Clinical Global Impression (CGI) scale, Guy, 1976)
Study Design	RCT
Source of funding	National Coordinating Centre for Health Technology Assessment (NCCHTA), Southampton, UK
Limitations	1. Results reported as median values and inter-quartile ranges which may indicate skewed data. As a result it is not possible to calculate effect sizes for this study 2. The statistical analysis reported compares scores at week 4 rather than at the week 12 end point 3. No data could be extracted for the ABC-C, the effect on carers, quality of life, or symptom severity/improvement 4. No adjustment was made for multiple statistical comparisons
Notes	• N=11 dropouts by week 12 in the Risperidone group; N=6 dropouts in the Haloperidol group; and N=8 drop-outs in the placebo group • Analysis was by intention to treat, inputting missing values by last observation carried forward • Baseline differences in MOAS scores controlled for in statistical analysis

Study ID	VANDENBORRE1993
Bibliographic reference	Vanden Borre, R., Vermote, R., Buttiëns, M., *et al.* (1993) Risperidone as add-on therapy in behavioural disturbances in mental retardation: a double-blind placebo-controlled cross-over study. *Acta Psychiatrica Scandinavica, 87*, 167-171.
Methods	**Allocation:** Randomised **Matching:** No matching **Blindness:** Double-blind **Setting:** In-patient **Raters:** Not reported **Country:** Belgium
Participants	**Diagnosis:** DSM-III-R intellectual disability **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Not reported **N:** 37 **Age:** 15-58 years (mean: 30.5 years) **Sex:** Not reported **Ethnicity:** Not reported **IQ:** Not reported; severe or profound intellectual disabilities **Inclusion/exclusion criteria:** Individuals aged 15-65 years, of either sex, could be include in the study. A diagnosis of mild, moderate,

	severe, or profound mental retardation (DSM-III-R) had to be established. Despite optimisation of current treatment, participants presented such persistent behavioural disturbances as hostility, aggressiveness, irritability, agitation, hyperactivity, automutiliation and autism that required psychotropic medication. Participants suffering from a severe organic disease affecting the absorption, distribution, metabolism or excretion of the test drug or from a mental disorder other than the target diagnosis were excluded. Participants with a history of alcohol or drug abuse were also excluded, as were women with pregnancy potential, pregnancy or lactation.
Interventions	1. Risperidone (oral solution, 4-12mg/day, mean final dose 8.3mg/day) (N=37 but for analysis N=19 as this is a crossover study) 2. Placebo (oral solution) (N=37 but for analysis N=19 as this is a crossover study) **Duration:** **Intervention:** 3 weeks per intervention (total of 8 weeks) **Follow-up:** 8 weeks
Outcomes	Primary outcomes were symptoms severity/improvement (as measured by the Clinical Global Impressions (CGI) scale), and challenging behaviour (as measured by the Aberrant Behaviour Checklist (ABC))
Study Design	RCT (crossover)
Source of funding	Not reported
Limitations	1. Results reported for primary outcomes do not allow for a calculation of effect sizes 2. Results are indicative of group differences in adverse events. However, narrative description of results means data cannot be extracted in order to quantify this finding
Notes	• During the whole study period, the existing medication was to be continued unchanged. The consumption of concomitant medication was evenly distributed in both groups; buterophenones, phenothiazines and benzodiazepines were the most frequently used concomitant medicines. • Both groups were comparable in sex distribution, target symptom and diagnosis (mostly severe or profound mental retardation) • Two patients dropped out under placebo: one after 7 days because of agitation and one after 9 days because of extrapyramidal symptoms. Five patients dropped out under risperidone treatment: one because of an intercurrent event (respiratory infection) after 15 days; and 4 for adverse events, 1 for hypotension after 1 day, 1 for hypotension and sedation after 6 days, 1 for sedation after 7 days, and 1 because of agitation after 15 days. • All participants were included in the efficacy analysis and in the safety analysis • Adverse reactions were more numerous under risperidone treatment. Sedation was reported 10 times and drowsiness 6 times as a treatment-emergent adverse event under risperidone treatment; these symptoms did not emerge under placebo

	• There were no statistically significant changes in systolic or diastolic blood pressure, heart rate, ECG or body weight during this trial. No relevant alterations in haematology, blood biochemistry or urinalysis were detected.

Study ID	VANHEMERT1975
Bibliographic reference	van Hemert, J.C.J. (1975) Pipamperone (Dipiperon, R3345) in troublesome mental retardates: a double-blind placebo controlled cross-over study with long-term follow-up. *Acta Psychiatrica Scandinavica, 52*, 237-245.
Methods	**Allocation:** Randomised **Matching:** No matching **Blindness:** Double-blind **Setting:** Inpatient **Raters:** Not reported **Country:** Netherlands
Participants	**Diagnosis:** DSM II mental retardation **Coexisting conditions:** All participants presented strong aggressiveness or other troublesome behaviour, not induced by their environment (e.g. agitation or aggressiveness towards the other patients) **Qualifying Diagnostic Assessment:** Not reported **N:** 20 **Age:** 22-42 years (median: 33 years) **Sex:** Male: 0; Female: 20 **Ethnicity:** Not reported **IQ:** Not reported; N=9 moderate intellectual disabilities, N=10 severe intellectual disabilities, and N=1 profound intellectual disabilities **Inclusion/exclusion criteria:** Not reported
Interventions	1. Pipamperone (oral tablets, 40-80mg/day) (N=20, but N=10 for analysis as crossover study) 2. Placebo (oral tablets) (N=20, but N=10 for analysis as crossover study) **Duration:** **Intervention:** 3 weeks per intervention (total of 6 weeks) **Follow-up:** 4 months (open-label continuation)
Outcomes	Primary outcome was challenging behaviour (as measured by change scores on a 10-item scale)
Study Design	RCT (crossover)
Source of funding	Janssen Pharmaceutica provided the medication
Limitations	1. Results reported for primary outcomes do not allow for calculation of effect sizes
Notes	• Other psychotropic drugs, including hypnotics were not admitted • Both groups comparable as to age, diagnosis, and body weight at the onset of treatment • Apart from drowsiness in N=3 during pipamperone treatment, no side effects were reported or observed

1.5.2 Characteristics of excluded studies

ADAMS2004

Reason for exclusion	Sample size for analysis of completers is less than 10 per arm

ADAMS2011

Reason for exclusion	Data could not be extracted

ADVOKAT2000

Reason for exclusion	Co-morbid psychosis

ALKAISI1974

Reason for exclusion	Co-morbid epilepsy and the primary outcome is reduction of seizures

AMMINGER2007

Reason for exclusion	Sample size is less than 10 per arm

AMORE2011

Reason for exclusion	Significant baseline differences between groups in primary outcome measure not controlled for in analysis

ANAGNOSTOU2006

Reason for exclusion	Sample size is less than 10 participants per arm

ANDARI2010

Reason for exclusion	Sample size is less than 10 per arm for analysis as this is a crossover study

ANDERSEN2008

Reason for exclusion	Data could not be extracted due to narrative reporting of results

BERTOGLIO2010

Reason for exclusion	Data could not be extracted

BHAUMIK1997

Reason for exclusion	Co-morbid epilepsy

BOACHIE1997

Reason for exclusion	Co-morbid psychosis

BREUNING1982

Reason for exclusion	Data could not be extracted

BRODKIN1997

Reason for exclusion	Data could not be extracted

BUITELAAR1990

Reason for exclusion	Sample size is less than 10 per arm for analysis as this is a crossover study

BUITELAAR2000

Reason for exclusion	From an intellectual disabilities population sift but not an intellectual disability population, IQ>70

CONIGLIO2001

Reason for exclusion	Data could not be extracted

COPLAN2003

Reason for exclusion	Data could not be extracted

COSKUN2009

Reason for exclusion	Mean age <15 years

CRAFT1980

Reason for exclusion	Co-morbid psychosis

DANFORS2005

Reason for exclusion	Sample size is less than 10 per arm

DOLSKE1993

Reason for exclusion	Sample size is less than 10 per arm

DRMIC2008

Reason for exclusion	Data could not be extracted

GHUMAN2009

Reason for exclusion	Sample size is than 10 per arm

GIANNOTTI2006

Reason for exclusion	Data could not be extracted

GUASTELLA2010

Reason for exclusion	Sample size is less than 10 per arm for analysis as this is a crossover study

HANDEN2000

Reason for exclusion	Sample size is than 10 per arm

HELLINGS2010

Reason for exclusion	Data could not be extracted

HENRY2006

Reason for exclusion	Mean age <15 years

HENRY2009

Reason for exclusion	Mean age <15 years

HOLLANDER2000

Reason for exclusion	Mean age <15 years

HOLLANDER2003

Reason for exclusion	Sample size is less than 10 per arm for analysis as this is a crossover study

HOLLANDER2005

Reason for exclusion	Mean age <15 years

HOLLANDER2007

Reason for exclusion	Sample size is less than 10 per arm for analysis as this is a crossover study

HONOMICHL2002

Reason for exclusion	Sample size is less than 10 per arm

JAMES2009

Reason for exclusion	Clinically relevant data could not be extracted

JOHNSON2010

Reason for exclusion	Data could not be extracted. It was unclear if F-values reported were for main effects or interaction values

JYONOUCHI2005

Reason for exclusion	Clinically relevant data could not be extracted

KASTNER1993

Reason for exclusion	Co-morbid epilepsy

KERN2001

Reason for exclusion	Data could not be extracted

KERN2002

Reason for exclusion	Sample size is less than 10 per arm

LELORD1981

Reason for exclusion	Data could not be extracted

LIGHTDALE2001

Reason for exclusion	Data could not be extracted

LONSDALE2002

Reason for exclusion	Clinically relevant data could not be extracted

LOTT1996

Reason for exclusion	Data could not be extracted (narrative)

LYNCH1985

Reason for exclusion	Data could not be extracted

MALT1995

Reason for exclusion	Co-morbid psychosis

MCDOUGLE1996

Reason for exclusion	Sample size for analysis of completers is less than 10 per arm as this is a crossover study

MEGUID2008

Reason for exclusion	Data could not be extracted. ANOVA reported for change from baseline scores but the variables and participants included is unclear

MOFFATT1970

Reason for exclusion	Co-morbid epilepsy

MOLLOY2002

Reason for exclusion	Data could not be extracted

NAZNI2008

Reason for exclusion	Data could not be extracted

NICKELS2008

Reason for exclusion	Data could not be extracted

OWLEY2001

Reason for exclusion	Data could not be extracted

OWLEY2010

Reason for exclusion	Mean age <15 years

POLITI2008

Reason for exclusion	Data could not be extracted

QUINTANA1995

Reason for exclusion	Sample size is than 10 per arm

ROBERTS2001

Reason for exclusion	Data could not be extracted

ROMEO2009

Reason for exclusion	Efficacy data duplicated from TYRER2008

RUEDRICH1999

Reason for exclusion	Co-morbid psychosis

RUEDRICH2008

Reason for exclusion	Co-morbid psychosis

RUGINO2002

Reason for exclusion	Data could not be extracted

STIGLER2004

Reason for exclusion	Data could not be extracted

THALAYASINGAM2004

Reason for exclusion	Data could not be extracted

TODA2006

Reason for exclusion	Data could not be extracted

TROOST2005

Reason for exclusion	Mean age <15 years

TYRER2009

Reason for exclusion	Data duplicated from TYRER2008

UNIS2002

Reason for exclusion	Data could not be extracted

VALICENTIMCDERM2006

Reason for exclusion	Mean age <15 years

WASSERMAN2006

Reason for exclusion	Data could not be extracted. Time x group interaction data reported.

WEIR1968

Reason for exclusion	Data could not be extracted as the results from the comparison of interest are reported as NS

WHITELEY2010

Reason for exclusion	Data could not be extracted

ZARCONE2001

Reason for exclusion	Sample size for analysis is less than 10 per arm as it is a crossover study

1.5.3 References of excluded studies

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1.6 ORGANISATION AND DELIVERY OF CARE: SETTINGS FOR CARE

1.6.1 Characteristics of included studies

Study ID	BARLOW1991
Bibliographic reference	Barlow, J. & Kirby, N. (1991) Residential satisfaction of persons with an intellectual disability living in an institution or in the community. *Australia and New Zealand Journal of Developmental Disabilities, 17*, 7-23.
Methods	**Allocation:** Non-randomised **Matching:** No matching **Blindness:** Non-blind **Setting:** Residential versus community **Raters:** Self-report via interview with investigator **Country:** Australia
Participants	**Diagnosis:** Intellectual disability (mild intellectual disability) **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Not reported **N:** 31 **Age:** 20-51 years (means: residential mean: 28.5 years; community mean: 32.8 years) **Sex:** Male: 16; Female: 15 **Ethnicity:** Not reported **IQ:** Not reported **Inclusion criteria:** Not reported
Interventions	1. Residential institution group (N=16). This residential institution was called Balyana and attempted to improve on traditional institutional models by providing individual rooms with bathrooms for each resident, low staff to resident ratios and relatively few restrictions. Leisure facilities included a swimming pool, tennis courts, an oval, games room, and a small auditorium. Residents completed training programs in personal hygiene, room care, and laundry, and in community living skills 2. Community group (N=15). All of the community group were living in the community without support services and all were renting except one who was buying a flat **Duration:** **Intervention:** Not applicable **Follow-up:** Average amount of time spent living at residential institution 6 months-8 years (mean: 3.5 years); those in the community had been resident there for 1 month-2 years (mean: 1 year)
Outcomes	The primary outcome was resident satisfaction as assessed via interview with the investigator which was based on the Satisfaction Qustionnaire of Seltzer and Seltzer's (1978) Community Adjustment Scale. Satisfaction subscales included: residential satisfaction; leisure satisfaction; work satisfaction;financial satisfaction; and interpersonal satisfaction. Data were extracted for residential satisfaction as this was the only outcome for which the authors found significant group differences.
Study Design	Observational (cohort study)

Source of funding	Not reported
Limitations	1. Group differences in duration of residency in each setting
Notes	• N=2 were removed from the residential institution group for the analysis due to inconsistent reporting for one participant and persistent acquiescence for the other participant. As a result N=14 for the residential institution group. • For the purposes of analysis the residential institution was taken as the experimental group

Study ID	BHAUMIK2009
Bibliographic reference	Bhaumik, S., Watson, J.M., Devapriam, J., *et al*. (2009) Aggressive challenging behaviour in adults with intellectual disability following community resettlement. *Journal of Intellectual Disability Research, 53*, 298-302.
Methods	**Allocation:** Not applicable - no control group **Matching:** Not applicable - no control group **Blindness:** Non-blind **Setting:** Residential to community **Raters:** Carer-report scale **Country:** UK
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** Many individuals also had co-existing health problems; 36 (73%) were incontinent, 2 (4%) had a hearing impairment; 17 (35%) had a visual impairment; 30 (61%) had mobility problems and 32 (65%) suffered from epilepsy **Qualifying Diagnostic Assessment:** Vineland Scale **N:** 49 **Age:** 31-96 years (means: Males: 50.8 years; Females: 49.3 years) **Sex:** Male: 36; Female: 13 **Ethnicity:** White N=49 **IQ:** Not reported - 34 (69%) had profound ID, 11 (22%) had severe ID, 3 (6%) had moderate ID, and 1 (2%) had mild ID **Inclusion criteria:** The adult residents who left a long-stay hospital in Leicestershire and were relocated to a number of community-based placements between 2004 and 2006
Interventions	1. Relocation from residential to community (N=49) **Duration:** **Intervention:** Not applicable **Follow-up:** 18 months
Outcomes	Primary outcome was aggressive challenging behaviour as measured by the Modified Overt Aggression Scale (MOAS)
Study Design	Observational (before-and-after)
Source of funding	Leicestershire Partnership NHS Trust and the Department of Health Policy Research Programme
Limitations	1. No control group 2. Efficacy data cannot be extracted 3. Median scores reported which may indicate skewed data

Notes	• Participants followed for 12 months after discharge but change from baseline results reported based on baseline (6 months before discharge) and 6 month (after discharge) comparison

Study ID	BOURAS1993
Bibliographic reference	Bouras, N., Kon, Y. & Drummond, C. (1993) Medical and psychiatric needs of adults with a mental handicap. *Journal of Intellectual Disability Research, 37*, 177-182.
Methods	**Allocation:** Not applicable - no control group **Matching:** Not applicable - no control group **Blindness:** Non-blind **Setting:** Residential to community **Raters:** Clinician-rated **Country:** UK
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** DSM III-R **N:** 71 **Age:** Range not reported (mean: 46.1 years) **Sex:** Male: 46; Female: 25 **Ethnicity:** Not reported **IQ:** Not reported (46% severe mental handicap; 24% moderate mental handicap; 30% mild mental handicap) **Inclusion criteria:** Not reported
Interventions	1. Mentally handicapped adults resettled from large institutions to community facilities including 'staffed houses' **Duration:** **Intervention:** Not applicable **Follow-up**: 1 year
Outcomes	Data were collected and reported on behaviour problems, utilization of medical and psychiatric services, staff opinion on behaviour disturbance, psychiatric diagnosis and medical input for physical illness, as measured by clinical assessment pre- and post-resettlement using the 'Assessment and Information Rating Profile' (Bouras & Drummond, 1992), by seeing the resident, interviewing a care worker and looking at case notes. However, data could only be extracted for behaviour problems.
Study Design	Observational (before-and-after study)
Source of funding	Not reported
Limitations	1. No control group 2. Efficacy data could not be extracted
Notes	

Study ID	CHOU2008
Bibliographic reference	Chou, Y-C., Lin, L-C., Pu, C-Y., *et al*. (2008) Outcomes and costs of residential services for adults with intellectual disabilities in Taiwan: a comparative evaluation. *Journal of Applied Research in Intellectual Disabilities, 21*, 114-125.
Methods	**Allocation:** Non-randomised **Matching:** Matched on resident's disability level, age and gender **Blindness:** Non-blind **Setting:** Residential-versus-community **Raters:** Self-report and scales rated by front line practitioners and residential managers (or administrators) **Country:** China
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Not reported **N:** 248 **Age:** Range not reported (means: small residential home mean: 28.6 years; group/community home mean: 30.5 years); institution mean: 29.5 years) **Sex:** Male: 177; Female: 71 **Ethnicity:** Not reported **IQ:** Not reported (majority moderate to severe intellectual disabilities) **Inclusion criteria:** Not reported
Interventions	1. Small residential group home (N=103) 2. Institution (N=76) Data was also reported for group/community home residents (N=69). However, that data is not extracted here as the authors statistical analysis (which controlled for group differences in adaptive/maladaptive behaviour) suggested that the largest group differences lay with the groups selected. **Duration:** **Intervention:** Not applicable **Follow-up:** Not reported
Outcomes	Primary outcomes included: quality of life as measured by the Quality of Life Questionnaire (QOLQ; Schalock & Keith, 1993); choice making as measured using the Residence Choice Assessment Scale (RCAS; Kearney et al. 1995); community inclusion as scored using the Use of Community Facilities Scale (UCFS) and measured the variety of community places and activities that the residents used and were engaged in; and family contact which was assessed by the frequency of face-to-face visits between the participants and his/her family members
Study Design	Observational (cross-sectional)
Source of funding	Department of Social Affairs, Ministry of Interior, Taiwan, China
Limitations	1. Significant differences between the groups in adaptive and maladaptive behaviour. However, this was controlled for in the authors' statistical analysis and significant differences remained
Notes	

Study ID	CHOU2011
Bibliographic reference	Chou, Y.C., Pu, C., Kröger, T., *et al.* (2011) Outcomes of a new residential scheme for adults with intellectual disabiliites in Taiwan: a 2-year follow-up. *Journal of Intellectual Disability Research, 55*, 823-831.
Methods	**Allocation:** Not applicable - no control group **Matching:** Not applicable - no control group **Blindness:** Non-blind **Setting:** Community **Raters:** Self-report **Country:** Taiwan
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Diagnoses of classification and level of disability were conducted by the health authorities, and the severity of the intellectual disability was categorised in accordance with the person's IQ score and social adaptation skills **N:** 49 at time 1; 29 at time 5 **Age:** Time 1: 19-57 years (mean; 27 years); Time 5: 21-59 years (mean: 30.7 years) **Sex:** Time 1: Male: 33; Female: 16. Time 5: Male: 24; Female: 5 **Ethnicity:** Not reported **IQ:** Not reported. Time 1: 33% severe/profound intellectual disabilities; Time 5: 31% severe/profound intellectual disabilities **Inclusion criteria:** Participants were new in homes (only been in new homes for 1-2 months)
Interventions	1. Time 1 - Residential scheme which involved individuals with intellectual disabilities moving from their family home or from institutions to small-scale residential homes (N=49). This scheme provided accomodation in ordinary housing in established residential areas and all were a few minutes' walk from the town/city centre. Each home was limited to six or fewer residents and was staffed by support services 24 hours a day. 2. Time 5 - Participants still living in these residential homes 2 years later (N=29). 20 residents had left and moved back to their families (N=14) or institutions (N=6). The authors report the results of a subgroup analysis which compares outcomes for participants moving from an institution with participants moving from family homes. However, this data could not be extracted as the sample size for analysis is too small for the end-point scores. **Duration:** **Intervention:** 2 years **Follow-up:** 2 years
Outcomes	The primary outcome was quality of life as measured by the Quality of Life Questionnaire (QoL-Q; Schalock & Keith, 1993). The level of family contact was also examined, although the outcome measure for this item was less clear.
Study Design	Obeservational (before-and-after)
Source of funding	Ministry of Interior of the Taiwan Government and National Science Council (NSC 95-2412-H-010-001-SSS)

Limitations	1. Lack of a control group
Notes	

Study ID	CULLEN1995
Bibliographic references	Cullen, C., Whoriskey, M., Mackenzie, K., *et al*. (1995) The effects of deinstitutionalization on adults with learning disabilities. *Journal of Intellectual Disability Research, 39*, 484-494.
Methods	**Allocation:** Non-randomised **Matching:** Matched on age (within 5 years), sex, length of institutionalisation, and adaptive behaviour score (overall ABS score) **Blindness:** Non-blind **Setting:** Residential to community **Raters:** Staff-report and self-report **Country:** UK
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Not reported **N:** 100 **Age:** 20-60 years (majority 31-50) **Sex:** Not reported **Ethnicity:** Not reported **IQ:** Not reported - more than N=70 moderately or severely intellectually disabled **Inclusion criteria:** Not reported
Interventions	1. Participants moving from residential to community settings (N=50) 2. Participants staying in residential settings (N=50) Duration: Intervention: Not applicable Follow-up: 30 months
Outcomes	The primary outcomes were level of adaptive/maladaptive behaviour, community living skills, social skills and quality of life. Outcome measures included direct observation of a sample of community living skills (pedestrian skills, using a bus, ordering in a restaurant, and using public telephone), the Adaptive Behaviour Scale (ABS), staff- and self-report social skills, and behavioural observations of quality of life and quality of care, and interactions. Data were extracted for ABS overall score, quality of life, and staff-rated social skills.
Study Design	Observational (cohort)
Source of funding	Scottish Office Home and Health Department (Grant No. K/PPR/2/2/C798)
Limitations	1. No statistical correction made to control for multiple comparisons
Notes	

Study ID	DAGNAN1994A
Bibliographic reference	Dagnan, D., Howard, B. & Drewett, R.F. (1994a) A move from hospital to community-based homes for people with learning disabilities: activities outside the home. *Journal of Intellectual Disability Research, 38*, 567-576.
Methods	**Allocation:** Non-randomised **Matching:** Matched on sex and on the Wessex categories coding for ability to walk with help, visual disability, auditory disability, and speech ability. Age was matched within 5 years. **Blindness:** Non-blind **Setting:** Residential to community **Raters:** Self-report **Country:** UK
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** 4 participants were non-ambulant and 4 had some sensory impairments **Qualifying Diagnostic Assessment:** Not reported **N:** 36 **Age:** Range not reported (means: community mean: 42 years; institution mean: 41 years) **Sex:** Not reported **Ethnicity:** Not reported **IQ:** Not reported **Inclusion criteria:** Participants left the hospital between 31 July 1985 and 1 January 1988. They had lived in the hospital for at least 12 months prior to leaving, and short-stay residents were excluded from the study
Interventions	1. Participants moving from hospital to community-based homes (N=18) 2. Participants remaining resident at the hospital (N=18) **Duration:** **Intervention:** Not applicable **Follow-up:** 18 months
Outcomes	The primary outcome was activities outside the home as measured by diary self-report on the number and features of trips outside the home. Data were extracted for the number of trips outside the home
Study Design	Observational (cohort)
Source of funding	Northern Region Health Authority under the Care in the Community: Mental Handicap programme (grant MH/85/07)
Limitations	1. Small sample size
Notes	

Study ID	DAGNAN1998
Bibliographic reference	Dagnan, D., Ruddick, L. & Jones, J. (1998) A longitudinal study of the quality of life of older people with intellectual disability after leaving hospital. *Journal of Intellectual Disability Research, 42*, 112-121.
Methods	**Allocation:** Not applicable – no control group **Matching:** Not applicable – no control group **Blindness:** Non-blind **Setting:** Residential to community **Raters:** Self-report **Country:** UK
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Not reported **N:** 29 **Age:** 39-93 years (mean: 61 years) **Sex:** Not reported **Ethnicity:** Not reported **IQ:** Not reported **Inclusion criteria:** Not reported
Interventions	1. Hospital-to-community transition group (N=29) Duration: Intervention: Not applicable Follow-up: 53 months
Outcomes	Quality of life as measured by The Questionnaire on Quality of Life
Study Design	Observational (before-and-after)
Source of funding	Not reported
Limitations	1. Small sample size 2. No control group 3. Efficacy data cannot be extracted
Notes	• Participants followed for 53 months but statistical analysis extracted compares pre-move (5 months before the move) with 30 months (post-move) scores

Study ID	DONNELLY1996
Bibliographic reference	Donnelly, M., McGilloway, S., Mays, N., *et al*. (1996) One and two year outcomes for adults with learning disabilities discharged to the community. *British Journal of Psychiatry, 168*, 598-606.
Methods	**Allocation:** Not applicable – no control group **Matching:** Not applicable – no control group **Blindness:** Non-blind **Setting:** Residential to community **Raters:** Staff **Country:** UK
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Not reported **N:** 214 **Age:** Not reported **Sex:** Not reported **Ethnicity:** Not reported **IQ:** Not reported **Inclusion criteria:** Not reported
Interventions	1. Long-stay patients discharged from residential settings to live in community (N=214) **Duration:** **Intervention:** Not applicable **Follow-up:** 2 years
Outcomes	Primary outcomes were skills and behavioural problems as assessed by staff using standardized checklists. Data were extracted for challenging behaviour as measured by the Problems Questionnaire (PQ; Clifford, 1987) which assesses dangerousness, psychological impairment, management problems, socially unacceptable behaviour, and problems relating to attitudes and relationships
Study Design	Observational (before-and-after)
Source of funding	Not reported
Limitations	1. Participant characteristics very under-specified 2. No control group 3. Efficacy data cannot be extracted
Notes	• Participants were followed for 2 years, however, the statistical analysis extracted compared pre-discharge to 12-months post-discharge scores

Study ID	GASKELL1995
Bibliographic reference	Gaskell, G., Dockrell, J. & Rehman, H. (1995) Community care for people with challenging behaviours and mild learning disability: an evaluation of an assessment and treatment unit. *British Journal of Clinical Psychology, 34*, 383-395.
Methods	**Allocation:** Not applicable – no control group **Matching:** Not applicable – no control group **Blindness:** Non-blind **Setting:** Residential **Raters:** Staff report using standardized assessments **Country:** UK
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Not reported **N:** 34 **Age:** 18-46 years (mean: 29.2 years) **Sex:** Male: 24; Female: 10 **Ethnicity:** Not reported **IQ:** Not reported **Inclusion criteria:** Not reported
Interventions	1. Mental Impairment Evaluation and Treatment Service (MIETS) (N=34). This hospital-based unit seeks to prepare clients with a mild intellectual disability and challenging behaviours for resettlement in the community. 3 broad categories of interventions were used: medication, behavioural techniques (including anger management, graded exposure to stimuli and reinforcement), and skills training (including social skills, sex education, and daily living skills) **Duration:** **Intervention:** Not reported **Follow-up:** Progress of clients from pre-admission to 6-months post-discharge
Outcomes	Primary outcome was changes in behaviour over time as measured by the Vineland and the Adaptive Behaviour Scale Part II. Data were extracted for the ABS (II) violent behaviour domain
Study Design	Observational (before-and-after)
Source of funding	Grant from the Nuffield Foundation
Limitations	1. Small sample size and ABS data only available for half of the participants 2. No control group 3. Efficacy data cannot be extracted
Notes	

Study ID	HASSIOTIS2009
Bibliographic reference	Hassiotis, A., Robotham, D., Canagasabey, A., *et al*. (2009) Randomized, single-blind, controlled trial of a specialist behaviour therapy team for challenging behaviour in adults with intellectual disabilities. *American Journal of Psychiatry, 166*, 1278-1285.
Methods	**Allocation:** Randomised **Matching:** No matching **Blindness:** Single-blind **Setting:** Community **Raters:** Not reported **Country:** UK
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** Assumption that patients may well have co-morbid ill mental health **Qualifying Diagnostic Assessment:** Not reported **N:** 63 **Age:** Range not reported (means: experimental group mean: 39.6 years; control group mean: 41.3 years) **Sex:** Male: 37; Female:23 **Ethnicity:** White N=60 **IQ:** Not reported - 42 participants with mild/moderate and 21 with severe/profound intellectual disability **Inclusion criteria:** Service users were age 18 or over with any severity of intellectual disability. They were referred to the behaviour therapy team by members of the community intellectual disability teams, and needed to have behaviour severe enough to place the individual or others at risk, or placement breakdown was imminent despite other supports being offered. Service users in whom staff believed the challenging behaviour was the direct consequence of a mental disorder were excluded.
Interventions	1. Specialist behaviour therapy team (N=32). The team adopted a multidimensional model including applied behaviour analysis and positive behavioural support to address the problem behaviours without resorting to aversive strategies. Treatment involves a detailed functional analysis of the presenting problem and a comprehensive report is produced based on the functional analysis with recommendations for a multi-element intervention plan. Caregivers are expected to employ behavioural strategies and training is provided to enhance their skills 2. Standard treatment group (N=31). This service consists of five community intellectual disabilities teams, and the teams offer a range of interventions including pharmacotherapy, nursing, and enhancement of adaptive skills. **Duration:** **Intervention:** Mean of 9 contacts **Follow-up:** Mean of 6 months
Outcomes	Primary outcome was challenging behaviour as assessed by the Aberrant Behaviour Checklist (ABC). Outcomes of interest were the ABC irritability, hyperactivity, and lethargy subscales. Cost data was also reported but not extracted.
Study Design	RCT (narrative reporting)

Source of funding	South Essex Partnership University Foundation NHS Trust (grant code GRG3)
Limitations	1. Cannot extract data for efficacy as median values and interquartile ranges were reported. This may also imply that the data was skewed. We are thus restricted to analysing the results from this study via narrative review
Notes	

Study ID	HEMMING1983
Bibliographic reference	Hemming, H. (1983) The Swansea relocation study of mentally handicapped adults. *International Journal of Rehabilitation Research, 6*, 494-495.
Methods	**Allocation:** Non-randomised **Matching:** Matched on sex **Blindness:** Non-blind **Setting:** From institution to community **Raters:** Not reported **Country:** UK
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Not reported **N:** 50 at baseline; N: 32 at 5.5 year follow-up **Age:** Not reported (adults) **Sex:** Not reported **Ethnicity:** Not reported **IQ:** Not reported **Inclusion criteria:** Not reported
Interventions	1. Mentally hanidcapped adults who lived in large institutions and had been selected for transfer to two new small units (N=50 at time 1; N=32 at follow-up) **Duration:** **Intervention: Not applicable** **Follow-up:** 5.5 years
Outcomes	Primary outcome was adaptive behaviour (as measured by the AAMD's Adaptive Behaviour Scale (ABS))
Study Design	Observational (before-and-after)
Source of funding	Not reported
Limitations	1. Demographic data for control group (participants who remained in the institution) are reported. However, no between-group data analysis is reported. 2. Efficacy data could not be extracted
Notes	

Study ID	HOLBURN2004
Bibliographic reference	Holburn, S., Jacobson, J.W., Schwartz, A.A., *et al*. (2004) The willowbrook futures project: a longitudinal analysis of person-centered planning. *American Journal on Mental Retardation, 109*, 63-76.
Methods	**Allocation:** Non-randomised **Matching:** Matching was based on residence, age (±5 years), gender, intellectual level (e.g. mild to severe mental retardation), presence of psychiatric diagnosis (yes/no), and overall severity or magnitude of maladaptive behaviour **Blindness:** Non-blind **Setting:** Residential **Raters:** Objective measure **Country:** USA
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** 53% had psychiatric diagnosis **Qualifying Diagnostic Assessment:** Not reported **N:** 38 **Age:** 19-61 years (mean: 38.6 years) **Sex:** Male: 29; Female: 9 **Ethnicity:** Not reported **IQ:** Not reported (68.4% severe/profound mental retardation) **Inclusion criteria:** Participants were residing at four developmental centres in New York City that were operated by the New York State Office of Mental Retardation and Developmental Disabilities.
Interventions	1. Person-Centred Planning (PCP) (N=20). Planning occurred in four phases: introduction; development of a personal profile; creation of a vision of the future; and follow-along. The intervention was a slight modification of Mount's (1992, 1994) Personal Futures Planning. Person-centred planning meetings were held approximately once per month at the residence of the focus person until the first three phases were complete; thereafter, they occurred less frequently and the schedule depended on the intricacies of each team process. Team composition varied but often consisted of a facilitator, co-facilitator, service user, family member, behaviour specialist, service coordinator or social worker, bridge-builder, direct-support staff, and unit or house manager. 2. Traditional interdisciplinary service planning (ISP) (N=18). This group of matched peers lived in same developmental centres and received the type of individual habilitation planning typically provided to residents of large intermediate care facilities. The ISP teams typically met quarterly in the developmental centre. The teams were interdisciplinary, largely composed of professional staff (e.g. client coordinator, nurse, psychologist, speech therapist, teacher) who meet to discuss assessments, review progress toward service plan goals, and develop new written habilitative goals and methodologies to be pursued over the ensuing weeks and months. **Duration:** **Intervention:** Not reported **Follow-up:** 3 years
Outcomes	The primary outcome reported was The Person-Centred Planning Quality of Life Indicators (Holburn et al. 1996). However, data could

	not be extracted for this outcome. Data was also reported for the number of participants moving from institutional living to community living arrangements and this data was extracted
Study Design	Observational (parallel groups)
Source of funding	New York State Office of Mental Retardation and Developmental Disabilities (Albany, New York) and its Institute for Basic Research in Developmental Disabilities (Staten Island, New York)
Limitations	1. Bridge building funds only available to person-centred planning participants. However, only half of the experimental group who moved into the community used such resources which might suggest that this fund did not create an advantage favouring the person-centred planning group
Notes	

Study ID	KEARNEY1995
Bibliographic reference	Kearney, C.A., Durand, V.M. & Mindell, J.A. (1995) It's not where but how you live: choice and adaptive/maladaptive behavior in persons with severe handicaps. *Journal of Developmental and Physical Disabilities, 7*, 11-24.
Methods	**Allocation:** Non-randomised **Matching:** No matching **Blindness:** Non-blind **Setting:** Transitional developmental centre (between relocation from large developmental centre to smaller residential facilities) versus direct relocation to smaller community residences **Raters:** Staff-report based on standardized measures Country: USA
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** Secondary diagnoses included seizure disorders (21.1%), Down's Syndrome (7%) and others (8.8%, e.g. cerebral palsy) **Qualifying Diagnostic Assessment:** Not reported **N:** 57 **Age:** Range not reported (mean: 34.83 years) **Sex:** Male: 30; Female: 27 **Ethnicity:** Not reported **IQ:** Not reported – severe intellectual disabilities (3.5%) or profound intellectual disabilities (96.5%) **Inclusion criteria:** Not reported
Interventions	1. Transitional developmental centre before placement into intermediate care facilities (N=18) 2. Direct placement into intermediate care facility (N=39) **Duration:** **Intervention:** Not applicable **Follow-up:** One year
Outcomes	Primary outcome was levels of adaptive/maladaptive behaviour as measured by the Adaptive Behaviour Scale, Vineland Maladaptive Behaviour Scale, and the Resident Choice Assessment Scale. Data was

	extracted for the AAMD Adaptive Behaviour Scale
Study Design	Observational (cross-sectional)
Source of funding	Not reported
Limitations	1. Discrpancy in sample size between two groups
Notes	

Study ID	MCCONKEY2007
Bibliographic reference	McConkey, R., Abbott, S., Walsh, P. N., *et al*. (2007) Variations in the social inclusion of people with intellectual disabilities in supported living schemes and residential settings. *Journal of Intellectual Disability Research, 51*, 207–217.
Methods	**Allocation:** Non-randomised **Matching:** No matching **Blindness:** Non-blind **Setting:** Residential versus community **Raters:** Key-worker **Country:** UK & Ireland
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** 22.3% epilepsy **Qualifying Diagnostic Assessment:** Not reported **N:** 620 (N=241 for data extracted) **Age:** Range or mean not reported (61% aged under 50 years) **Sex:** Male: 331; Female: 289 **Ethnicity:** Not reported **IQ:** Not reported **Inclusion criteria:** Not reported
Interventions	1. Dispersed supported living (N=103) where person holds tenancy agreement for an ordinary house or apartment and support staff are provided according to assessed needs and they visit on a regular basis. The houses are dispersed among other properties 2. Residential homes (N=138) where an average of 19 people reside in a home Data were also reported for clustered supported living (N=132), small group homes (N=152), and campus settings (N=95). However, that data is not extracted here **Duration:** **Intervention:** Not applicable **Follow-up:** Not reported. 54% of dispersed supported living group and 64% of residential home group had been living there for more than 5 years
Outcomes	The primary outcome was social inclusion as measured by number of friends outside the home, number of neighbours in the area who know name, frequency of family contact, guests to stay in home, visitors to home, stayed away overnight, and use of community amenities (including cafe, pubs, shops, cinema, and places of worship). Data could only be extracted for number of community amenities used in past months

Study Design	Observational (cross-sectional)
Source of funding	Big Lottery Fund through a grant to Triangle Housing Association; and Department of Health and Children in the Republic of Ireland
Limitations	1. Limited data could be extracted from the study as a measure of variation (SD) was only reported for one scale item
Notes	

Study ID	MOLONY1990
Bibliographic reference	Molony, H. & Taplin, J.E. (1990) The deinstitutionalization of people with developmental disability under the Richmond program: I. changes in adaptive behavior. *Australia and New Zealand Journal of Developmental Disabilities, 16*, 149-159.
Methods	**Allocation:** Non-randomised **Matching:** No matching **Blindness:** Non-blind **Setting:** Community versus residential **Raters:** Staff report based on standardized assessments **Country:** Australia
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Raven's Coloured Progressive Matrices and Peabody Picture Vocabulary Test **N:** 57 (N=44 for data extracted) **Age:** 18-69 years (means: hostel to group home mean: 31.6 years; hospital to group home mean: 46.2 years; & stayed in hospital mean: 43.5 years) **Sex:** Male: 31; Female: 26 **Ethnicity:** Not reported **IQ:** Untestable-80 (medians: hostel to group home median: 45/50; hospital to group home median:54/45, & stayed in hospital median: could not be determined) **Inclusion criteria:** Not reported
Interventions	1. Participants who moved from a hospital ward to a group home (N=13) 2. Participants who stayed in the hospital over the entire period of study (N=31) Data were also reported for participants who had moved from a hostel to a group home (N=13). However, that data is not extracted here **Duration:** **Intervention:** 1 year **Follow-up:** 1 year
Outcomes	Primary outcome was adaptive behaviour as measured by the Vineland Adaptive Behaviour Scales
Study Design	Observational (cohort)
Source of funding	Research grant from the Prince Henry Hospital Centenary Research Fund

Limitations	1. Discrepancy in sample size between two groups
Notes	

Study ID	RAGHAVAN2009
Bibliographic reference	Raghavan, R., Newell, R., Waseem, F., *et al.* (2009) A randomized controlled trial of a specialist liaison worker model for young people with intellectual disabilities with challenging behaviour and mental health needs. *Journal of Applied Research in Intellectual Disabilities, 22*, 256-263.
Methods	**Allocation:** Randomised **Matching:** No matching **Blindness:** Non-blind **Setting:** Community **Raters:** Independent researcher carried out post-intervention assessments **Country:** UK
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** N=7 with challenging behaviour, N=1 with ASD, N=2 with Down's syndrome, N=1 with cerebral palsy, N=1 with Joubert's syndrome, and N=4 with epilepsy **Qualifying Diagnostic Assessment:** Not reported **N:** 26 **Age:** 13-25 years (means: experimental group mean: 17 years; control group mean: 19 years) **Sex:** Not reported **Ethnicity:** N=23 Pakistani families, and N=3 Bangladeshi families **IQ:** Not reported – N=10 with mild intellectual disabilities, N=8 with moderate intellectual disabilities, and N=8 with severe intellectual disabilities **Inclusion criteria:** Not reported
Interventions	1. Additional help of a liaison worker in accessing relevant services (N=12) 2. Normal service interventions (N=14) **Duration:** **Intervention:** 9 months **Follow-up:** 9 months
Outcomes	Primary outcome was the number of contacts with services as this best reflected the aim of the study to determine whether introduction of the specialist liaison service could enhance access to such services. Secondary outcomes included measures of challenging behaviours: Strengths and Difficulties Questionnaire (SDQ) and the Problem Behaviour Inventory (PBI) from the Behaviour Assessment Guide. Data was extracted for the number of contacts with services
Study Design	RCT
Source of funding	Foundation for People with Learning Disabilities and the Baily Thomas Charitable Fund
Limitations	1. Efficacy data could not be extracted 2. Small sample size

Study ID	SCHALOCK1984
Bibliographic reference	Schalock, R.L., Gadwood, L.S. & Perry, P.B. (1984) Effects of different training environments on the acquisition of community living skills. *Applied Research in Mental Retardation, 5*, 425-438.
Methods	**Allocation:** Non-randomised **Matching:** Matched on gender, age, IQ, duration of prior community living skills training, skill level on the community living skills screening test, medication history, and the number of recorded negative behaviour incidents **Blindness:** Non-blind **Setting:** Current-living versus centre-based **Raters:** Independent assessment by 2 instructional staff prior to the study **Country:** USA
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** WAIS **N:** 20 **Age:** Range not reported (mean: 31 years) **Sex:** Male; 10; Female: 10 **Ethnicity:** Not reported **IQ:** Range not reported (mean: 51) **Inclusion criteria:** Not reported
Interventions	1. Community Living Skills (CLS) Training within current living environment (group home or staffed apartment) (N=10) 2. CLS Training within centre-based training environment (large group home adjacent to the adult developmental centre (N=10) **Duration:** **Intervention:** 1 year **Follow-up:** 1 year
Outcomes	Primary outcome was community living skill acquisition and skill maintenance. Data was extracted for average number of skills gained across community living skills behavioural domains
Study Design	Quasi-experimental (parallel groups)
Source of funding	Not reported
Limitations	1. Small sample size
Notes	

Study ID	SCHWARTZ2003
Bibliographic reference	Schwartz, C. (2003) Self-appraised lifestyle satisfaction of persons with intellectual disability: the impact of personal characteristics and community residential facilities. *Journal of Intellectual and Developmental Disability, 28*, 227-240.
Methods	**Allocation:** Non-randomised **Matching:** No matching **Blindness:** Non-blind **Setting:** Community **Raters:** Social workers **Country:** Israel
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** 57-61% had additional diagnosis **Qualifying Diagnostic Assessment:** Not reported **N:** 247 **Age:** 18-70 years (mean: 33.7 years) **Sex:** Male: 122; Female: 125 **Ethnicity:** Not reported **IQ:** Not reported. Mild intellectual disabilities N=131; moderate or above intellectual disabilities N=116 **Inclusion criteria:** To be eligible participants had to be verbally articulate, that is, without any severe hearing or expressive language problems, and to have been living in their current residence for at least a year at the time of the study
Interventions	1. Group home (GH) (N=147) 2. Semi-independent apartment (SIA) (N=57) Data was also reported for an independent apartment (IA) (N=43) group. However, that data is not extracted here **Duration:** **Intervention:** Not applicable **Follow-up:** 1 year
Outcomes	The primary outcome was resident satisfaction as measured by the Lifestyle satisfaction scale (LSS).
Study Design	Observarional (cross-sectional)
Source of funding	Not reported
Limitations	1. Differences in sample sizes across groups 2. Significant differences in demographic factors found between groups, e.g. group home residents oldest, and participants in independent apartments had the highest mean score for adaptive behaviour and the lowest mean score for challenging behaviour 3. No correction for pre-test group differences
Notes	

Study ID	SIAPERAS2006
Bibliographic reference	Siaperas, P. & Beadle-Brown, J. (2006) A case study of the use of a structured teaching approach in adults with autism in a residential home in Greece. *Autism, 10*, 330-343.
Methods	**Allocation:** Not applicable – no control group **Matching:** Not applicable – no control group **Blindness:** Non-blind **Setting:** Residential **Raters:** Staff report **Country:** Greece
Participants	**Diagnosis:** DSM-IV ASD **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Childhood Autism Rating Scale (CARS) **N:** 12 **Age:** 16-30 years (mean: 21.3 years) **Sex:** Male: 8; Female: 4 **Ethnicity:** Not reported **IQ:** All the participants also had intellectual disabilities, ranging from mild to severe **Inclusion criteria:** Residents of the residential home
Interventions	1. Treatment and Education of Autistic and related Communication Handicapped Children (TEACCH) approach (N=12), individualized but basic aspects include: Strong cooperation between staff & parents; different areas designated for each activity; daily visual schedules; strong work rules, e.g. 'first work then play'; transition area; structured activities; visual prompts **Duration:** **Intervention:** Not applicable **Follow-up:** 6 months
Outcomes	Primary outcome was adaptive behaviour as measured by staff-report questionnaire (based on Vineland Adaptive Behaviour Scales) and observation checklist
Study Design	Observational (before-and-after)
Source of funding	Not reported
Limitations	1. No control group 2. Efficacy data cannot be extracted 3. Small sample size
Notes	

Study ID	SPREAT1998
Bibliographic reference	Spreat, S., Conroy, J.W. & Rice, D.M. (1998) Improve quality in nursing homes or institute community placement? implementation of OBRA for individuals with mental retardation. *Research in Developmental Disabilities, 19*, 507-518.
Methods	**Allocation:** Non-randomised **Matching:** Matched on sex, year of birth (within 2 years), and scores on the sum of 4 academic items from the Behaviour Development Survey Scale Score (within 2 points) **Blindness:** Non-blind **Setting:** Residential to community **Raters:** Interviewers contracted by the state **Country:** USA
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Not reported **N:** 80 **Age:** Range not reported (mean: 40 years) **Sex:** Male: 18; Female: 22 **Ethnicity:** White N= 65, other N= 15 **IQ:** Not reported **Inclusion criteria:** Not reported
Interventions	1. Individuals moved from nursing homes to various community-based supported living arrangements (N=40) 2. Individuals who remained in the nursing home over the study period (N=40) *Duration:* *Intervention:* Not applicable *Follow-up:* 4 years
Outcomes	The primary outcomes were adaptive behaviour and challenging behaviour severity as measured by a modified version of the Behaviour Development Survey. Data could only be extracted for adaptive behaviour
Study Design	Observational (cohort)
Source of funding	Not reported
Limitations	
Notes	• Overlapping dataset with SPREAT2002 but reporting on different outcome meausures

Study ID	SPREAT2002
Bibliographic reference	Spreat, S. & Conroy, J.W. (2002) The impact of deinstitutionalization on family contact. *Research in Developmental Disabilities, 23*, 202-210.
Methods	**Allocation:** Not applicable - no control group **Matching:** Not applicable - no control group **Blindness:** Non-blind **Setting:** Residential to community **Raters:** Data collected by graduate students and staff from Sociology Department **Country:** USA
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** Not reported **Qualifying Diagnostic Assessment:** Not reported **N:** 177 **Age:** Range not reported (means: 26-27 years) **Sex:** Male: 106; Female: 71 **Ethnicity:** Cohort 1: 69.7% white, 21.2% black, 6.1% American Indian, 3% other; cohort 2: 85.7% white, 5.4% black, 8.9% American Indian; cohort 3: 73.7% white, 13.2% black, 13.2% American Indian; cohort 4: 72% white, 14% black, 12% American Indian, and 5% other **IQ:** Not reported – Majority have profound intellectual disabilities Inclusion criteria: Not reported
Interventions	1. Residents discharged from large public institution to small supported living arrangements (N=177; cohort 1 discharged in 1992, N=33; cohort 2 discharged in 1993, N=56; cohort 3 discharged in 1994, N=38; cohort 4 discharged in 1995, N=50) **Duration:** **Intervention:** Not applicable **Follow-up:** Over 5 years
Outcomes	Primary outcome was family contact as measured by the Developmental Disabilities Quality Assurance Questionnaire (DDQAQ)
Study Design	Observational (before-and-after)
Source of funding	Not reported
Limitations	1. No control group 2. Efficacy data cannot be extracted
Notes	• Overlapping dataset with SPREAT1998 but reporting on different outcomes

Study ID	WEHMEYER2001
Bibliographic reference	Wehmeyer, M.L. & Bolding, N. (2001) Enhanced self-determination of adults with intellectual disability as an outcome of moving to community-based work or living environments. *Journal of Intellectual Disability Research, 45*, 371-383.
Methods	**Allocation:** Not applicable – no control group **Matching:** Not applicable – no control group **Blindness:** Non-blind **Setting:** Residential to community **Raters:** Self-report **Country:** USA
Participants	**Diagnosis:** Intellectual disability **Coexisting conditions:** Not reported. **Qualifying Diagnostic Assessment:** Not reported. **N:** 31 **Age:** 24-62 years (mean: 40.8 years) **Sex:** Male: 17; Female: 14 **Ethnicity:** Not reported **IQ:** Range not reported (mean: 60.25) **Inclusion criteria:** Participants needed to be able to complete self-report measures
Interventions	1. Moving from a more restrictive work or living environment to a less restrictive work or living environment (N=31; N=8 moved from more to less restrictive living environment, e.g. institution/nursing home to group home or community, or group home to community living; and N=21 moved from more to less restrictive work setting, e.g. day programme to sheltered workshop or competitive employment, or sheltered workshop to competitive employment) **Duration:** **Intervention:** Not applicable **Follow-up:** 1 year (assessment at 6 months prior to scheduled move and 6 months after transition)
Outcomes	The primary outcome was self-determination as measured by the Arcs's Self-Determination Scale: Adult Version and the Autonomous Functioning Checklist (AFC)
Study Design	Observational (before-and-after)
Source of funding	US Department of Education NIDRR grant (no. HH133G50178)
Limitations	1. No control group 2. Efficacy data cannot be extracted
Notes	

1.6.2 Characteristics of excluded studies

ARONOW2005

Reason for exclusion	Data could not be extracted

BEADLEBROWN2009

Reason for exclusion	Data could not be extracted

BIGBY2008

Reason for exclusion	Data could not be extracted

BURCHARD1991

Reason for exclusion	Data could not be extracted

CLARKE1992

Reason for exclusion	Mean age <15 years

CUMMINS1990

Reason for exclusion	Data could not be extracted

DAGNAN1994B

Reason for exclusion	Smaller but overlapping dataset with DAGNAN1994A

DAGNAN1995

Reason for exclusion	Data could not be extracted

DAGNAN1996

Reason for exclusion	Sample size is less than 10 per arm

DOCKRELL1995

Reason for exclusion	Sample size for analysis is less than 10 per arm

DONNELLY1997

Reason for exclusion	Sample size is less than 10 per arm

DONNER2010

Reason for exclusion	Co-morbid schizophrenia or mood disorder

EMERSON2000A

Reason for exclusion	Data could not be extracted

EMERSON2000B

Reason for exclusion	Data could not be extracted

EMERSON2001

Reason for exclusion	Data could not be extracted

EMERSON2004

Reason for exclusion	Paper concerned with description of care across settings

FELCE1985

Reason for exclusion	Sample size is less than 10 per arm

FELCE1992

Reason for exclusion	Sample size is less than 10 per arm

FERNANDO1997

Reason for exclusion	Co-morbid psychiatric disorders

FORRESTERJONES2006

Reason for exclusion	Data could not be extracted

GERBER2011

Reason for exclusion	Sample size for analysis is less than 10 per arm

GLISSON2010

Reason for exclusion	Co-morbid psychiatric disorders

GOODMAN2008

Reason for exclusion	Sample size is less than 10 per arm

GREGORY2001

Reason for exclusion	Data could not be extracted

HATTON1995

Reason for exclusion	Sample size for analysis is less than 10 per arm

HEAL1989

Reason for exclusion	Data could not be extracted

HELLER1998

Reason for exclusion	Paper concerned with predictive values of participant characteristics

JANSSEN1999

Reason for exclusion	Paper concerned with quality of service

JAWED1993

Reason for exclusion	Data could not be extracted

KON1997

Reason for exclusion	Data could not be extracted

KRAUSS2005

Reason for exclusion	Data could not be extracted

LEGAULT1992

Reason for exclusion	Data could not be extracted

LOVELL1999

Reason for exclusion	Mean age <15 years

LOWE1993

Reason for exclusion	Sample size is less than 10 per arm

LOWE1996

Reason for exclusion	Data could not be extracted

OLIVER2005

Reason for exclusion	Co-morbid psychiatric disorders

ONEILL1981

Reason for exclusion	Outcome not of interest (overall activity levels)

ONEILL1985

Reason for exclusion	Outcome not of interest (overall activity levels)

OWEN2008

Reason for exclusion	Sample size for analysis is less than 10 per arm

PAHL1987

Reason for exclusion	Not primary data

PANERAI2009

Reason for exclusion	Mean age <15 years

PERRY2003

Reason for exclusion	Paper concerned with quality of service

PIERCE1990

Reason for exclusion	Data could not be extracted

RAPLEY1998

Reason for exclusion	Data could not be extracted

READ2004

Reason for exclusion	Data could not be extracted

ROBERTSON2000

Reason for exclusion	Paper concerned with predictive values of participant characteristics

ROBERTSON2004

Reason for exclusion	Data could not be extracted

SCHWARTZ1995

Reason for exclusion	Data could not be extracted

SHERMAN1988

Reason for exclusion	Sample size is less than 10 per arm

SOURANDER1996

Reason for exclusion	Mean age <15 years

SPREAT1987

Reason for exclusion	Data could not be extracted

STANCLIFFE1998

Reason for exclusion	Data could not be extracted

STANCLIFFE2000

Reason for exclusion	Data could not be extracted

STRAUSS1998

Reason for exclusion	Data could not be extracted

TABERDOUGHTY2010

Reason for exclusion	Sample size is less than 10 per arm

TREFFERT1973

Reason for exclusion	Mean age <15 years

VALENTI2010

Reason for exclusion	Mean age <15 years for whole sample and data cannot be extracted for adolescent subgroup

VANBOURGONDIEN2003

Reason for exclusion	Sample size is less than 10 per arm

WALSH2001

Reason for exclusion	Data could not be extracted

YOUNG2004

Reason for exclusion	Sub-group analysis meant that data could not be extracted

YOUNG2006

Reason for exclusion	Data could not be extracted

1.6.3 References of excluded studies

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Clarke, R.T. (1992) Wrapping community-based mental health services around children with a severe behavioral disorder: an evaluation of project wraparound. *Journal of Child and Family Studies, 1*, 241-261.

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