# FOR THE NEW ZEALAND AUTISM SPECTRUM DISORDER GUIDELINE

# **CONTENTS**

CONTENTS	2
NTRODUCTION	3
Method	3
Types of evidence tables	4
Levels of evidence	4
Grading	4
Practice questions	6
Evidence Tables	10
EVIDENCE TABLES FOR PART 1: DIAGNOSIS AND INITIAL ASSESSMENT OF ASD	11
EVIDENCE TABLES FOR PART 2: SUPPORT FOR INDIVIDUALS, FAMILIES AND CARERS	55
EVIDENCE TABLES FOR PART 3: EDUCATION FOR LEARNERS WITH	112
EVIDENCE TABLES FOR PART 4: TREATMENT AND MANAGEMENT OF	
EVIDENCE TABLES FOR PART 5: LIVING IN THE COMMUNITY	316
EVIDENCE TABLES FOR PART 6: PROFESSIONAL LEARNING AND DEVELOPMENT	357
EVIDENCE TABLES FOR PART 7: MĀORI PERSPECTIVES	360
EVIDENCE TABLES FOR PART 8: PACIFIC PEOPLES' PERSPECTIVES	362
EVIDENCE TABLES FOR APPENDICES	365

#### INTRODUCTION

These evidence tables support the New Zealand Autism Spectrum Disorder Guideline. The tables are being presented to provide a transparent link between the strength of the available evidence and the grading of the recommendations in the ASD Guideline.

#### Method

The New Zealand ASD Guideline was originally written in individual sections by three workstreams and experienced Māori and Pacific researchers. Separate methodologies were followed by the different contributors when developing the ASD Guideline. In summary, the Assessment and Diagnosis workstream (Workstream 1) adapted the National Autism Plan for Children 2003, developed in the United Kingdom, for New Zealand circumstances for the preparation of Part 1 of the ASD Guideline. The Education workstream (Workstream 2), the Support and Transition workstream (Workstream 3) and additional work by Workstream 1 on pharmacological interventions based the development of their sections on broad evidence-based principles. This involved the development of practice questions or topics, identification and appraisal of evidence to answer the questions, development of evidence tables, and graded recommendations based on the body of evidence. The recommendations were graded according to the system used by the New Zealand Guidelines Group.

Although the sections of the ASD Guideline were originally prepared separately by the different workstreams, reflecting different areas of expertise, these sections were merged into one overall document. The contributions of the workstreams to the merged guideline are as follows:

Part 1: Workstream 1 (for young children) and Workstream 3 (for young people and adults)

Part 2: Workstreams 2 and 3

Part 3: Workstream 2

Part 4: Workstreams 1, 2 and 3

Part 5: Workstream 3

Part 6: Workstream 2 (in consultation with workstreams 1 and 3)

The inclusion criteria for the literature searches and identification of other evidence were broad, and a wide variety of different types of evidence were considered: autism-specific studies; double-blind randomised controlled trials; systematic reviews; case reports; papers of general interest on the topic; published guidelines; published reviews of relevant literature; writing from experts in the field; first person accounts from people with ASD; practice experience and expert opinion; the lived experiences of people with ASD and their parents; and policy and position papers.

A detailed description of the methods used by the workstreams and further information about the guideline development process is provided in Appendix 1 of the ASD Guideline. The process that was followed by the Māori and Pacific

peoples' team is described in the Māori perspectives and Pacific peoples' perspectives chapters in the ASD Guideline.

# Types of evidence tables

There are two types of evidence tables included in this document. Some of the evidence tables in Part 4, assessing the benefits and harms of medications, follow a strictly quantitative format, based on the study design. This format was considered unsuitable to describe the evidence for all other sections of the Guideline, which include expert opinion and qualitative evidence as well as quantitative studies. Therefore, the evidence tables in Part 1, 2, 3, 4 (in part), 5, 6, 7 and 8 have a much broader and more general format to deal with the variety of evidence that has been gathered.

#### Levels of evidence

For each study selected for inclusion in the ASD Guideline, a level of evidence grade was assigned. Levels of evidence were only assigned to published studies, reports and guidelines. It was not considered appropriate to assign levels of evidence to most books and websites, as adequate information for their assessment and evaluation was not always available. The level of evidence grades were based on an objective assessment of the design and quality of each study, report or guideline, as described below.

Level of evidence	
Strong study where all or most of the validity criteria are met	+
Study where not all of the criteria are met but the results of the study are not likely to be affected in a major way	~
Weak study where very few of the validity criteria are met and there is a high risk of bias	х

Graded recommendations were then developed from the body of evidence addressing each clinical question based on the consistency, volume, relevance and applicability of the evidence summarised in the evidence tables.

#### **Grading**

Recommendations for the draft ASD Guideline have been graded using the NZGG grading system (information on this system can be found on <a href="https://www.nzgg.org.nz">www.nzgg.org.nz</a>). Prior to this decision being made, Workstream 1 had used the grades applied by the NAPC UK guideline. These grades were analysed and converted to NZGG grades, where possible.

The NZGG grading system is a two-tier system with the following steps:

1. Critical appraisal of individual studies

Each relevant study was critically appraised using a checklist and was assigned an overall level of evidence, indicating whether the study met most or all of the criteria in the checklist, some of the criteria or very few of the criteria  $(+, \sim \text{ or } x)$ .

2. Weighing the body of evidence and development of graded recommendations

For each clinical question, the relevant body of evidence summarised in evidence tables was considered. Decisions were made on the quality (level of evidence), quantity (number of studies answering the clinical question), consistency (consistency of the findings), applicability (applicability to a New Zealand setting) and clinical impact of all the studies forming the body of evidence that were relevant to each question. Recommendations were then developed based on the totality of the evidence for each clinical question by the Guideline writers. The recommendations were graded by the following system:

Grading of recommendations	
The recommendation is supported by GOOD evidence (where there is a number of studies that are valid, applicable and clinically relevant).	А
The recommendation is supported by FAIR evidence (based on studies that are mostly valid, but there are some concerns about the volume, consistency, applicability and/or clinical relevance of the evidence that may cause some uncertainty, but are not likely to be overturned by other evidence).	В
The recommendation is supported by EXPERT OPINION only (from external opinion, published or unpublished, eg, consensus guidelines).	С
No recommendation can be made. The evidence is insufficient (either lacking, of poor quality or conflicting, and the balance of benefits and harms cannot be determined).	I

Where a recommendation is based on the clinical and educational experiences of members of the Guideline Development teams, this is referred to as a good practice point.

Good practice point:	
Where no evidence is available, best practice recommendations are made based on the experience of the Guideline Development teams or feedback from consultation within New Zealand.	✓

# **Practice questions**

#### Workstream 1

The section on diagnosis and assessment of young children in Part 1 of the guideline is based on the National Autism Plan for Children 2003 (NAPC). The National Autism Plan for Children addressed some of the questions asked by the Assessment and Diagnosis workstream. However, this left other questions that required further searching.

The questions on which members of the Assessment and Diagnosis workstream did literature searches were:

- 1. What is the role of diagnostic tools in diagnosing Autism Spectrum Disorders (ASD)?
  - a. What evidence is there that the tool is a valid instrument for the diagnosis of ASD?
  - b. What population has the tool been validated on?
  - c. Is the tool applicable to a New Zealand setting? Can the tool be used without modification with Māori, Pacific Peoples and Asian individuals?
  - d. How long does it take to administer the tool?
  - e. How many professionals are needed to administer the tool?
  - f. What is needed to make the tool available in New Zealand? Training? Qualifications required? Where can training be accessed? What is the cost of training? Ongoing costs – royalties?
  - g. What evidence is there that the tool leads to earlier or more accurate diagnosis? How does the cost of using the tool compare with other methods including experienced clinician assessment?
- 2. What is the role of Cognitive Assessment in the diagnosis of ASD?
  - a. Does performing a baseline cognitive assessment on individuals with ASD improve outcome?
  - b. Does performing a baseline cognitive assessment on individuals diagnosed with ASD enable more effective planning of an intervention programme and more efficient use of resources?
- 3. What pharmacological or other therapeutic agents are effective in children with ASD?
  - a. What pharmacological or other therapeutic agents have been used in children with ASD?
  - b. What evidence is there for effectiveness and safety?
  - c. What agents have been shown to be ineffective or unsafe?

Literature searches were carried out by NZHTA.

- Question 1 literature review was done by Dr David Newman and reviewed by members of the Guideline group. Further information is in Appendix 5 of the ASD Guideline.
- 2. Question 2 literature review was done by Dr Andrew Marshall and reviewed by members of the Guideline group. Further information is in Appendix 6 of the ASD Guideline.
- 3. Question 3 literature review was done by Dr Rosemary Marks and reviewed by members of the Guideline group.

#### Workstream 2

The following broad themes informed the formation of clinical questions:

- A. What are the broad aims for education of children and young people with ASD?
- B. How do we support the values and aspirations of families / whanau?
- C. What are the specific challenges that need to be addressed within NZ when educating children and young people with ASD?
- D. How do we evaluated teaching and learning outcomes from a child, family and education perspective?

#### In order to achieve these aims:

- 1. How do we ensure that the child's view is understood, considered and appreciated when planning for the child?
- 2. How do we ensure equal access and full participation within education and the community? (Includes view of disability, teacher attitudes).
- 3. What are the training / PD requirements for:
  - Who families/whanau, school staff, support staff, specialist staff What (content of training eg teaming issues....)
  - How and when (in-service, pre service, cross service, 1:1 coaching, workshops, printed materials etc)
- 4. How do institutions / organisations / systems / environments / settings need to plan and adapt to accommodate the needs of children with ASD and their families?
- 5. How can families be supported and empowered to plan, participate and advocate in the education of their child or young person and make informed choices about education placement?
- 6. How can families, schools, health and community agencies collaborate effectively to support the child and family and what are the elements of effective team practice?
- 7. What are the resources and supports which are currently available for students with ASD in the NZ education system?
- 8. What are effective practices for transition from one education setting to another?
- 9. What are the specific practices, interventions and strategies for effective teaching and learning in each educational setting?
- 10. How can we use the NZ curriculum framework to support teaching and learning for students with ASD?
- 11. What are the particular risk management issues for this population in regard to their behaviour?

#### Workstream 3

Workstream 3 used a series of topics to inform the literature searches commissioned for their input into the ASD Guideline.

A literature search was undertaken for adults between the ages of 18 and 65 years for best practice in the following areas:

- skills for independent living
- residential support
- respite care and planned breaks
- socialisation, relationships and sexuality
- recreation
- psychological assistance, psychotherapy and/or counselling
- behaviour support
- health and medical assistance
- occupational therapy
- physiotherapy
- communication support
- care and protection
- mental health
- criminal justice
- alternative treatments
- service Coordination
- workforce Development

#### and

- During transitions, such as:
  - home to school
  - primary to intermediate school
  - intermediate to secondary school
  - secondary school to tertiary education or workforce or vocational services
  - tertiary education to workforce or vocational services
  - living with parents to independent living
  - lifestyle changes (marriage/divorce, parenthood, changing jobs, moving towns).

An additional literature search took place on support and transition topics for 0 - 18 & 18 - 65 years. It should be noted that there were some limitations on the scope of this search. The information gathered was based on a search of databases only, rather than further identification and analysis of relevant literature that had to be undertaken separately. The topics covered included:

- 1. Assessment & Diagnosis
  - Assessment and Diagnosis of Adults
    - Sources of Diagnostic Assessment
    - Assessment and Diagnostic Processes

- Post Diagnosis Support 0 65
  - Support for People with ASD
  - Support for Families of People with ASD
  - Accessing the ASD Community
  - National Organisations
  - International Organisations
  - Advocacy and Self-Advocacy.

# 2. Residential Options and Support

- Independent Living Options
- Semi-independent/Supported Living Options
- Residential Services
- Skills for Independent Living
- Respite Care and Planned Breaks.

#### 3. Transition

- Marriage/divorce
- Parenthood
- Changing Jobs
- Residential Moves.

#### 4. Recreation and Leisure

- Children
- Young People
- Adults.

#### 5. Employment and Adult Education

- Tertiary Education
- Employment
- Vocational Services.

#### 6. Emotional and Mental Well-being

- Crisis Intervention
- Communication
- Counselling and Therapy
- Social Skills and Friendships
- Behaviour Support
- Mental Health Services
  - Psychopharmacology
  - Forensic Mental Health Services
  - Alternative Treatments for ASD (diet, mega vitamin therapy, holding therapy).

#### 7. Legal Issues

- Care and Protection
- Youth Justice
- Police
- The Criminal Justice System
- Courts: District, Family and High
- Welfare Guardians and Property Managers.
- 8. Physical Well-being
  - Primary Health Providers
  - Hospitals and Specialists
  - Occupational Therapy
  - Physiotherapy.
- 9. Needs of Others
  - Parents
  - Siblings
  - Grandparents Raising Children with ASD
  - Partners
  - Children of People with ASD
  - Formal Carers.

### 10. Workforce Development

#### **Evidence Tables**

When the references included in the evidence tables are first cited in the text of the ASD Guideline, a unique citation number identifies the particular reference, which is listed in this order in the References section of the Guideline. The evidence tables were initially compiled by the separate workstreams, based on appraisal of the relevant studies for each section but this resulted in extensive overlap. After the sections were merged, the format of the evidence tables was reorganised to follow the same sequence of citation numbers in the text of the Guideline, for easy identification of the reference.

The first 10 references relate to sources of the quotations from parents, carers, teachers, people with ASD and reports that highlight the personal experiences of all those affected by ASD. They are not included in the evidence tables. The remaining references are listed in the evidence tables in the order in which they are first cited in the text of the Guideline, although in many cases there are multiple citations of some references throughout the Guideline.

# **EVIDENCE TABLES FOR PART 1: DIAGNOSIS AND INITIAL ASSESSMENT OF ASD**

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
11	National Initiative for Autism: Screening and Assessment. (2003). National Autism Plan for Children: plan for the assessment, diagnosis and access to early interventions for pre-school and primary school aged children with autism spectrum disorders. London: The National Autistic Society.  EVIDENCE-BASED GUIDELINE  Level of evidence: +	Evidence based guideline. Focused on children up to 8 years of age.		Recommendations: Multidisciplinary assessment recommended.  Detailed information on diagnostic procedures, processes and tools.	Published in collaboration with The Royal College of Psychiatrists, The Royal College of Paediatrics and Child Health, and the All Party Parliamentary Group on Autism.
12	World Health Organisation. The ICD-10 classification of mental and behavioural disorders : Diagnostic Criteria for Research BOOK			Classification of mental and behavioural disorders according to agreed criteria.	

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
13	American Psychiatric Association (1994). Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) BOOK			Categorisation of mental disorders.	
14	Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D., Charman, T. (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). Lancet 368: 21-215. COHORT STUDY  Level of evidence: +	Population cohort of 56,946 children aged 9-10 years was studied. Screening was undertaken of all those with a current diagnosis of ASD (n-255) and those judged to be at risk for being an undetected case (n=1,515).	A stratified subsample (n=255) received a comprehensive diagnostic assessment, including standardised clinical observation and parent interview assessments of autistic symptoms, language and IQ. Consensus diagnoses of childhood autism and other ASDs were derived and a sample weighting procedure used to estimate prevalence.	The prevalence of childhood autism was 38.9 per 10,000 (95% CI 29.9 to 47.8) and that of other ASDs was 77.2 per 10,000 (52.1 to 102.3) making the total prevalence of all ASDs 116.1 per 10,000 (90.4 to 141.8). A narrower definition of childhood autism (combining clinical consensus with instrument criteria for past and current presentation) resulted in a prevalence of 24.8 per 10,000 (17.6 to 32.0).	The authors concluded that the prevalence of autism and related ASDs found in this study is substantially greater than previously recognised. It is not clear what the reasons are for this increase.
15	Fombonne E (2003).	Discussion of the relevance of	Multiple	The survey reported a rate of 34	The estimate is

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
	The prevalence of autism. <i>JAMA</i> 289: 87-89. EDITORIAL Level of evidence: x	a survey of prevalence of autism among 3 – 10-year-old children in Atlanta in the USA and how the findings compare with other estimates.	ascertainment sources for ASD diagnosis.	per 10,000 for ASDs in the 3 - 10 year-old children.	likely to be an underestimate as children with mild or high functioning ASD are likely to have been missed.
16	National Institute of Mental Health (2006). Autism Spectrum Disorders. Accessed from www.nihm.nih.gov/pu blicat/autism.cfm 29 May 2006.  REPORT Level of evidence: x	Report on the web of the prevalence, diagnosis and treatments of ASDs. No methodology described.			Addendum added in February 2007.
17	Szatmari, P., Bryson, S., Boyle, M., Streiner, D., Duku, E. (2003). Predictors of outcome among high functioning children with autism and Asperger syndrome. Journal of Child Psychology and Psychiatry and Allied Disciplines; 44:520-8.	Cohort study. 68 high-functioning pre-school children with PDD, aged 4-6 years.	<ul> <li>Autism Behaviour Checklist.</li> <li>Vineland Adaptive Behavior Scales.</li> <li>Autism Diagnostic Interview.</li> <li>Arthur Adaptation of the Leiter Scales.</li> </ul>	The explanatory power of the predictor variables was greater for communication and social skills than for autistic symptoms.  The power of prediction was stable over time but did differ by PDD subtype.  In general, the association between language skills and outcome was stronger in the autism group than in the AS group.	

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
	STUDY – COHORT  Level of evidence: +		<ul> <li>The Berry         Visual-Motor         Integration Test.</li> <li>Stanford-Binet         Intelligence         Scale, Fourth         Edition.</li> </ul>		
18	Wing, L. (1997). The autistic spectrum.  Lancet 350: 1761-1766.  NON SYSTEMATIC REVIEW – EXPERT OPINION  Level of evidence: x	No search criteria but research cited.		Addresses aetiology, diagnosis, education, management, training, prevalence and prognosis.	Lorna Wing is an experienced clinician and researcher of autism.
19	Jordan, R.R. (2005). Diagnosis and the identification of special education needs for children at the 'able' end of the autism spectrum: reflections on social and cultural influences. Autism News: Orange County and the rest of the world; 2(1):13-16.	Expert opinion.		Research in 1990s suggested that no clear distinction between autism and Asperger Syndrome could be justified.  Recent research focuses on differentiating the categories at the 'borderlands' of autism, ie, the point where individuals might be distinguished from persons with language disorders or nonpathological variations of human development – the 'eccentric and unusual'.  There are individuals within	

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
	EXPERT OPINION  Level of evidence: x			society who would meet a number, if not all, of the criteria for an ASD, yet remain undiagnosed and apparently undisturbed by their differences.	
				Certain categories (ie, Asperger Syndrome) are often misunderstood or inconsistently applied, and may be used to deny service, so there are research-based and pragmatic reasons for using the broader concept of ASD.	
20	Burger, F., & Lang, C. (1998). Diagnoses commonly missed in childhood: long-term outcome and implications for treatment. <i>The Psychiatric Clinics of North America</i> , 21(4), 927-940.  EXPERT OPINION  Level of evidence: x	Expert opinion.  Two case studies of young men assessed as adults, but who had been diagnosed with ADHD and schizophrenia in childhood.		Both subjects more appropriately described as having ASD. Importance of full developmental, family and educational history of adults discussed.	Both authors qualified with MDs, Department of Psychiatry, University of Utah School of Medicine.
21	Better Health Channel. (May 2004). Asperger Syndrome and Adults. Retrieved 6/10/04, 2004, from http://www.betterheal	On-line information on Asperger Syndrome and adults. Rigorous approval process for published material.		Covers typical adult symptoms, emotions of other people, sexual codes of conduct, being a partner or parent, the workplace, careers, common issues for partners, and sources of help.	Produced in Australia in consultation with Autism Victoria.

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
	th.vic.gov.au/bhcv2/b hcarticles.nsf/pages/ Asperger syndrome and adults  EXPERT OPINION Level of evidence: x				
22	The National Autistic Society. (2003). How can I get a diagnosis as an adult? Retrieved 6/10/04, 2004, from http://www.nas.org.uk /nas/jsp/polopoly.jsp? d=255&a=3341  EXPERT OPINION Level of evidence: x	On-line information on ASD.		Covers diagnosis in adults and bringing up the subject with your doctor.	
23	Wing, L. (1997). The autistic spectrum. A guide for parents and professionals. London: Constable.  BOOK – EXPERT OPINION	Expert opinion.		Discussion of the development of ASD in infancy, the variation in the condition and common problems. Also gives suggestions for ways of dealing with the difficulties.	Practical suggestions by an experienced clinician and researcher of autism. Aimed at parents of children with ASD, people with ASD themselves and professionals just starting to work in

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
					the area.
24	Perry, R. (1998). Misdiagnosed ADD/ADHD; rediagnosed PDD. Journal of the American Academy of Child and Adolescent Psychiatry, 37(1), 113-114.  EXPERT OPINION	Expert opinion based on cases of five boys (aged 9 - 16) who had all been previously diagnosed with ADD/ADHD.		All children rediagnosed as PDD-NOS or AS.  Diagnosis should be left to specialists.  Developmental family and educational history extremely important.	Richard Perry is Clinical Director of Psychiatry at New York State School of Medicine.
	Level of evidence: x				
25	Birch, J. (2003). Congratulations! It's Asperger Syndrome. London: Jessica Kingsley Publishers Ltd.  EXPERT OPINION	Autobiography/book.			Jen Birch is a New Zealand woman with ASD.
26	Deimel, L. (2004). How diagnosis can change an outlook on employment for Asperger Syndrome people: a personal account. <i>Good</i>	Personal account.		Diagnosis of ASD improved quality of life, assisted in identifying services and supports, and aided employment.	Laurie Deimel is a UK-based man with Asperger Syndrome.

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
	Autism Practice, 5(1), 26-30.				
	EXPERT OPINION				
	Level of evidence: x				
27	Ministry of Health (1996). Well Child: Tamariki Ora Schedule. REPORT Level of evidence: x				National schedule of services that provide 'well child' care, including screening, surveillance, education and support services to all NZ children from birth to 5 years and their family and whānau.
28	Howlin, P., Moore, A. (1997). Diagnosis in autism: a survey of over 1,200 patients in the UK. Autism: International Journal of Research and Practice 1: 135-162.  SURVEY  Level of evidence: ~	Almost 1300 parents who were members of autistic societies in the UK were surveyed using a pilot questionnaire.	The survey focused on parents views of the diagnostic process (age at which diagnosis made, time taken to obtain a diagnosis and the professionals involved). Differences in geographical area were also assessed.	Children are being diagnosed earlier than in previous decades but the average age at diagnosis was about 6 years. There were also wide regional variations in diagnosis. The amount of practical help provided when the diagnostic process is completed is generally very limited.	

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
29	English, A., Essex, J. (2001). Report on autistic spectrum disorders: a comprehensive report into identification, training and provision focusing on the needs of children and young people with autistic spectrum disorder and their families within the West Midland region. Warwick: Warwickshire County Council for the West Midlands, SEN Regional Partnership	Comprehensive report of the provision of services for children and young people with ASD in the West Midlands in the UK. The methodology specified was consultative research (expert opinion) requiring consultation with all stakeholders (parents/carers, schools, support services, education officers, educational psychologists and colleagues in health and social services). A critique of current practice – strengths and weaknesses – was undertaken to ascertain models of good practice to develop provision for the future.	Various means were employed: Carers Questionnaire, workshops, conferences and working parties, individual interviews with professionals and families and a sample of school visits.	A wide range of recommendations were provided from the consultative process. Some of the recommendations were:  • multi agency approach required for identification, assessment and diagnosis  • joint agencies should be linked by collaborative processes  • training required for all staff interacting with people with ASD and access provided for specialist expertise  • there should be a range of educational provision (from mainstream to specialist schools) linked to the needs of the particular child.	
	Level of evidence: ~				
30	Cox, A., Charman, T., Baron-Cohen, S., Drew, A., Klein, K., Baird, G., Swettenham, J., Wheelwright, S. (1999). Autism spectrum disorders at 20 and 42 months of	Population of 17,173 children from 9 districts in the South East Health Region in the UK were studied.	The study population was screened by Health Visitors using the CHAT at their routine 18 month developmental check (children with profound	<ul> <li>Clinical diagnosis was stable (children with a diagnosis of autism or PDD at 20 months also received the same diagnosis at 42 months).</li> <li>Clinical diagnosis also reasonably sensitive.</li> <li>Clinical diagnosis for PDD and Asperger Syndrome lacked</li> </ul>	

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
	age: stability of clinical and ADI-R diagnosis. Journal of Child Psychology and Allied Disciplines; 40: 719-732  DIAGNOSTIC STUDY  Level of evidence: ~		developmental delay excluded). A second CHAT screening was conducted 1 month later and the children consistently failing the key items were divided into groups (high risk of autism, medium risk of autism and developmentally normal). A sample of 50 children was selected from this group for diagnostic assessment (ADI-R and clinical assessment) at 20 and 42 months.	sensitivity at 20 months (several children who subsequently received these diagnoses at 42 months received diagnoses of language disorder or general developmental delay or, in 2 cases, were considered normal at 20 months).  ADI-R had good specificity but poor sensitivity at detecting childhood autism at 20 months; also the stability of diagnosis from 20 to 42 months was good. ADI-R at age 20 months was not sensitive to the detection of related PDDs or Asperger syndrome.	
31	Lord, C., Magill- Evans, J. (1995). Peer interactions of autistic children and adolescents. Development and Psychopathology 7: 611-626. OBSERVATIONAL STUDIES	Two observational studies of 3 types of participants:  • verbal high-functioning children and adolescents with autism  • non-autistic behaviourally disordered children of equivalent verbal skills and chronological age; and  • verbal age-matched normally developing	<ul> <li>Peabody Picture Vocabulary Test Revised</li> <li>Wechsler Intelligence Scale for Children – Revised or Wechsler Adult Intelligence Scale – Revised.</li> </ul>	Study 1: The 8 autistic participants were consistently more likely to be not interacting and less likely to be engaged in any purposeful activity than the 16 other children. During the 2 weeks, time interacting and purposeful activity increased overall.  Study 2:	Sample size very small.

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
	Level of evidence: ~	students during integrated summer day camps. Observations made during free play sessions and observers coded the behaviour.  Objectives of study 1:  1. What is the frequency and nature of spontaneous interaction of autistic children and adolescents when they are given the opportunity to interact with non-autistic peers in a supportive and familiar setting?  2. How do these interactions change as the students come to know each other? Objective of study 2:  1. What was the quality of their initiations to peers and the relationship of this quality to successful outcome in terms of ongoing interactions?		The 11 autistic children and adolescents produced fewer initiations than did the 20 other children and were less likely to smile or coordinate several behaviours with eye contact during an initiation. Autistic participants were consistently more likely not to receive a response to their initiation than the other groups, although there was no identifiable relationship between the quality of the initiation and the likelihood of receiving a response.	
32	Stone, W.L., Ousley, O.Y., Hepburn, S.L., et al. (1999). Patterns of adaptive behaviour in very young children with autism.	30 children diagnosed with autism were compared with 30 controls with developmental delay (less than 36 months of age) matched on chronological age and mental age.	Vineland Adaptive Behaviour Scales used to investigate patterns of adaptive behaviour.	The autistic group had weaker socialisation and communication skills and greater discrepancies between adaptive behaviour and mental age than the control group. There were different patterns of	The authors claim that adaptive behaviour profiles may be useful for the identification of subgroups of

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
	American Journal of Mental Retardation 104(2): 187-199. OBSERVATIONAL STUDY Level of evidence: ~			relations between adaptive behaviour domains and cognitive and language skills for the 2 groups.	children with autism.
33	California Department of Developmental Services. (2002). Autistic Spectrum Disorders: Best Practice for Screening, Diagnosis and Assessment. California: California Department of Developmental Services.  GUIDELINE Level of evidence: +	Evidence-based guideline. Not appraised with the AGREE tool.		Recommendations:  Factors that commonly prompt initial referral include:  • symptom changes and diagnostic dilemmas  • social deficits  • difficulty meeting academic expectations  • considerations such as family, cultural, community, or other demographic factors that mediate the dysfunctional quality of behaviours.  Interdisciplinary team recommended.  In exceptional cases a single clinician with experience evaluating ASD can make a diagnosis.  Symptoms of ASD which are influenced by the person's level of	

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
				maturity, lifetime experiences, and cognitive ability.	
				As people get older differential diagnosis becomes more complex.	
				Assessment should cover:  • relevant background information  • parent/caregiver interview  • child health history  • developmental and behavioural history  • family medical and mental health  • medical evaluation  • direct behaviour observation  • cognitive assessment  • adaptive functioning.	
				Check for co-existing and co-morbid conditions.	
				Formulation is the process of integrating the assessment information systematically, thus enabling the diagnostic team to attend to differential diagnosis sufficiently, finalise their opinion, and develop recommendations.	
				Written report essential.	

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
34	Volkmar, F. R., Cook, E. H., Pomeroy, J., Realmuto, G., & Tanguay, P. (1999). Practice parameters for the assessment and treatment of children, adolescents, and adults with autism and other pervasive developmental disorders. Journal of the American Academy of Child and Adolescent Psychiatry, 38, 32S-54S.  NON SYSTEMATIC REVIEW  Level of evidence: +	Detailed review.		Recommendations: Interagency and/or Multidisciplinary assessment should cover:  • historical information (pregnancy, neonatal and developmental history; medical history; family and psychosocial factors; intervention history)  • psychiatric examination (observational settings, overall developmental level, special problem behaviours)  • medical assessment (physical condition and co-morbidities, neurological assessment, audiological and vision examinations, laboratory studies, consultative services, developmental and intelligence testing, adaptive skills)  • speech-language communication assessments  • occupational and physical therapy assessments  • family and parental support  • differential diagnosis.	
35	Rescorla, L., Schwartz, E. (1990). Outcomes of toddlers with specific expressive language delay. <i>Applied</i>	Longitudinal study of 25 boys diagnosed as having specific expressive language delay (SELD) in the 24 to 31 month period. At the time of diagnosis, all subjects had	Not clear what measures were used for measurement of language.	Half of the boys still had very poor expressive language at follow up – they spoke at best in short telegraphic sentences and many had moderately severe articulation disorders with quite poor	Authors suggest that children with SELD at 24 to 30 months of age are at risk for continuing

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
	Psycholinguistics 11: 393-407.  OBSERVATIONAL STUDY  Level of evidence: ~	Bayley MDI scores above 85, Reynell Receptive Language Age scores within 4 months of their chronological age and Reynell Expressive Language scores at least 5 months below chronological age. Follow up occurred between 3 and 4 years of age.		intelligibility. The 12 boys with better outcome had a range of language skills. All spoke in sentences to some extent and each displayed some mastery of early morphemes.	language problems.
36	Filipek, P.A., Accardo, P.J., Baranek, G.T., et al. (1999). The screening and diagnosis of autistic spectrum disorders. Journal of Autism and Developmental Disorders; 29(6): 439-484.  PRACTICE CONSENSUS GUIDELINE  Level of evidence: +	Comprehensive search of the literature focusing mainly on literature published since 1990; Medline and PsycInfo in all languages plus other supplementary searching of reviews and books.  Multidisciplinary consensus panel initiated by the Child Neurology Society and the American Academy of Neurology and later expanded to include representatives of 9 professional organisations and 4 parent organisations with liaison from the US NIH.	Consensus opinion based on the literature.	Sensitive and specific developmental screening instruments include: ASQ, the BRIGANCE Screens, CDI, PEDS (Grade 2+).  The Denver II cannot be recommended (Grade 2).  Autism specific screening tools that have adequate sensitivity and specificity are CHAR, and ASQ (Grade 2).  Diagnostic tools for autism that have been shown to have adequate sensitivity and specificity include:  GARS PIA ADI-R (gold standard) CARS ADOS-G (gold standard).	

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
				The appropriate diagnosis of autism requires a dual level approach:  • routine developmental surveillance  • diagnostic evaluation.	
37	Filipek, P.A., Accardo, P.J., Baranek, G.T., et al. (2000). Practice Parameter: screening and diagnosis of autism. Neurology 55: 468-479.  CONSENSUS PRACTICE GUIDELINE  Level of evidence: +	Ibid (see above).	Ibid (see above).	Ibid (see above).	
38	California Department of Developmental Services. (2003). Autistic spectrum disorders. Changes in the California caseload. An update: 1999 through 2002. California: Department of Developmental	An audit updating a previous document that indicated a substantial increase in the numbers of people diagnosed with ASD entering the 21 regional ASD centres in California.		Increased prevalence of ASDs indicated by auditing of the demand on services.	Authors noted that research was ongoing to explain the increased prevalence of ASD.

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
	Services.				
	REPORT				
	Level of evidence: +				
39	Powell, A. (2002). Taking Responsibility: Good practice guidelines for services – adults with Asperger Syndrome. London: National Autistic Society. GUIDELINE	Guideline (not evidence- based, includes bibliography). Not appraised with the AGREE tool.		Recommendations:  • multi-disciplinary assessments recommended.  • detailed written report needed.  • post diagnostic support needed.	Result of Avon Asperger Syndrome Project 1999-2002, funded by the Department of Health.
	Level of evidence: x				
40	Morgan, H., Jones, G., & Jordan, R. (2001). Autistic Spectrum Disorders: A Guide to Services for Adults with Autism Spectrum Disorders for Commissioners and Providers. London: The Mental Health Foundation.  EXPERT OPINION	Guide to services developed by the Mental Health Foundation and the Foundation for People with learning Disabilities (UK). No research cited.		Multi-agency assessment helpful in providing well-rounded diagnostic assessment.	Hugh Morgan is Chief Executive Officer for the West Midlands Autistic Society, Glenys Jones is an educational psychologist and lecturer in autism at the University of Birmingham, and Rita Jordan is a clinician and lecturer in autism at the University of

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
					Birmingham.
41	Tidmarsh, L., & Volkmar, F. R. (2003). Diagnosis and epidemiology of autism spectrum disorders. Canadian Journal of Psychiatry - Revue Canadienne de Psychiatrie, 48(8), 517-525.  NON SYSTEMATIC REVIEW	Overview. No information on search criteria. Cites research.  Describes diagnostic methods and recommends tools.		Findings: Diagnosis of ASD needs further clarification, particularly with respect to PDD-NOS.  More research is needed on the epidemiology of autism-related medical and psychiatric disorders and outcome.	Fred Volkmar is an internationally respected clinician and researcher who has extensive knowledge of ASD.
	Level of evidence: x				
42	Attwood, T. (1998). Asperger's Syndrome: a Guide for Parents and Professionals. London: Jessica Kingsley Publishers.  EXPERT OPINION	Book/Expert opinion.  A guide on ASD for parents and professionals. Provides practical advice and information.		Recommendations: Diagnostic assessments should cover:  • social, language, cognitive and movement skills  • qualitative aspects of the child's interests  • developmental and behavioural history  • engineering situations to elicit behaviour and check for diagnostic signs  • language skills  • cognitive skills  • movement skills  • alternative diagnoses and	Tony Attwood is an internationally respected professional who has an extensive knowledge of ASD.

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
				<ul><li>explanations</li><li>secondary psychiatric conditions.</li></ul>	
				Information from teachers, occupational therapists and speech therapist is also very useful.	
43	Evans, I. M. (2000).  Protocol for the development of a model regional service for persons with Autism. Hamilton: University of Waikato.  EXPERT OPINION Level of evidence: x	Proposal (draft).		Suggests a protocol for the development of ASD services for Midland region of New Zealand.	Ian Evans was Professor of Psychology at the University of Waikato.
44	Werry, J. (1998). Extracts from the Report to the Director-General of Health Under s47 of the Health and Disability Services Act 1993 on Casey Albury. Wellington: Ministry of Health. REPORT	Report.		Recommends a range of government initiatives needed to address the needs of the New Zealand ASD population and their families.	John Werry is an internationally respected clinician who has extensive knowledge of ASD.

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
	Level of evidence: x				
45	Curry, D. (1998). Autism Services in New Zealand. Wellington: Autism Services Project Team.  REPORT Level of evidence: ~	Report on the services provided to people, and their families, in New Zealand with ASD.		Recommendations: Establishment of ASD lead agency, common definition of ASD needed, service and infrastructure development, training of professionals and services, establishment of ASD centre of excellence, identification of people with ASD, public awareness, and information sharing with Māori, Pacific Island and Asian people.	Commissioned by Ministry of Health, wide consultation.
46	Berney, T. (2004). Asperger syndrome from childhood into adulthood. Advances in Psychiatric Treatment, 10, 341-351.  NON SYSTEMATIC REVIEW  Level of evidence: x	Review (search not specified).		Differential diagnosis should consider a range of anxiety states (listed), ADHD, schizophrenia, personality disorders and obsessive compulsive disorder.  Advice given to prevent mistaking Asperger Syndrome for psychoses.	
47	Carter, A., Volkmar, F. R., Sparrow, S. S., Wang, J., Lord, C., Dawson, G., et al. (1998). The Vineland Adaptive Behaviour Scales: supplementary norms	Development of special population norms for children and adults with autism. 684 subjects, in 4 groups: mute children under 10 years of age; children with at least some verbal skills under 10 years of age, mute individuals	Vineland Adaptive Behaviour Scales	<ul> <li>Findings</li> <li>Significant differences detected.</li> <li>Recommended that testers use Vineland Adaptive Behaviour Scales special population norms as well as national norms when evaluating people</li> </ul>	

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
	for individuals with autism. Journal of Autism & Developmental Disorders, 28(4), 287-302.  OBSERVATIONAL STUDY  Level of evidence: +	10 years of age and older; individuals with at least some verbal skills 10 years of age and older.		with ASD.	
48	Freeman, B. J., Del'Homme, M., Guthrie, D., & Zhang, F. (1999). Vineland Adaptive Behaviour Scale scores as a function of age and initial IQ in 210 autistic children. Journal of Autism & Developmental Disorders, 29(5), 379-384.  OBSERVATIONAL STUDY Level of evidence: +	Use of human growth modelling statistics to examine score changes in 440 subjects with ASD as a function of age and IQ.	<ul> <li>Vineland         Adaptive         Behaviour         Scale.</li> <li>Wechsler         Preschool and         Primary Scales         of Intelligence –         Revised.</li> <li>Wechsler         Intelligence         Scales for         Children – Third         Edition.</li> <li>Wechsler Adult         Intelligence         Scale – Revised.</li> </ul>	<ul> <li>Findings</li> <li>Rate of growth in communication and daily living skills domains was related to initial IQ.</li> <li>Rate of growth of social skills domain was not related to initial IQ.</li> </ul>	
49	Kraijer, D. (2000). Review of adaptive behaviour studies in mentally retarded	Review of comparison studies on instruments of adaptive behaviour used with people who have ASD and an	<ul><li>Vineland Social Maturity Scale.</li><li>Vineland</li></ul>	<ul> <li>Findings</li> <li>Close correspondence between VABS results and SRZ, GGZ and SMZ combined.</li> </ul>	

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
	persons with autism/pervasive developmental disorder. Journal of Autism & Developmental Disorders, 30(1), 39-47.  NON SYSTEMATIC REVIEW  Level of evidence: ~	intellectual disability.	Adaptive Behaviour Scales (VABS).  Social Functioning Scale for the Mentally Retarded (SRZ).  Maladaptive Behaviour Scale for the Mentally Retarded (SGZ).  Gross Motor Skills Scale for the Mentally Retarded (SMZ).	Performance of people with ASD and an intellectual disability is particularly poor in social skills/socialization, and less poor in communication. No difference in self-help/daily living.	
50	Paul, R., Miles, S., Cicchetti, D., Sparrow, S. S., Klin, A., Volkmar, F. R., et al. (2004). Adaptive behaviour in autism and pervasive developmental disorder – not otherwise specified: microanalysis of scores on the Viineland Adaptive Behaviour Scales. Journal of Autism & Developmental Disorders, 32(2),	Study of diagnostic accuracy. Subjects were 40 children with pervasive developmental disorder aged between 4 and 11 years.	Vineland Adaptive Behaviour Scales.	Findings Children with PDD-NOS and children with autism differ only in very specific areas (expressive language, syntax and pragmatics) when adaptive behaviour is assessed.	

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
51	223-228.  OBSERVATIONAL STUDY  Level of evidence: +  Gillberg, C. (1998).	Review covering diagnostic	Children and adults	Findings	Christopher
	Asperger Syndrome and high-functioning autism. <i>British Journal of Psychiatry</i> , 172, 200-209.  NONSYSTEMATIC REVIEW  Level of evidence: ~	concepts and criteria, some controversial diagnostic issues, background factors, outcome, and intervention guidelines. No search criteria given. Outlines diagnostic and differential diagnostic processes.	addressed.	<ul> <li>Concluded that it is currently unclear whether autism spectrum disorders represent separate, overlapping, or identical conditions.</li> <li>Research needed into many aspects of HFA/AS.</li> <li>Some individuals with AS have persistent problems and consult adult psychiatrists.</li> <li>Adult psychiatrists need training in HFA/AS.</li> </ul>	Gillberg is an internationally respected clinician and researcher who has an extensive knowledge of ASD.
52	Khouzam, H. R., El-Gabalawi, F., Pirwani, N., & Priest, F. (2004). Asperger's disorder: a review of its diagnosis and treatment. Comprehensive Psychiatry, 45(3), 184-191.  NONSYSTEMATIC REVIEW	Review of diagnosis and treatment of Asperger syndrome. Search not described.		Findings  Presents diagnostic criteria for Asperger Syndrome in ICD-10 and DSM-IV, and that developed by Gillberg and Gillberg (1989).  Assessment must cover:  • social abilities and interactions • emotional abilities and behaviours • neuropsychological assessment • communication assessment	

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
	Level of evidence: x			<ul> <li>stereotyped behaviour and special interests</li> <li>movement difficulties</li> <li>sensory functioning</li> <li>adaptive functioning.</li> </ul>	
53	Klin, A., & Volkmar, F. R. (2000). Treatment and intervention guidelines for individuals with Asperger Syndrome. In Klin, A., Volkmar, F.R., & Sparrow, S.S. (Eds.), Asperger Syndrome (pp. Chapter 12, pp. 340-366). New York: Guilford.  NON SYSTEMATIC REVIEW  Level of evidence: ~	Book chapter.	Extensive references.	Findings: Recommends need to establish better definition of AS, with suggestions for research.	Ami Klin and Fred Volkmar are internationally respected clinicians and researchers who have extensive knowledge of ASD.
54	Siegel, D. J., Minshew, N. J., & Goldstein, G. (1996). Wechsler IQ profiles in diagnosis of high- functioning autism. Journal of Autism & Developmental	Study of diagnostic accuracy. Subjects were 45 children and 36 adults with HFA.	<ul> <li>Wechsler         Intelligence         Scales for         Children –         Revised Edition.</li> <li>Wechsler Adult         Intelligence         Scale – Revised</li> </ul>	<ul> <li>Findings</li> <li>Pattern of verbal IQ score being less than performance IQ score was found, but magnitude of difference was small.</li> <li>People with HFA can demonstrate a wide range of</li> </ul>	

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
	Disorders, 26(4), 389-405. OBSERVATIONAL STUDY Level of evidence: +		Edition.	<ul> <li>ability levels.</li> <li>Use of IQ score profiles in the diagnosis and differential diagnosis of autism in high-functioning individuals not considered valid.</li> </ul>	
55	Volkmar, F. R., Lord, C., Bailey, A., Schultz, R. T., & Klin, A. (2004). Autism and pervasive developmental disorders. <i>Journal of Child Psychology &amp; Psychiatry</i> , 45(1), 135-170.  NON SYSTEMATIC REVIEW  Level of evidence: ~	Review of key accomplishments in ASD and highest directions for future research. Search not described.		<ul> <li>Findings</li> <li>Diagnosis more consistent and rigorous.</li> <li>ADHD common.</li> <li>Continued debate on causes.</li> <li>New developmental models for ASD helpful.</li> <li>Areas for future research: study of ASD as it first develops (infants and very young), and specific processes that underlie the disorder.</li> </ul>	
56	Campbell, J. M. (2005). Diagnostic assessment of Asperger's Disorder: a review of five third-party rating scales. Journal of Autism & Developmental Disorders, 31(1), 25-35.	Systematic review of 5 tools used in the assessment of Asperger Syndrome.  Manuals and published reports evaluated according to Bracken standards of psychometric adequacy.	<ul> <li>Asperger Syndrome Diagnostic Scale.</li> <li>Autism Spectrum Screening Questionnaire.</li> <li>Childhood Asperger</li> </ul>	<ul> <li>Findings</li> <li>All scales had significant limitations.</li> <li>Krug Asperger Disorder Index had strongest psychometric properties and most thorough item selection.</li> </ul>	

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
	SYSTEMATIC REVIEW Level of evidence: +		Syndrome Test.  Gilliam Asperger Disorder Scale.  Krug Asperger Disorder Index. Also comments upon (but does not review):  Autism Spectrum Quotient and the Australian Scale for Asperger Syndrome.		
57	Howlin, P. (2000). Assessment instruments for Asperger Syndrome. Child Psychology and Psychiatry Review, 5(3), 120-129.  NON SYSTEMATIC REVIEW  Level of evidence: ~	Review of diagnostic instruments for Asperger Syndrome. No search criteria given.	<ul> <li>ICD-10.</li> <li>Criteria developed by Wing (1981), Gillberg and Gillberg (1989), Tantam (1991), and Szatmari, Bremner and Nagy (1989).</li> <li>Diagnostic Interview of Social and Communication Disorders.</li> <li>Australian Scale for Asperger Syndrome.</li> <li>Pervasive</li> </ul>	<ul> <li>Findings</li> <li>No adequately standardised diagnostic instruments specifically designed for Asperger Syndrome exist.</li> <li>Those instruments that exist require further research in order to demonstrate validity, reliability, specificity, and sensitivity.</li> <li>Most instruments are screening only.</li> <li>Unrealistic to assume that a single instrument can be used in isolation to ascertain diagnosis.</li> <li>Deficits in instruments are related to the absence of clear diagnostic criteria for Asperger</li> </ul>	Patricia Howlin is an internationally respected clinician and researcher who has an extensive knowledge of ASD.

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
			Developmental Disorders Questionnaire.  • Autism Spectrum Quotient.  • Autism Spectrum Screening Questionnaire.	Syndrome.	
58	de Bildt, A., Sytema, S., Ketelaars, C., Kraijer, D., Mulder, E., Volkmar, F. R., et al. (2004). Interrelationship between Autism Diagnostic Schedule – Generic (ADOS-G), Autism Diagnostic Interview – Revised (ADI-R), and the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) classification in children and adolescents with mental retardation. Journal of Autism & Developmental Disorders, 34(2), 129-137.	Study of diagnostic accuracy and inter-relationships between two standardised ASD assessments and DSM-IV-TR. Subjects were 184 children and adolescents with mental retardation.	Autism     Diagnostic     Observation     Schedule –     Generic.      Autism     Diagnostic     Interview –     Revised.      DSM-IV-TR.	<ul> <li>Findings</li> <li>Fair agreement between ADI-R and ADOS-G.</li> <li>Both instruments measured ASD validly and reliably, even in low-functioning children.</li> <li>Combination of ADI-R and ADOS-G considered to be of diagnostic value.</li> </ul>	

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
	OBSERVATIONAL STUDY Level of evidence: +				
59	Mazefsky, C., & Oswald, D. (2006). The discriminative ability and diagnostic utility of the ADOS-G, ADI-R, and GARS for children in a clinical setting. <i>Autism</i> , 10(6), 533-549.  CROSS SECTIONAL STUDY  Level of evidence: +	Study of diagnostic accuracy. N = 38, aged 22 months to 8 years, 72% male, 32 with autism, 27 with other PDD, 19 with non-ASD diagnosis.	<ul> <li>Autism         Diagnostic         Observation         Schedule –         Generic (ADOS-G).</li> <li>Autism         Diagnostic         Interview –         Revised (ADI-R).</li> <li>Gilliam Autism         Rating Scale         (GARS).</li> </ul>	ADOS-G and ADI-R produced similar results to original studies, and high rate (75%) of agreement with multi-disciplinary team diagnosis. However, ADOS-G and ADI-R use was associated with more frequent use of autism as a diagnosis, rather than PDD.  GARS was not effective, and consistently under-estimated the likelihood of autism.	
60	Le Couteur, A., Lord, C., Rios, P., Robertson, S., Holdgrafer, M., & McLennan, J. (1989). Autism Diagnostic Interview: a standardised investigator-based instrument. Journal of Autism & Developmental Disorders, 19(3),	Study of diagnostic accuracy. 16 autistic and 16 non-autistic mentally handicapped individuals.	Autism Diagnostic Interview, structured interview.	Findings Scale significantly differentiated between subjects with ASD and those without.	

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
61	363-387.  OBSERVATIONAL STUDY  Level of evidence: +  Lord, C., Rutter, M., & Le Couteur, A. (1994). Autism Diagnostic Interview – Revised: A revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. Journal of Autism and Developmental Disorders, 24, 659-685.  OBSERVATIONAL STUDY	Study of diagnostic accuracy. Subjects were the 25 preschool children with ASD, and 25 preschool children with intellectual disability.	Autism Diagnostic Interview – Revised (ADI-R).	Findings  Revised scale differentiated appropriately.  Suitable for children and adults.	
	Level of evidence: +				
62	Le Couteur, A., Lord, C., Rutter, M. Autism Diagnostic Interview – Revised (ADI-R). Los Angeles, CA: Western	Published test.	Autism Diagnostic Interview – Revised.	Semi-structured interview for caregivers of children and adults, for diagnosis of autism, according to DSM V and ICD-10 criteria.  Administration takes 90 minutes to	

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
	Psychological Services, 2003. PUBLISHED TEST Level of evidence: +			3 hours.  Substantial training required for administrator.	
63	Lord, C., Risi, S., Lambrecht, L., Cook, E., Leventhal, B., DiLavore, P., 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 & Developmental Disorders, 30(3), 205-223.  OBSERVATIONAL STUDY Level of evidence: +	Study of diagnostic accuracy. Subjects were 223 children and adults with ASD.	Autism Diagnostic Observation Schedule – Generic, a standardised method of observing current social and communication behaviours.	Findings Psychometric properties excellent.  Good diagnostic validity.	
64	Lord, C., Rutter, M., DiLavore, P.C., Risi, S. Autism Diagnostic	Published test.	Autism Diagnostic Observation Schedule (ADOS).	Diagnostic instrument for autism and pervasive developmental disorder across ages (toddlers to	

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
65	Observation Schedule – WPS (WPS edition). Los Angeles: Western Psychological Services, 1999.  PUBLISHED TEST Level of evidence: +  Gillberg, C., Gillberg, C., Rastam, M., & Wentz, E. (2001). The Asperger Syndrome (and high- functioning autism). Diagnostic Interview (ASDI): a preliminary study of a new structured clinical interview. Autism, 5(1), 57-66.  OBSERVATIONAL STUDY Level of evidence: +	Study of diagnostic accuracy. 17 children and adults with a neuropsychiatric disorder, and 7 controls.	Asperger     Syndrome     Diagnostic     Interview, a     structured     clinical interview.     DSM-IV.	adults), developmental levels and language skills.  Standardised behavioural observation and coding system.  Administration time 30 - 40 minutes.  Significant training required.  Findings ASDI identified all people with ASD.  Inter-rater reliability and test-retest stability good.  May be good tool for preliminary diagnostic decisions in clinical setting.	
66	Nylander, L., Gillberg C. (2001). Screening for autism spectrum disorders in adult psychiatric out-	1,323 adult psychiatric outpatients from a clinic in Lund were screened for ASD. Analysis of the psychiatric records of 66 patients scoring	22 of the 31 patients were clinically examined and 3 psychometric aspects of the	17 patients were found by clinical examination to have an ASD. Another 2 patients scoring low on the ASDASQ were known to have an ASD. Therefore, at least 19	The authors concluded that adult psychiatric patients sometimes have undiagnosed

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
	patients: a preliminary report. Acta Psychiatrica: 103(6): 428-434.  OBSERVATIONAL STUDY  Level of evidence: ~	high on the Autism Spectrum Disorder in Adults Screening Questionnaire (ASDASQ) yielded 31 patients with suspected ASD.	questionnaire (inter-rater and test re-test stabililty and internal consistency) were studied.	patients in this population (1.4%) had a definite ASD.  The ASDASQ showed good reliability across and within raters. Internal consistency was excellent.	autism spectrum disorders. The ASDASQ can be useful for screening.
67	Baron-Cohen, S., Wheelwright, S., Skinner, R., Martin, J., & Clubley, E. (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(1), 5- 17.  OBSERVATIONAL STUDY Level of evidence: +	Study of diagnostic accuracy of the Autism Spectrum Quotient with adult subjects: 58 with HFA/AS (45 males, 13 females), 174 randomly selected controls (67 males, 98 females), 850 university students (454 males, 386 females), and 16 winners of the UK Mathematics Olympiad (15 males, 1 female).	<ul> <li>Autism         Spectrum         Quotient, a self         report         questionnaire.</li> <li>DSM IV &amp; ICD         10 criteria for         autism and         Asperger         Syndrome.</li> </ul>	Findings: Adults with HFA/AS scored higher than controls on the Autism Spectrum Quotient. University students did not differ significantly from control group, but those studying science scored significantly higher than those studying humanities and social sciences. Mathematics Olympiad Winners scored significantly higher than humanities students.	
68	Garnett, M.S., Attwood, A.J. (1998).	Diagnostic test.	Australian Scale for Asperger's	Test reproduced.	

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
	The Australian Scale for Asperger's Syndrome. In: Atwood T, editor. Asperger's Syndrome: a guide for parents and professionals. London: Kingsley; 17-19.		Syndrome (ASAS).		
69	Williams, J., Scott, F. J., Stott, C., Allison, C., Bolton, P., Baron-Cohen, S., et al. (2005). The CAST (Childhood Asperger Syndrome Test): test accuracy. <i>Autism</i> , 9(1), 45-68.  OBSERVATIONAL STUDY  Level of evidence: +	Study of diagnostic accuracy. Subjects were 1,925 children aged 5 - 11 in mainstream schools.	<ul> <li>Childhood         Asperger         Syndrome Test         (CAST).</li> <li>Autism         Diagnostic         Observation         Schedule –         Generic (ADOS-G).</li> <li>Autism         Diagnostic         Interview –         Revised (ADI-R).</li> </ul>	<ul> <li>Findings</li> <li>CAST identified children with ASD. 100% sensitivity, 97% specificity, and 50% positive predictive value.</li> <li>Useful screening test for ASD in epidemiological research.</li> <li>Not enough evidence to use CAST for screening within the general population.</li> </ul>	
70	Skuse, D., Warrington, R., Bishop, D., et al.	Study of diagnostic accuracy. Clinical subjects were 50 children referred to Child	Developmental,     Diagnostic and     Dimensional	<ul> <li>Test re-test and inter-rater reliabilities mostly &gt;0.6.</li> <li>Concurrent validity very good</li> </ul>	

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
	(2004). The Developmental, Diagnostic and Dimensional Interview (3di): a novel computerised assessment for autism spectrum disorders. Journal of the American Academy of Child and Adolescent Psychiatry; 43:5.  DIAGNOSTIC STUDY  Level of evidence: +	Psychiatric Clinic (mean age 11.4 years, range 6.0 - 16.2, 78% male). Controls were children referred to paediatric clinic (mean age 10.1, range 2.5 - 15.6, 25% male).  Two further samples: 16 children recruited from unit specialising in education of children with specific language impairment (aged 6 - 10 years); and parents of 13 children seen at Social and Communication Disorders Clinic (children aged between 3 and 13),	Interview (3di).  Autism Diagnostic Interview – Revised (ADI-R).  Children's Communication Checklist.  Algorithms written in accordance with ICD-10.  Ravens Coloured Progressive Matrices.  British Picture Vocabulary Scale.	<ul> <li>(mean kappa 0.74).</li> <li>Criterion validity excellent</li> <li>Discrimination between autistic spectrum versus non-autistic subjects was almost perfect (sensitivity 1.0; specificity &gt;0.97).</li> <li>Concludes that 3di is an efficient, accurate means of assessment in clinical and normal population.</li> </ul>	
71	Wing, L., Leekam, S. R., Libby, S. J., Gould, J., & Larcombe, M. (2002). The Diagnostic Interview for Social and Communication Disorders: background, interrater reliability and clinical use. Journal of Child Psychology and Psychiatry,	Study of diagnostic accuracy. Subjects were 82 children aged 3 - 11 with ASD.		Inter-rater reliability high.	

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
72	43(3), 307-325.  OBSERVATIONAL STUDY  Level of evidence: +  Leekam, S. R., Libby, S. J., Wing, L., Gould, J., & Taylor, C. (2002). The Diagnostic Interview for Social and Communication Disorders: algorithms for ICD-10 childhood autism and Wing and Gould autistic spectrum disorder. Journal of Child Psychology and Psychiatry, 43(3), 327-342.  OBSERVATIONAL STUDY  Level of evidence: +	Study of diagnostic accuracy. Subjects were the parents of 36 children with autism, 17 children with learning disabilities and 14 children with language disorders.	Diagnostic Interview for Social and Communication Disorders (DISCO).     ICD 10.	Findings  Results indicated that DISCO was a reliable instrument for diagnosis when sources of information were from the whole interview.  DISCO particularly effective for diagnosing disorders of the broader autism spectrum.	
73	Gilliam, J.E. Asperger's Disorder Scale. Austin, Texas: Pro-Ed Inc., 2001. PUBLISHED TEST	Published test.	Gilliam Asperger's Disorder Scale (GADS).	Scale for parent, or professional who knows person well. For ages 3 to 22. Administration takes 5 - 10 minutes.	

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
	Level of evidence: +				
74	Krug, D.A., Arick, J.R. (2003). Krug Asperger's Disorder Index. Austin, Texas: Pro-Ed Inc. PUBLISHED TEST Level of evidence: +	Published test.	Krug Asperger's Disorder Index (KADI).	Scale for administration to parents on individuals aged 6 - 22 years.  Administration takes 15 - 20 minutes.	
75	Jordan, R.R. (1999). Autistic spectrum disorders: an introductory handbook for practitioners. London: David Fulton.  BOOK	Book.		<ul> <li>Chapter on psychological theories on the nature of autism includes:</li> <li>theory of mind theory proposes a cognitive deficit in autism linking neurological abnormalities to multiple behavioural manifestations.         The seminal work was a study by Baron-Cohen et al (1985).     </li> <li>central coherence: first postulated by Frith, 1989, that a weak drive for central coherence could account for the difficulties in autism not accounted for by the theory of mind theory.</li> <li>executive function (Ozenoff and colleagues) is the idea that a disorder of executive</li> </ul>	

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
				control functions might be responsible for the fundamental disorders of autism.	
76	Russell, J. Cognitive theories of autism. In: Harrison, G., Owen, W., editors. Cognitive deficits in brain disorders. London: Erlbaum, 2002.  EXPERT OPINION  Level of evidence: x	Book chapter reviewing theory. Search criteria not given.		<ul> <li>Three cognitive theories of autism:</li> <li>theory of mind mechanisms</li> <li>weak central coherence theory</li> <li>executive dysfunction theory.</li> </ul> Reviewer provides critical analysis and research to criticise theory of mind and weak central coherence theory. Supports executive dysfunction theory (area of own research).	
77	Baron-Cohen, S. (2001). Theory of mind and autism: a review. International Review of Mental Retardation, 23, 169+  EXPERT OPINION  Level of evidence: x	Book section (review of theory of mind and autism). No search details given.		'Mindblindness', also known as deficit in the person's 'theory of mind', is the ability to reflect on the contents of one's own and others' minds.	Simon Baron- Cohen is an internationally respected researcher in ASD.
78	Hill, E.L. (2004). Executive dysfunction in autism. Trends in Cognitive Sciences 8(1): 26-32.	Expert opinion. No methodology stated.		School aged and adult autistic individuals have impairments in executive dysfunction. They show a certain type of perseverative behaviour taken to indicate a deficit in mental flexibility.	

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
	NON SYSTEMATIC REVIEW				
	Level of evidence: x				
79	Baron-Cohen, S. (2004). Autism: research into causes and intervention. Paediatric Rehabilitation, 7, 73-78.  NON SYSTEMATIC REVIEW  Level of evidence: x	Presents cognitive theories and summaries of research findings. No search details given.			<ul> <li>Good data supporting mindblindness theory.</li> <li>Good data supporting empathising – systemising theory.</li> <li>Poor data on deficits in executive functioning.</li> <li>Central coherence theory needs further testing.</li> </ul>
80	Gillberg, C., Billstedt, E. (2000). Autism and Asperger Syndrome: coexistence with other clinical disorders. Acta Psychiatrica Scandinavica 102(5): 321-330.	Selective review of the literature detailing data pertaining to symptoms and disorders sometimes encountered in connection with autism or Asperger Syndrome. Methodology not explicitly stated so difficult to evaluate the likelihood of bias.		A large number of medical conditions, psychiatric disorders and behavioural and motor dyscontrol symptoms are associated with autism and Asperger Syndrome.	Authors conclude that comorbidity is to be expected in ASDs – directly or indirectly. There is a great need for indepth research in this area.

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
	NON SYSTEMATIC REVIEW				
	Level of evidence: x				
81	Gillberg, C., Coleman, M. (2000). Chapter 11: Double syndromes. In: <i>The</i> biology of autistic syndromes. 3 <sup>rd</sup> ed: Cambridge University Press.	Non systematic discussion. No methodology explicitly described.		Discussion of comorbidity in ASD.	
	CHAPTER IN BOOK				
	Level of evidence: x				
82	See reference no. 13.				
83	Macintosh, K., & Dissanayake, C. (2004). Annotation: the similarities and differences between autistic disorder and Asperger's disorder: a review of the empirical evidence. Journal of Child Psychology & Psychiatry, 45(3), 421-434.	Systematic review of studies using qualitative statistical analyses. Search described.		<ul> <li>Findings</li> <li>Few qualitative differences between autistic disorder and Asperger's disorder.</li> <li>Insufficient evidence currently to establish Asperger's disorder as a syndrome distinct from high-functioning autism.</li> </ul>	
	SYSTEMATIC				_

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
	REVIEW Level of evidence: +				
84	Rinehart, N. J., Bradshaw, J. L., Brereton, A. V., & Tonge, B. J. (2002). A clinical and neurobehavioural review of high- functioning autism and Asperger's disorder. Australian and New Zealand Journal of Psychiatry, 36, 762-770.  SYSTEMATIC REVIEW  Level of evidence: +	Systematic review of clinical and neuropsychological studies of high-functioning autism and Asperger's disorder. Search criteria described.		Findings It is premature to rule out the possibility that HFA and AS may be clinically, and possibly neurobiologically, separate.	
85	Baron-Cohen, S., & Wheelwright, S. (2004). The empathy quotient: an investigation of adults with Asperger Syndrome or high functioning autism, and normal sex differences. Journal of Autism &	Two studies of diagnostic accuracy of the Empathy Quotient with adults. Study 1: 90 subjects with HFA/AS (65 males, 25 females). Study 2: 197 subjects drawn from the general population (71 males, 126 females).	<ul> <li>Empathy         Quotient, a self         report         questionnaire.</li> <li>DSM IV &amp; ICD         10 criteria for         autism and         Asperger         Syndrome.</li> </ul>	<ul> <li>Findings</li> <li>Adults with HFA/AS scored significantly lower on the Empathy Quotient than did controls.</li> <li>Sex difference found in Empathy Quotient scores in general population (females score higher).</li> </ul>	

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
86	Developmental Disorders, 34(2), 163-175.  OBSERVATIONAL STUDY  Level of evidence: +  Baron-Cohen, S., Richler, J., Bisarya, D., Gurunathan, N., & Wheelwright, S. (2003). The systemizing quotient: an investigation of adults with Asperger syndrome or high- functioning autism, and normal sex differences. London: The Royal Society.  OBSERVATIONAL STUDY  Level of evidence: +	Two studies of diagnostic accuracy of the Systemising Quotient with adults.  • Study 1: 278 subjects drawn from the general population (114 males, 164 females).  • Study 2: 47 subjects with HFA/AS (33 males, 14 females) matched with 47 subjects from Study 1.	<ul> <li>Systemising         Quotient and         Empathy         Quotient, both         self-report         questionnaires.</li> <li>DSM IV &amp; ICD         10 criteria for         autism and         Asperger         Syndrome.</li> </ul>	Findings  • Adults with HFA/AS scored significantly higher on the Systemising Quotient and lower on the Empathy Quotient than did controls.  • Sex difference found in Systemising Quotient scores in general population (males score higher on SQ, females score higher on EQ).	
87	Rutherford, M. D., Baron-Cohen, S., & Wheelwright, S. (2002). Reading the mind in the voice: a study with normal adults with Asperger	Study of diagnostic accuracy. 19 adult subjects with HFA/AS, and 20 normal controls.	Voice Test, researcher administered.	<ul> <li>Findings</li> <li>The Voice Test distinguished adults with HFA/AS from controls.</li> <li>People with HFA/AS have difficulty extracting mental</li> </ul>	

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
	Syndrome and high- functioning autism. Journal of Autism & Developmental Disorders, 32(3), 189-194.  OBSERVATIONAL STUDY  Level of evidence: +			state information from vocalisations.	
88	Caron, M.J., Mottron, L., Rainville, C., et al. (2004). Do high functioning persons with autism present superior spatial abilities? Neuropsychologia; 42(4):467-81. OBSERVATIONAL STUDY Level of evidence: +	Experimental study using cognitive tasks.  Clinical group of 16 adolescents and adults with high-functioning autism (11 males) or Asperger Syndrome (4 males, 1 female), with IQ scores in the average range. Control group of 16 typically developing participants matched on gender, age, education, performance IQ and laterality.	Accuracy and error rates.	No differences between experimental and controls in route learning, reversing a route, and pointing tasks.  HFA/AS performed better than controls in transfer of knowledge between micro and macro scales.	
89	Howlin, P. (2003). Outcome in high- functioning adults with autism with and without early language delays: implications for the differentiation	Cohort study of 24 adults with autism who had shown early delays in language, and 42 individuals (meeting ADI-R criteria) reported to have had no language delay. All participants at least 18 years old, and IQ of 70 or above.	Autism Diagnostic Interview – Revised.	No significant differences found in either ADI-R algorithm scores, or in their algorithm scores on individual domains. Social outcome ratings and ADI-R scores based on current functioning also failed to differentiate between the	

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
	between autism and Asperger Syndrome. Journal of Autism and Developmental Disorders, 33(1), 3– 13.			groups.	
	OBSERVATIONAL STUDY - COHORT Level of evidence: +				
90	Brogan, C. A., & Knussen, C. (2003). The disclosure of a diagnosis of an autistic spectrum disorder. <i>Autism</i> , 7(1), 31-46.  OBSERVATIONAL STUDY – SURVEY  Level of evidence: +	Qualitative research on satisfaction of disclosure process. Subjects were 126 parents of children diagnosed with ASD. 334 questionnaires send out originally.	Self-report questionnaire, postal survey.	Findings High level of satisfaction with disclosure associated with positive ratings of the professional's manner, the quality of the information provided, written information, the opportunity to ask questions, if early suspicions had been accepted by professionals, diagnosis of Asperger Syndrome, definite diagnosis, and child not in current educational placement.	
91	Moyes, R. (2003). Settling into the Diagnosis of Asperger Syndrome. In Holliday, L, Willey (Ed.). Asperger Syndrome and Adolescence: Living with the Ups, the Downs and Things in	Book chapter.		When informing of diagnosis, give adolescents time to ask questions, understand what is being said, and voice concern.  People diagnosed with ASD may need post-diagnostic.  Common issues include doubt about the diagnosis, depression	

Ref No	Reference, Study Type & Rating	Methods and Participation	Measures	Outcomes/Results	Notes
	Between. London: Jessica Kingsley Publishers.  EXPERT OPINION Level of evidence: x			and despair, anger and fear.	
92	Coplan, J. (2000). Counselling parents regarding prognosis in autistic spectrum disorder. Paediatrics, 105(5), 65-66.  EXPERT OPINION Level of evidence: x	Expert opinion.		Child's needs and prognosis outlined via 4 basic premises:  • atypical development occurs along a continuum from mild to severe  • that phenotypic expression of ASD varies with age  • ASD of any degree of severity can occur in combination with any degree of general intelligence  • long-term prognosis represents the joint impact of ASD and the child's general level of intelligence.	Author from the Department of Pediatrics, University of Pennsylvania School of Medicine.

## **EVIDENCE TABLES FOR PART 2: SUPPORT FOR INDIVIDUALS, FAMILIES AND CARERS**

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
93	Broach, S., Camgoz, S., Heather, C., Owen, G., Potter, D., & Prior, A. (2005). How people with autism spectrum disorders and their families are still missing out on their rights. Retrieved 13/01, 2005, from http://www.nas.org.uk  OBSERVATIONAL STUDY  Level of evidence: ~	Postal survey of 2,300 members of the NAS in England and Wales. 548 were returned (29% response rate). A further 41 adults with ASD (Asperger Syndrome, high/functioning autism) were surveyed (post, phone or in person).	The survey examined 7 areas of everyday life where people with ASD, their families and carers often needed additional support: social care, financial support and benefits, transport, housing, play and leisure, advocacy, support for carers.	<ul> <li>Findings</li> <li>Highlighted areas of need.</li> <li>Identified areas of difficulty.</li> <li>Made recommendations for change to ensure people with ASD and their families receive rights and entitlements to enhance social inclusion and independent living.</li> <li>Many of the required changes are relatively minor and support would be cost effective long term.</li> </ul>	Report based on services provided in England and Wales.
94	Olley, J. G., & Guttentag, S. S. (1999). Autism: Historical overview, definition, and characteristics. In Zager, D.B. (Ed.). Autism: Identification, education and treatment (2nd ed), (pp 3-22). Mahwah, New Jersey: Lawrence Erlbaum	An overview of the research history, and present knowledge of ASD characteristics, etiology and treatment.		<ul> <li>Autism places unusual stress on parents – some reports suggest that the child's lack of interpersonal responsiveness and the severity of the symptoms are factors.</li> <li>Focus of treatment now on the family rather than just the child.</li> <li>Siblings experience their own stresses.</li> <li>Siblings bear more responsibilities than those with a typically developing brother</li> </ul>	Comprehensive and clear coverage of what is currently known about ASD.

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	Pub.  BOOK CHAPTER  Level of Evidence: ~			or sister but do not as a whole have more adjustment problems than others.  • Siblings have successfully been taught behavioural methods for working with their brother or sister.	
95	Bromley, J., Hare, D.J., Davison, K., Emerson, E. (2004). Mothers supporting children with autistic spectrum disorders: social support, mental health status and satisfaction with services. Autism 8:409-23.  QUALITATIVE STUDY  Level of evidence: ~	68 mothers participated (caring for 71 children with ASD), recruited by letter, leaflets, posters. The study examined the impact of a range of factors on the psychological well-being of parents with ASD to explore aspects of social support, mental health status and satisfaction with services, and investigated areas of unmet need, care breaks and advise needs.	All mothers were interviewed at home using a structured format and incorporating the following measures:  • subscales of the AAMR Adaptive Behaviour Scale (ABS: Lambert et al., 1993)  • developmental Behaviour Checklist (DBC: Einfeld & Tongue, 1994); modified Family Support Scale (FSS: Dunst et al, 1988); Unmet needs (Chamba, 1999); General Health  • questionnaire 12 (GHQ-12:	A range of needs was identified. High levels of psychological distress were associated with low levels of support from within family and bringing up child with challenging behaviour, potentially remedial through specific health and social interventions. Evidence suggests that the provision of respite care may facilitate more successful coping by mothers of autistic children.  Limitations of study:  study based in the UK  minority of mothers approached chose to participate; may be unrepresentative of the wider population; fewer mothers of ethnic minorities; fewer mothers living in poverty  sample was self-selected  study relied on mothers reporting ASD rather than evidence of diagnostic process analyses cannot determine	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
			Goldberg & Willliams, 1988)  uptake of support services Client Service Receipt Inventory (CSRI: Beecham, 1995).	causality.	
96	National Research Council. (2001). Educating Children with Autism. Washington, DC: National Academy Pr. GOVERNMENT REPORT Level of Evidence: +	Report to the US Department of Education's Office of Special Education. Integrates scientific, theoretical and policy literature concluding with recommendations on best practice for the education of children with ASD from birth to age 8.		<ul> <li>Parents play multiple roles.</li> <li>Parents need specialised knowledge and skills about ASD and its treatment.</li> <li>Participation in treatment has a cost for the parents.</li> <li>Support of partner important indicator of the quality of parenting in the home.</li> <li>Learning effective teaching methods can have positive effect on family stress, an increase in adaptive behaviour and more leisure options for the family.</li> <li>Need to provide culturally sensitive services.</li> <li>Involvement of parents aids generalization of skills.</li> <li>Parents need both initial training and on-going support.</li> <li>Parents often advocates for their child.</li> <li>Parents need to have</li> </ul>	A rigorous examination of the literature on ASD. Includes clear and precise recommendations that are unmistakably based on the literature reviewed.

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				<ul> <li>knowledge of the education system and ASD to be good advocates.</li> <li>Little known about how to prepare parents to be effective advocates.</li> <li>Mothers who blame themselves or feel the child's disability is a catastrophe make less effective adaptations.</li> <li>Psychological hardiness and perceived social support help mothers to cope.</li> <li>Family needs change over time</li> <li>The needs of siblings must be considered.</li> <li>Siblings are at greater risk of ASD and should be monitored for signs.</li> </ul>	
97	Bailey, A., Palferman, S., Heavey, L., & Le Couteur, A. (1998). Autism: The phenotype in relatives. <i>Journal of Autism and Developmental Disorders</i> , 28(5), 369-392.  NON SYSTEMATIC REVIEW	Review of 31 studies looking at relatives of ASD probands and controls from 1980; to determine if relatives of people diagnosed with ASD are sometimes affected by difficulties conceptually related to ASD behaviours and related personality traits.		<ul> <li>Findings</li> <li>Significant social difficulties affect a substantial minority of first-degree relatives of people with ASD.</li> <li>A larger proportion show apparently related personality traits.</li> <li>Relatives can manifest behavioural characteristics that range in severity from disorders on the PDD spectrum to possibly isolated social or communicative difficulties or</li> </ul>	Differing methodological factors impacted on findings that are variable and that made clear conclusions difficult to quantify.

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	Level of evidence: ~			traits.  Little consistent evidence across studies that relatives are at special risk for other psychiatric disorders  Further research in molecular genetics is required to determine which genes predispose people towards ASD.	
98	Symon, J. B. (2001). Parent education for autism: Issues in providing services at a distance. Journal of Positive Behaviour Interventions, 3, 160–74.  LITERATURE REVIEW  Level of Evidence: ~	Reviews literature on ASD interventions with a focus on the difficulties in reaching families in rural and outlying area, and on family-focused interventions.		<ul> <li>Family stress from factors such as limited financial resources, lack of services, insufficient support systems and services. These can contribute to an unfavourable prognosis.</li> <li>Parents now more involved in interventions and supports to empower families.</li> <li>Parent education programmes have been shown to reduce problem behaviours and collateral effects in better family functioning.</li> <li>Intervention models of parent professional collaboration have shown better results than interventions targeted at only one level.</li> <li>Need to provide educational programmes and resources for children and adults living in rural areas.</li> </ul>	Does not indicate how the literature reviewed was chosen (ie, comprehensive database search, selected journals or dates), or in the majority of cases give details about the studies themselves. Covers a wide range of ASD-related issues without much depth. Perhaps owing to this lack of detail the paper's discussion points do not appear to be unequivocally grounded in the

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				<ul> <li>Key challenges in rural areas are – transportation, lack of local support, isolation, few employment opportunities, geography and limited financial resources.</li> <li>Evidence that education for managing behaviour can be provided through telephone contact and printed materials.</li> <li>Education also supplied through television.</li> <li>Parents in rural areas also require social support as well as services.</li> <li>Parents of children with disabilities suffer stress from a number of sources – lack of resources and trained staff as well as financial pressures, need to become an advocate for their child, problem behaviours, heavy caregiving responsibilities, concerns about the child's future.</li> <li>Stress levels can be alleviated if provided with adequate support.</li> <li>Ecocultural approach recognises external resources, such as extended family, and professionals and agencies can serve factors to mediate</li> </ul>	research reviewed.

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				stressful events.  Variables associated with successful coping (cognitive) adaptation individual attempts to gain mastery or control, find positive meaning in the experience, choosing positive forms of self evaluation.  Positive effects of including parents in intervention – round the clock intervention, increases quantity and quality of intervention, increases maintenance and generalisation.  Successful interventions result in increased leisure time for family.  For parent education to be successful families may need support in other areas first eg respite care, counselling peer networks.  Collaborative approach considers child and family characteristics and designs interventions to fit.  Ecocultural theory considers that family values are embedded in daily routines. Interventions should respect these routines.	
99	Gray, D. (1997).	Part of an ongoing study of the	In depth semi-	Findings	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	High-functioning autistic children and the construction of 'normal family life'. Social Sciences Med., 44(8), 1097-1106.  OBSERVATIONAL STUDY - QUALITATIVE  Level of evidence: ~	social experiences of families with ASD based in Melbourne, Australia. The study examines the experiences of participants whose children have high-functioning autism or Asperger Syndrome. Responses were thematically analysed.	structured interviews.	Normal family life linked to factors such as:      ability to socialise     emotional quality of interactions among family members     perceptions of rituals and routines in 'normal' families     presence of aggressive tendencies     seen in context of work, school and the human services designed to support them. Few parents in the study perceived they had family normality.	
100	Gray, D. (2002). Ten years on: A longitudinal study of families of children with autism. Journal of Intellectual & Developmental Disability, 27(3), 215-222.  OBSERVATIONAL STUDY – QUALITATIVE  Level of evidence: ~	A longitudinal (decade), ethnographic study of the psychosocial adaptation of a cohort of parents of children with autism. 8-10 years on, 28 of the original 35 participants agreed to participate in the present study.	Interviews duplicating the original questions and, where appropriate, questions were modified for current relevance.	<ul> <li>Findings</li> <li>Parents experience a series of stages in their adaptation to their child's autism.</li> <li>Outcomes for most of the families were favourable. Successful coping was the result of accumulated skills that affected parents' perspectives and helped them to manage.</li> <li>Not all families experienced improvements.</li> <li>Families with children who were violent were noted to be under considerable stress and the level of service provision to be unsatisfactory.</li> <li>Lack of residential care was</li> </ul>	Study based in New South Wales and Queensland, Australia.

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				seen to be an issue for all families. Most adult children were still living at home.	
101	Gray, D. (2003). Gender and coping: The parents of children with high- functioning autism. Social Science & Medicine, 56, 631- 642.  OBSERVATIONAL STUDY – QUALITATIVE  Level of evidence: ~	A qualitative analysis of the role of gender and coping among parents of children diagnosed with high-functioning autism, in an ongoing study of the social experiences of 21 families with ASD based in Melbourne, Australia; included a literature review and information from participants.		Findings:  ASD reduced all of the families to traditional patterns of gender relations.  Mothers were most likely to have experienced the negative impact of disability on their daily lives.  Areas affected were:  emotional distress  career disruption  primary role in medical referral process and follow up  primary role in sorting child's education problems  more likely to be held responsible for their child's behaviour.	
102	Lewis, S., Kagan, C., & Heaton, P. (2000). Dual-earner parents with disabled children. Family patterns for working and caring. <i>Journal of Family Issues</i> , 21(8), 1031-1060.	Qualitative study of family strategies for caregiving and income generation. 64 dualincome earning parents participated (32 families). Sample was generated to ensure a range of situations where parents combined employment with care; participated in a range of	In depth semi- structured interviews.	<ul> <li>Findings</li> <li>Flexible community-based and employer supports are crucial to help parents with disabled children to work and care.</li> <li>Informal and formal community-based support and flexibility from professionals is needed to enable families to develop appropriate strategies to</li> </ul>	UK based. Social context and time of research may have different implications for duplication of this study.  Difficulty in recruiting ethnic

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	OBSERVATIONAL STUDY – QUALITATIVE Level of evidence: ~	occupations and income; children were aged between 6 months and 29 years and reflected a range of physical and learning disabilities. A small percentage of participants were from ethnic minorities. Interviews were transcribed and analysed according to a framework based on factors contributing to decision-making including economic, ideological, social supports and barriers to combine work and care.		<ul> <li>manage multiple commitments.</li> <li>Gender expectations influence the way in which income is generated.</li> <li>Demands of raising disabled children continue into adulthood.</li> </ul>	minority families for the study prevented examination of work/family issues for this population.
103	Jarbrink, K., & Knapp, M. (2001). The economic impact of autism in Britain. Autism, 5(1), 7-22.  SYSTEMATIC REVIEW  Level of evidence: ~	Study to estimate the economic impact of autism in the UK, based on published evidence and the re-analysis of data held at the Centre for the Economics of Mental Health (CEMH). Literature search included library and electronic databases, selected journals and library catalogues for books and reports. Researchers were invited to contribute information. Previous research held at the CEMH identified a further 228 people with ASD and a		Conservative estimates of costs as information relates mainly to day care, special education and living support. Information about cost input from families is limited. Uncertainty about accurate incidence of ASD means calculations are conservative. Study concludes that evidence of early interventions can have significant impact by reducing behavioural problems, which impact on the need for out-of-home care and supported employment services, with consequent cost implications.	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
		number of studies and surveys.			
104	Jarbrink, K., Fombonne, E., & Knapp, M. (2003). Measuring the parental, service and cost impacts of children with autistic spectrum disorder: A pilot study. Journal of Autism and Developmental Disorders, 33(4), 395-402.  OBSERVATIONAL STUDY – SURVEY Level of evidence: ~	Pilot study of a research instrument developed specifically to collect cost information for individuals with ASD. Provides an outline of the elements to be included and how to approach the collection of cost information related to informal care. A diary survey (14 days) was also kept by the 16 carer participants. Ethical approval also given for the study.	Questionnaire developed from the Client Service Receipt Inventory (1986), used in more than 200 evaluations of interventions related to mental health, learning and physical disability, old age and child and family problems.	Findings Tentative evidence points to considerable economic burden for parents and gives an indication of the associated costs of ASD.	Pilot acknowledges the following limitations:  no control group focus on children participants were active members of a parent organisation. Research instrument would need to be adapted for adults in paid work. Instrument is context-specific and would need adapting to different age groups, countries and cultures.
105	Loynes, F. (2001). The impact of autism. A report compiled for the All Party Parliamentary Group on Autism, from www.nas.org.uk  NON SYSTEMATIC REVIEW	A report compiled for the All Party Parliamentary Group on Autism, United Kingdom.	Evidence was gathered by a literature review, personal correspondence with expert professionals, parents and people with ASD.	Report includes a series of recommendations for future action and:  • demonstrates the far-reaching financial and social cost implications of ASD  • emphasises that preventative costs will save expensive crisis management  • recommends a few changes to	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	Level of evidence: x			national provision of services in the UK would impact positively on the quality of life for people with ASD, their families and carers.	
106	Hastings, R.P., Beck, A. (2004). Practitioner review: stress intervention for parents of children with intellectual disabilities. Journal of Child Psychology and Psychiatry and Allied Disciplines 45(8):1338-49.  NON SYSTEMATIC REVIEW  Level of evidence: ~	Parents of children with intellectual disabilities are at increased risk for stress and other mental health problems. The review considered the evidence base for psychological intervention to remediate stress.	Did not include a description of methodology to review literature search. Included a search from outside of the disability field. Authors noted that group interventions in published literature on parent stress often contain multiple components. A separate search was conducted for group interventions using CBT methods – authors found it difficult to isolate evidence for CBT and stress.	<ul> <li>Evidence suggests standard service models eg, respite, case management/keyworkers, probably help to reduce parental stress. Eg, respite, case management/key workers.</li> <li>A key worker case management model would probably lead to the most positive outcomes for parents.</li> <li>Strongest evidence for cognitive behavioural group interventions/stress in mothers and the value of parent-led support networks.</li> <li>Implementing any form of more structured intervention appears to have a positive impact over no support or receipt of standard services.</li> <li>Parent-to-parent model – where parents act as contacts for other parents in similar circumstances can be effective in reducing parental stress.</li> <li>Group interventions using CBT approach/techniques can be</li> </ul>	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				effective in reducing parental stress and improving mental health.  • More research is needed to enhance evidence base for alternative models, including culturally appropriate elements to the research, and how and when to involve other family members.  • More research and clinical development are needed to establish a firmer evidence base for stress interventions. Practical implications include the need for general parent training interventions and behavioural programmes for challenging behaviours.	
107	Attfield, E., Morgan, J. (2007). Living with ASD Guidance for Parents, Carers and Siblings: Sage Publications. EXPERT OPINION	Authors have professional interest and experience working with people with ASD and their families.	Expert opinion.	Provides an account of life with autism and guidance for parents, carers and siblings including positive strategies for daily living, getting educational needs met, working together and finding information, help and support.	Information, help and support – relates to services in the UK.
108	Bevan-Brown, J. (2004). <i>Māori</i> Perspectives of Autistic Spectrum	Semi-structured, face-to-face, group interviews with caregivers of Māori children with ASD. Participants were	Semi-structured interview covering the following topics:  • participant	Difficulties with diagnosis – identifying the condition in very young children, wait and see attitudes, long waiting lists,	No information is given as to how the data was analysed, or whether

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	Disorder. Report to the Ministry of Education. Wellington, NZ: Ministry of Education. QUALITATIVE STUDY  Level of Evidence: +	parents and whānau of 19 Māori children with a diagnosis of ASD or ASD tendencies (5 pre-schoolers, 9 primary school children, 5 secondary school students). In total 51 individuals were involved across 17 interview groups. Families were accessed by approaching every 15 <sup>th</sup> family from a list of Māori children with ASD which was compiled by paediatricians and Ministry of Education, Special Education staff. All participants lived in the North Island of New Zealand at the time of interviewing. Data is reported using a thematic approach with extensive quotes.	understanding of ASD in relation to their child  barriers faced barriers overcome helpful services helpful/successful teaching/learning/socialisation strategies accessibility issues cultural issues arising in assessment and diagnosis cultural issues arising in service provision cultural issues arising in education and evaluation what would have been helpful in the past? what would be helpful in the future? future dreams for your child.	disbelief of parents, existence of other conditions in the child, initial inaccurate diagnosis, delays caused by red tape, rural location.  Information needs – support for person visiting and explaining about diagnosis and about services and entitlements. Also need to know how to assist the child, the future implications. Support for transition to next part of education system.  Knowledge of ASD varied among parents. Parent organisations and the internet were used.  Impairments hindered child's participation in cultural events and culturally valued behaviours.  Parents played different roles – some wanted to be more involved in child's education.  Considerable variation in degree of support from whānau. Some experienced a lack of understanding of ASD.  Many experienced a wide range of helpful people and services.  Barriers experienced included – shortage of information,	reliability checks were performed on the themes identified. The data are, however, reported indicating the number of caregivers who commented on each aspect of a theme, and gives potentially valuable insights which are likely to generalise to other Māori caregivers.

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				services funding and qualified personnel; difficulty accessing services; organisational, procedural and system hassles; financial strain; personal and family stress; attitudes of professionals and the community; lack of knowledge about ASD among professionals.  • Education professionals should not make decisions about what is culturally appropriate for the children without consulting.	
109	Mahoney, G., Kaiser, A., Girolametto, L, MacDonald, L., Robinson, C. Safford, P., & Spiker, D. (1999). Parent education in early intervention: A call for a renewed focus. Topics in Early Childhood Special Education, 19, 131-40.  THEORETICAL PAPER  Level of Evidence: ~	Provides a history of, and rationale for, parent education as a component of early intervention. Discusses opportunities, challenges and suggests best practice principles in interventions using parent education.		<ul> <li>Important development in early intervention the shift to providing service in collaboration with families.</li> <li>Need to develop culturally sensitive and collaborative approaches adapted to the family and child's needs.</li> <li>To be effective intervention needs to be embedded in daily routines.</li> <li>Criticism identified about parent education; – the burden that home programming places on parents, the relationship between parents and professionals in parent education, the implicit blaming of parents, the role conflict for</li> </ul>	A tightly constructed literature review that appears to reach conclusions soundly based on the parent education literature reviewed.

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				parents, cultural bias of parent education.  Family-centred philosophy – involves parents as more active and equal partners.  One study showed that mothers' preferences were for parent education over other forms of family support.  Parents engaging in parent mediated early intervention should be a choice but it may not be the right choice for some parents at some times.  Parent education requires specific expertise in understanding adult learning.	
110	Evans, S., Di Ferdinando, G., Wood, C., Harrison, T., & Dunning, M. (June 2003). Early intervention system. Service guidelines. Children with autism spectrum disorders. In Department of Health and Senior Services (Ed.).  GUIDELINE  Level of evidence: ~	An early intervention autism task force convened by The Department of Health and Senior Services, to develop recommendations for the Service Guidelines, to assist service coordinators, providers and families in designing quality intervention for children with ASD. Shaped by recommendations from the early education task force, existing state policies and procedures of early intervention conclusions and recommendations made by the		<ul> <li>Recommendations</li> <li>Families' knowledge, beliefs, aspirations, values, culture and preferences for services must be recognised and used for planning and delivery of supports and services.</li> <li>Families and referral sources must understand the purpose of evaluation and assessment processes.</li> <li>Families must be assisted to access specific diagnostic information and relevant resources as early as possible.</li> </ul>	Some applications related to state regulations.

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
		National Research Council, Educating Children with Autism (2001), the Guidelines support the mission of early intervention, promote consistency in service delivery across the state of New Jersey and address the needs of children with ASD and their families.			
111	Diggle, T., McConachie, H. R., & Randle, V. R. L. (2004). Parent- mediated early intervention for young children with autism spectrum disorder. Oxford: The Cochrane Library.  SYSTEMATIC REVIEW Level of evidence: +	Review to determine if parent-mediated early intervention has been shown to be effective for children and parents in the treatment of children (1-6.11 years) with ASD.  Located over 15,000 articles; 2 studies met review criteria, neither contained a large number of participants and were not directly comparable.	Randomised or quasi-randomised studies were analysed. Data came from a range of psychological, educational and biomedical databases, search of bibliographies, reference lists of key articles, contact with field experts and hand search of key journals.	<ul> <li>Findings</li> <li>Better outcomes for children receiving intensive intervention involving parents but primarily delivered by professionals, than found for parent-mediated early intervention.</li> <li>No differences found for measures of parent and teacher perceptions of skills and behaviours.</li> <li>Recommended further research.</li> </ul>	The review had little to offer for practice implications; review based on two studies with small numbers of participants; both studies unable to be compared.
112	Bevan Brown, J. (2001). Evaluating special education services for learners from ethnically diverse groups: getting it right.	No methodology stated – expert opinion. Author does cite references but in a non systematic way.		Discussion of evaluation issues in special education services for Māori children in New Zealand. Examples of cross-cultural misunderstanding and miscommunication are described and strategies to avoid them	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	Journal of the Association for Persons with Severe Handicaps 26: 138- 147.  NON SYSTEMATIC REVIEW – EXPERT OPINION Level of evidence: x			discussed.	
113	Birkin, C., Anderson, A., Moore, D., & Seymour, F. (2003). NAS EarlyBird Programme uptake study; Report to the Ministry of Health. Auckland, NZ: University of Auckland.  RETROSPECTIVE QUESTIONNAIRE STUDY COMBINED WITH QUALITATIVE INTERVIEWS  Level of Evidence: ~	Comprises 2 studies. The first is a telephone survey of 77 New Zealand caregivers of children with ASD from one large urban centre, one small urban area and a rural area. Participants were accessed through Autism New Zealand, Needs Assessment Teams, and Health Services. Data is reported in the form of descriptive and comparative statistics, which were analysed according to the survey questions.  The second study uses faceto-face, semi-structured interviews with 7 participants (2 Māori, 4 Pasific Peoples and 1 Korean) key informants (parents and education	1) Telephone survey addressing the following questions: Who finds out about EarlyBird? What determines the decision to participate? Are there barriers to accessing the programme related to diagnosis?  2) Semi-structured interview addressing the question of whether there are particular barriers to participation in EarlyBird for New	Some parents identified some barriers to participating in Early-Bird – language barriers, difficulties in obtaining a diagnosis, difficulties in attending the programme through distance, childcare etc. they also identified the need for a more community-focused approach.	Non-response bias in telephone survey led the majority of respondents being Autism New Zealand members, and to under-representation of Māori and Pasific Peoples caregivers. No information is given as to how the qualitative data was analysed, or whether reliability checks were performed on the themes identified. Despite these weaknesses the report provides some useful

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
		workers) to investigate barriers to EarlyBird participation within these ethnic groups. Data is reported thematically for each ethnic group.	Zealand ethnic minority groups.		insights into uptake issues and barriers specific to programmes run in New Zealand conditions.
114	Anonymous. The sibling project. Retrieved from www.asdin.org.nz, 12 January 2005.  DESCRIPTION OF AN ONGOING SERVICE  Level of evidence: project not evaluated.	This project was established in 1999 within the Department of Psychological Medicine at the Women's and Children's Hospital in Adelaide to develop and coordinate services for families and, in particular, brothers and sisters of children with special needs (disability and chronic illness).			
115	Meyer, D., & Vadasy, P. (1996). Living with a brother or sister with special needs. A book for sibs. USA: University of Washington Press.  EXPERT OPINION	Book. Includes bibliographical references.		A small section on ASD. A resource for siblings, parents, teachers and other professionals.	Donald Meyer: Professional who works with families of people with special needs; Director of the Sibling Support project in Seattle. Patricia Vadasy is a research associate at Washington Research Institute and author of several publications

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
					on children with special needs.
116	Roeyers, H., & Mycke, K. (1995). Siblings of a child with autism, with mental retardation and with a normal development. Blackwell Science Ltd, 21(5), 305-319.  OBSERVATIONAL STUDY – QUALITATIVE  Level of evidence: ~	Examined factors that may influence the sibling relationships of children with and without a disabled sibling.  Included 60 siblings between 8-15 years.  Study used control groups: 20 had a sibling with autism; 20 had a sibling with intellectual disability and 20 had a non-disabled sibling.	Data was collected by questionnaire; Sibling Inventory of Behaviour Sibling Stress and Coping Inventory.	Findings Having a disabled sibling does not necessarily lead to a problematic sibling relationship. Longitudinal research needed to determine if positive relationships are sustained as children/siblings grow older. Knowledge of ASD was related to positive sibling relationships. Support groups may be a meaningful source of information and support.	
117	Rivers, J., & Stoneman, Z. (2003). Sibling relationships when a child has autism: Marital stress and support coping. Journal of Autism and Developmental Disorders, 33(4), 383-393.  OBSERVATIONAL STUDY – QUALITATIVE  Level of evidence: ~	Study of siblings relationships. 50 families who had a child with autism participated.	Data collected through self-report inventories and questionnaires.  The Sibling Inventory of Behaviour (modified 1987) and modified version of the Satisfaction with the Sibling Relationship Scale (1989) were used to assess the	<ul> <li>Findings</li> <li>Typically developing siblings expressed satisfaction with their sibling relationships.</li> <li>Parents were less positive.</li> <li>When marital stress was greater, the sibling relationship is compromised.</li> <li>Informal social support did not protect siblings from the negative effects of marital stress.</li> <li>No consistent evidence that heavy access of service systems positively supports</li> </ul>	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
			sibling relationship.	sibling.  • Evidence that interaction with the formal service system may sometimes compromise positive family functioning relationships.	
118	Pilowsky, T., Yirmiya, N., Doppelt, O., Gross-Tsur, V., & Shalev, R. (2004). Social and emotional adjustment of siblings of children with autism. <i>Journal of Child Psychology and Psychiatry</i> , 45(4), 855-865.  OBSERVATIONAL STUDY – QUALITATIVE  Level of evidence: ~	Comparison of social and emotional adjustment, behaviour problems, socialisation skills, and sibling relationships among 30 siblings of children with autism, 28 siblings of children with intellectual disability and 30 siblings of children with developmental language disorders. Siblings of children with ASD were screened out. Study involved siblings of children with autism only.	The Weinberger Adjustment Inventory; short version of the Vineland Adaptive Behaviour Scale (social domain) and the Child Behaviour Checklist.	<ul> <li>Findings</li> <li>Adjustment of siblings to children with autism is in sharp contrast to the severe social and emotional disabilities characteristic of autism and noteworthy considering the stress involved in having a sibling with autism.</li> <li>Research for the social and emotional adjustments of siblings of children with autism offer inconsistent results.</li> <li>Contradictory research may be owing to choice of comparison groups.</li> </ul>	
119	Harris, S. (1994). Siblings of children with autism. A guide for families. Bethesda: Woodbine House  EXPERT OPINION	Book.	Describes how information needs of siblings will change with age. Provides practical strategies, information and references.	A guide for families, to support siblings who live with a brother or sister with ASD. Also reported on the variable responses of research describing the impact of ASD on siblings.	Sandra Harris is a researcher and clinician who works with families with children diagnosed with ASD.

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
120	Glasberg, B. A. (2000). The development of siblings' understandings of understanding of autism spectrum disorders. Journal of Autism and Developmental Disorders, 30(2), 143-156.  OBSERVATIONAL STUDY – QUALITATIVE  Level of evidence: ~	Guidelines that offer information relevant for siblings at different ages. Interviews were conducted with 63 siblings who had a brother/sister with autism and related disorders, and parents.	An adapted interview method measures cognitive sophistication in thinking about illness (Bobace & Walsh 1979, 1980).	Findings  Parents accurately estimate their child's understanding of the definition of ASD but tend to overestimate their child's understanding of the disorder's impact.	
121	Tichon, J., & Yellowlees, P. (2003). Internet social support for children and adolescents. Journal of Telemedicine and Telecare, 9, 238-240.  CASE REPORT Level of evidence: ~	This case report studied on- line conversations of 58 participants aged from 7-17 years in Sibkids, an online support group for children who have a sibling with special needs.	On-line support messages sent over 3 consecutive months were thematically analysed.	Findings: Three main categories of social support were identified:	
122	Margetts, J.K., Le Couteur, A., Croom, S. (2006). Families in	The experiences of 6 grandparents of children diagnosed with ASD were	Qualitative research project using purposive	Three key themes emerged: parental bond towards grandchild and adult child; searching for	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	a state of flux: the experience of grandparents in autism spectrum disorder. Child: Care, Health and Development; 32(5):565-74.  QUALITATIVE STUDY  Level of evidence: ~	examined to help prioritise service user needs, establish a culture of participation and to help inform clinical assessment work. The work was Ethics approved.	sampling technique and semi- structured interviews. Interviews were transcribed and cross-checked for accuracy with participants, and data analysed and coded.  None of the literature searched to identify psychosocial effects on the family of an autistic child, addressed the role of grandparents (31 key papers). Google search included information sources for grandparents	meaning; holding the family together.  Further research advised to investigate therapeutic and costeffectiveness of involving grandparents as part of the assessment process. Random sampling would be appropriate.	
123	Worrall, J. (2003). Grandparents raising grandchildren. Ma nga kaumatua hei tautoko te tipurangi ake o nga mokopuna. Auckland, New	Handbook developed to support grandparents raising grandchildren in New Zealand.		<ul> <li>Provides practical ideas for:</li> <li>caring for self</li> <li>caring for children across the age range</li> <li>how to cope with the effects of abuse and neglect</li> <li>legal issues</li> </ul>	The handbook does not have a specific section on raising children with disability or ASD.

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	Zealand: Grandparents Raising Grandchildren Trust.  EXPERT OPINION			supports available from social and government agencies.  References provide a list for further reading, contact details for helping agencies and details for support groups and coordinators.	
124	Newport, J., Newport, M. (2007). Mozart and the whale. An unexpected love story. New South Wales: Allen and Unwin.	Expert opinion. Insights into the thoughts and feelings of 2 individuals who have AS.		An account of 2 adults with Asperger Syndrome who meet and get married. One is an expert with numbers and the other an artistic savant.	
125	Aston, M. C. (2001). The other half of Asperger Syndrome. London: National Autistic Society.  EXPERT OPINION	Book . A guide to living in an intimate relationship with a partner who has Asperger Syndrome. Information is drawn from research and the author's professional and personal experiences.	N/A	<ul> <li>Provides a guide to living with ASD.</li> <li>Provides basic facts about Asperger Syndrome.</li> <li>Provides international sources of help and information, further reading and references.</li> </ul>	Author is a couple's counsellor.
126	Anonymous. Aspar: support and advocacy for people raised by parents with an autistic spectrum disorder or Asperger Syndrome. Retrieved from	Website set up to offer support to the adult children of AS parent(s).			

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	www.aspar.klattu.co m.au 11 January 2005.				
	WEBSITE				
	Level of evidence: x				
127	Linehan, S. J. (2004). Parenting problems for parents with Asperger's Syndrome. Retrieved 11/01/2005, from http://www.aspires- relationships.com/arti cles parenting probl ems for parents wit h_as  EXPERT OPINION Level of evidence: x	Commentary is supported by references.		Explanation of how the cognitive profile of a person with ASD might affect parenting approach. Has implications for the children of parents who have ASD. Further research in this field encouraged.	Commentary for ASpar, a website offering support and advocacy for people raised by parents with ASD. Sheila Jennings Linehan is a family lawyer and mediator.
128	McCabe, P., McCabe, E., & McCabe, J. (2003). Living and loving with Asperger Syndrome. London: Jessica Kingsley.	Book. Information drawn from personal experiences that offer three different perspectives.		Relationships can adjust to accommodate the effects of living with someone who has Asperger Syndrome. Issues can be resolved.	Authors include Patrick McCabe (Asperger Syndrome), his wife Estelle and teenage son Jared.

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	EXPERT OPINION				
129	Roberts, J.M.A., & Prior, M. (2006). A review of the research to identify the most effective models of practice in early intervention for children with autism spectrum disorders. Australian Government Department of Health and Aging, Australia.  SYSTEMATIC REVIEW  Level of evidence: +	Systematic review used to inform an evidence-based Report. Research evidence was summarised, evidence determined to be sound/or otherwise and, where possible, suggestions made as to how the evidence might relate to programmes available in Australia for children with autism and their families.	Multiple database searches limited to publication dates 2003-2006 inclusive. Reference lists of retrieved documents were hand searched to identify additional publications.	The authors noted the considerable challenges to find research that meets scientific criteria. The authors also noted the 'flagrant perversion or disregard for evidence' in much of the research on ASD and lack of empirical evidence in the field of psychotherapy. Parents of children with autism play a critical role in supporting their children's learning; parents require emotional support, advice and training to work with their children; access to up-to-date and accurate information about treatment options and support services.  Information, support and training should be provided for the entire family unit. The needs of ethnic minorities, socio-economically disadvantaged families and those in rural settings require special consideration.  There is a need for more specific investigation on the effects of siblings. Siblings need information and support post diagnosis and	Report prepared for Australian Government.  Family-based interventions p73-78 were considered for the NZ ASD Guideline.

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				on-going support throughout their development.	
130	Faleafa, M. (2004). Pacific ASD Guidelines Fono Report. Ministry of Health, Ministry of Education.			Report of outcomes from a consultation fono held in NZ to understand issues related to Pacific peoples and ASD.	
	REPORT Level of evidence:				
	not evaluated.				
131	Huakau, G., Bray, A. (2000). 'Talking disabilities' from a Pacific Perspective. Dunedin: Donald Beasley Institute.			Report of 'talking disabilities' from a Pacific perspective.	
	REPORT				
	Level of evidence: not evaluated.				
132	Newsom, C., Hovanitz, C.A. (1997). Autistic disorder. In: Mash, E.J., Terdal, L.G., editors. Assessment of childhood disorders. 3rd ed.	Chapter on ASD includes discussion on assessment of families from the perspective of intervention to improve the function or wellbeing of other family members. Understanding of key factors influencing effectiveness of	Methods/tools/ inventories to assess parental stress were discussed.  Parent training identified as one of	Formal assessment of the effects of treatment on the family may be required to demonstrate treatment gains and to verify the absence of significant new difficulties.	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	New York: Guilford Press; Chapter 8, p 408-438. CHAPTER IN BOOK – EXPERT OPINION Level of evidence: x	parents as teachers should help identify parents who would profit from parent training, help identify barriers to accessing training and may increase maintenance of gains through parent training.	the most widely accepted intervention methods for ASD children.		
133	Mahoney, G., O'Sullivan, P., Dennebaum, J. (1990). A national study of mothers' perceptions of family- focused intervention. Journal of Early Intervention 14: 133- 146.  CROSS SECTIONAL STUDY – SURVEY  Level of evidence: ~	Participants were 503 mothers of birth to 6-year-old handicapped children who were enrolled in intervention programs throughout the United States. A systematic sampling procedure was used to ensure results were generalised. The aim of the study was to identify the types of family intervention services mothers were currently receiving and the type of services they would like to obtain.	Participants completed a Family-focused Intervention Scale.	The most common services were providing parents information about their child and helping parents and families become involved in the early intervention system. Resource assistance and personal family assistance were the least common services provided. Generally, the need for family services was greater than that currently being received.	Survey was geared towards families of handicapped children – only 5% were autistic.
134	Mahoney, G., Filer, J. (1996). How responsive is early intervention to the priorities and needs of families? Topics in Early Childhood Special Education	Objective was to examine the status of early intervention programs with regard to the manner in which they worked with parents and families 4 years after legislation was passed.	Questionnaire designed to determine parents' level of participation in early intervention and the types of family services they	Findings  • Early intervention programs provided significantly higher levels of family services related to child information, family instructional activities and systems engagement as compared to personal/family	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	16: 437-457.  QUALITATIVE SURVEY  Level of evidence: ~	Participants identified from early intervention programs of 5 southeastern states in the USA – 700 questionnaires were distributed, with a 60% response rate.	received, the extent to which the services were actually responsive to the parents' needs and to collect information about child and family characteristics that might affect participation in early intervention services.  Also used the Family-focused Intervention Scale and the Family Environment Scale.	<ul> <li>and resource assistance.</li> <li>Services were rated more favourably in home-based programs and centre-based programs with home-based components, than in programs with only centre-based services.</li> <li>The services that families reported receiving were positively correlated with their ratings of the desirability of services.</li> <li>Families' needs for services were significantly higher than the level of services that they reported currently receiving.</li> <li>The types of services families received depended, in part, on the location where they lived.</li> </ul>	
135	Willey, L.H. (2004). Aspie Land (as experienced by one of its citizens). Autism New Zealand National Conference paper, Christchurch 2004.  EXPERT OPINON Level of evidence: x	Expert opinion.		Discussion of Asperger's most pressing issues from the perspective of an insider.	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
136	United States Public Health Service. (2001). Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation. Report of the Surgeon General's Conference on Health Disparities and Mental Retardation. (No. 02NLM: WM 308 C645 2002). Washington D. C.  EVIDENCE-BASED GUIDELINE  Level of evidence: +			<ul> <li>Goals include:</li> <li>integrate health promotion into community environments of people with mental retardation</li> <li>increased knowledge and understanding of health and mental retardation, ensuring that knowledge is made practical and easy to use</li> <li>improve the quality of health care for people with mental retardation</li> <li>train heath care providers in the care of adults and children with mental retardation</li> <li>ensure that health care financing produces good outcomes for adults and children with mental retardation</li> <li>increase sources of heath care services for people with mental retardation, ensuring that heath care is easily accessible.</li> </ul>	
137	Lian, W. B., Ho, S. K. Y., Yeo, C. L., & Ho, L. Y. (2003). General practitioners' knowledge on childhood developmental and behavioural disorders. Singapore Medical Journal,	Pilot study of a knowledge survey. Subjects were 48 GPs based in Singapore.		Low scores for factual questions on ASD.  Some myths about ASD were believed.	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	44(8), 397-403.  OBSERVATIONAL STUDY – SURVEY  Level of evidence: ~				
138	Marshall, M. C. (2002). Asperger's Syndrome: implications for nursing practice. Issues in Mental Health Nursing, 23, 605-615.  NON SYSTEMATIC REVIEW  Level of evidence: x	Summary of literature. Search not described.		Nurses need training in AS.  Nursing should identify children with AS, and alter processes accordingly.	
139	Klein, U., & Nowak, A. J. (1998). Autistic disorder: a review for the pediatric dentist. American Academy of Pediatric Dentistry, 20(5), 312-317.  NON SYSTEMATIC REVIEW  Level of evidence: ~	Summary of ASD and review of dental literature since 1969. Search criteria not described.		Review of dental literature suggested that:  • people with ASD can have compromised oral hygiene and increased risk of caries and periodontitis  • some medications cause dental problems  • dentists should 'tell-show-do', use short and clear commands, and positive reinforcement	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				<ul> <li>no sedation method is more effective</li> <li>restraint to enable treatment and avoid more intrusive measures may be warranted after explanation and obtaining written consent</li> <li>organisational changes to the office and appointment scheduling may be necessary.</li> </ul>	
140	Backman, B., & Pilenro, C. (1999). Visual pedagogy in dentistry for children with autism. Journal of Dentistry for Children, 66(5), 325- 331.  OBSERVATIONAL STUDY (CONTROLLED)  Level of evidence: x	Trial of the use of a model of visual pedagogics for the introduction of dentistry. Subjects were 16 children with autism (15 boys and one girl, aged 3.3 to 6 years). Post-hoc control group were 16 children of the same age (unspecified) contacted through the National Society of Autism (Sweden) after 1.5 years of intervention for the experimental group.	Degree of cooperation with 9 dentistry tasks.  Number of visits required to achieve criteria for cooperation in each task.	Subjects were more cooperative than post-hoc control group over a range of dental procedures (however data difficult to analyse and report).	
141	Wittert, D. (2004). Autism and the Pervasive Developmental Disorders. Retrieved 25/11/04, 2004, from	Web-based opinion.		Advice for nurses dealing with children with autism in clinic and hospital settings includes:  • prepare the child with photographs that show what will occur	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	http://nsweb.nursings pectrum.com/ce/ce13 4.htm EXPERT OPINION Level of evidence: x			<ul> <li>get parents to bring a familiar toy or book</li> <li>choose words carefully</li> <li>be familiar with what calms the child in case of tantrum.</li> </ul>	
142	Isen, D. B. (2002, 2/8/02). Autism and Dentistry. Retrieved 25/11/04, 2004, from http://www.bbbautism.com/aso_009_wkshp.htm  EXPERT OPINION Level of evidence: x	Web-based presentation on dental hygiene for people with autism.		Presentation covers:	
143	Miyawaki, T., Kohjitani, A., Maeda, S., Egusa, M., Mori, T., Higuchi, H., et al. (2004). Intravenous sedation for dental patients with intellectual disability. Journal of Intellectual Disability Research,	Cohort retrospective study reviewing dental records of 73 patients with intellectual disabilities and 19 without. All aged between 20 and 29. All had undergone intravenous sedation.	Efficacy of sedation.  Medication dosage.  Wake-up times.	Intravenous sedation effective in all ID and non-ID patients.  Required dose of medication significantly higher for ID patients.  Wake-up times similar.	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	48(8), 764-768.  OBSERVATIONAL STUDY  Level of evidence: +				
144	Polimeni, M. A., Richdale, A. L., & Francis, A. J. P. (2005). A survey of sleep problems in autism, Asperger's disorder and typically developing children. Journal of Intellectual Disability Research, 49 (4), 260-268.  OBSERVATIONAL STUDY  Level of evidence: +	Cohort study of 53 children with autism (aged 2 - 16), 52 children with Asperger syndrome (aged 4 - 17), and 66 typically developing children (aged 2 - 11).	Sleep survey completed by parents.  Behavioural Evaluation of Disorders of Sleep (BEDS) completed by parents.	High prevalence of sleep problems in all groups, but significantly more problems reported in autism (73%) and Asperger Syndrome (73%) groups, than typically developing group (50%).	
145	Richdale, A. L. (1999). Sleep problems in autism: prevalence, cause and intervention. Developmental Medicine and Child Neurology, 41, 60-66.	Review of sleep problems in children. No information on search criteria.		Children with autism may suffer from sleep problems at higher rates than other children.  High rate of sleep problems in autism is independent of IQ level.  Problems with sleep onset and maintenance.	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
146	REVIEW Level of evidence: x	Cohort study of 20 adults with	Toronto Alexthymia	Little data on parasomnias.  Behavioural programmes and/or melatonin can be effective.	
	Tani, P., Lindberg, N., Joukamaa, M., Nieminen-von Wendt, T., von Wendt, L., Appelberg, B., et al. (2004). Asperger Syndrome, alexithymia and perception of sleep. Neuropsychobiology, 49, 64–70.  OBSERVATIONAL STUDY  Level of evidence: +	Cohort study of 20 adults with Asperger Syndrome and 10 adult controls.	Scale (TAS)  Basic Nordic Sleep Questionnaire (BNSQ)	Subjects with Asperger Syndrome achieved statistically significantly higher scores on the TAS than controls.  Subjects with Asperger Syndrome achieved statistically significantly higher scores on components of the BNSQ, indicating:  • difficulty falling asleep • longer subjective sleep latency during working days • general feeling of low sleep quality • excessive sleepiness after awakening and during day time • more frequent irresistible tendency to fall asleep during free time • need of longer sleep.	
147	Dalldorf, J. (2002, 1/1/04). An Introduction to the Medical Aspects of Autism. Retrieved 25/11/04, 2004, from http://www.teach.com/medinfo.htm	Web-based clinical opinion on medical conditions that could enhance developmental or behavioural problems.		Medical conditions listed are:     seizures     middle ear infections     dental disease     nutritional deficiencies     constipation     allergy     medications	Joanna Dalldorf is a Paediatric Consultant.

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	EXPERT OPINION  Level of evidence: x			sleep disturbances.	
148	Lochbaum, M. R., & Crews, D. J. (1995). Letter to the editor: Exercise prescription for autistic populations. Journal of Autism & Developmental Disorders, 25(3), 335-336.  EXPERT OPINION Level of evidence: x	Letter to editor drawing upon preliminary research findings with adolescents with ASD.		Notes that exercise has been recommended for managing stereotypic behaviours of people with ASD.  Recommends:  • monitor heart rate during exercise testing and training phases of an exercise treatment programme  • future research on anaerobic exercise with people with ASD needed.	
149	Robertson, S. (1997). How do young women with autism and Asperger Syndrome and their families prepare for and cope with menstruation? Unpublished Dissertation for Degree of Bachelor of Social Sciences (Human Services), Auckland College of	Unpublished dissertation for Degree of Bachelor of Social Sciences (Human Services).		Diagnosis of ASD allowed parents to better support the menstruation needs of their daughters.  Difficulties identified on medical advice, support and intervention.  Training for human services workers needed.  Resources not being utilised.  Young women with autism are vulnerable in intimate	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	Education, Auckland.			relationships.	
	EXPERT OPINION				
	Level of evidence: x				
150	Roberts, J. (2005). Book review: Healthcare for children on the autism spectrum. A guide to medical, nutritional and behavioral issues. Volkmar, F.R. & Wiesner, L.A. Bethesda, MD: Woodbine House, 2004. ISBN 0- 933149-97-2. Journal of Intellectual and Developmental Disability, 30(1), 63- 64.  EXPERT OPINION Level of evidence: x	Book review.		Medical, nutritional and behavioural issues in autism well covered.  Book recommended for parents and professionals.	
151	Wakefield, A.J., Murch, S.H., Anthony, A. et al. (1998). Ileal-	Investigation of 12 children who were referred to a paediatric gastroenterology unit with a history of normal	Gastroenterological , neurological and developmental assessment.	Onset of behavioural symptoms was associated by parents with the MMR vaccination in 8/12 children, with measles infection in	The authors have not proved that the relationship between autism

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	lymphoid-nodular hyperplasia, non-specific colitis and pervasive developmental disorder in children. Lancet 351: 637-641.  CASE SERIES  Level of evidence: x	development followed by loss of acquired skills, including language, together with diarrhoea and abdominal pain.		1 child and otitis media in another. All 12 children had intestinal abnormalities. Behavioural disorders included autism (9), disintegrative psychosis (1) and possible postviral or vaccinal encephalitis (2).	and MMR vaccine is causal.
152	Parker, S.K., Schwartz, B., Todd, J. et al. (2004). Thimerosal- containing vaccines and autistic spectrum disorder: a critical review of published original data. Pediatrics 114(3): 793-804.  SYSTEMATIC REVIEW Level of evidence: +	Systematic review of articles in the English language published between 1966 and 2004 that assessed the association between thimerosal-containing vaccines and ASD/NDDs or pharmacokinetics of ethylmercury in vaccines.		12 publications met the selection criteria, 10 epidemiological studies and 2 pharmacokinetic studies of ethylmercury. The epidemiological evidence did not support an association between thimerosal-containing vaccines and ASD (many studies were of poor quality). Pharmacokinetic studies suggest that the half-life of ethylmercury is significantly shorter when compared with methylmercury.	The epidemiological studies that supported the link had significant design flaws that invalidated their conclusions.  The conclusion of the authors about a lack of association is supported by the findings of the pharmacokinetic studies.
153	Stratton, K., Gable, A., Shetty, P. et al. (2004). <i>Immunisation</i> Safety Review: Measles-Mumps- Rubella Vaccine and	Thorough examination of all the evidence to date on the association between MMR vaccine and autism.		An assessment of the evidence regarding a hypothesised causal association between MMR vaccine and autism, an assessment of the broader significance for society of the	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	Autism. National Academy Press. BOOK			issues surrounding the MMR- autism hypothesis and the committee's conclusions and recommendations based on these assessments.	
	Level of evidence: +			doocoomento.	
154	Taylor, B., Millar, E., Lingam, R. et al. (2002). Measles, mumps and rubella vaccination and bowel problems or developmental regression in children with autism: population study. <i>BMJ</i> 324: 393-396.  CASE SERIES  Level of evidence: ~	Population study with case note review linked to independently recorded vaccine data.  Participants were 278 children with core autism and 195 children with atypical autism (identified from computerised disability registers and born between 1979 and 1998).		The proportion of children with developmental regression (25%) or bowel symptoms (17%) did not change significantly over the 20 years of the study (the vaccine was introduced halfway through). No significant difference was found in rates of bowel problems or regression in children who received the MMR vaccine before their parents became concerned compared with those who received the vaccine only after such concern and those who had not received the MMR vaccine. A possible association between nonspecific bowel problems and regression in children with autism was seen but was unrelated to the MMR vaccine.	
155	Honda, H., Shimizu, Y., Rutter, M. (2005). No effect of MMR withdrawal on the incidence of autism: a total population study. <i>Journal of</i>	A longitudinal examination of the cumulative incidence of ASD up to age 7 for children born from 1988 to 1992 and its relationship with vaccine frequency in Kohoku ward in Japan.		The MMR vaccination rate declined significantly in the birth cohorts of years 1988 to 1992 and no vaccinations were delivered in 1993 and thereafter. The cumulative incidence of ASD up to age 7 increased significantly in the	The authors concluded that MMR vaccination is most unlikely to be a main cause of ASD and its withdrawal cannot

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	Child Psychology and Psychiatry and Allied Disciplines 46(6): 572-579.  CASE SERIES  Level of evidence: ~			birth cohorts of years 1988 to 1996 and rose dramatically beginning with the birth cohort of 1993.	be expected to lead to a reduction in the incidence of ASD.
156	Ahearn, W.H. (2007). Is eliminating casein and gluten from a child's diet a viable treatment for autism? In Judd SJ (ed). Autism and Pervasive Developmental Disorders Sourcebook. First ed. Omnigraphics Inc.  BOOK CHAPTER – EXPERT OPINION  Level of evidence: x	Expert opinion.		A discussion of the issues to do with restricting the diet of a child with autism.	
157	Legge, B. (2002). Can't eat, won't eat: dietary difficulties and autistic spectrum disorders. Philadelphia: Jessica	Expert opinion.		Written by the parent of a child with Asperger Syndrome with severely restrictive eating preferences. The book is an attempt to reassure parents and suggest practical methods of	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	Kingsley Publishers.  BOOK – EXPERT OPINION			dealing with the problem. The author draws from her own experiences but also has consulted widely with other parents, children and professionals with a knowledge of dietary difficulties.	
158	Wheeler, M. Mealtime and children on the autism spectrum: beyond picky, fussy and fads. Accessed from: www.iidc.indiana.edu /irca/Medical/mealtim e.html 13 August 2007. WEBSITE – EXPERT	Expert opinion		Discussion and acknowledgement of the link between eating and feeding problems and ASD. Discussion includes medical assessments, behavioural problems, environmental problems and strategies for addressing eating and feeding problems.	
159	OPINION  National Advisory Committee on Health and Disability. (2003). To Have an 'Ordinary Life'. Community membership for adults with an intellectual disability. (No. ISBN 0478- 25239-X). Wellington.	Strategy based on systematic reviews of literature undertaken by Donald Beasley Institute (reviews accessed).		Recommendations were:  The systemic neglect of the health of adults with an intellectual disability be urgently addressed directing the Ministry of Health to ensure that:  • primary health care providers are aware of the health needs of adults with an intellectual disability and have:	The National Advisory Committee on Health and Disability is an independent committee appointed by, and reporting directly to, the New Zealand Minister of Health.

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				clearly developed policies for access to services         comprehensive health assessment tools for people with an intellectual disability         appropriate staff education programmes, including peer review processes         health promotion material produced that is directed towards and accessible by this population         prescribing practices for this population consistent with current New Zealand best practice guidelines.  Directing the Ministry of Health to ensure that service provider contracts include recognition and adequate funding, and that the disability support role includes assistance for people with an intellectual disability to regularly access health care.	
				Directing District Health Boards to examine access to their	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				secondary and tertiary services for people with an intellectual disability, identify barriers and take active steps to minimise or remove them, and utilise their Disability Services Advisory Committees to provide ongoing monitoring of this.	
160	Jansen, D. E. M. C., Krol, B., Groothof, J. W., & Post, D. (2004). People with intellectual disability and their health problems: a review of comparative studies. Journal of Intellectual Disability Research, 48(2), 93 - 102. SYSTEMATIC REVIEW Level of evidence: +	Systematic review of international literature published between 1995 and 2002. Electronic search of Medline, Embase and Current Contents of comparative research using a control group of people without an intellectual disability.		Health care needs in people with an intellectual disability frequently not recognised, and therefore not met.  Issues identified included:  • communication difficulties  • problems obtaining patient histories  • difficulties in problem determination  • GP lack of skills, knowledge, training and experience.  Changes needed:  • training in providing health care to people with an intellectual disability  • GP awareness of specific problems of this population.	
161	Ziviani, J., Lennox, N., Allison, H., Lyons, M., & Del Mar, C. (2004). Meeting in	Qualitative study involving 5 GPs, 3 people with intellectual disability, 7 carers and 2 advocates.	Interview.	GPs and people with ID were concerned about communication difficulties.	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	the middle: improving communication in primary health care consultations with people with an intellectual disability. Journal of Intellectual and Developmental Disability, 29(3), 211-225.  OBSERVATIONAL STUDY  Level of evidence: +			Carers and advocates indicated insufficient skills and knowledge to provide the level of assistance required in the consultation.	
162	Dawson, G., & Watling, R. (2000). Interventions to facilitate auditory, visual, and motor integration in autism: A review of the evidence. Journal of Autism and Developmental Disorders, 30(5), 415-421.  REVIEW  Level of Evidence: +	Review of evidence regarding prevalence of sensory motor abnormalities in autism; review of effectiveness of 3 interventions – sensory integration, traditional integration therapy and auditory integration therapy, to address sensory motor abnormalities.	Review of evidence looked at:  • prevalence of sensory processing abnormalities in autism  • prevalence of fine and gross motor impairments  • types of motor impairments  • effectiveness of sensory integration therapy	<ul> <li>Prevalence of sensory processing and motor abnormalities in ASD is high.</li> <li>Literature supports view that sensory processing abnormalities may be important to address in therapeutic interventions to reduce rigidity and stereotyped behaviours.</li> <li>The review found little systemic, controlled research for sensory integration.</li> <li>No empirical studies of traditional therapy were found.</li> <li>Identified 4 objective studies for sensory integration but these were small scale and therefore no recommendations could be</li> </ul>	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
			National survey (Watling, Deitz, Kanny, & McLaughlin, 1999) to identify common components of intervention programmes for children with autism.	made. • 5 studies of Auditory Integration Training – existing empirical evidence provides no, or at best inconclusive, support for use of this intervention.	
163	Donnellan, A., & Leary, M. (1995). Movement differences and diversity in autism/mental retardation. Appreciating and accommodating people with communication and behaviour challenges. Pacific Beach, CA: DRI Press.  NON SYSTEMATIC REVIEW – BOOK Level of evidence: x	Book. Expert opinion that explores established paradigms and theory about the abilities of people diagnosed with ASD and intellectual disability. Reviews studies of movement disturbance and difference. The authors suggest alternative paradigms and recommend fresh approaches to skill acquisition. A postscript chapter provides commentary on facilitated communication (FC).	Non systematic review of the literature.	Effective teaching strategies identified include:  • discrete trial format  • accommodations — personalised strategies that assist in temporarily overcoming differences in movement (rhythm, emotional, visual, verbal, tactile, use of object, smell, cognitive, kinetic)  • functional ABC analysis.  Guidelines for reviewing the validity of FC are recommended.	Dr Donnellan is a member of the Professional Advisory Panel of the Autism Society of America and the Autism National Committee. Martha Leary is a Speech Pathologist with 30 years of experience working with people with ASD.
164	Birch, J. (2005).			Personal experiences of transport	Personal

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	Personal communication with author.  EXPERT OPINION  Level of Evidence: x			issues; support needs relating to this issue; implications for cost and impact on community participation, social, work etc.	communication to the BPG writer.
165	Jordan, R. (1996, 27/3/96). Educational implications of autism and visual impairment. Paper presented at the Autism and Visual Impairment Conference, Edinburgh.  EXPERT OPINION  Level of evidence: x	Web-published conference paper on the educational implications of the co-occurrence of blindness and autism.		Blindness and autism can coexist.  Teachers of the visually impaired have many skills, which should make them effective teachers of children with autism.  Similarities in behavioural characteristics of blindness and autism include:  • room hugging  • spinning themselves and objects  • self-stimulation  • echolalia and reversal of pronouns.  Problems of dual disability include:  • difficulties in attending to auditory information  • teachers needing to adapt resources from both fields.	
166	Carvill, S. (2001). Sensory	Systematic review. Electronic search using keywords		Studies that addressed the relationship of blindness in autism	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	impairments, intellectual disability and psychiatry. Journal of Intellectual Disability Research, 45(6), 467-483.  SYSTEMATIC REVIEW  Level of evidence: +	(mental retardation, sensory impairment, deaf, blind, deaf-blind, mental illness, psychiatry) of Medline, Embase and Psych-lit. Manual search of journals. Relevant references in papers cited included.		have varied in their methodology from subjective diagnoses with no formal use of criteria, to others that have employed diagnostic tools and DSM criteria.  Consistent finding that autistic-like symptoms are fairly common in blind children.  Some blind children can develop a complete picture of autism.  Many authors suggest that appropriate support for blind children could lessen the severity of the autistic symptoms.  Fewer studies addressing autism and hearing impairment.  No studies looking specifically at autism in those who are deafblind.	
167	Hobson, R. P., Lee, A., & Brown, R. (1999). Autism and congenital blindness. Journal of Autism and Developmental Disorders, 29(1), 45- 56.	Study of diagnostic accuracy. Subjects were 9 congenitally blind children with an autistic-like syndrome (aged 5 - 8 years), and 9 sighted autistic children (matched on age and verbal mental age).	<ul> <li>Childhood         Autism Rating         Scale.</li> <li>Behaviour         Checklist for         Disordered         Preschoolers.</li> <li>Play Items for         Disordered</li> </ul>	No statistically significant difference between groups on any measure.	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	OBSERVATIONAL STUDY Level of evidence: +		Preschoolers.  • DSM-III-R.		
168	Pawletco, T. (2002). Autism and visual Impairment. Focal Points, 1(2).  EXPERT OPINION  Level of evidence: x	Information and advice for parents of children with visual impairment and autism.		Children with autism can be visually impaired as well.  Strategies useful for dual diagnosed children differ from those for children who are only visually impaired.  Controversial issues include:  • behavioural symptoms of dual diagnosed children being treated in isolation  • behaviours commonly seen in visual impairment being viewed as emotional or behavioural problems in dually diagnosed children, or indications of impaired mother-child attachment.	
169	Pawletco, T., & Rocissano, L. (2000, 17/1/03). Autism in the visually impaired child. Retrieved 25/11/04, 2004, from http://www.tsbvi.edu/ Education/vmi/autism	Web-based information for parents of autistic, visually impaired children.		Addresses issues in diagnosis, and expression and autistic symptoms in visually impaired children.	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	<u>-vi.htm</u>				
	EXPERT OPINION				
	Level of evidence: x				
170	Creedon, M. P. (1989). Autism and deafness: A psychologist's perspective. Retrieved 25/11/04, 2004, from http://www.boystown hospital.org/parents/i nfo/genetics/austism. asp  EXPERT OPINION Level of evidence: x	Clinical account of teaching sign to a 6-year-old hearing impaired and autistic boy.		No data.	
171	Roper, L., Arnold, P., & Monteiro, B. (2003). Co- occurrence of autism and deafness. Autism, 7(3), 245- 253. OBSERVATIONAL STUDY (CROSS- SECTIONAL) Level of evidence: +	Study of diagnostic accuracy involving 13 deaf people (aged 15 - 24) with autism and 2 matched control groups (12 hearing autistic and 15 deaf intellectually disabled).	Autism Screening Instrument.	No significant differences between deaf autistic and hearing autistic groups.  Deaf autistic group had been diagnosed with autism at a significantly later age than the hearing autistic group.	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
172	The Children's Hospital of Philadelphia. (2004, 3/1/05). Raising Deaf Kids: A World of Information About Children with Hearing Loss: Autism. Retrieved 29/8/05, 2005, from http://www.raisingdea fkids.org/special/autis m/  EXPERT OPINION Level of evidence: x	Web-based information on autism in deaf babies and children.		Includes possible signs of autism and Asperger Syndrome in deaf babies and children, and sources of help.	
173	Rosenhall, U., Nordin, V., Sandstrom, M., Ahlsen, G., & Gillberg, C. (1999). Autism and hearing loss. Journal of Autism and Developmental Disorders, 29(5), 349-357.  OBSERVATIONAL STUDY	Cohort study of 199 children and adolescents with autistic disorder (153 boys, 46 girls).	Audiological evaluation.	Mild to moderate hearing loss diagnosed in 7.9% of subjects.  Unilateral hearing loss in 1.6% of subjects.  Pronounced to profound bilateral hearing loss or deafness in 3.5% of subjects.  Hyperacusis affected 18% of the autistic group, and 0% of the matched comparison group.  Otitis media (23.5%) and related	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	Level of evidence: +			conductive hearing loss (18.3%) increased in autistic disorder.	
174	Grandin, T. (2004). My experiences with visual thinking sensory problems and communication difficulties. <i>NZASD Digest</i> Number 850. Retrieved 1/11, 2004 EXPERT OPINION Level of Evidence: x	Article retrieved from the internet. Covers sensory processing difficulties and visual thinking. Includes personal experiences and compares those to common experiences of other people's (ASD) experiences.		Sensory processing problems may explain some autistic behaviours, and differences in cognitive processes may explain others. Provides observations for educational strategies.	Author (adult with ASD) who describes her experiences with autism.
175	Baranek, G. T. (2002). Efficacy of sensory and motor interventions for children with autism. Journal of Autism & Developmental Disorders, 32(5), 397-422.  SYSTEMATIC REVIEW  Level of Evidence: +	Summary of empirical literature with respect to sensory and motor development/abnormalities in children with autism and 2) evaluation of the scientific basis of sensory and motor interventions and 3) description of implications for future research.  Searches conducted using MEDLINE, CINAHL & PSYCINFO databases, specific to children with ASD.  Manual searches made of key references from articles.	Searches confined to studies relating to young children with ASD.	<ul> <li>Assessment and treatment should be carried out by therapists with appropriate experience in ASD.</li> <li>Efficacy of sensory and motor interventions not objectively demonstrated by the research/data and need further investigation.</li> <li>The summary notes that empirical evidence converges to confirm existence of sensory and motor difficulties for many children with autism.</li> <li>Motor skill concerns have substantial implications for individualised educational interventions.</li> </ul>	The study made a number of recommendations for education and practice. Literature studied was limited and suffered from a variety of methodological limitations. Much of the evidence comes from parent observations (please note age restriction of literature studied).

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
176	Dunn, W., Myles, B. S., & Orr, S. (2002). Sensory processing issues associated with Asperger syndrome: A preliminary investigation. American Journal of Occupational Therapy, 56, 97-102.  OBSERVATIONAL STUDY  Level of Evidence: ~	Study to identify the sensory processing patterns of children with Asperger Syndrome. Used a group comparison design.  Researchers compared the performance of 42 children with Asperger Syndrome (random sample) and 42 children without disabilities on section and factor scores of the Sensory Profile.	Sensory Profile is a standardised parent reporting measure of sensory processing, 125 item questionnaire.	<ul> <li>Children with Asperger         Syndrome were significantly         different from their peer group         without disabilities on 22 of 23         items.</li> <li>Both groups performed the         same on modulation of visual         input affecting emotional         responses and activity level.</li> <li>Finding suggests sensory         processing status in diagnostic         criteria might be warranted.</li> </ul>	Not reviewed in Baranek (2002).
177	Ontario Adult Autism Research and Support Network. Special forms of occupational therapy. Retrieved 23/11/, 2004, from http://www.ont- autism.uoguelph.ca/s p.shtml  EXPERT OPINION Level of Evidence: x	Website describing special forms of occupational therapy. Covers:  • sensory integration therapy  • art therapy  • music therapy  • animal-related therapy  • horticulture as therapy  • qualitative description.		Special forms of occupational therapy are used to help people with ASD to overcome their isolation progress developmentally and find ways of coping, and gain a sense of self and relatedness.	
178	Whitaker, P. (2002).	Paper describes a local	Significant	Findings:	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	Supporting families of preschool children with autism. <i>Autism</i> , 6(4), 411-426.  OBSERVATIONAL STUDY – QUALITATIVE  Level of evidence: ~	education project to provide support to families of preschool children with ASD. Reviewed:  • experiences of diagnosis; Earlybird programme; support worker's role; parental application of knowledge and skills (theory into practice) and support to do this  • support and care services.	dissatisfaction expressed by parents of children with ASD was followed up in a detailed postal questionnaire designed to identify specific areas of concern and need.	<ul> <li>the needs of parents of children with ASD are especially acute, particularly in the period after diagnosis and needs are first identified.</li> <li>the need for information and knowledge needs to be backed up with practical strategies to promote development and prevent management difficulties.</li> <li>support worker role provides a significant measure of support to families.</li> </ul>	
179	Weiss, M. J. (2002). Hardiness and social support as predictors of stress in mothers of typical children, children with autism, and children with mental retardation.  Autism, 6(1), 115-130.  OBSERVATIONAL STUDY— QUALITATIVE  Level of evidence: ~	Study assessed the effects of social support and hardiness on the level of stress in mothers of typical children and children with developmental disabilities.  120 participants: 40 mothers of children with autism, 40 mothers with children with intellectual disability and 40 mothers of typically developing children.	<ul> <li>Interpersonal Support Evaluation List (ISEL: Cohen and Hoberman, 1983).</li> <li>Functional social support measure (Ferrari, 1982).</li> <li>Informal support (Kimmel and Van der Veen, 1974.</li> <li>Locke and Wallace, 1959).</li> <li>Formal supports (Gill, 1988).</li> <li>Hardiness Test</li> </ul>	<ul> <li>Findings:</li> <li>parents of children with autism experience more negative effects of stress than parents of children with intellectual disability or parents of typically developing children.</li> <li>coping appears boosted by: esteem-boosting friendship, perceived social support from spouse.</li> <li>perceived availability of social support more important than actual support.</li> <li>coping boosted by perceptions of control and self-efficacy and a general self of purpose.</li> <li>Effective strategies included</li> </ul>	<ul> <li>Study limited to middle class families with 2 parents at home.</li> <li>Did not address impact of paternal or grandparent support.</li> <li>Absence of IQ data for children with autism who had an intellectual disability.</li> </ul>

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
			(Maddi, 1986; Maddi et al, 1979);.  Beck Depression Inventory (Beck, 1978).  Anxiety related symptoms (Caplan et al, 1975).  Stress-related somatic symptoms (Caplan et al, 1975).  Parental burnout (Maslach and Jackson, 1981).	teaching families advocacy skills, challenging pessimistic assumptions and more effective parent child interactions skills.	
180	Dunlap, G., & Fox, L. (1999). Supporting families of young children with autism. <i>Infants and Young Children,</i> 12(2), 48-54.  EXPERT OPINION  Level of evidence: x	Expert opinion.		Authors contend that effective family-centred support should result in improved longitudinal outcomes for the child and family. Family-centred support should:  • enhance family competence and confidence  • address support from a lifestyle perspective  • arrange for stability and continuity in support relationships.	Not ASD-specific. Authors are professors for child and families studies, applied research and educational support at local, state (Florida) and national levels.

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
181	Reid, S. (1999). The assessment of the child with autism: A family perspective. Clinical Child Psychology and Psychiatry, 4(1), 63-78.  EXPERT OPINION  Level of Evidence: x	Article describes the psychodynamic developmentally-informed approach to the assessment of children with autism.  Model is based on practice, research and professional observation, and appears not to have been subjected to peer or critical review.		<ul> <li>The approach pays attention to the impact on the family of living with a person with autism and recognises the resulting stresses and implications for the mental health of the family.</li> <li>The model provides an approach to assess needs and resources and supports the family to manage the range of supports and resources available to them.</li> </ul>	Approach was developed by the author under the auspices of the Tavistock Autism Research Workshop. Author is a Consultant Child and Adolescent Psychotherapist and Senior Tutor in Child Psychotherapy at the Tavistock Clinic.
182	Nucleus Group Report. (June 2002). The nucleus group report. Review current responses to meeting service needs of people with a disability and the effectiveness of strategies to support families. Australia.  SYSTEMATIC REVIEW Level of evidence: +	Research project aimed to identify service responses that could better meet the needs of disabled people and their families, to prevent or defer full-time residential care and support, and maintain natural family supports and the family unit; evaluate selected approaches to determine costs effectiveness of service responses against current models.	Review of published research; government reports and evaluations (Australia and overseas); descriptions of emerging promising practices in Australia and overseas; comprehensive literature review conducted by LaTrobe University (Cooper et al 2001).	Significant number of key findings were highlighted for:     service coordination     family support     independent living.	Recommendations inclusive of current service provision and government strategies and programmes in Australia.

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
183	Hecimovic, A., Powell, T. H., & Christensen, L. (1999). Supporting families in meeting their needs. In Zager, D. B (Ed.). Autism: Identification, education and treatment (2nd ed), (pp. 261-99). Mawah, NJ: Lawrence Erlbaum.  BOOK CHAPTER Level of Evidence: ~	Gives an introduction to the rationale and issues to be considered in planning family-focused services for ASD.		Professionals can play a useful role in supporting parents to enter support networks.	Tends to be overly reductionist in some places, and does not always clearly indicate when references refer specifically to autism or when they are from the general disability literature. Despite these problems does a good job of integrating current knowledge and theories to give a useful overview of a little analysed topic in ASD.
184	Dowling, M., & Dolan, L. (2001). Families with children with disabilities – inequalities and the social model. Disability and Society, 16(1), 21-35.  OBSERVATIONAL STUDY – QUALITATIVE	Qualitative study of way in which disabled people and their families suffer from unequal opportunities and social outcomes (social model of disability).  Research used a networking approach to canvass the opinions of 38 carers and service users and providers of respite care services,	Indepth qualitative interviews. The quality of family life was examined as well as the experience of unequal opportunities and outcomes in work, leisure, finance and quality of life.	Recommendations New practices and policies are suggested including:  • more extensive use advocated for the social model of disability in the application of welfare policies  • joint funding requiring interagency collaboration and the involvement of disabled people and their families in planning and implementation of service provision	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	Level of evidence: ~			education, training and public information so that communities are more accepting of disabled people and their families.	
185	Health Funding Authority (2000). Guidelines for needs assessment and service coordination agencies working with people with autism and their families/whānau. New Zealand: Health Funding Authority.  REPORT Level of evidence: x			Government report describing guidelines for needs assessment and service coordination agencies.	

## **EVIDENCE TABLES FOR PART 3: EDUCATION FOR LEARNERS WITH ASD**

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
186	Hurth, J., Shaw, E., Izeman, S. G., Whaley, K., & Rogers, S. (1999). Areas of agreement about effective practices among programs serving young children with Autism Spectrum Disorders. Infants and Young Children, 12, 17-26.  OBSERVATIONAL STUDY – SURVEY WITH QUESTIONNAIRE  Level of Evidence: ~	A study of validated, national programmes for ASD available in the USA to identify therapeutic commonalities. Eight representatives from 7 programmes were included. Representatives were asked to independently identify all the core elements of their programmes. Results were compiled and programme representatives then asked to rate the importance of each element on a scale of 1-5 and areas of agreement identified. The resulting core elements then went out in survey form to a larger group of 25 national programmes to gauge the level of agreement among the wider group; 19 responses were received.	A survey using a 1-5 scale response in which 1 represented 'not important to our programme', and 5 'an integral part of our programme'.	Details areas of agreement of effective programmes.  Areas of agreement: (1) Earliest possible start to intervention – some starting before diagnosis. (2) Systematic planful teaching – carefully planned, conceptual base, goal oriented and carefully assessed. (3) Specialised curriculum – attending to elements of the environment, imitating others, language comprehension and use, play and interacting socially with others. (4) Intensity of engagement, and amount of time child attending to and actively participating in the social and non-social environment. Programmes reported from 15 to 80 hours of active participation. (5) Individualise services for families – roles, need for support, priorities and resources considered. Also preference for setting considered. Involvement may include decision-making and collaboration and information training, and support for daily	Although a small sample group (N = 19), this appears to be a well thought out study and its conclusions bear out results found by other reviews of programmes.

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				living.  Areas of some agreement: (1) Structured environment – physical and instructional. (2) Elicit, facilitate or support certain skill acquisition etc. (3) Individualise services – meet needs strengths and interests. (4) Interventions in settings with typical children or in natural environments. (5) Developmentally appropriate practices – guided by information about child development and learning.	
187	Prizant, B. M., & Rubin, E. (1999). Contemporary issues in interventions for Autism Spectrum Disorders: A commentary. Journal of the Association for Persons with Severe Handicaps, 24, 199-208.  NON SYSTEMATIC REVIEW  Level of Evidence: ~	Outlines research evidence concluding that there is little evidence that any one approach is more effective than others in ASD intervention. Examines tenets of best practice, and the contributions and limitations of various approaches. Concludes by suggesting comprehensive assessment and outcome measures to determine appropriate intervention for a given individual.		<ul> <li>Recommendations</li> <li>Intervention approaches should demonstrate a logical consistency between long-term goals and teaching protocols</li> <li>Should address the core characteristics of ASD</li> <li>Better outcomes associated with earlier and more intensive interventions. No consensus on how the intensity of treatment is to be defined and whether the number of hours is the most crucial variable</li> <li>Approaches should be individualised to child's current developmental level and profile</li> </ul>	An overview of some of the difficulties involved in ascertaining efficacy in ASD interventions, and of current knowledge of best practice.

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				<ul> <li>of strengths and weaknesses</li> <li>Approaches should take into account current knowledge of child development.</li> <li>Research has supported effectiveness of a range of approaches.</li> <li>No evidence exists that any one approach is more effective than any other. No one approach is effective for all children. Available research suffers from methodological shortcomings.</li> <li>The evidence for intervention approaches should be derived from a number of sources; theories eg, developmental, learning theory, clinical and educational practice data, cumulative knowledge of best practice, social values and empirical data from experimental research.</li> <li>Findings</li> <li>Studies have focused on child variables and outcomes and ignored family variables.</li> <li>Much overlap between approaches.</li> <li>Fidelity of treatment has not often been measured.</li> </ul>	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				Studies not looked at variables outside of intervention package.	
188	Simpson, R. (1999). Early intervention with children with autism: the search for best practices. Journal of the Association of Persons with Severe Handicaps, 24, 218- 221.  EXPERT OPINION - THEORETICAL PAPER, INVITED COMMENTARY  Level of evidence: ~	An invited commentary to a special issue of the Journal focusing on early intervention for children with ASD. It is noted that a number of options may be used to benefit individual students with autism.		<ul> <li>Early intervention results in improved outcomes across the lifespan.</li> <li>Supports Koegel: should target central areas rather than narrowly defined unitary behaviours, eg, within stimulus prompting, child choice – natural reinforcers, selfmanagement strategies – selfselection and administration of reinforcers, training children to initiate questions – spontaneous self-initiations are an important target.</li> <li>McGee: incidental teaching of widespread applications – it is neither unsystematic nor unstructured. Good strategy to encourage generalisation.</li> <li>ABA can be used to teach functional skills.</li> <li>Koegel: quality of intervention as least as important as the duration.</li> <li>Supports Koegel: best practice not in isolated settings away from other children.</li> <li>ABA can occur in many</li> </ul>	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				settings including inclusive and community settings.  Koegal et al. – importance of social validity to treatment targets ie, pivotal responses.  ABA is not a synonym for a one-to-one discrete trial.  ABA and discrete trial training one of the most controversial – because of outcome claims, exclusivity, intervention personnel.  Serious doubt about claims of cure  Highly unlikely there will be either a cure or a single method to meet the needs of children with ASD.  Most effective practices those which incorporate a variety of best practices and include careful evaluation.  Need for establishing decision-making guidelines for determining which interventions are best suited for which students.	
189	Woods, J. J., & Wetherby, A. M. (2003). Early identification of and intervention for infants and toddlers	Reviews the literature on early identification and intervention for ASD. Summarises the findings of the National Research Council (2001) and makes recommendations.		Recommendations  • Evidence that children who participate in intensive intervention beginning by 3 years of age have a better outcome than those who begin	A document that draws quite heavily on the NRC report, but in which the issues for very young children are

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	who are at risk for Autism Spectrum Disorder. Language, Speech, and Hearing Services in Schools 34:180-93.  NON SYSTEMATIC REVIEW  Level of Evidence: ~			<ul> <li>after 5 years.</li> <li>Systematic teaching of communication with the following common ingredients: initiated by child, focus on child interests, embedded in natural environment, use natural reinforcers.</li> <li>Ongoing training and support for staff.</li> <li>Focus on social interaction, play, communication and generalisation.</li> <li>Predictability important for learning new skills and managing behaviour.</li> <li>Predictable routines support interactions between adults and children.</li> <li>Support for modern ABA approaches eg, Pivotal Skills training, Incidental teaching, Natural Language Paradigm.</li> <li>Optimal intensity is as yet not determined.</li> <li>More time in active, positive engagement results in better outcomes.</li> <li>Relationship of mutual respect, willingness to listen and learn, ask and answer questions, problem-solve individualised solutions, seek additional</li> </ul>	outlined and examined.

resources when necessary for	
each child and family.  Interventions based on family's priorities, concerns and interests.  Includes home and community settings that regular children move in. (It does not include segregated settings, clinics, hospitals etc).  Children in natural settings must have adequate support.  Learn functional and meaningful skills.  Finding ways of embedding in natural environments: environmental arrangement, natural reinforcers, time delay, contingent imitation ie, an adult imitating the child within their field of vision.  Little evidence to support weekly therapy sessions.  Support the effectiveness of a range of early intervention using a range of behavioural and naturalistic approaches.  Discrete trial result in improvements in IQ and some communication domains. Limitations of lack of spontaneity and generalisation.  Consistent and ongoing	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				communication between team members.	
190	Bryson, S; Rogers, S; Fombonne, E (2003) Autism spectrum disorders: Early detection, intervention, education and psychopharmacological management.  Canadian Journal of Psychiatry 48 (8) 506-516  NON SYSTEMATIC REVIEW  Level of evidence: ~	Reviews literature addressing 4 issues relating to children with autism and ASD: • Early detection • Intervention • Education • Psychopharmacological management.		Conclusions from the review:  The early detection of autism is limited by the lack of earlyscreening instruments that are sensitive as well as specific to autism (ASD).  The demonstrated effectiveness of early intervention for children with autism (ASD) warrants its widespread practice. However many questions remain:  what are the critical therapeutic components?  for whom?  for what domains of development  for what level of intensity and duration  Effective interventions all target specific skills and are carefully planned, individualised and monitored regardless of orientation.  Including the child with autism in regular classrooms presents challenges including the large number of teachers who need to be trained in evidence-based	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				teaching and behaviour management techniques, and for greater attention to the emotional and social well-being of the child with ASD.  Psychotropic drugs should be used judiciously in the treatment of children with autism (ASD).	
191	Fletcher-Campbell, F. (2003). Review of the research literature on educational interventions for pupils with Autistic Spectrum Disorders. Slough, UK: National Foundation for Educational Research.  NONSYSTEMATIC REVIEW  Level of Evidence: x	Reviews literature on educational interventions for children with ASD.		Recommendations  Those working with students need to be familiar with a variety of interventions.  Progress and parent satisfaction should be related to rhe level of expertise rather than specific placement.  El can have significant positive benefits.  Predictable teaching environments, visual clues, one to work, generalisation of skills.  Functional approach to problem-solving.  Carefully planned transitions from EC to school.  Provide a clear structure and set routine.  Use clear and unambiguous language.  Address the child individually at all times.	Does not indicate how the literature reviewed was chosen (ie, comprehensive database search, selected journals or dates), or give details about the studies reviewed. Misses some major contributors to ASD education literature (eg, Koegel, Dunlap). Conclusions do not appear to adequately sum up or reflect the literature reviewed.

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				<ul> <li>Provide warning of change of routine or activity.</li> <li>Recognise change in behaviour may reflect anxiety or stress.</li> <li>Protect the child from teasing and peers with understanding of disability.</li> <li>Use clear simple requests or instructions.</li> <li>Use visual aids.</li> <li>Allow access to obsessive behaviour as a reward for positive efforts.</li> <li>Curriculum should be focussed on understanding and use of language play and social interaction.</li> <li>Intense programmes at El should be for at least 20 hours per week at El</li> <li>Parental involvement.</li> <li>Prompt coordinated assessment of needs.</li> <li>Importance of key worker for effective parental support.</li> <li>Some evidence of benefits of early intervention within integrated settings. Need access to normally developing peers.</li> </ul>	
				Comments on reviewed research:  • Education-specific intervention	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				<ul> <li>literature limited.</li> <li>Most studies small scale.</li> <li>Many have methodological weaknesses.</li> <li>No cogent research evidence that any one intervention is more favourable across the cohort of students with ASD.</li> <li>No evidence that any intervention will cure autism.</li> </ul>	
192	Prizant, B., & Wetherby, A. (1998). Understanding the continuum of discrete-trial traditional behavioral to social-pragmatic developmental approaches in communication enhancement for young children with autism/PDD. Seminars in Speech and Language, 19, 329-53.  EXPERT OPINION – THEORETICAL PAPER  Level of Evidence: ~	Outlines a continuum of treatment options within the ABA literature. Suggests that current ABA treatments are moving more toward a socially-pragmatic developmental approach, which is more child-centred and ecologically valid.		<ul> <li>ABA may be more appropriate to teach some skills than others.</li> <li>Evaluation should involve video sampling and time sampling rather than counts of isolated behaviours.</li> <li>Measures need to go beyond traditional cognitive and language skills and look at characteristics such as emotional development, motivation, social competence, peer relationships and competence in natural environments.</li> <li>Generalisation can be a problem in traditional discrete trial training. Easier to achieve when skills are taught in contexts where needed.</li> <li>Spontaneous initiation of social communication is an important</li> </ul>	A review of developments and variations in the ABA area; a field in which some (see Fletcher-Campbell, 2003 and McWilliam, 1999) are inclined to misunderstand the degree of development since Lovaas.

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				goal rather than cue-dependent responding.  Child should be an active learner and social participant.  Role of caregiver very important in scaffolding learning to communicate.  The environment should be engineered to enhance motivation and opportunities for communication.  Natural social context and routines are important for learning social communication.  Makes the distinction between traditional behavioural approaches and 'modern' ABA.  Research supports and identifies a continuum of approaches based on the control of the teacher versus the child as active learner and social participant.  No one approach is equally effective for all children.  Available research suffers from methodological shortcomings.  Studies have focused solely on child variables and child outcomes.  Better outcomes are associated with earlier and more intensive treatments. No consensus on	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				<ul> <li>how intensity of treatment can be defined.</li> <li>Much overlap in approaches.</li> <li>Fidelity of treatment not measured and other variables outside the treatment have not been measured.</li> <li>Three broad approaches – discrete trial/traditional behavioural approaches, social pragmatic developmental approaches, middle ground eclectic approaches.</li> <li>Advocates eclectic approaches.</li> </ul>	
193	Lovaas, O.I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. Journal of Consulting and Clinical Psychology 55(1): 3-9.  OBSERVATIONAL STUDY  Level of evidence: ~	Behavioural intervention project (begun in 1970). Controlled non randomised observational study. Children were included if they had an independent diagnosis of autism, chronological age <40 months if mute and <46 months if echolalic and prorated mental age of 11 months or more at a CA of 30 months. 19 children were assigned to an intensive treatment experimental group (>40 hours of one-to-one treatment per week) and 19 to a control group (<11 hours of one-to-one treatment per week). An additional control	IQ scores (either Wechsler Intelligence Scale for Children – Revised or Stanford-Binet Intelligence Scale or Merrill-Palmer Preschool Performance Test.	<ul> <li>There were no differences in pre-treatment variables between the experimental group and control group 1 at baseline.</li> <li>The experimental group children gained, on average, 30 IQ points over control group children.</li> <li>47% of experimental group children achieved normal intellectual and educational functioning in contrast to only 2% of the control group.</li> </ul>	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
		group of 21 children was also studied.			
194	Maurice, C. Green, G, Luce S.C. eds (1996). Behavioral intervention for young children with autism: a manual for parents and professionals BOOK	n/a	n/a	n/a	
195	Koegel, R.L. Koegel L.K. Carter, C.M. (1999). Pivotal teaching interactions for children with autism. School Psychology Review 28: 576-594. NON SYSTEMATIC REVIEW Level of evidence: ~	No methodology described but discussion of current research.		Discussion of effective teaching interactions in the treatment of autism.	
196	Prizant, B.M. Wetherby, A.M. Rubin, E., et al. (2006). The SCerts Model: a comprehensive educational approach	n/a	n/a	n/a	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	for children with autism spectrum disorders. Baltimore: Brookes Publishing Co.				
197	Greenspan SI, Wieder, S. (1998). The child with special needs: encouraging intellectual and emotional growth. Cambridge, Mass: Addison-Wesley. BOOK	n/a	n/a	n/a	
198	Gutstein, S.E. Sheeley, R.K. (2002). Relationship development intervention with young children: social and emotional development activities for Asperger Syndrome, autism, PDD and NLD. London: Jessica Kingsley.	n/a	n/a	n/a	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	BOOK				
199	Heflin, L. J., & Alberto, P. A. (2001). Establishing a behavioural context for learning for students with autism. Focus on Autism and Other Developmental Disabilities, 16, 93-101.	Gives concrete, practical examples of ways in which educators can apply the principles of ABA in working with children with ASD.		<ul> <li>Principles of ABA emphasise the importance of ensuring that skills are generalised to contexts outside instructional setting.</li> <li>Practice in natural settings with naturally occurring reinforcers enhances generalization</li> </ul>	This article explains the rationale and application of ABA. The first author coordinates the teacher training programme in ASD at Georgia State University.
	EXPERT OPINION – THEORETICAL PAPER				
	Level of Evidence: ~				
200	McWilliam, R. A. (1999). Controversial practices: The need for a reacculturation of early intervention fields. <i>Topics in Early Childhood Special Education</i> , 19, 177-88.	Discussion of practices for treating disability which are by the definition of the author 'controversial'.		Suggests that the features of controversial practices are:  • a claim of cure  • questionable research  • when practitioner specialization is required  • a requirement for high intensity  • when treatment has been subjected to legal action.	Not specific to ASD but provides an overview of a number of well known, but in many cases, lesser documented, treatments relevant to this field. Tends, however, to be
	EXPERT OPINION - THEORETICAL PAPER Level of Evidence:			Quotes Wolery for important principles, which should be considered; children with autism children first, maintain a	dichotomous in its approach and fails to acknowledge that a lack of empirical evidence

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	~/x			longitudinal perspective, families must be intimately involved, curriculum should be community referenced.  Suggests that excessively intensive programmes are very costly and this tends to cause conflict.	does not always allow the conclusion that an approach is never efficacious for any individual. Dismisses treatments without acknowledging the wide individual variation in ASD and the resulting variation in treatment efficacy from person to person.
201	Simpson, R. (2003). Policy-related research issues and perspectives. Focus on Autism and other Developmental Disabilities, 18, 192- 6.  EXPERT OPINION – THEORETICAL DISCUSSION Level of Evidence: ~			Points out the need for validation of educational methods intended for use with children with ASD. Discusses ways in which this can be achieved, given the difficulties and potentially invalid findings that can result from large N control group research studies conducted within this diverse population. Discusses the current trend toward non-categorical special education training, and argues that there is a need for educators to receive autism-specific training if working with students with ASD.	The paper highlights the demands of planning special education services for ASD owing to the complex needs and heterogeneous nature of children in this population. The author is the acting chair of the Special Education Department at the University of Kansas and has worked as a special

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
					education teacher.
202	Mastergeorge, A. M., Rogers, S. J., Corbett, B. A., & Solomon, M. (2003). Non-medical interventions for Autism Spectrum Disorders. In Ozonoff, S. and S. J. Rogers and R. Hendren. (Eds.). Autism Spectrum Disorders: A research review for practitioners. (pp. 133-160). Washington DC: American Psychiatric Pub.  NON SYSTEMATIC REVIEW - BOOK CHAPTER  Level of Evidence: ~	Outlines non-medical interventions for autism. Uses the literature to discuss ways of teaching children with ASD across the following skill areas:  Ianguage  social competency managing unwanted behaviour academic skills.		Recommendations:  Begin early as soon as identified at risk rather than waiting for diagnosis.  Intervention should be individualised to the specific needs and challenges of the child  Intervention should be delivered and designed by experienced professional interdisciplinary teams.  Emphasis should be on language interventions.  Outlines different language approaches (refers to naturalistic behavioural interventions which equate to 'modern ABA').  Communication intervention should begin immediately and should involve daily teaching episodes.  Maintenance and generalisation should be planned across environments and communicative partners.  Social competency interventions important, including play.  Problem behaviour dealt with using positive behavioural approaches.	A comprehensive introduction to teaching children with ASD. Covers recent innovations in teaching social skills.  Mostly short term and small group studies.

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				<ul> <li>Frequent evaluation of progress and adjustment of plan accordingly.</li> <li>Be intensive.</li> <li>Involve families in development of goals, priorities and treatment plans, provide parent support and training and consultation.</li> <li>Professionals should frequently update their knowledge of the child's needs, family's current goals.</li> <li>Treatments should be based on sound theoretical constructs, rigorous methodologies, and studies of efficacy.</li> </ul>	
203	Simpson, R. L., de Boer-Ott, S. R., & Smith-Myles, B. (2003). Inclusion of learners with autism spectrum disorders in general education settings. <i>Topics in Language Disorders</i> , 23, 116-33.  EXPERT OPINION – THEORETICAL DISCUSSION  Level of Evidence: ~	Presents a model that may be used to facilitate successful inclusion of children with ASD into mainstream classrooms. Provides observational checklists that can be used to assess the key components proposed to contribute to the success of inclusion for these students.		<ul> <li>Recommendations</li> <li>Few models and procedures for successful placement and maintenance of students.</li> <li>Build administrators' attitudes as this sets the tone for the teaching personnel.</li> <li>Provide opportunities for all staff to discuss roles, attitudes and feelings.</li> <li>Provide for adequate planning time and consultation time.</li> <li>Ensure availability of teacher's aides when required.</li> <li>Reduce class sizes when a</li> </ul>	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				student with a disability is placed in a class.  Provide students with ASD social attitudinal supports.  Provide peers with supports and information.  Major components of ASD inclusion Collaboration Model: environmental and curriculum modifications, attitudinal and social support, coordinated team commitment, evaluation of inclusion procedures, home/school collaboration.	
204	Doughty, C. (2004). What is the evidence for the effectiveness of behavioural and skill-based early intervention in young children with Autism Spectrum Disorder (ASD)? New Zealand Health Technology Assessment Tech Brief Series, 3(1).  SYSTEMATIC REVIEW Level of Evidence: ~	Reviews original research, systematic reviews and meta-analyses pertaining to the efficacy of behavioural interventions for children with ASD. The scope was all studies in the above category published in English between January 2000 and December 2003.		<ul> <li>Findings</li> <li>Not clear from this review of studies if any one programme is more effective than any other.</li> <li>Children improve in functioning with behavioural intervention.</li> <li>Early intervention that utilises a social-developmental approach may be an effective treatment model.</li> </ul>	The author notes that owing to the report's brief this review focuses on 'best evidence' from group designs only and ignores single case experiments.

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
205	Heflin, L. J., & Simpson, R. (1998). Interventions for children and youth with autism: Prudent choices in a world of exaggerated claims and empty promises. Part II: Legal/policy analysis and recommendations for selecting interventions and treatments. Focus on Autism and other Developmental Disabilities, 13, 212- 20.  EXPERT OPINION – THEORETICAL PAPER Level of Evidence: x	Reviews US court cases that highlight the difficulties in generalising appropriate treatments for children with ASD. Proposes a set of guidelines for schools and parents to use when evaluating, and making choices between, the various interventions and treatments available.		<ul> <li>Staff must be able to articulate a variety of programmes so that a programme can be tailored to the particular student's needs.</li> <li>Any treatment that teaches skills that do not generalise should be eliminated.</li> <li>Systematic instruction.</li> <li>Generalisation should be programmed for.</li> <li>Emphasise should be on social and communicative needs.</li> <li>Review of Court decisions – little research to support different amounts of time.</li> <li>Parent involvement often not considered as part of the intervention.</li> <li>Reports study by Rogers suggesting 15 or more hours per week.</li> <li>Recommends family involvement in programming.</li> <li>Outcomes should be developmentally appropriate.</li> <li>Provides five questions for teams to ask before choosing programmes: (1) What are the anticipated outcomes of a particular option? (2) What are the potential risks? (3) How will the</li> </ul>	Provides a template for weighing up programme suitability and utility taking into account the needs of the child and family concerned. Paper published in a respected peer-reviewed journal.

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				option be evaluated? (4) What proof is available that the option is effective? (5) What other options would be excluded if this option was selected?	
				Lack of consensus regarding which methods are most effective. One of the greatest challenges facing the field is the need to ascertain which treatments are suitable for which individual.  In choosing treatments, potential negative outcomes both for the student and for the family and for school personnel should be	
				considered (physical health, behaviour, quality of life). Claims of cures should be viewed as suspect.	
206	Schwartz, I. S. (1999). Responses to McWilliam: Controversy or lack of consensus? Another way to examine treatment alternatives. Topics in Early Childhood Education 19: 189-			Suggests that, in contrast to McWilliam's definition of a controversial treatment, social validity (and disagreements about it) is the most salient feature of controversial treatments.  Suggests guidelines for evaluating the social validity of a given treatment.	A modification to the views outlined in McWilliam's paper.
	98.			Recommendations:  • Families need information to	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	EXPERT OPINION – THEORETICAL PAPER Level of evidence: ~			<ul> <li>make choices about intervention approaches.</li> <li>Social validity for the family is very important.</li> <li>Professionals should be able to discuss a variety of treatments and alternatives with families.</li> <li>Requires expertise and time.</li> <li>Poses 4 questions that may be used to test social validity.</li> </ul>	
207	Dunn, L.M. (2000). Using 'learning stories' to assess and design programs for young children with special needs in New Zealand. Infants and Young Children 13: 73-82.  EXPERT OPINION Level of evidence: x			Description of the model of 'learning stories' and how it fits into the NZ educational context. The author also describes her experiences in using this model.	
208	McConnell, S. R. (2002). Interventions to facilitate social interactions for young children with autism: Review of available research and recommendations for educational	Reviews 47 primary research studies on social development in ASD. All were published in peer reviewed journals through to May 2000. Reports extensively on those principles and techniques that have been investigated in the hope of improving social interactions.		Recommendations     Fade direct intervention, transferring control for prompting social interactions to transportable or naturally occurring contingencies.     Monitor effects of interventions, and social interaction development over extended	A systematic review of the relevant literature. Recommendations clearly based on the literature.

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	interventions and future research. Journal of Autism and Developmental Disorders, 32, 351-71.  SYSTEMATIC REVIEW  Level of Evidence: ~	Provides recommendations for educational practice.		<ul> <li>periods of time.</li> <li>Arrange the environment to prompt and support social interaction.</li> <li>Assess social interactions in naturalistic settings, including homes and classrooms with children and adults as interactive partners.</li> <li>Teach specific social skills to children with ASD and typically developing peers and provide in situ intervention to prompt social interaction.</li> <li>Extend treatment throughout the day and to other activities.</li> </ul>	
209	Dawson, G. &, Osterling, J. (1997). Early intervention in autism: Effectiveness and common elements of current approaches. In Guralnick, M. (ed). The Effectiveness of Early Intervention: Second Generation Research, Baltimore, MD; Paul H Brookes Publishing.  EXPERT OPINION – BOOK CHAPTER			All of the programmes were effective in:  • fostering positive school placements  • significant developmental gains for a substantial percentage of students. (Only one programme had a control group).  Common elements of the programmes:  • curriculum content – ability to attend to environment – especially people: ability to imitate others; ability to comprehend and use language; ability to play appropriately with	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				toys; ability to socially interact with others.  • highly supportive teaching environments and generalisation strategies.  • need for predictability and routine  • functional approach to problem behaviours  • planned transition from preschool  • family involvement  • intensity of intervention – range of hours was from 15-40 hours.  Promising intervention methods for infants:  • closely following the child's lead, usually involving imitation.	
210	Ministry of Education (1996). Te Whaariki. Wellington: Learning Media, New Zealand. REPORT Level of evidence: x			Ministry of Education early childhood curriculum policy statement. A framework for providing tamariki/children's early learning and development within the socio-cultural context. It emphasises the learning partnership between kaiako/teachers, parents and whānau/families.	
211	Dettmer, S., Simpson, R. L., Smith-Myles, B., &	Evaluates the effectiveness of visual supports in transitioning children with ASD from one	Observational data recording latency in seconds between	Individuals with ASD have difficulty in processing and retaining non-visual	A small study where the reversal adds veracity to the

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	Ganz, J. B. (2000). The use of visual supports to facilitate transitions of students with autism. Focus on Autism and other Developmental Disabilities, 15, 163–9.  OBSERVATIONAL STUDY - SINGLE SUBJECT  Level of Evidence: ~	activity to another.  Method: two children with ASD were observed through baseline (in which verbal and physical prompts and proximity control were used), and intervention phases (using visual supports). An ABAB reversal design was used.	caregiver instruction and child's movement toward the new activity.	information.  Visual supports can be used to maintain attention, understand spoken language and sequence and organise the environment.	experiment.
212	Olley, J. G. (1999). Curriculum for students with autism. School Psychology Review, 28, 595-607.  EXPERT OPINION – THEORETICAL PAPER  Level of Evidence: ~	Reviews theoretical approaches to curriculum and the integration of these approaches, gives examples of application of curriculum to reduce problem behaviour and facilitate learning, and examines the research that supports various elements of curriculum.		Assessment  Many tests are useful – IQ, adaptive behaviour, language, play and neuropsychological functioning.  Tests must be interpreted carefully in light of characteristics of ASD.  Key areas of curriculum:  self help – compliance and imitation skills need to be taught  use of strategies such as interspersing learning trials with preferred activities	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				<ul> <li>self-management – goal to teach to work independently, manage own behaviour, motivated by learning rather than by artificial reinforcer – visual schedules, building in choices, appropriate levels of difficulty and natural reinforcers</li> <li>cognition – cognitive skills are an essential component – thinking skills, concepts, problem-solving and other broad skills rather than individual discrete skills.</li> <li>play – primary vehicle for teaching social skills, particularly at pre-school</li> <li>motor skills – some small studies in the literature show that these may help problem behaviours</li> <li>transition curriculum – social and academic skills and skills for adult functioning – work skills, community functioning and leisure, domestic skills.</li> <li>Different types of assessment data:</li> <li>standardised tests – must be interpreted carefully in light of characteristics of autism, provide a description of</li> </ul>	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				strengths and weaknesses, motivational characteristics and preferences. May help to inform – type of task, difficulty level, amount of attention, language skills, motivational characteristics skills etc.  • behavioural assessment – functional assessment of behaviour, task analysis.  • Selection of curriculum – made on the basis of child assessment and family preferences  • Individualise curriculum – normal developmental expectations, predictable routines and individualised schedules. Match curriculum to individual learning style and behaviour characteristics of student  • Curriculum content and sequence are decided on the basis of individual student progress.	
213	Mirenda, P., & Erickson, K. A. (2000). Augmentative communication and literacy. In Warren, S.F. & Reichle, J. (Eds). Autism	Summarises literature related to the use of augmentative and alternative communication (AAC) in supporting literacy development in children with ASD.		<ul> <li>Impact of imitation and motor deficits mitigates the use of manual signing.</li> <li>AAC interventions have been shown in many empirical studies to provide both receptive and expressive</li> </ul>	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	Spectrum Disorders (Communication and Language Intervention Series, Vol 9) (pp. 333-67). Baltimore: Paul H. Brookes.  NON SYSTEMATIC REVIEW - BOOK CHAPTER  Level of Evidence: ~			communication supports to individuals with challenging behaviours.  • AAC – communication techniques that can be used in addition to, or instead of, whatever speech or gestures or vocalisations a child may have.  • Must have a strong communicative foundation for the skills – more than just identifying symbols.  • Need to extend communicative functions and extend nonverbal means. Developmental model suggests that natural gestures and vocalisations is a good place to start.  • Outlines the participation model as a process for assessment and intervention for AAC. Consideration should be given to: communication needs in different environments, partner interaction strategies and abilities, environmental barriers, the individual's capabilities (sensory, motor, cognitive and expressive and receptive communication).  • Because of the obvious relation of photos and pictograms to the concepts they represent, and	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				visual spatial strengths often seen in people with ASD, these may be the most suitable. Natural gestures should be also encouraged in a multi-modal communication system.  Important to consider how intelligible the symbols are to the communication partners.  Research supports use of visual-graphic systems for people with ASD.  The use of AAC does not hinder the development of speech and may enhance it (this includes those older than five).  Computer technology enhances motivation, increases attention, and decreases challenging behaviour.  Report studies which detail the success of using visuospatial symbols such as photos and line drawings with people with ASD.  Research evidence supports the use of visual-graphic systems with individuals with ASD  Multi modal approach to AAC. This supports, and is in addition to, whatever speech, gestures,	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				or vocalisations the student may have.  • Understanding has received less attention until recently (eg, pictorial or written schedules, within task schedules, rule scripts).  • When introducing AAC, individuals need numerous communication opportunities in natural settings with responsive partners.  • Hyperlexia, precocious selftaught ability to read words with an apparent lack of comprehension. Occurs most often in children with ASD. Research suggests hyperlexia stems from a problem with general language comprehension rather than with reading comprehension (all readers require general background knowledge and general language understanding to comprehend text).  • Children with ASD should not be viewed as incapable of learning to comprehend what they read but should not be expected to comprehend all the words they can decode.	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				<ul> <li>Children with ASD appear to learn to read through the same developmental process as others. A balanced approach to learning to read recommended (ie, more than one instructional method is used).</li> <li>Both literacy and AAC learning should be embedded in social contexts if they are to generalise and be used spontaneously.</li> </ul>	
214	New York State Department of Health (1996). Clinical Practice Guideline: Report of Recommendations: Autism/Pervasive Development Disorders, Assessment and Intervention for Young Children (0-3 years). Retrieved 20 <sup>th</sup> November 2005, from: http://www.health.stat e.ny.us/community/in fants_children/early_i ntervention/autism/			Children often demonstrate echolalia, pronoun confusion, verbal perseveration, abnormalities of prosody (rate, rhythm, inflection and volume). Often do not have gestures, such as point to show shared interest, shaking head for no, convey emotion through facial expression, engage in pantomime.	The very brief literature review provided does not seem detailed or comprehensive enough to support the report's recommendations.
	POLICY				

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	GUIDELINES (NOT EVIDENCE BASED)				
	Level of Evidence: x				
215	Prizant, B. M., Wetherby, A. M. & Rydell, P. J. (2000). Communication intervention issues for children with autism spectrum disorders. In Wetherby, A.M & Prizant, B.M (Eds.). Autism spectrum disorders: a transactional developmental perspective (pp 193- 224). Baltimore: Paul H. Brookes.  EXPERT OPINION – BOOK CHAPTER  Level of Evidence: ~	Outlines issues in developing language and communication skills in children with ASD. Explores the contributions of traditional and contemporary ABA and the developmental social pragmatic model to language skills. Describes the SCERTS model for enhancing communication and socioemotional abilities.		<ul> <li>Most functional communicative abilities emerge from self generated and self-motivated goals</li> <li>Assessment of intentions expressed by child is important</li> <li>In typically developing children – at preverbal stage – 2 main communicative functions: behave regulation, social interaction, joint attention</li> <li>Children with ASD find function of behave regulation easiest and joint attention the most difficult.</li> <li>Early speech is often echolalic – this serves a variety of communicative functions.</li> <li>Echolalia may reappear during times of confusion or tiredness</li> <li>Assessment should document even unconventional means</li> <li>Core issues to be addressed – expressing communicative intent, expending range of communicative functions, targeting symbolic means, supporting transition from echolalic speech to creative</li> </ul>	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				language, acquisition of more conventional means to communicative participation.  • Assessments and interventions place emphasis on communicative abilities within meaningful routines and events and using a variety of family members and others as informants of progress.  Assessments should therefore take these into account.	
216	Kasari, C. Freeman, S. & Paparella, T. (2006). Joint attention and symbolic play in young children with autism: a randomized controlled intervention study. Journal of Psychology and Psychiatry, 47 (6) 611-620  RCT  Level of evidence: ~	Participants: 58 children with autism aged between 3 and 4 years (46 were boys)  Children were randomly selected for a joint attention intervention, a symbolic play intervention and a control group  Interventions were conducted for 30min daily for 5-6 weeks	Structured assessments of joint attention and play skills and mother/child interactions were collected pre and post intervention using: • early social communication scales • structured play assessment • caregiver child interactions (coded video recording). Both discrete trial and milieu teaching techniques were	Both intervention groups improved significantly over controls on certain behaviours:  • Children in the joint attention group demonstrated more showing and responsiveness to joint attention on the structured assessment and child-initiated joint attention in the mother/ child interactions  • Children in the play group showed more diverse types of symbolic play in interactions with their mothers and higher play levels on the play assessment and in interactions with their mothers.	Little detail given on situation for control group. No individual data given to show whether intervention was equally successful for all children.

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
			used in the intervention		
217	Preston, M. (1998). Including children with: Autistic spectrum disorders. Special Children, 115, 15-17.  PRACTICE PAPER Level of Evidence: x	Briefly introduces the ASD diagnosis and presents some practical classroom strategies.		<ul> <li>Need for educational diagnosis and caution against confusion between medical diagnosis and diagnosis for education.</li> <li>Students with ASD will have difficulty with – nuances of communication, abstract ideas, figurative language, reading the emotions of other people.</li> </ul>	A brief paper with its emphasis on practice rather than research findings. Suggestions have good face validity.
218	lovannone, R., Dunlap, G., Huber, H., & Kincaid, D. (2003). Effective educational practices for students with Autism Spectrum Disorders. Focus on Autism and other Developmental Disabilities, 18, 150- 65.  NON SYSTEMATIC REVIEW Level of Evidence: ~	Integrates findings from reviews of best practice in intervention with ASD. Describes six core elements that have empirical support and are considered essential to sound, comprehensive instructional programmes.		<ul> <li>Findings</li> <li>Students with ASD vary greatly in their presentation of their unique preferences, interests and learning styles - this requires individualised instructional support needs.</li> <li>Focus on child's strengths and weaknesses to determine the most appropriate intensity and level of instruction to meet the child's goals.</li> <li>Effective educational practices which have been shown to be useful</li> <li>Systematic Instruction: involves careful planning – valid goals, instructional procedures, evaluating, achieving high</li> </ul>	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				<ul> <li>levels of engagement.</li> <li>Outcomes of studies showed: increase in on-task behaviours, increase in behaviours such as language, social and motor behaviours, reduction in inappropriate behaviours, increase in acquisition and generalisation.</li> <li>Structure is achieved when the curriculum (activities, schedule and environment) is clear to the student.</li> <li>Test – observe for 10 minutes and identify what each student is supposed to be doing.</li> <li>Structure allows the student to predict what is currently happening and what will happen next, anticipate requirements of specific settings and learn and generalise a variety of skills.</li> <li>Strategies to achieve structure: organise the setting, provide a schedule of activities, plan and provides choice making, provide behavioural support, define specific areas of the classroom and school, provide timetables etc, facilitate transitions, flexibility and change.</li> </ul>	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				<ul> <li>Priming strategies allow the student to preview information and activities that usually trigger problem behaviours before they actually become involved in the setting. This can be done through video priming and social stories.</li> <li>Social stories most informal and anecdotal support.</li> <li>Incorporate the child's preferences and special interests into the instructional programme. Studies show that this causes more self-initiation of questions, enhanced engagement in tasks, and increased social interactions.</li> <li>Support needs to facilitate high rates of engagement. This needs deliberate planning, changes to the physical environment, systematically using materials and activities and using the student's interests and initiations.</li> <li>Teach pivotal skills such as motivation, self-initiation and responding to multiple cues. Strategies to do this include: providing choices, varying tasks, interspersing easy and difficult tasks, reinforcing all</li> </ul>	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				attempts and the use of natural reinforcers.	
219	Charlop-Christy, M. Carpenter, M. Lee, L. Le Blanc, L & Kellet, K. (2002). Using the Picture Exchange Communication System (PECS) with children with autism: assessment of PECs acquisition, speech, social communicative behaviour and problem behaviour. Journal of Applied Behaviour Analysis, 35 213-231  CASE SERIES  Level of evidence: ~	3 participants who each had a diagnosis of autism – a 12-year-old male, a 3 year 8 month male and a 5 year 9 month male. The children did not or rarely spoke and did not or rarely displayed spontaneous speech.  A multiple baseline design across participants was used to evaluate the collateral effects of PECS training on the domains of speech, social communicative behaviour and problem behaviour in free play and academic settings. One session was conducted for each of the two settings each week.  Follow-up sessions were conducted after a 10 month interval for one child.	Frequency count of the number of trials required to reach to reach to reach criterion.  Videotapes of sessions were coded for spontaneous and imitative speech and social communication and problem behaviour.	<ul> <li>All three children mastered PECS.</li> <li>Emergent speech occurred (both spontaneous and imitated in all 3 children. This was generalised to novel people and in two non-training settings</li> <li>Social communication increased.</li> <li>Each participant experienced a decrease in one of more problem behaviour.</li> </ul>	
220	Ganz, J. & Simpson, R. (2004). Effects on communicative requesting and speech development of the Picture Exchange	Three children (a female aged 5 years 8 months, a male aged 7 years 2 months and a male aged 3 years 9 months) with diagnoses of autism spectrum disorders, developmental delay and characteristics of	Observers collected data on each participant's proficiency relative to the PECS criteria, the number of intelligible words	<ul> <li>All 3 participants made progress in mastering PECS.</li> <li>All demonstrated increases in intelligible words during trials and generalised skills with a variety of adults.</li> </ul>	No baseline data was collected and no speech samples were collected outside the intervention setting.

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	Communication System in children with characteristics of autism. Journal of Autism and Developmental Disorders. 34 (4) 395-409  CASE SERIES  Level of evidence: ~	autism. All children were preverbal or had limited functional speech (10 or less words used functionally).  Single subject design within subjects with changing criterion.  Each child was trained in the use of PECS according to the manual. 2 to 5 training sessions took place each week until participants had mastered the first 4 phases of PECS.	and non-word vocalisations.  Videotapes were used to collect samples of speech and analysed for grammar, syntax and vocabulary	Complexity of sentences increased.	
221	Marks, S. U., Shaw-Hegwer, J., Schrader, C., Longaker, T., Peters, I., Powers, F., & Levine, M. (2003). Instructional management tips for teachers of students with Autism Spectrum Disorder (ASD). Teaching Exceptional Children, 35, 50-5.	Provides classroom strategies for modifying learning to suit the child with ASD.		<ul> <li>Allow students to use other modes for presenting work (eg, videotaping using a computer).</li> <li>Allow students to use a computer when writing is required eg, to take notes or complete an assignment.</li> </ul>	Good face validity. The rating reflects the fact that while the literature is used to identify areas of difficulty there is (as yet) little research available on how effective the interventions recommended have been.
	EXPERT OPINION -				

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	THEORETICAL PAPER				
	Level of Evidence: x				
222	Mirenda, P. (2003). 'He's not really a reader': Perspectives on supporting literacy development in individuals with autism. <i>Topics in Language Disorders</i> , 23, 271-82.  EXPERT OPINION – THEORETICAL PAPER  Level of Evidence: ~	Describes practical strategies that can be used by teachers and parents to promote literacy learning in children with ASD.		<ul> <li>Many students considered too cognitively impaired or not ready despite demonstrating literacy skills such as print awareness.</li> <li>'Readiness' models shown to be outdated.</li> <li>Do not need verbal speech to learn literacy skills.</li> <li>Special interests should be channelled into activities that enable the child to read, write, draw and communicate until that particular interest wanes.</li> <li>Students benefit from the use of multiple instructional strategies carefully matched to ages/stages of development.</li> <li>Students should be encouraged to use – decoding, analogy, prediction and sight skills.</li> <li>Computer programmes matched to the stage the child is at can be particularly helpful.</li> <li>Advanced literacy skills and AAC appear to support the development of speech.</li> <li>Particular interests should be</li> </ul>	Uses research evidence and personal accounts to support the interventions suggested.

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				used to motivate learning.  Should attempt to develop skills at the phase the children are at as well as those that will allow them to advance to the next stage.	
223	Charlop-Christy, M. H., & Kelso, S. E. (1999). Autism. In Schwean, V.L. & Saklofske, D.H. (Eds). Handbook of Psychosocial Characteristics of Exceptional Children (pp. 247-273). New York: Kluwer Academic/Plenum.  NON SYSTEMATIC REVIEW – BOOK CHAPTER  Level of Evidence: ~	An overview of research on assessing and training social skills in children with autism. Critiques current approaches to intervention, and makes suggestions for further research.		<ul> <li>Findings</li> <li>Social deficits are hallmarks of ASD. Problems are obvious from early infancy (eg, babies not responding normally to physical contact).</li> <li>Cooperative and imaginative play and appropriate play with toys is lacking.</li> <li>Children may not seek comfort from parent when frightened.</li> <li>Show little or no interest in interacting with their peers and ignore social initiations. Lack of appropriate speech interferes with social interactions.</li> <li>Recommendations</li> <li>Assessment by structured observations – across a thirty minute period. Interacting with parent, therapist and stranger.</li> <li>Note details of interactions and play.</li> <li>Focus of intervention: Social interaction – skills – social initiations eg, sharing materials,</li> </ul>	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				organising activities and assisting in performance of activity. Use of peer self-evaluation. Peer mediators own social repertoire important (socially skilled, friendly and outgoing) and may need to be increased. Peer responsiveness very important factor. Skills to encourage and extend conversations. Buddy systems set up.  • Sometimes number of interactions increased but 'friendship' was not established.  • Play skills – development of play skills helps problemsolving.  • Initiate play, co-op play and socio dramatic play and complements. Play increased through using preferred toys. Use of video modelling and self-monitoring.  • Social speech – verbal responsiveness, spontaneity, initiation and elaboration and conversational speech.	
				Recommendations for peer mediated interventions:  • teach non handicapped peers	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				skills for interacting and understanding of child with ASD – prompt and reinforce social interactions with child with ASD.  • both peers and child with ASD benefit as frequency and quality of interactions are improved.  • limitations – poor generalisation and maintenance of skills by peers (may be owing to lack of responding by child with ASD.  Recommendations for individual level interventions:  • direct training of social skills – increases independence. Appropriate interactions increase likelihood of future interactions.  • this intervention directly increases the skills of the child with ASD – improves frequency and quality  • limitation – peers lack of response because may not recognise attempts and may not provide sufficient social reinforcement.	
				Recommendations for combination of individual and peer	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				<ul> <li>training of child and peers usually in the natural environment also includes engaging children with ASD in group activities</li> <li>improves skills of both groups simultaneously</li> <li>limitation – very time-consuming process for training and subsequent supervision. When trained peers are not present interaction decreases.</li> <li>Recommendations for family level interventions:</li> <li>skills gained in clinic or school generally do not generalise to home. Parents and siblings taught skills to enhance social interactions. Also training in how to teach the child new skills</li> <li>extends effects beyond treatment environment to home and community settings.</li> </ul>	
224	Paul, R. (2003). Promoting social communication in high functioning individuals with autistic spectrum disorders. <i>Child</i>	Reviews research pertaining to social skills in children with developmental disabilities. Relates findings to the social learning needs of children with Asperger Syndrome.		Findings  • Social and communication difficulties most disabling part of ASD.  • High rates of depression reported in adolescence are generally attributed to these	A useful and comprehensive summary of the literature on social skills.

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	Adolescent Psychiatric Clinics of North America, 12, 87-106.  NON SYSTEMATIC REVIEW Level of Evidence: ~			<ul> <li>difficulties.</li> <li>Social skills most in need of attention from the earliest point of diagnosis and continuing throughout life. Therefore social communication goals should be a priority for the IEP.</li> <li>Students require direct instruction on the actual target behaviours.</li> <li>Context for instruction needs to be developmentally appropriate – pre-school – pretend dramatic and toy play with supportive visual info.  Elementary school – games with rules, lunch buddies, and social skills groups focused around interests with visual supports – discussion groups of peers with ASD to allow sharing feelings about disability, social networks consisting of trained peers.</li> <li>Children require abundant opportunities to practise new skills in natural settings to achieve generalisation and maintenance (leaving the child to sink or swim in the natural environment is not sufficient – the aid of peers needs to be utilised).</li> </ul>	

Peers can aid target children best when they receive training in techniques to facilitate conclusion and interaction with friends with ASD.  Intensive peer training has well demonstrated efficacy. Simpler forms of training also bring results – need to train several peers so there are repeated opportunities to interact.  Intervention guidelines for students with Aspergers Syndrome (Klin & Volkmar, 2000) include (1) Use of visual supports. (2) Social perception training (ie, teaching the student to read social cues). (3) Training in conventional	Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
pragmatic and conversational rules (scripts, video modelling, and role play can be used). (4) Training to improve prosody. (5) Teaching children selfmonitoring skills to keep track of their own behaviour.  Useful programmes:  Pre-schoolers: guided participation model (Schuler and Wolfberg, 2000), coaching by adults and mediation by peers for preschoolers who					best when they receive training in techniques to facilitate conclusion and interaction with friends with ASD.  Intensive peer training has well demonstrated efficacy. Simpler forms of training also bring results – need to train several peers so there are repeated opportunities to interact.  Intervention guidelines for students with Aspergers Syndrome (Klin & Volkmar, 2000) include (1) Use of visual supports. (2) Social perception training (ie, teaching the student to read social cues). (3) Training in conventional pragmatic and conversational rules (scripts, video modelling, and role play can be used). (4) Training to improve prosody. (5) Teaching children selfmonitoring skills to keep track of their own behaviour.  Useful programmes:  Pre-schoolers: guided participation model (Schuler and Wolfberg, 2000), coaching by adults and mediation by	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				have verbal skills, incidental teaching to increase quantity of verbal initiations, script fading procedures which make use of reading skills, Stay, Play Talk – simple version of peer mediation.  School age and Adolescents: typically developing young people begin to engage in social interactions primarily by 'just talking'.  Students with Asperger Syndrome may have the language but have difficulty using it to engage in social interactions.  Interventions: hybrid techniques including pivotal verbal behaviours, such as asking questions, visual supports, verbal rehearsal, video modelling, peer mediated approaches, such as social skills groups and peer networks like Circle of Friends (these require specific training for peers).  Social Stories, and Do, Watch, Listen, Say, although in use, do not have research support at this time.  One study of Social Stories	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				showed that the intervention increased skill levels in some participants and there was some generalisation to other settings. Another study showed a decrease in frequency of inappropriate behaviours and anxiety levels. Limited evidence about generalisation and maintenance has been reported.	
225	Schuler, A. L., & Wolfberg, P. J. (2000). Promoting peer play and socialisation: The art of scaffolding. In Wetherby, A.M. & Prizant, B.M. (Eds.). Autism spectrum disorders: a transactional developmental perspective (pp. 251-277). Baltimore: Paul H. Brookes.  EXPERT OPINION – BOOK CHAPTER  Level of Evidence: ~	Discusses the challenges of teaching play skills to children with ASD. Argues that the highly directive teaching approaches commonly used in ASD are inappropriate to teach play. Describes play scaffolding and the integrated play group model for teaching play skills.		<ul> <li>Findings:</li> <li>Development of symbolic play and peer interaction has presented a challenge to intervention.</li> <li>Children with ASD may obtain a verbal repertoire but seldom use it to relate to peers and engage in pretend play. May use it for requests and protest but not for more social functions such as commenting, describing or sharing. Peer play of critical importance to expand and diversify the communicative repertoires of children.</li> <li>Practitioners need to recognise the 'culture of play' and use socially referenced forms of learning rather than adult controlled forms. Provides a</li> </ul>	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				context for the coordination of joint action and social referencing.  Without specific support, children with ASD gravitate towards repetitive play (manipulating objects, enacting elaborate routines to pursuing obsessive interests.  Children with ASD have problems with: entering and sustaining social play, and pretend play, they avoid and resist social overtures and have little or no self-initiation or approach peers in an obscure or one-sided fashion.  Peer play has not received much attention but studies show children with ASD are capable of learning more complex and diverse forms of play when supported by an adult.  Interventions that do target play tend to focus on specific skills – often with limited success. Without the interpersonal skills and flexible modes of representation that develop in the context of play it is difficult for children to develop friendships or nurture social	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				relationships. Also aids in the development of symbolic capacities, interpersonal skills and social knowledge.  Observation skills are an important assessment tool — this will identify unconventional forms of expression and may indicate particular needs, emotional states, desires preferences etc. which may be missed by other forms of assessment.  Interactions with more competent peers need to be supported.  Intuitive approaches — guided largely by intuition and hunches. Limitation — difficult to teach to others and difficult to analyse when it breaks down.  Highly directive approaches — pursuit of compliance and accuracy. Limitation — often fail to acknowledge child initiations. Specific behaviours learnt but tend not to generalise to other settings or interactions.  Demand for compliance difficult because the nature of play equals self-imposed activity.  Implications for interventions (based on studies of effective	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				practitioners) – aim should be to foster social transitions in supportive contexts. (1) Knowledge of ASD. (2) Understanding of play. (3) Provide a secure base for play – predictable and accepting play environment. (4) Setting the stage for play – organising enticing play environments with appropriate props. (5) Ritualising and dramatising play – builds anticipation through effective use of rituals and exaggerated affect. (6) Narrating scripts – create play scenarios and narrate scripts following children's lead. Expand on children's actions, verbalisations and social interactions. (7) Scaffolding – the provision of secure and predictable support structures within their zone of proximal development for all children in the setting. (8) Facilitating peer mediation and social understanding – support to understand the communicative behaviour of playmates. (9) Theory of mind – practitioners need to draw on their own theory of mind to appreciate their student's view of the world	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				etc. (10) Reflective practice – careful monitoring allows continual adjustments to physical environment, sociocultural ecology activities and developmental status etc.	
226	Barnhill, G. P., Cook, K. T., Tebbenkamp, K., & Myles, B. S. (2002). The effectiveness of social skills intervention targeting nonverbal communication for adolescents with Aspergers Syndrome and related pervasive developmental delays. Focus on Autism and Other Developmental Disabilities, 17, 112-118.  OBSERVATIONAL STUDY – SMALL GROUP DESIGN Level of Evidence: x	Eight adolescents with AS or related PDDs participated in one hour of social skills training, and 2-3 hours of directed social activity sessions each week for 8 weeks. The aim was to enhance participants' nonverbal social skills.  In this study adolescents with AS were taught skills in reading non-verbal communication.	Diagnostic Analysis of Nonverbal Accuracy 2 (DANVA2) was used to evaluate participants' recognition of emotion through facial expression and tone of voice pre- and post-intervention.	<ul> <li>Students with Asperger Syndrome have a qualitative impairment in social interaction.</li> <li>Difficulties with using multiple non-verbal behaviours, peer relationships, sharing enjoyment and demonstrating social or emotional reciprocity.</li> <li>Lack of much research on interventions specifically for students with Asperger Syndrome.</li> <li>Social skill deficits pose the greatest challenge to these students – often motivated to have friends but their social clumsiness and difficulty in appreciating the other's point of view result in social isolation.</li> <li>Individuals with AS have distinct social needs that should be considered when designing treatment options.</li> <li>Results showed that participants made no significant gain in learning skills and did</li> </ul>	This is an interesting study, and clearly enhanced the lives of the children involved, which is a fantastic outcome on the small scale. However, the benefits of social skills groups have already been established (eg, Mesibov, 1984). As this paper does not help to identify critical features or content in social skills programmes, and is unable to report evidence of participants generalising social skills to children outside the initial group, it adds little to current empirical

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				not generalise learning to other settings. However some friendships were formed within the group and there was still contact a number of months after the study. A sense of trust in each other also developed.	knowledge.
227	Marks, S. U., Schrader, C., Longaker, T., & Levine, M. (2000). Portraits of three adolescent students with Aspergers Syndrome: Personal stories and how they can inform practice. Journal of the Association for Persons with Severe Handicaps, 25, 3-17.  OBSERVATIONAL STUDY – QUALITATIVE  Level of Evidence: ~	Semi-structured, individual, face-to-face interviews with three adolescents (one 13 years and two 15 years old) with Asperger Syndrome. Telephone interviews with parents.	Student semi- structured interviews covered student's views of themselves, their disability, and their experiences of school. Interviews with parents covered history of student, and out-of- school social activities.	<ul> <li>Findings</li> <li>Students with AS are often perceived as odd by their peers and are socially isolated.</li> <li>Particularly at risk during adolescence. Aware of differences but do not know what to do or why they are different.</li> <li>Outlines three case studies.</li> <li>Conclusion from the case studies</li> <li>All students had limited social opportunities. There was a paucity of friendships and few social activities although students had a social awareness and desire for friendships. None had a "best friend". All students were in inclusive settings but physical inclusion does not guarantee social inclusion.</li> <li>Practice implications</li> <li>Build a climate of</li> </ul>	Although too small a sample to be able to draw conclusions, this research provides fascinating and useful insights into the school and social experiences of adolescents with AS.

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				understanding and acceptance among peers and students – build in awareness of differences and disabilities in the school curriculum, provision of increased social opportunities and social skills training.  Classroom membership profoundly affected by classroom teacher. Teachers need information about AS.  Adolescence is a key time to target skills because students with AS begin to show a more mature interest in learning how to interact with peers more effectively.  Peer buddies and circles of friends may be effective.  Explore student's interest areas and incorporate in intervention (eg, create club around interest). This gives the student the opportunity to be presented in a more competent light.	
228	Broderick, C., Caswell, R., Gregory, S., Marzolini, S. & Wilson, O. (2002). Can I join the club? – a social integration scheme for	Reports on the effectiveness of a social skills group run for adolescents with AS aged 12-15 years in mainstream schooling.  Method: Measurement of 2	Self-report questionnaires. The Piers-Harris Children's Self Concept Scale, and a non-specified social skills	<ul> <li>Findings</li> <li>Students with Aspergers have recognised difficulties with social integration but there has been little evaluation of the strategies to overcome them.</li> <li>Negative social experiences</li> </ul>	A very brief report, but one which gives both baseline and follow-up data. Gains are reported in self-esteem for all participants post

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	adolescents with Aspergers Syndrome. Autism, 6: 427-431.  OBSERVATIONAL STUDY – SURVEY WITH QUESTIONNAIRE Level of Evidence: x	groups at 3 points in time: before group 1 started their club, at completion of group 1 and commencement of group 2, and at completion of group 2.	questionnaire (not clear if designed by researchers).	may leave children with low self-esteem and increase the risk of depression as they grow older.  Interventions are particularly warranted in early adolescence as this is when children develop increasing self-awareness.  Social skills training by itself is not sufficient as difficulty with generalisation needs to be addressed.  Outcome of training followed by support in the natural setting showed that skills increased and were generalised and that students gradually became more independent in new settings. (No long term follow-up on this study).	programme. Not enough information is given to comment on the effect on social skills. No indication is given of the number or characteristics of adolescents in each group, or whether groups were randomly assigned. Overall, an interesting paper on a seemingly promising programme. Unfortunately, the paper is so brief it is not possible to be clear on the quality of the research. An outline of the successful elements of this programme is available from the authors and this is likely to be a useful document to supplement the

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
					information reported here.
229	McGee, G. G., Morrier, M. J., & Daly, T. (1999). An incidental teaching approach to early intervention for toddlers with autism. Journal of the Association for Persons with Severe Handicaps, 24, 133- 146.  OBSERVATIONAL STUDY  Level of Evidence: ~ (programme description) x (evaluation study)	Describes the Walden Toddler Model programme in detail. Provides some preliminary efficacy data for the programme in which before and after data on language and social behaviour is reported for 28 children participating for 6 months.	Five minute video taped observations were scored for verbalisation and peer proximity.	<ul> <li>Incidental teaching developed to overcome generalisation problems of traditional behavioural interventions.</li> <li>Social engagement must be a first priority.</li> <li>Expressive verbal language, engagement with toys, social responsiveness to adults, social tolerance/imitation of peers, independence in daily living.</li> <li>Early childhood should be fun. Teaching occurs in the course of children's ongoing play ensuring children enjoy and cooperate with instructions. This fits with the traditional early childhood approach.</li> <li>Goals embedded in natural activities, supplemental one-to-one in natural contexts. One-to-one instruction when difficult to ensure a sufficient number of teaching episodes for a given skill from the natural environment.</li> <li>Early goals – encouraged to play near, play in the same or similar activities as their peers,</li> </ul>	This paper provides a detailed description of a programme that appears to be well grounded in research and includes many potentially useful elements. However, although outcome data showed improvements on both language and peer proximity there are no baseline data reported. Lack of these data means that the effect of child maturation and natural change over time cannot be excluded from the gains recorded. Thus further study on the efficacy of the programme is required.

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				watch other children and to imitate gross motor actions, sharing of materials.  • Walden Toddler Programme – 30 hours per week (combined home and centre input) and an incidental teaching approach.  • Programmes composed of: staff training, environmental arrangement, activity choices and family component (training, advocacy preparation, networks of support).  • Principles – early is essential, more is better, family involvement is critical, social development requires early inclusion.  • Involvement of the family critical – increases intervention time.  • Intervention must be carefully planned – children must be directly taught how to interact with one another.  • Environmental arrangement – child-selected teaching materials, systematic display and rotation of toys.  • At least a monthly assessment of sensory preferences that helps identify the attributes of toys that will be appealing.	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				Incidental teaching procedures     – vigorous speech shaping,     active social instruction, wait –     ask – say – show – do     procedure, promotion of     engagement, checklist-based     performance appraisals.	
230	Krasny, L., Williams, B. J., Provencal, S., & Ozonoff, S. (2003). Social skills interventions for the autism spectrum: Essential ingredients and a model curriculum. Child Adolescent Psychiatric Clinics of North America 12, 107-22.  NON SYSTEMATIC REVIEW  Level of Evidence: ~	Review of social skills training programmes outlining the elements that have been identified in a number of studies as critical to successful programmes.		<ul> <li>Reviews research which shows some gains from social skills groups but problems with generalisation.</li> <li>Outlines the PROGRESS CURRICULUM.</li> <li>Essential ingredients in group interventions:         <ul> <li>make the abstract concrete; define skills and problems, make if/then rules, use visual cues</li> <li>provide structure and predictability in sessions; use opening and closing rituals, transition routines</li> <li>provide scaffolding for language; provide models and scripts, group children by language ability, use visual supports</li> <li>provide multiple and varied learning opportunities</li> <li>include activities that necessitate a focus on another</li> </ul> </li> </ul>	Excellent guide to what is known to be useful in running social skills programmes.  Some methodological issues in the studies eg, lack of reporting on generalisation.

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				person; work groups or pairs, foster cooperation, highlight peers' preferences and interests  • foster self-awareness and self-esteem; identify individual strengths – examine ASD strengths and positive attributes  • select ecologically relevant goals  • programme in a sequential and progressive manner; simplify complex behaviours into specific skills, integrate and practise mastered skills together  • provide opportunities for programmed generalisation and ongoing practise; schedule activities in other settings, practise with varied people, collaborate with parents and teachers.	
231	Strain, P. S. (2001). Empirically based social skill intervention: A case for quality-of-life improvement. Behavioural Disorders, 27, 30–6.	Review and summary of research conducted by one research team 1974 - 2001. Outlines some useful general principles relating to teaching social skills to children with ASD.		<ul> <li>Research has questioned assumptions about assessment of social behaviour, the most important foci of change, and the best intervention agents.</li> <li>Early efforts to explain poor generalisation focused on poor instructional strategies or learner characteristics. The</li> </ul>	A useful summary of the results and understandings gained from one team's research. Limited by the lack of scope of the review in referencing and

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	EXPERT OPINION – THEORETICAL PAPER Level of Evidence: x			current author's research suggests generalisation is dependent on the responsiveness of peers and the social integration of the setting itself.  Previously the focus for intervention was on the deficits in the child's behaviour. This resulted in an endless range of skills to be taught.  Conclusions from this research: (1) Use of adults as mediators leads to poor generalisation, diverse peer interventionists successful (including other children with disabilities), socially responsive settings were associated with generalised responding, entire social ecology target of intervention. (2) Diagnostic categories are poor predictors of intervention responsiveness (the only consistent predictor is intervention fidelity), interventions should focus on 'goodness of fit' between child and environment, interventions should be adjusted to meet the needs of the child eg, intensity, motivational systems etc. (3) Assessment focus has moved	positioning the findings against other author's research.

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				from discrete behaviours to an observational coding system, which acknowledged the reciprocal nature of social behaviour – who does what with whom and effect on social behaviour. Includes observations of social behaviours such as sharing, asking someone to play, demonstrating affection.  • Assessment of outcomes shows extra development in peer trainers in comparison with other socially successful children. After working as a peer trainer, children showed fewer disruptive behaviours, were socially more competent with other children, and were more positive and accepting of disabilities.  • Studies of the behaviour of children who have friends (whether with disabilities or not) highlighted the importance of 4 essential skills – sharing, organising play by making suggestions, assisting others, and showing affection.  • Also important to have exchanges of a minimum length (not just a matter of time	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				but also the number of turns – for pre-schoolers at least 4 turns). Interaction pattern should be reciprocal (ie, an equitable ratio of turns).  If these skills are the target, good maintenance and generalisation is seen over a 5 year period. Also improves quality of life.  Where generalisation occurs, it is attributable to high levels of peer responsiveness.  Day-to-day variability in social behaviour is a direct consequence of peer responsiveness.  Developmentally integrated settings have a facilitative impact (autism only settings have been found to be 'toxic' for social behaviour development).  Access to more inclusive settings is the most effective strategy.  Consequence of immediate reinforcement by adults was termination of the child-to-child interaction and move of focus to the adult.  Peers are the most successful instructional agents.	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				<ul> <li>Criteria for peer selection: must attend school regularly, display positive initiations during free play, must follow adult directions reliably.</li> <li>Process for training peer: explanation of the task, training to expect rejection through role play, practice with adult to make social bids (ie, request to play accompanied by handing a toy – toys are selected on the basis of the preference of the child with ASD).</li> </ul>	
232	Smith Myles, B. Simpson, R.L. (2001). Understanding the hidden curriculum: an essential social skill for children and youth with Asperger Syndrome. Intervention in School and Clinic 36: 279- 286.  EXPERT OPINION Level of evidence: x			Discusses the theory of the hidden curriculum and gives practical suggestions for helping children and youth learn using this technique.	
000		,			
233	Greenspan, S.I.	n/a	n/a	n/a	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	Weider, S. (2003). Engaging autism: the Floortime approach to helping children relate, communicate and think. Da Capo Press. BOOK				
234	Sherratt, D. (2002) Developing pretend play in children with autism. <i>Autism</i> , 6(2): 169-179  CASE SERIES  Level of evidence: ~	5 children aged between 5 & 6 years, all with a diagnosis of autism and additional learning difficulties.  The intervention was across 4 months and took place in a special school.  A multiple baseline design across subjects was used with 3 phases of about 5 weeks. Phase 1 – Teacher modelled a play script then invited children to play using the same materials. Simple symbolic transformations were used. Children watched the teacher and peers at play on video as well as participating in play scenarios. Phase 2 – Teacher selected materials and set parameters	Pre test & post test  None of the children had used any symbolic play when observed formally and informally.  Reynell Language Development Scales showed all children had verbal comprehension less than 34 months.  Non-verbal comprehension of under 66 months for all children.  Test of Pretend	During the course of the 4 months the 5 children were able to exhibit some symbolic acts within unprompted settings.  The most able participants were able to include complex symbolic manipulations within their play and show some spontaneous symbolic play in unstructured settings.	Individual scores are given in the text.

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
		of play by example. Multiple transformations were used. Children observed teacher and then played in pairs. Phase 3 – Teacher gave no guidance but suitable materials were freely available. Children were shown a video replay of any spontaneous play.	Play and the Symbolic Play Test was used for the developmental level of each child's symbolic play (all children scored at three years 9 months or below on these tests.  (Researchers warn standardised test scores should be treated with caution because of the difficulty of testing these children. One child refused the post intervention test.)		
235	Gray, C. Garand, J. (1993). Social stories: improving responses of students with autism with accurate social information. Focus on Autistic Behavior, 8: 1-10.	Expert opinion. A descriptive paper by one of the proponents and originators of social stories. No evaluation included.		The article explains how social stories can help improve the behaviour and learning of children with autism.	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
236	EXPERT OPINION  Level of evidence: x  Scattone, D., Wilczynski, S., Edwards, R. (2002). Decreasing disruptive behaviours of children with autism	Multiple baseline across participants. 3 children with diagnoses of autistic disorder.	Observers recorded data using a 10 sec cued partial interval recording system	All students recorded a decrease in disruptive behaviour Boy 1 – 50% to 4.6% Boy 2 – 66.9% to 18.75% Boy 3 – 18.15% to 5.1%	
	using social stories. Journal of Autism and Developmental Disorders 32 (6) 535 -543  CASE SERIES  Level of evidence: ~	<ul> <li>Boy 1 – 7 years old</li> <li>Spoke in complete sentences and was capable of reading</li> <li>IQ – 40</li> <li>Peabody Picture Vocabulary Test – 40</li> <li>Expressive vocab tests – 40</li> <li>Boy 2 – 15 years old</li> <li>Capable of reading</li> <li>Kaufman Assessment Battery for Children (Mental processing composite) – 82</li> </ul>	during 20 minute observations 3 times per week during baseline and intervention. Occurrence of target behaviours was recorded. Teacher acceptability of the social stories was also rated.		
		<ul> <li>Boy 3 – 7 years old</li> <li>Not able to read</li> <li>Kaufman – Assessment Battery for children (Mental processing composite) – 67</li> <li>Social stories were developed</li> </ul>			

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
		which related to particular disruptive behaviours for each child.			
237	Hutchins, T. and Prelock, P. (2006). Using social stories and comic strip conversations to promote socially valid outcomes for children with autism. Seminars in Speech and Language 27 (1) 47-59  CASE SERIES Level of evidence: x	A-B design Participants were a 6-year-old boy with ASD who was verbal and a 12-year-old girl with diagnosis of ASD and seizure disorder.  Autism Diagnostic Observation Schedule was used to confirm diagnosis - confirmed for both children Peabody Picture Vocabulary Test (3 <sup>rd</sup> ed) was used to assess receptive language Boy – standard score of 97 Girl – standard score of 64  A personal history (semi- structured interview) was used to collect data on the nature of the child's educational setting, parent participation, child functioning and to identify social situations which the child found difficult.	Parent diaries were kept (baseline for 2 weeks and during 6-week intervention period) for general impressions of specific behaviours targeted by the Social Stories and Comic Strip Conversations. Parents also rated behaviour on a 10 point Likert-type scale.	Boy – reports suggest a high rate of success (scores of 10) after the 8 <sup>th</sup> day of intervention.  Girl – reports suggest no change from the baseline to the intervention phase.  Hypothesis about factors possibly contributing to different outcomes:  • level of receptive and expressive language  • severity of ASD  • age.  Conclusion – further research needed to identify factors associated with specific outcomes.	
238	Watling, R. L., Deitz, J., & White, O. (2001). Comparison of sensory profile	Describes the sensory based behaviours of children with ASD aged between 3 and 6 years as reported by their	Sensory Profile completed by parents.	<ul> <li>Sensory and perceptual abnormalities common.</li> <li>Quotes Dawson and Watling:</li> </ul>	The Sensory Profile questionnaire measures General Processing,

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	scores of young children with and without autism spectrum disorders. American Journal of Occupational Therapy, 55, 416-23.  OBSERVATIONAL STUDY – COMPARATIVE SURVEY  Level of Evidence: ~	parents. Method: Group comparison design. 40 children with autism matched with a group of 40 children without ASD and compared on sensory characteristics.		<ul> <li>30% to 100% of children with ASD have sensory processing abnormalities.</li> <li>Much of the research has weak methodology.</li> <li>Study showed hypo and hypersensitivities.</li> <li>Parent report may be unreliable and therefore the Sensory Profile should be used in conjunction with clinical observations and other measures.</li> </ul>	Auditory Processing, Visual Processing, Tactile Processing, Vestibular Processing, and Oral Sensory Processing. The tool was normed on children aged 3-10 years and was assessed by the Mental Measurements Yearbook as having good veracity as a measure of sensory sensitivity.
239	Smith Myles, B. S., Cook, K.T., Miller, N.E., & Rinner, L. (2000). Asperger Syndrome and sensory issues: Practical solutions for making sense of the world. Shawnee Mission, KS: Autism Asperger Publishing.  EXPERT OPINION – BOOK	Explains sensory processing and integration, and describes the behaviours children with Asperger Syndrome may exhibit if experiencing sensory difficulties. Gives practical solutions for assisting.		Table about the location and function of the sensory system. Information on Sensory Profile (Dunn, 1999).	Uses a non-technical style, and is aimed at parents, teachers and teacher aides. The low evidence rating reflects the lack of relevant citations. However, it should be kept in mind that this is intended as a practical resource rather than an authoritative

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
240	Level of Evidence: x  McLaren, S. (2005).	30 teachers, parents, and	Questions focused	Children with auditory processing	No information was
	Noise and at risk children in early childhood education centres. Early childhood Folio. 9 39-43  SURVEY – EXPERT OPINION  Level of evidence: x	other educational professionals participated in open-ended questionnaires or interviews about the effect of noise in early childhood centres.  The focus children had hearing impairment, otitis media, Down syndrome, ASD, ADHD, speech difficulties and/or developmental delay or the children were gifted.	on how noise affects these groups in terms of responses, behaviour, ability to communicate and learn.  Participants were also asked to identify strategies that could be implemented to control noise and identify areas of concern.	difficulties, particularly those with ASD, and the gifted, appeared to be most affected. Lack of quiet spaces was identified as one of the most pressing issues which affect the integration of children with special needs. Alarms and sirens caused distress.  Recommendations Provision of suitable quiet spaces. Coverage of noise issues should be covered in Education Early Childhood Centre Regulations. Early childhood centres should be treated as sensitive activities when construction noise is in the vicinity. A resource kit should be developed for the early childhood sector on the management and control of noise.	given about who had made the diagnoses of the children.
241	Marr, D. Mika, M. Miraglia, J. Roerig,	4 boys and 1 girl who attended a pre-school programme for	<ul><li>Sensory Profile</li><li>Time sampling</li></ul>	Three of the children showed significant improvements in	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	M. & Sinott, R. (2007). The effect of sensory stories on targeted behaviours in preschool children with autism. Physical and Occupational Therapy in Pediatrics 27 (1) 63-77.  CASE SERIES  Level of evidence: ~	children with autism. All had a diagnosis of autism Aged between 4 years 8 months and 5 years 2 months Inclusion criteria included:  • hypersensory modulation issue by scoring in the 'definitive difference' on at least one subset of the sensory profile.  • understood a simple story as rated by the classroom teacher  • free of visual and hearing impairments  • have approximately the same amount of time spent in other services eg, therapy  • display at least one behaviour that interferes with education as identified by their teacher.  (One participant dropped from study because of repeated absences).  • A 5-day baseline where targeted behaviour was recorded and a nonsensory story was read on a one-to-one basis three	data form developed by the authors used to record targeted behaviours.	targeted behaviours during the intervention phase.  The 4th child's behaviour improved in the baseline stage suggesting that the one-to-one attention from the teacher reading the story may have effected change.  3 of the 4 children showed an increase in their targeted behaviours when the sensory stories were stopped.	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
		times per day.  Intervention phase for 12 days. The individualised sensory story was read to participants 3 times per day.  Post intervention (5 days). The reading of the sensory stories ceased and another story was read.			
242	National Autistic Society. Accessible Schools: Increasing access for disabled pupils. Retrieved 25 <sup>th</sup> October, 2005, from: <a href="http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=245&amp;a=2381">http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=245&amp;a=2381</a> .  EXPERT OPINION – REPORT Level of Evidence: x	Gives some possible suggestions for adjusting school environments to accommodate the sensory needs of children with ASD.		Recommendations Small alterations to the physical environment of the school can have significant benefits:	Although recommendations have good face value they are not comprehensive, and there is no attempt to ground suggestions by citing relevant literature.
243	Happe, F. (1994).  Autism: an introduction to psychological theory. Cambridge, Mass.: Harvard University	Outlines various theories of autism, and reviews research on diagnosis, social and communication aspects of ASD.		<ul> <li>Behavioural therapies and education can have enormous impact but core biological and cognitive deficits cannot be cured.</li> <li>Central coherence: This is the</li> </ul>	The author is a research scientist with the British Medical Council. She was one of the pioneers of

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	Pr.  EXPERT OPINION – BOOK  Level of Evidence: ~			ability to draw together diverse information to construct higher level meaning in context. "Seek out experiences and make a coherent story from them" (Wing, 1981). (1) Language taken literally without appropriate regard for the context. (2) Tendency to focus on the parts rather than seeing the whole – words may be processed singly without consideration for the context of the sentence. Seen as a cognitive style rather than a deficit and is an advantage on some tasks. Fragmentary processing may lead to resistance to change.  Theory of mind: This is the ability to understand that people have beliefs and desires about the world and that it is these mental states that determine a person's behaviour. People with autism lack ability to think about thoughts and so are impaired in some social, communicative and imaginative skills.  Executive function: covers a multitude of higher cognitive capacities and overlaps with	research exploring theory of mind in autism.

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				the other theories.	
244	Connor, M. (1999). Children on the autistic spectrum: Guidelines for mainstream practice. Support for Learning, 14, 80-6.  EXPERT OPINION - TRAINING INFORMATION  Level of Evidence: ~	A brief summary of ASD intended for teachers and classroom assistants including definition, incidence, causes, identification, key features, intervention and management, and classroom strategies.		Explanation of ASD models:  Theory of mind (Baron Cohen, 1998):  • ondividual cannot readily appreciate the feelings, knowledge or beliefs in other people nor fully recognise or interpret his own thought processes.  • leads to stilted language interaction, lack of social consciousness and weakness in understanding social situations.  Also lists stimulus over-selectivity – refers to responding to only part of a stimulus rather than the whole (also occurs in social situations – inability to hold 'multiple attention'). Stress can result from over stimulation.  Central coherence:  • inability to use context or to generalise from one task or setting to the next. Each experience is discrete and no overall pattern is perceived – leads to difficulties in planning ahead, self-organisation.	A good introductory article. Its main strength is in the section on classroom strategies, which gives clear and concrete suggestions likely to be of immediate assistance for teachers.

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				Structure helps this difficulty – the individual tends not to learn by observing the experience of other children – may need direct teaching.	
				Literalness in language usage:  • particular problem with instructions.	
				<ul> <li>Weakness in gaze monitoring:</li> <li>pragmatic language assumes both speaker and listener are focusing on the same thing</li> <li>some of these cognitive difficulties may explain why more is needed than the traditional ABC approach to problem behaviour ie, the adult's perception of antecedents and consequences may be very different to the child's</li> <li>classroom practice needs to take into account: lack of generalisation, lack of incidental learning, literalness of understanding, difficulty with group activities, reaction to over stimulation, range of meanings which may be behind apparent non-compliance.</li> </ul>	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				Other strategies  Clear structure and daily routine, using clear and unambiguous language, making clear which behaviours are acceptable, not asking rhetorical questions, providing a warning of a change of routine or activity, ensuring consistency among all staff, change in manner or behaviour may come from stress, specific teaching of social rules and how feelings are expressed, protecting the child from teasing, into how and why questions, charts to record progress and reinforcement, enhanced supervision during practical or physical activities.	
245	Magiati, I., & Howlin, P. (2001). Monitoring the progress of preschool children with autism enrolled in early intervention programmes. <i>Autism</i> , 5, 399-406.  OBSERVATIONAL STUDY  Level of Evidence: ~	Compares the Bayley, Merrill-Palmer, and Vineland scales for cognitive assessment.  Method: 24 children with ASD aged 27-58 months (mean 39.6) were assessed on the same day on the Bayley and Merrill-Palmer scales. The Vineland scale was also completed (it is unclear when this was done) scores were compared across the three	Comparative scores on the Bayley, Merrill-Palmer and Vineland scale.	<ul> <li>Findings</li> <li>Cognitive tests are not designed for children whose development is markedly delayed or uneven.</li> <li>The use of standardised tests with children has been criticised amongst some practitioners as inappropriate and invalid because of their communication difficulties and impaired social understanding (Koegel, Keogel and Smith,</li> </ul>	No information given about whether the order of testing was randomised (ie, which tool was used first). Giving 2 full intelligence scales to a child in one day, given the length of time and concentration required by the

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
		instruments.		<ul> <li>Despite the problems, standardised tests remain one of the most efficient means of measuring children's functioning across a range of different abilities.</li> <li>Care is required in the interpretation of the test scores especially with young children.</li> <li>Apparent changes in IQ may be owing to variability in the use of different tests at pre and post testing.</li> <li>Particularly challenging with pre-school children as most infant tests span a limited age range.</li> <li>Recommendations</li> <li>The same measures should be used at pre and post test whenever possible.</li> <li>No initial or follow-up assessment should rely on a single measure.</li> <li>Language assessments should always be included as part of the overall assessment to establish whether some difficulties might be owing in some part to the child's inability to understand instructions.</li> </ul>	child to complete these tests, could affect results on the second instrument owing to fatigue, or lack of motivation. If no randomisation was used this may have influenced the findings. The Vineland, being a parent report scale, will not have been affected by this.

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
246	Brownell, M. T. & Walther-Thomas, C. (2001). Steven Shore: Understanding the autism spectrum: What teachers need to know. Intervention in School and Clinic, 36, 293-9, 305.  EXPERT OPINION – PERSONAL EXPERIENCE  Level of Evidence: ~	An interview with Steven Shore, author of 'Beyond the wall: Personal experiences with autism and Asperger Syndrome'. Covers general information about ASD, and tips for teachers, as well as Steven's personal experiences of autism.		<ul> <li>Students with Asperger         Syndrome may show some of         the following characteristics –         selective attention particularly         towards special intellectual         interests (teachers should use         this to engage students in         learning and socialization);         literal interpretation of         language; difficulty in         prioritising and organising         tasks; difficulty absorbing and         processing changes.</li> <li>Without structure a child may         feel as though they're drowning         in a million subtasks – difficulty         in prioritising and organising         tasks.</li> <li>Students may need to develop         accommodations rather than         always trying to master work         and study skills eg, recording or         getting a copy of notes rather         than trying to take notes form         verbal presentations.</li> <li>Teachers should build on         students' interests – helps keep         them focused, engaged and         motivated and serves as a         bridge to new topics and skills.</li> <li>Students need support to         maintain focus and         concentration.</li> </ul>	Highly valid as first-hand information on ways in which children with ASD may be helped to feel more comfortable at school.

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
247	Harrower, J. K., & Dunlap, G. (2001). Including children with autism in general education classrooms: A review of effective strategies. Behavior Modification, 25, 762-84.  NON SYSTEMATIC REVIEW  Level of Evidence: ~	Reviews the research on methods for promoting successful inclusion of children with autism into mainstream classrooms.		<ul> <li>Strategies discussed</li> <li>Pre task sequencing:         embedding a difficult request in         a series of short, easy requests         and reinforcing compliance with         easy requests</li> <li>Pivotal response training:         increase motivation by         incorporating choices,         reinforcing attempts, modelling,         and natural consequences,         incorporating maintenance         trials, increasing         responsiveness to multiple         cues, teaching self-         management and self-initiation</li> <li>Useful strategies for altering         routines and environments         (antecedents): priming, prompt         delivery, picture scheduling</li> <li>Self-management: involves         teaching the student to         discriminate between         appropriate and inappropriate         behaviour, monitor behaviour         over time, reinforce own         behaviour</li> <li>Peer mediated interventions:         peer tutoring, utilising peer         supports to improve social         interaction skills, cooperative         learning</li> </ul>	Provides practical suggestions for promoting inclusion, which are clearly based on research evidence.

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				<ul> <li>Multi component interventions: combination of a variety of approaches, eg, buddy systems with information for classmates</li> <li>Delayed contingencies: increase independent functioning.</li> </ul>	
248	Horner, R. H., Carr, E. G., Strain, P. S., Todd, A. W. & Reed, H. K. (2002). Problem behaviour interventions for young children with autism: A research synthesis. Journal of Autism and Developmental Disorders, 32, 423-46.  SYSTEMATIC REVIEW  Level of Evidence: ~	Summarises meta-analyses of behavioural research since 1988, and publications on behavioural intervention for ASD published between 1996 and 2000. Outlines the elements common to successful behaviour support for children with ASD.		<ul> <li>Findings</li> <li>Young children with ASD are at risk of developing problem behaviours.</li> <li>If behaviours are not addressed they will maintain or worsen.</li> <li>Most studied behaviours aggression/destruction, disruptions/tantrums, self injury and stereotypy.</li> <li>'Waiting out' problem behaviours in the hope that children will grow out of them is not effective.</li> <li>Problem behaviours are maintained by their functional effect.</li> <li>Early use of behavioural interventions can reduce problem behaviours by 80% to 90%.</li> <li>Prevention:</li> <li>Interventions recently developed are stimulus-based</li> </ul>	Literature selection is well described. Findings are usefully summarised and clearly reflect the literature.

No Type and Rating	
and instruction-based – used to be emphasis on consequence based.  • Use strategies such as – change the physical characteristics of the setting, after schedules, modify curriculum and redesign social groupings.  • Change from changing individuals to fit the environment to changing the environment to thanging the environment to match the needs of the child.  Functional assessment  • Those interventions developed from functional assessment are most likely to be successful (concern that many interventions reported do not adequately use assessment information when planning the intervention).  • Identifies problem behaviour, identifies antecedents for both occurrence and nonoccurrence, and identifies the events that maintain the behaviour. Data collection from direct observation to confirm variables.  • Build an intervention that	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				controls stimulus event, teaches socially appropriate behaviour that makes the child more competent and has the same function as the problem behaviour, organises consequences to prevent reinforcement of problem behaviour and reinforces competing behaviour.  Fits with the values and systems of those who carry out.  Comprehensive interventions Characteristics Interventions should address all problems, be driven by functional assessment outcomes, be applied across all of the child's day, typically incorporate multiple intervention procedures, fit the context where they are implemented. No particular interventions are uniquely effective for children with ASD. Important elements: organise environments to maximise contingent access to rewarding activities and outcomes, minimise presentations of aversive events.	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				<ul> <li>Environments should have the following features: high level of child engagement, access to preferred activities and rewards, consistent and predictable scheduling, access to typical peers, effective system of communication.</li> <li>Very important to identify the reinforcers specific to a given individual.</li> <li>Systems change which may be needed to support programmes:         <ul> <li>Less well developed literature</li> <li>3 aspects:</li></ul></li></ul>	
				Key features of environments to	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				prevent behaviour problems:  • high level of child engagement, access to preferred activities, consistent and predictable scheduling, access to typical peers, effective system of communication.	
				<ul> <li>Successful interventions</li> <li>Control of stimulus based events.</li> <li>Teach socially appropriate behaviours that make the child more competent in the environment and produce the same effect as problem behaviours.</li> </ul>	
				<ul> <li>Major findings</li> <li>Behavioural interventions are effective.</li> <li>Functional assessment increases the likelihood of success.</li> <li>Typical agents for the intervention improve effects.</li> <li>Systems change increases the likelihood of success.</li> </ul>	
249	Meyer, L. & Evans, I. (2006). Literature review on intervention with challenging	Multi method review including a meta analysis.  The focus of the review is children and youth who have		Relevant conclusions:  • There is no meaningful evidence of difference in treatment responsiveness for children diagnosed with ASD in	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	behaviour in children and youth with developmental disabilities. Report prepared for the Ministry of Education, Wellington, New Zealand  REVIEW AND META-ANALYSIS  Level of evidence: +	behaviour challenges and a diagnosis of intellectual disability, developmental delay, severe learning difficulties, severe traumatic brain injury and /or autistic spectrum disorder		comparison to children with other diagnoses.  • Skills replacement training outperformed other single treatments (eg, antecedents or consequences) and performed best in combination with systems change.	
250	Mullins, J. Christian, L. (2001). The effects of progressive relaxation training on the disruptive behaviours of a boy with autism. Research in Developmental Disabilities, 22: 449- 462 CASE STUDY Level of evidence: ~	12 year old boy diagnosed with autism and mild mental retardation who was receiving special education services from a local elementary school and home-based behavioural intervention services.  Target behaviours were disruptive vocal and non-vocal behaviours occurring when the child was alone, had low levels of supervision or was in demanding or stressful situations from which he wanted to escape.  Progressive relaxation procedures were taught. Three conditions were used to	Behavioural relaxation scale used to measure behaviours before and after training. Leisure sessions were videotaped.	<ul> <li>Participant acquired progressive relaxation skills.</li> <li>Displayed more relaxed behaviours after performing procedures.</li> <li>Showed a decrease in duration of disruptive behaviours after completing relaxation training prior to a leisure activity.</li> </ul>	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
		determine the effects during leisure activity sessions: relaxation training prior to leisure session cued relaxation no relaxation prior to session (baseline)			
251	Johnston, S. S., & O'Neill, R. E. (2001). Searching for effectiveness and efficiency in conducting functional assessments: A review and proposed process for teachers and other practitioners. Focus on Autism and Other Developmental Disabilities, 16, 205-14.  NON SYSTEMATIC REVIEW  Level of Evidence: ~	Reviews literature on differing approaches to assessment and functional analysis. Approaches outlined include direct and indirect assessment, and descriptive and experimental analysis of behaviour.		<ul> <li>Findings</li> <li>Staff who work with students with problem behaviours can accurately identify some of the variables.</li> <li>Steps in functional assessment: Describe the problem behaviour; identify the events and circumstances that are associated with occurrence; identify the consequences; develop hypotheses regarding the social function or purpose of the behaviour; collect direct observational data that support the hypotheses (gives useful flowchart of questions to ask at each step).</li> <li>Direct (observations) and indirect (interviews checklists etc.) are both helpful forms of data collection. These should be collected by those most familiar with the child. Which to use is based on the extent of</li> </ul>	A good summary of an area of behaviour modification that is often confusing for educators. Gives sensible suggestions for developing assessment-based interventions.

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				prior knowledge held by the team.  • Functional analysis (experimental manipulation not recommended when behaviour may put self and others at risk).  • Sometimes validation of the hypotheses by intervention may be appropriate rather than collecting more data.  • Some support plans do not relate to assessment but are more like the plans they would have done prior to assessment.	
252	Dunlap, G., Hieneman, M., Knoster, T., Fox, L., Anderson, J., & Albin, R. W. (2001). Essential elements of in-service training in positive behavior support. Journal of Positive Behavior Interventions, 2, 22- 32.  EXPERT OPINION – THEORETICAL DISCUSSION Level of Evidence: ~	Outlines the process of inservice training for positive behaviour support – a set of assessment and intervention strategies aimed at reducing problematic behaviour. Presents a proposed core curriculum for building the skills needed to practice positive behaviour support, and describes a team training model, which has already been widely adopted in the US.		Recommendations: Positive behaviour support — outgrowth of ABA. Contrasts with traditional management strategies, which focus on manipulation of consequences and punishment. Based on person-centred values, reductions in undesirable behaviours and increases in desirable behaviours, access to richer and more satisfying lifestyles.  Training needed in the following: establishing a collective vision and goals for intervention (understanding of contexts and functions affecting a person's	Notes that a great deal of research of effectiveness has been documented in home, community and school settings.  Gives a template for planning inservice training in positive behaviour support. Dunlap is a leading researcher in the field of behaviour support, and ASD intervention.

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				behaviour, nature of the environment, and people who support the individuals)  collaborating and building teams among families and professionals. Conducting functional assessment (including child's history, preferences and circumstances). Designing comprehensive behaviour support plans – proactive, educative and functional in nature  implementing intervention strategies  monitoring and evaluating outcomes – ongoing process of assessment, planning and intervention and evaluation  infusing positive behaviour support into broader systems eg, school, family and community – this leads to generalisation  training through multidisciplinary team collaboration; case study format; dynamic training process (with examples, activities, practise and feedback); comprehensive training – broadening of	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				effective intervention perspectives; networking, systems change and community building.	
				<ul> <li>support plans using positive behaviour support usually contain multiple elements, including antecedent, consequence and contextual manipulations all of which are identified on an individual basis</li> <li>plan for durable change through environmental manipulation, skills development, and lifestyle enhancement (good contextual fit – resources, needs and routines as well as individual and the rest of the team)</li> <li>short term prevention and crisis management may be an important part of the plan.</li> </ul>	
253	Gresham, F. M., Beebe- Frankenberger, M. E., & MacMillan, D. L. (1999). A selective review of treatments for children with autism: Description and methodological considerations.	Outlines and critiques several ASD treatment programmes and evaluates the empirical evidence relating to each.		<ul> <li>Recommendations</li> <li>Treatment should be based on individual assessment information that dictates particular treatment procedures for a given child.</li> <li>No new treatment should be implemented until an assessment determines whether it will be appropriate</li> </ul>	Presents an appraisal of existing treatments and their evidence.

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	School Psychology Review, 22, 559-75.			for a specific child with ASD.	
	NON SYSTEMATIC REVIEW				
	Level of Evidence: ~				
254	Meyer, L. H., & Evans, I. M. (1989). Nonaversive intervention for behavior problems. Baltimore: Paul Brookes.  EXPERT OPINION – BOOK Level of Evidence: ~	Provides a summary of evaluation methods, and ways to judge meaningful outcomes, which can be used in designing interventions to target problem behaviour.		<ul> <li>Evaluation of outcomes of interventions for problem behaviours</li> <li>Improvement in target behaviour.</li> <li>Acquisition of alternative skills and positive behaviours.</li> <li>Positive collateral effects and absence of side effects.</li> <li>Reduced need for medical and crisis management services for self and for others.</li> <li>Less restrictive placement and greater participation.</li> <li>Quality of life improvement – happiness, satisfaction, choices.</li> <li>Perception of improvement by family and significant others.</li> <li>Expanded social relationships and informal support networks.</li> </ul>	
255	Harrison, J. (1998). Improving learning	Reviews research to suggest strategies to enhance learning		Findings  Other students need to	Effectively ties research to
	opportunities in	in students with ASD in		understand the particular	practice.

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	mainstream secondary schools and colleges for students on the autistic spectrum. British Journal of Special Education, 25, 179-83.  NON SYSTEMATIC REVIEW – THEORETICAL PAPER  Level of Evidence: ~	mainstream schools.		<ul> <li>interests of the student with ASD and understand their reactions when they're anxious or upset.</li> <li>Secondary schools pose challenges – through the need to respond to many different adults and peers, different classes and expectations.</li> <li>Difficulties may occur from: over selectivity, tendency to process only one cue or component, storing of irrelevant details, failure to recognize crucial pieces of information or the point of information.</li> <li>Helped by – highlighting key words, a personalised plan of the school, personal routines, explanations about changes in routines, teaching problemsolving, recognising and discarding irrelevant information, memorising and retrieving information.</li> <li>Schools can help by helping the student to make connections (research shows that this is most likely to happen in the mainstream where functional reinforcers are plentiful and good role models exist). Increasing tolerance</li> </ul>	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				towards the student. Improving the self-management of the student. Developing parent partnerships.	
256	Ministry of Education (2001). Schooling in New Zealand: a guide.  REPORT  Level of evidence: ~			This guide to schools in NZ looks at the school system, what schools teach and how schools are run.	
257	Snell, M.E., Janney, R. (2000). Collaborative Teaming. Baltimore: Paul H. Brookes. BOOK	n/a	n/a	n/a	

## **EVIDENCE TABLES FOR PART 4: TREATMENT AND MANAGEMENT OF ASD**

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
258	Howlin, P. (1998). Practitioner review: psychological and educational treatments for autism. Journal of Child Psychology & Psychiatry, 39(3), 307-322.  NON SYSTEMATIC REVIEW Level of evidence: ~	Review (search not described).		Reviewed studies up to 1996, findings were:  • positive results for intensive behavioural programmes, TEACCH educational programme, other educational approaches, and early intervention programmes  • mixed results for pharmacological treatments and music therapy  • some or small benefits for gentle teaching and vigorous physical exercise  • little difference detected for auditory integration training  • few benefits for facilitated communication  • inconclusive results for the 'option method', sensory integration therapy, pet therapies  • unproven scotopic sensitivity training (Irlen lenses), holding therapy, Dolman-Delacato method, Higashi Schools and daily life therapy, cranial osteopathy, psychotherapy and dietary and vitamin treatments.	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				No single mode of treatment ever likely to be effective for all children and families.	
				Intervention should be based on individual needs.	
				Many challenging behaviours result from the child's fundamental difficulties in communication and social understanding, or from ritualistic and obsessive tendencies.	
259	Attwood, T. (2003). Frameworks for behavioral interventions. Child and Adolescent Psychiatric Clinics of	Expert opinion.		Examines the developmental stages, and the cognitive behavioural model, to accommodate the profile and skills of people with Asperger Syndrome.	Tony Attwood is an internationally respected professional who has an extensive knowledge of ASD.
	North America, 12, 65-86.  EXPERT OPINION  Level of evidence: x			Describes alterations necessary and appropriate inputs.	
260	Bradley, E. A., Summers, J. A., Wood, H. L., & Bryson, S. E. (2004). Comparing rates of psychiatric and behavior disorders in adolescents and	Cohort study of 8 males and 4 females with ASD and severe intellectual disability (mean age 16.3 years). Controls matched by age, gender and non-verbal IQ.	<ul> <li>Autism         Diagnostic         Interview –         Revised (ADI-R).</li> <li>Diagnostic         Assessment for</li> </ul>	Findings Participants with ASD showed significantly greater disturbances in 7 out of 13 subscales of DASH-II.	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	young adults with severe intellectual disability with and without autism.  Journal of Autism & Developmental Disorders, 34(2), 151-161.  OBSERVATIONAL STUDY – QUALITATIVE  Level of evidence: +		the Severely Handicapped – II (DASH-II).		
261	Green, J., Gilchrist, A., Burton, D., & Cox, A. (2000). Social and psychiatric functioning in adolescents with Asperger syndrome compared with conduct disorder. Journal of Autism & Developmental Disorders, 30(4), 279-293.  OBSERVATIONAL STUDY – QUALITATIVE Level of evidence: +	Cohort study of 20 male adolescents with Asperger Syndrome and 20 male adolescents with severe conduct disorder.	Social and Emotional Functioning interview (SEF).      Isle of Wight Semistructured Informant and Child Interviews (IOW).	<ul> <li>Findings</li> <li>AS group showed severe impairments in practical social functioning despite good cognitive ability and lack of significant early language delay.</li> <li>High levels of obsessional disorders found in AS group.</li> <li>Both groups had high levels of depression, suicidal ideation, tempers, and defiance.</li> </ul>	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
262	Howlin, P. (1997).  Autism: preparing for adulthood. London: Routledge.  EXPERT OPINION Level of evidence: x	Book.		Psychological therapies, particularly those using a cognitive-behavioural approach may be used to repair the loss of confidence and self-esteem that often follows illness of this kind (ie, depression).	Patricia Howlin is an internationally respected clinician and researcher who has an extensive knowledge of ASD.
	20101 01 0110011001 %			Use of direct behavioural strategies can be very effective.	memeage or res.
				Interventions need to incorporate direct, practical advice about strategies for change. Introspection alone, even for very able clients, is rarely effective and may well prove counterproductive.	
				Families and individuals may be resistant to inpatient hospital treatment (fears of being misunderstood, more distressed because of upheaval, concerns about medication).	
				Relatively little study of medical treatments for psychiatric disturbances. Although in the past there have been overwhelming claims for effectiveness of certain drugs, there is little to substantiate these assertions.	
				Debate exists whether psychiatric disturbances are co-morbid	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				disorders or underlying symptoms of ASD.	
				Treatment is most appropriate when derived from comprehensive diagnostic and ongoing assessments.	
				No one option works for all people with ASD.	
263	Hare, D. J., & Malone, C. (2004). Catatonia and autistic spectrum disorders. <i>Autism</i> , 8(2), 183-195. NON SYSTEMATIC REVIEW Level of evidence: ~	Review (search not specified) and case study.  13 articles cited that refer to catatonia in people with developmental disorders. Most case studies.		<ul> <li>Findings</li> <li>Conclusion that autistic catatonia probably best considered as an expression of underlying ASD rather than a co-morbidity.</li> <li>Interventions should be derived from an understanding of the individual's sensory, perceptual and neurocognitive functioning, rather than from the diagnostic label of catatonia.</li> <li>Intensive structured behavioural interventions seem the most appropriate form of intervention.</li> </ul>	
264	Wing, L., & Shah, A. (2000). Catatonia in autistic spectrum disorders. <i>British Journal of Psychiatry</i> , 176, 357-	Cohort study of 506 people with ASD referred to a specialist clinic.	Semi-structured interview of carer or parent.	<ul> <li>Findings</li> <li>30 individuals (6% of referrals) met criteria for catatonia.</li> <li>17% of subjects aged 15 or</li> </ul>	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	362. OBSERVATIONAL STUDY – QUALITATIVE Level of evidence: +			above met criteria for catatonia.	
265	Clarke, D., Baxter, M., Perry, D., & Prasher, V. (1999). The diagnosis of affective and psychotic disorders in adults with autism: seven case reports. <i>Autism</i> , 3(2), 149-164. CASE STUDY Level of evidence: x	Case reports of 7 men (aged 16-47) with ASD.		No firm conclusions. ASD may increase vulnerability to psychoses.	
266	Dhossche, D. K., Wing, L., Ohta, M. & Neumarker, K. (Eds.) (2006). Catatonia in Autism Spectrum Disorders in Bradley, R. J., Harris, R. A. & Jenner, P. (Series Editors). (2006). International Review of Neurobiology, Volume 72.	Special edition of journal.		Covers catatonia in ASD in the following areas: classification, assessment, biology, treatment, and blueprints.  Based on limited evidence.  Strong calls for more research.	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	EXPERT OPINION				
	Level of evidence: x				
267	Frazier J, Doyle R, Chiu S, et al. (2002).	Case report of 13-year-old boy.		Symptoms of bipolar disorder undiagnosed for years.	
	Treating a child with Asperger disorder and comorbid bipolar disorder. <i>American</i>			Interventions of limited effect until bipolar disorder identified and treated.	
	Journal of Psychiatry. 159: 13- 21.			Important to assess for, and treat comorbid psychiatric disorders.	
	CASE STUDY				
	Level of evidence: x				
268	Bondy, A., & Frost, L. (2001). The Picture Exchange Communication	Descriptive article of advantages of using PECS over traditional approaches to communication.		PECS is a training system to teach children with ASD a rapidly acquired, self-initiated functional communication system.	
	System. <i>Behavior Modification</i> , 25(5), 725-744.			PECS combines behavioural and developmental perspectives.	
	EXPERT OPINION			Six phases taught:  • how to communicate	
	Level of evidence: x			<ul> <li>distance and persistence</li> <li>discrimination between symbols</li> <li>sing phrases</li> </ul>	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				<ul><li>answering a direct question</li><li>commenting</li></ul>	
269	Clements, J., & Zarkowska, E. (2000). Behavioural Concerns and Autistic Spectrum Disorders: Explanations and Strategies for Change. London: Jessica Kingsley Publishers Ltd.  EXPERT OPINION Level of evidence: x	Book.		Text described the use of behavioural techniques in ASD, with emphasis on ensuring safe, moral and ethical application of the technology.	
270	Myles, B., & Southwick, J. (1999). Asperger Syndrome and Difficult Moments: Practical Solutions for Tantrums, Rage and Meltdowns. Kansas: Autism Asperger Publishing Co. EXPERT OPINION Level of evidence: x	Book.		Practical text on behavioural and educational techniques.	
271	Howlin, P. & Yates, P. (1999). The	Description of group programme for 10 men with	Checklist completed by men	Programme over 1 year, 2.5 hours per month. Specific agenda	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	potential effectiveness of social skills groups for adults with autism. Autism, 3(3) 299-307.  OBSERVATIONAL STUDY  Level of evidence: x	autism or Asperger Syndrome, non-verbal IQ in normal range, mean age 28.4 years.	and their families.  Video monitoring of conversational ability.	(provided) and opportunity for men to respond to events of importance.  Teaching format included role-play, team activities, structured games, and incorporated feedback from video recordings.  Positive outcomes reports, but many methodological problems.  Support for adults with autism in the community is lacking.  More research is needed, but groups could provide significant support.  Format used was not very expensive or time-consuming.	
272	Mudford, O. C. (2004). Autism and pervasive developmental disorders. In J. L. Matson, R. Laud & M. Matson (Eds.), Behavior Modification for Persons with Developmental Disabilities (pp. 213-	Systematic review. Reference to previous systematic reviews and search of PsycINFO database between 1995 and November 2002.  At least 700 research reports identified between 1961 and late 2002.		<ul> <li>Findings</li> <li>Definitions vary and much research has methodological considerations.</li> <li>Interventions to reduce behavioural excesses are more likely to be individualised, constructional and guided by the results of functional assessment than was the case in the first three decades of research.</li> </ul>	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	252). Kingston NY: NADD Press. SYSTEMATIC REVIEW Level of evidence: +			<ul> <li>The emphasis on individualisation of intervention procedures contradicts any notion that behaviour change technology can be applied as if from a cookbook.</li> <li>Advocates for widespread early intensive behavioural interventions managed by parents and clinically directed by a self-declared 'ABA consultant' are advised to review the disappointingly equivocal preliminary research on that model of service delivery.</li> </ul>	
273	Herbert, J.D. Sharp, I.R., Gaudiano, B.A. (2002). Separating fact from fiction in the etiology and treatment of autism. The scientific review of mental health practice. 2002; 1(1):40.  NON SYSTEMATIC REVIEW  Level of evidence: ~	Review (search not specified).		Many bold claims made about treatment of autism. Often inconsistent with established scientific theory and unsupported by research.  Addresses theories on etiology of autism.  • Questionable treatments: sensory-motor therapies (facilitated communication, auditory integration training, sensory integration therapy), psychotherapies (psychoanalysis, holding therapy, Options therapy/SON	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				RISE).  • Promising treatments: applied behaviour analysis: (Young Autism Project/Lovaas, other comprehensive behavioural progammes such as LEAP, Denver Health Sciences Program, Project TEACCH), and psychopharmacotherapy.  Although promising ABA data exist, claims of 'cure' and 'recovery' from autism are misleading and irresponsible. Difficult to justify in light of extant scientific literature on ABA programmes for autism.	
274	Green, C. J., Bassett, K., & Kazanjian, A. (2000). Critical appraisal of submitted cost- benefit models of 'Lovaas' early intensive behavioural intervention for autism. Vancouver: University of British Columbia: Centre of Health Services and Policy Research.	Critical appraisal.		At best, the cost benefit models demonstrated the obvious: if an effective treatment for autism was available that resulted in normally-functioning children starting at an early age, it would massively reduce public service costs (as well as human suffering) over the life time of a person with autism.      However it is premature to draw conclusions regarding	Report made in relation to proceedings before the Supreme Court of British Columbia against the Government of British Columbia regarding provision of services for treatment of children with autism.

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	NON SYSTEMATIC REVIEW OF COST STUDIES Level of evidence: +			absolute effectiveness of treatment options. Until effectiveness is established, cost-benefit economic models are meaningless.  Research effort would more appropriately be directed to determine actual costs, both absolute and relative, of existing autism treatment programmes.	
275	Bassett, K., Green, C. J., & Kazanjian, A. (2000). Autism and Lovaas treatment: A systematic review of effectiveness evidence. Vancouver: University of British Columbia: Centre for Health Services and Policy. SYSTEMATIC REVIEW Level of evidence: +	Systematic review of Current Contents, Embase, HealthStar, and Medline. Identified 1,200 abstracts, and 150 articles met inclusion criteria. No studies comparing alternative behavioural intervention programmes, or randomised control trials of behavioural intervention programmes were identified as meeting the inclusion criteria.		Findings  Four controlled studies of treatment programmes were identified that reported overall outcomes for children.  • Lovaas (1987) and McEachin et al (1993) are the only authors to date claiming to have evidence that their treatment programme resulted in children attaining 'normal functioning'.  • Lovaas (1987) and McEachin et al (1993) suffer from several major methodological limitations. Serious concerns raised.  • Effectiveness claim in Lovaas et al (1987) that half the children achieved normal or	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				near-normal functioning remains uncorroborated.  Insufficient evidence to conduct a cost-benefit analysis of early, intensive treatment programmes in terms of 'normalisation' of children diagnosed with autism.	
276	Bodfish, J. W. (2004). Treating the core features of autism: are we there yet? Mental Retardation & Developmental Disabilities Research Reviews. 10(4), 318-26.  NON SYSTEMATIC REVIEW  Level of evidence: ~	Review (search not described).		Primary goal in treatment should be to improve deficits in language usage, impairments in social reciprocity, and presence of behavioural rigidity.  Non-established treatments described. Important to counsel families to guard against acting on unfounded claims for treatment, or increasing their hopes for change to this level. Non-established treatments are costly in time and money, and some have adverse effects.  Behavioural/psychoeducational treatment approaches and biomedical treatment approaches are empirically validated treatments. Treatment largely symptomatic.	
277	Howlin, P. (2005). The effectiveness of	Review paper, search not described. Based on content		Sections on pharmacological interventions, educational	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	interventions for children with autism. Journal of Neural Transmission. Supplementum (69):101-19.  NON SYSTEMATIC REVIEW  Level of evidence: ~	of chapter on interventions in Howlin, P. (2004). Autism and Asperger Syndrome: preparing for adulthood. Routledge, London.		programmes, early behaviourally based programmes, and 'alternative' interventions.  No single approach has been demonstrated to be superior to all others or to be equally effective for all individuals.  Guidelines that may help improve daily life for many families:  • treatment programmes should be individually designed, take account of an individual's cognitive level, severity of autistic symptomatology and overall developmental level. Chronological age and temperament/personality are also important factors  • structured educational/daily living programmes, with emphasis on visually based cues can provide an individual with autism, a predictable and readily understandable environment, minimising confusion and distress  • interventions should take account of the core deficits of autism. Much achieved by ensuring communication used by others is appropriate to	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				comprehension level and verbal messages augmented by visual cues. Programmes with focus on social-communication deficits may have significant effects. Stereotyped and ritualistic tendencies frequently become progressively more unacceptable with age and should be effectively managed from early childhood  many undesirable or challenging behaviours are a reflection of limited behavioural repertoires or poor communication skills. Focus on skill enhancement, and establishment of more effective communication strategies are often the most successful means of reducing difficult or disruptive behaviours  family-centred treatment approaches result in greater generalisation and maintenance of skills. Development of management strategies, that can be implemented consistently but do not demand extensive sacrifice in terms of time, money or other aspects of	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				family life, seem most likely to offer benefits for all involved. Practical support from skilled professionals is crucial for families in the early years. Professional advice should help families to make contact with appropriate parent organisations, educational and social service networks, and find assistance with the financial burden.	
278	Freeman, B. (1997). Guidelines for evaluating intervention programs for children with autism. Journal of Autism and Developmental Disorders, 27(6), 641-651. EXPERT OPINION Level of evidence: x	Opinion.		<ul> <li>Advice as follows:</li> <li>approach any new treatment with hopeful scepticism</li> <li>remember the primary goal of treatment should be to help the person become a fully functioning member of society</li> <li>beware of any programme that claims to be effective for all people with ASD</li> <li>be aware of any programme that thwarts individualisation</li> <li>be aware that any treatment represents one of several options for the person with ASD</li> <li>be aware that treatment should always depend on individual assessment information that points to it as</li> </ul>	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				<ul> <li>an appropriate option for a particular child</li> <li>be aware that no new treatment should be implemented until its proponents can specify assessment procedures necessary to determine whether it is appropriate for an individual</li> <li>be aware that debate over use of various techniques are often reduced to superficial arguments over who is right, moral, ethical and who is a true advocate</li> <li>be aware that often new treatments have not been validated.</li> </ul>	
279	Grice, B. L. (1997). Judging the effectiveness of a treatment: a list of criteria for parents to use to evaluate a child's programme. Paper presented at the Conference of the Autistic Association of New Zealand, Wellington.	Opinion.		List of questions for parents, which address the critical issues for success of any treatment:  • What is the specific detail of the treatment?  • Who is the treatment for?  • What are the outcomes of treatment?  • How can effectiveness of the treatment be judged?  • Are there any negative side effects?	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	EXPERT OPINION Level of evidence: x			<ul> <li>What safeguards are in place if problems occur?</li> <li>What evidence supports this treatment?</li> <li>How do I interpret the evidence?</li> <li>What qualifications does the therapist hold?</li> <li>What sort of qualification is held?</li> <li>Who can do the treatment?</li> <li>What guarantees of professional integrity are available?</li> </ul>	
280	Edelson, S. M. (2004). How to determine if a treatment really helped. Retrieved 20/9/04, 2004, from http://www.autism.or g/determine.html  EXPERT OPINION Level of evidence: x	Web-based information.		It is important to be objective when determining whether a treatment truly helped.  If a treatment is not helping, it does not make sense to continue, especially if it involves a great deal of time, money or effort.  'Tips' to determine whether the person has improved from the specific treatment:  • try treatment for about 2 months before beginning a new one  • complete the Autism Treatment Evaluation Checklist monthly for a few	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				months prior to the intervention, then monthly following the intervention  • tell no one that a new treatment has started  • people who do not know that a new treatment has started can, independently, compile a list of changes that they have noticed and compare their observations  • parents and others should note in writing when the child's behaviour surprises them.  Before trying a new treatment, learn as much as possible about it. Seek out positive and negative reports.  No treatment will help everyone with autism.	
281	Simpson, RL. (2005). Evidence-Based Practices and Students With Autism Spectrum Disorders. Focus on Autism and Other Developmental Disabilities. 20(3):140-9.	Review (search not described) of interventions for students.		Recommends that professionals and parents consider the following questions when selecting a programme or method of intervention:  • What are the efficacy and anticipated outcomes that align with a particular practice, and are the anticipated outcomes in harmony with the needs of the student?	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	NON SYSTEMATIC REVIEW Level of evidence: ~			<ul> <li>What are the potential risks associated with the practice?</li> <li>What are the most effective means of evaluating a particular method or approach?</li> <li>Evaluation table of interventions and treatments for learners with ASD</li> <li>Scientifically-based practice (applied behaviour analysis, discrete trial teaching, pivotal response training, Learning Experiences: An Alternative Program for Preschoolers and Parents).</li> <li>Promising practice (playoriented strategies, Picture Exchange Communication System, incidental teaching, structured teaching/TEACCH, augmentative alternative communication, assistive technology, joint action routines, cognitive behavioural modification, cognitive learning strategies, social stories, social decision-making strategies, sensory integration).</li> <li>Limited supporting information for practice (Gentle Teaching, option method/Son Rise, floor</li> </ul>	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				time, pet/animal therapy, relationship development intervention, cognitive scripts, cartooning, power cards, scotopic sensitivity syndrome/Irlen lenses, auditory integration training, megavitamin therapy, Feingold diet, herb/mineral and other supplements, music therapy, art therapy).  • Not recommended (holding therapy, facilitated communication).	
282	McVilly, K. (2002).  Positive Behaviour Support for People with Intellectual Disability. Sydney, The Australian Society of the Study of Intellectual Disability.  BOOK – EXPERT OPINION  Level of evidence: x			Practical guide, with the components of positive behaviour support explained in detail.	Keith McVilly is considered to be an expert in the field of intellectual disability.
283	Carr,J.E., Sidener, T.M. (2202). On the relation between applied behavior	Review of all publications listed in PsycINFO that included discussion of the definition of positive behaviour		Provides support from applied behaviour-analytic literature arguing that positive behaviour support emphasises important	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	analysis and positive behavioral support. The Behavior Analyst; 25: 245-53.  NON SYSTEMATIC REVIEW  Level of evidence: ~	support.  Evidence from applied behaviour-analytic literature provided to support position.		features of applied behaviour analysis, and therefore the approaches are compatible and inclusive.  Positive behaviour support qualities (listed in literature) that are compatible with applied behaviour analysis are:  • person centred planning  • functional assessment  • positive intervention strategies  • multifaceted interventions  • focus on environment  • meaningful outcomes  • focus on ecological validity  • systems level intervention.	
284	Autism Special Interest Group. (2004, 15/9/04). Revised Guidelines for Consumers of Applied Behavior Analysis Services to Individuals with Autism and Related Disorders. Retrieved 20/1/05, from http://www.abaintern ational.org/sub/mem bersvcs/sig/contactin	Website of the Association for Behavior Analysis.		<ul> <li>All children and adults with autism have the right to effective education and treatment based on the best available scientific evidence.</li> <li>Formal crediting of professional behaviour analysts through the Behavior Analyst Certification Board can provide safeguards for consumers.</li> <li>Tremendous gap between supply</li> </ul>	The Association for Behavior Analysis is a professional organisation, with stringent membership criteria.

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	fo/Autism.asp GUIDELINE – NOT APPRAISED			of qualified behaviour analysts and the demand for ABA services.	
	Level of evidence: +			Credentialing has been in place at an international level since 2000.	
				Autism SIG recommends that consumers determine if those who claim to be qualified to direct ABA programmes for people with autism meet the following minimum standards:	
				<ul> <li>certification by the Behavior Analyst Certification Board, or documented evidence of equivalent education, professional training and supervised experience on applied behavior analysis</li> <li>at least one full calendar year of hands-on training in providing ABA services directly to people with ASD under the supervision of a Board Certified Behavior Analyst or the equivalent with at least 5 years of experience of ABA programming for individuals with autism</li> <li>additional training in directing and supervising ABA programmes for individuals with autism (details listed).</li> </ul>	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
285	Mandre, E. (2002b, 10-12 April 2002). Individualized educational treatment for adult psychiatric patients with autism spectrum disorders. Paper presented at the 12th Annual International Durham Conference on Autism, Durham. EXPERT OPINION Level of evidence: x	Conference paper.		No existing treatment method in adult psychiatry designed specifically for people with ASD.  Symptoms of ASD described in format recognisable to professionals in adult psychiatry.	
286	Mandre, E. (2002a). From medication to education: people with autism in adult psychiatry. Lund University, Lund. EXPERT OPINION Level of evidence: x	Summary of doctoral dissertation.		When people with ASD are treated within psychiatry, they encounter many assumptions as to what they are supposed to know and understand about social situations and how to communicate with people in their environment.  Psychiatry personnel require reorientation in thinking in order to apply new theoretical knowledge on autism.	
287	Hare, D. J. (2004). Developing cognitive behavioural work with people with	Overview and opinion.		Cognitive behaviour therapists can adapt techniques to suit people with ASD. Advice	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	ASD. Good Autism Practice, 5(1), 18-22.			includes:	
	EXPERT OPINION			<ul> <li>teach social skills training and strategies to improve theory of</li> </ul>	
	Level of evidence: x			<ul> <li>mind</li> <li>minimise anxiety about the therapeutic process by being explicit about roles, times, goals, and using techniques like repertory grid</li> <li>be flexible about the length of sessions, and leaving the treatment room</li> <li>avoid direct challenges to personal beliefs, as these may be misinterpreted as a personal attack; instead, examine the rationale and evidence and collaboratively develop alternative interpretations and beliefs</li> <li>use visual imagery</li> <li>encourage clients to write down positive things, rather than rely on changing thoughts in their head</li> <li>concentrate on well-defined and specific difficulties</li> <li>incorporate specific behavioural techniques where appropriate, such as relaxation strategies, thought stopping or systematic</li> </ul>	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				desensitisation.	
288	Connolly, S.D., Bernstein, G.A., Work Group on Quality I. (2007). Practice parameter for the assessment and treatment of children and adolescents with anxiety disorders. Journal of the American Academy of Child & Adolescent Psychiatry; 46(2): 267-83.  SYSTEMATIC REVIEW and CLINICAL CONSENSUS Level of evidence: +	Systematic review 1996 to 2004, re children and adolescents with anxiety disorders. Searches in Medline, OVIDMedline, PubMed and PsycINFO; review bibliographies of book chapters and review articles; and asking colleagues for suggested source materials. Coding system defined for recommendations based on the evidence.		Consider Asperger Syndrome when conducting differential diagnosis.  Treatment planning should be multi-modal, consider severity and impairment of the anxiety disorder.  Psychotherapy should be considered as part of treatment.  Five components of cognitive behaviour therapy:  • psycho-education about the illness and CBT  • somatic management and skills training  • cognitive restructuring  • exposure methods  • relapse prevention plans.  All to be done with positive reinforcement to increase motivation, and according to suggested treatment manuals.  Parent, and child and family interventions incorporated in a range of therapy, including CBT.	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
289	Attwood, T. (2003). Cognitive Behaviour Therapy. In Holliday, Willey L. (Ed.). Asperger	Book chapter.		When secondary mood disorder is diagnosed, clinicians need to know how to modify standard psychological treatments to accommodate AS.	Tony Attwood is an internationally respected professional who has an extensive knowledge of ASD.
	Syndrome in Adolescence: Living with the			CBT has direct applicability to clients with AS who are known to have distortions in thinking.	
	Ups, the Downs			Sections on:	
	and Things in Between. London:			assessment	
	Jessica Kingsley Publishers Ltd.			affective education	
	EXPERT			cognitive restructuring	
	OPINION			stress management	
	Level of evidence: x			self-reflection	
				practice	
				other modifications to CBT.	
290	Reaven, J., & Hepburn, J. (2003). Cognitive-behavioral treatment of obsessive- compulsive disorder in a child with Asperger syndrome. Autism, 7(2), 145- 164. CASE REPORT	Case report. 7-year-old female child with Asperger syndrome.	<ul> <li>Children's Yale-Brown         Obsessive         Compulsive         Scale I(CY-BOCS).</li> <li>Behavioural         observation.</li> </ul>	Findings: CY-BOCS score decreased from 23 to 8 after 14 treatment sessions.  Adaptation of March and Mulle (11998) CBT protocol for children and adolescents described.	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	Level of evidence: x				
291	Attwood, T. (2004). Expert opinion and advice. Cognitive behaviour		CBT research only recently applied to people with ASD.	Tony Attwood is an internationally	
	therapy for children and adults with Asperger syndrome. Behaviour Change,			Few systematic and vigorous published research studies or case histories.	respected professional who has an extensive
	21(3), 147-161. EXPERT OPINION			Author is currently undertaking research.	knowledge of ASD.
	Level of evidence: x			Advice on modifying CBT covers the following areas:	
				<ul> <li>affective education</li> <li>cognitive restructuring</li> <li>the emotional toolbox</li> <li>physical tools</li> <li>relaxation tools</li> <li>social tools</li> <li>thinking tools</li> <li>special interest tools</li> <li>other tools</li> <li>inappropriate tools</li> <li>unusual tools.</li> </ul>	
292	Chui, J. Tordoff, J. Kennedy, J. et al. (2004). Trends in accessibility to medicines for children in New Zealand: 1998-2002. British Journal of	Review of the availability of medicines for children in NZ between 1998 and 2002. Review of the New Ethicals Catalogue, New Ethicals Compendium, product data sheets and the NZ	Availability was examined firstly by determining the licensing, labelling and suitability of formulations of medicines for children in NZ	There was a decrease in the total number of medicines licensed in NZ from 2,014 to 1,840 but there was an increase in the number and percentage of suitable formulations that were licensed for paediatric use from 616 to 642. The number of suitable	The authors concluded that there have been modest improvements in licensing of medicines for children in NZ from

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	Clinical Pharmacology 57(3): 322-327. REVIEW Level of evidence: +	Pharmaceutical Schedule covering the years 1998 to 2002 inclusive.	using product information, and secondly by determining the availability of subsidised medicines (by reference to the Pharmaceutical Schedule).	paediatric formulations that were subsidised decreased from 281 to 260. The number of orally available chemical entities with suitable formulations, licensed and subsidised for paediatric use declined from 101 to 94, but all of these chemical entities that were withdrawn had therapeutic alternatives that were licensed and subsidised. Only 36% of new medicines that had licensing for children were licensed for the 0 to 23 month age group.	1998 to 2002.
293	Santosh, P.J., Baird, G., Pityaratstian, N. et al. (2006). Impact of comorbid disorders on stimulant response in children with attention deficit hyperactivity disorder: a retrospective and prospective effectiveness study. Child: Care Health and Development 32(5): 575-583.  OBSERVATIONAL STUDY —	2 studies:  (1) Retrospective study of n=174 children and adolescents who had received a stimulant medication for a period of at least 8 weeks in a clinic at Guys Hospital in London, UK. There were 2 subgroups: those who had 'pure ADHD' and those who had ADHD plus ASD.  (2) Quasi-experimental within-subjects repeated measures study of n=52 children divided into ADHD alone and coexisting ADHD and ASD.	(1) Clinical Global Impression (CGI) and Therapeutic Efficacy Index (TEI) Scales. (2) CGI, TEI, PONS-C (Clinician completed profile of neuropsychiatric symptoms) and the side effects module of the Treatment Outome Rating Scale.	After treatment with stimulants, the subjects in both groups showed statistically significant improvements in target symptoms of hyperactivity, impulsivity, inattention, oppositionality, aggression and intermittent explosive rage. The CGI measures also improved in each group with no statistically significant difference in the degree of improvement between each group. Side effects were also described.	

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	RETROSPECTIVE + OBSERVATIONAL STUDY – REPEATED MEASURES				
294	Level of evidence: x  Gringas P (2000).  Practical paediatric psychopharma- cological prescribing in autism: the potential and the pitfalls. <i>Autism;</i> 4: 229-247.  NON SYSTEMATIC REVIEW  Level of evidence: ~	Methodology not described. Author describes 2 approaches to psychopharmacological management of children with autism in the light of the best evidence available and personal experience from a medical centre in the UK.		The evidence supporting 2 approaches is described in narrative format.	
295	McClellan, J.M., Werry, J.S. (2003). Evidence-based treatments in child and adolescent psychiatry: an inventory. Journal of the American Academy of Child and Adolescent Psychiatry 42: 1388- 1400. SYSTEMATIC	Search of published reviews, primary studies (RCTs) and the American Academy of Child and Adolescent Psychiatry Practice Parameters.		Evidence supports the use of stimulant medications for ADHD and SSRIs for obsessive compulsive disorder. There is reasonable evidence addressing SSRIs for anxiety disorders and moderate to severe depressive disorder and risperidone for autism. The psychosocial interventions best supported by well designed studies are cognitive-behavioural and behavioural interventions,	This review is not specific to autism.

Ref No	Reference, Study Type & Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	REVIEW Level of evidence: +			especially for mood, anxiety and behavioural disorders. Family- based and systems of care interventions also have been found effective.	
296	Santosh, P.J., Baird, G. (1999). Psychopharma- cotherapy in children	No methodology described although studies cited to support the author's opinions.		The prevalence of psychiatric disorders is increased in children and adults with intellectual disability.	Not specific to autism.
	and adults with intellectual disability. Lancet; 354: 233-242.			There is a substantial misdiagnosis of mental disorders in these individuals.	
	EXPERT OPINION – NON SYSTEMATIC REVIEW			There is a strong need for evidence-based practice in the prescribing and monitoring of drugs in this population,	
	Level of evidence: x			especially since many of the drugs are unlicensed for use in children.	

The following evidence tables have been formatted according to published quantitative checklists for quality.

Reference 297: Hollander, E. Phillips, A. Chaplin, W. et al. *Neuropsychopharmacology* 2005; Mar 30 (3): 582-9; A placebo controlled crossover trial of liquid fluoxetine on repetitive behaviours in childhood and adolescent autism.

Design/Grade	Randomised controlled trial – Grade 1	DB crossover
Outcomes	Primary	Assess response of repetitive behaviours in children with ASD to low dose fluoxetine.
	Secondary	
Design	• N	44
	Age, sex, race, and other relevant risk factors	5-16Y; 30M:9F; other relevant data provided
	Inclusion and exclusion criteria	Autism, Asperger Disorder & PDD-NOS by ADI-R, ADOS-G and DSM IV. Excl: psychotic disorders; seizure history & clinically significant medical illness. No concurrent medications and other interventions.
	Power	Not stated
	Method of randomisation	Not stated
	Intervention	8/52 FLU* or PLB: 4/52 washout: 8/52 PLB or FLU
	Blinding	Y DB
	Length of follow-up	20/52
	Completeness of follow-up	5 randomised subjects omitted from final analysis (see below)
Validity	<ul> <li>Is the study type appropriate for the questions being asked?</li> </ul>	Yes
	Was the study population typical of patients with this disease?	Υ
	Were the treatment/control groups comparable at baseline?	Υ
	Was the intervention compared to placebo and/or best accepted intervention?	Y
	Was there compliance with the intervention?	Υ
	Was there equal intensity of observation of study and control subjects?	Υ

	<ul> <li>Was the process of observation likely to affect the outcome?</li> </ul>	N
	Intention to treat analysis?	N
	Did conclusions about safety take into account the limited size of the study?	Y
	Is effectiveness proven?	Y
	Summary	Valid study
Results	Quantified results (ie, incidence/1000)	Y
	Relative risk (RR) and 95% CI	N
	Absolute risk reduction (ARR)	N
	Number needed to treat (NNT), 95% CI, and time period	N
	P values (exact values if possible)	Υ
	Include adverse outcomes	Y
Authors' Conclusions		Low dose fluoxetine is effective in reducing repetitive behaviours in children with autism. Longer term larger studies are needed to replicate the results.
Reviewer's Summary		Agree with overall conclusion. I would not agree that 0.8mg/kg/day is low dose. There should have been intention to treat analysis.

62 enrolled 39 analysed

18 failed criteria or noncompliant 3 non-compliant + 1 'dropped before week 4 because lack of efficacy'

1 additional subject dropped because of lost pharmacy records, therefore impossible to be sure of the subject's randomisation.

Abstract states 45 children randomised, so inconsistency of data. No inconsistency within body of paper.

\*Fluoxetine dose:0.25mg/day for week 1

- 0.3mg/kg/day for week 2
- 0.5mg/kg/day for week 3
- 0.8mg/kg/day for weeks 4-8

Dose lowered if side effects.

Reference 298: Wheeler D.M., Hazell, P., Silove, N. et al. Selective serotonin reuptake inhibitors for the treatment of autism spectrum disorders (protocol). *The Cochrane Database of Systematic Reviews* 2004; (1).

Design/Grade	Systematic review – Grade depends on primary studies used for systematic review	
Outcomes	Primary     Secondary	<ul> <li>Core features of autism</li> <li>Non-core behaviours</li> <li>Global assessment of health and function</li> <li>Quality of life for the individual or their family</li> </ul>
Design	<ul> <li>Focused on a discrete clinical question</li> <li>Explicit description of literature search</li> <li>State methodological standards used to select studies for inclusion in meta-analysis</li> <li>Demographics of study populations – age, sex, race</li> </ul>	<ul> <li>Yes</li> <li>Yes</li> <li>RCTs only, standardised measures for outcomes</li> <li>No limitations, diagnosis of PDD using standardised instrumen</li> </ul>
Validity	<ul> <li>Is the study type appropriate for the questions being asked?</li> <li>Data tested for homogeneity</li> <li>Evidence of publication bias</li> <li>Summary</li> </ul>	<ul> <li>Yes</li> <li>N/A (protocol only</li> <li>N/A (protocol only</li> <li>N/A (protocol only)</li> </ul>
Results	<ul> <li>Quantified results</li> <li>Odds ratio (OR) and 95%CI</li> <li>Absolute risk reduction (ARR)</li> <li>Number needed to treat (NNT) with 95% CI and time period</li> <li>P values (exact values if possible)</li> </ul>	<ul> <li>N/A (protocol only)</li> </ul>
Authors' Conclusions		N/A (protocol only)
Reviewer's Summary		N/A (protocol only)

Reference 299: Gordon, C. T., Rapoport, J. L., Hamburger, S. D. et al. (1992). Differential responses of seven subjects with autistic disorder to clomipramine and desipramine. *American Journal of Psychiatry*, 149, 363-366.

Design/Grade	Randomised controlled trial	
Outcomes	<ul><li>Primary</li><li>Secondary</li></ul>	Effectiveness of clomipramine for obsessive and stereotypical behaviour in ASD compared with placebo and desipramine.
Design	<ul> <li>N</li> <li>Age, sex, race, and other relevant risk factors</li> <li>Inclusion and exclusion criteria</li> <li>Power</li> <li>Method of randomisation</li> <li>Intervention</li> <li>Blinding</li> <li>Length of follow-up</li> <li>Completeness of follow-up</li> </ul>	7 M:F 5:2; 6-18Y; ASD by DSM-IIIR criteria and ADI NS Randomisation by NIH pharmacy Clomipramine vs desipramine or placebo Y 12/52 2/7 dropped out during trial, but data from dropout date used
Validity	<ul> <li>Is the study type appropriate for the questions being asked?</li> <li>Was the study population typical of patients with this disease?</li> <li>Were the treatment/control groups comparable at baseline?</li> <li>Was the intervention compared to placebo and/or best accepted intervention?</li> <li>Was there compliance with the intervention?</li> <li>Was there equal intensity of observation of study and control subjects?</li> <li>Was the process of observation likely to affect the outcome?</li> <li>Intention to treat analysis?</li> <li>Did conclusions about safety take into account the limited size of the study?</li> <li>Is effectiveness proven?</li> <li>Summary</li> </ul>	Y N/A – participants acted as own control Y N/A – participants acted as own control N Y N See comment
Results	Quantified results (ie, incidence/1000)	Clomipramine was superior to desipramine and placebo on

	<ul> <li>Relative risk (RR) and 95% CI</li> <li>Absolute risk reduction (ARR)</li> <li>Number needed to treat (NNT), 95% CI, and time period</li> <li>P values (exact values if possible)</li> <li>Include adverse outcomes</li> </ul>	standardised ratings of autism, anger, repetitive and compulsive behaviour. Clomipramine and desipramine were equally superior to placebo on ratings of hyperactivity. Side effects were minor and did not differ between drugs.  Parents of all participants elected to continue with clomipramine after the study.
Authors' Conclusions		Clomipramine is effective in reducing obsessive compulsive symptoms. Further studies of other SSRIs needed. Relationship of serotonergic agents and pathophysiology needs exploration.
Reviewer's Summary		Agree with authors'assessment but trial very small with short time-frame.

Reference 300: Gordon, C. T., State, R. C., & Nelson, J. E. (1993). A double-blind comparison of clomipramine, desipramine, and placebo in the treatment of autistic disorder. *Archives of General Psychiatry*, 50, 441-447.

Design/Grade	Randomised controlled trial	
Outcomes	<ul><li>Primary</li><li>Secondary</li></ul>	Effectiveness of clomipramine for obsessive and stereotypical behaviour in ASD compared with placebo and desipramine.
Design	<ul> <li>N</li> <li>Age, sex, race, and other relevant risk factors</li> <li>Inclusion and exclusion criteria</li> <li>Power</li> <li>Method of randomisation</li> <li>Intervention</li> <li>Blinding</li> <li>Length of follow-up</li> <li>Completeness of follow-up</li> </ul>	24 (30) M:F 15:9; 6-18Y; ASD by DSM-IIIR criteria and ADI NS Randomisation by NIH pharmacy Clomipramine vs desipramine or placebo Y 12/52 24/30 completed study
Validity	<ul> <li>Is the study type appropriate for the questions being asked?</li> <li>Was the study population typical of patients with this disease?</li> <li>Were the treatment/control groups comparable at baseline?</li> <li>Was the intervention compared to placebo and/or best accepted intervention?</li> <li>Was there compliance with the intervention?</li> <li>Was there equal intensity of observation of study and control subjects?</li> <li>Was the process of observation likely to affect the outcome?</li> <li>Intention to treat analysis?</li> <li>Did conclusions about safety take into account the limited size of the study?</li> <li>Is effectiveness proven?</li> <li>Summary</li> </ul>	Y Y Y Y Y N Y See comment

Results	<ul> <li>Quantified results (ie,, incidence/1000)</li> <li>Relative risk (RR) and 95% CI</li> <li>Absolute risk reduction (ARR)</li> <li>Number needed to treat (NNT), 95% CI, and time period</li> <li>P values (exact values if possible)</li> <li>Include adverse outcomes</li> </ul>	Significant improvement in obsessive compulsive symptomatology with clomipramine. Self injurious behaviour diminished but not measured as an outcome.
Authors' Conclusions		Clomipramine is effective in reducing obsessive compulsive symptoms. Further studies of other SSRIs needed. Relationship of serotonergic agents and pathophysiology needs exploration.
Reviewer's Summary		Agree with authors' assessment.

Reference 301: Remington, G., Sloman, L., Konstantareas, M., Parker, K., & Gow, R. (2001). Clomipramine versus haloperidol in the treatment of autistic disorder: a double-blind, placebo-controlled, crossover study. *Journal of Clinical Psychopharmacology*, 21, 440-444.

Design/Grade	Randomised controlled trial	
Outcomes	<ul><li>Primary</li><li>Secondary</li></ul>	Effectiveness of clomipramine in ASD compared with haloperidol and placebo.
Design	<ul> <li>N</li> <li>Age, sex, race, and other relevant risk factors</li> <li>Inclusion and exclusion criteria</li> <li>Power</li> <li>Method of randomisation</li> <li>Intervention</li> <li>Blinding</li> <li>Length of follow-up</li> <li>Completeness of follow-up</li> </ul>	37 (36) M:F 30:6; 10-36Y (mean 16.3); ASD by DSM-IV criteria independently confirmed by two specialists No previous use or only incomplete clinical trial of clomipramine or haloperidol. No other psychotropic medications during study. Power – 20 pts of clomipramine in ASD compared with haloperidol Randomisation by Latin square Clomipramine vs haloperidol vs placebo Y 21/52 (7/52 each phase) 36 completed study; however, some did not complete every phase of the study, but evaluations continued throughout.
Validity	<ul> <li>Is the study type appropriate for the questions being asked?</li> <li>Was the study population typical of patients with this disease?</li> <li>Were the treatment/control groups comparable at baseline?</li> <li>Was the intervention compared to placebo and/or best accepted intervention?</li> <li>Was there compliance with the intervention?</li> <li>Was there equal intensity of observation of study and control subjects?</li> <li>Was the process of observation likely to affect the outcome?</li> <li>Intention to treat analysis?</li> <li>Did conclusions about safety take into account the limited size of the study?</li> </ul>	Y Y Y Y Y N N Partially for clomipramine/Y for haloperidol

	<ul><li>Is effectiveness proven?</li><li>Summary</li></ul>	
Results	<ul> <li>Quantified results (ie,, incidence /1000)</li> <li>Relative risk (RR) and 95% CI</li> <li>Absolute risk reduction (ARR)</li> <li>Number needed to treat (NNT), 95% CI, and time period</li> <li>P values (exact values if possible)</li> <li>Include adverse outcomes</li> </ul>	Results analysed on intention to treat and on numbers completing full therapeutic trial.
Authors' Conclusions		Haloperidol was superior to Clomipramine on Intention to Treat analysis for autistic symptom severity and irritability/hyperactivity. Results comparable for those who completed trial. Clomipramine not more effective for stereotypy, and not better tolerated.
Reviewer's Summary		Agree with authors' assessment.

Reference 302: McCracken J.T., McGough, J., Shah, B., Cronin, P., Hong, D., Aman, M.G., et al. Research Units on Pediatric Psychopharmacology Autism Network. Risperidone in children with autism and serious behavioral problems. *New England Journal of Medicine* 2002;347(5):314-21.

Design/Grade	Randomised controlled trial – Grade 1	
Outcomes	<ul><li>Primary</li><li>Secondary</li></ul>	Treatment of aggression in children 5-17 with ASD.
Design	<ul> <li>N</li> <li>Age, sex, race, and other relevant risk factors</li> <li>Inclusion and exclusion criteria</li> <li>Power</li> <li>Method of randomisation</li> <li>Intervention</li> <li>Blinding</li> <li>Length of follow-up</li> <li>Completeness of follow-up</li> </ul>	101 (270 screen: 112 excluded; 57 declined) 8.8 ± 2.7y; 82m:19f; ASD to DSM IV criteria using ADI-R; CGI-S score>18 x 2 Power NS Randomisation method NS RISP dose according to weight<20k (max 2.5mg/day) 20-45k (max 2.5mg/day) &>45k (max 3.5mg/day) Parents and assessing clinicians 8/52 3 withdrawn from Rx gp; 17 withdrawn from plb gp
Validity	<ul> <li>Is the study type appropriate for the questions being asked?</li> <li>Was the study population typical of patients with this disease?</li> <li>Were the treatment/control groups comparable at baseline?</li> <li>Was the intervention compared to placebo and/or best accepted intervention?</li> <li>Was there compliance with the intervention?</li> <li>Was there equal intensity of observation of study and control subjects?</li> <li>Was the process of observation likely to affect the outcome?</li> <li>Intention to treat analysis?</li> <li>Did conclusions about safety take into account the limited size of the study?</li> <li>Is effectiveness proven?</li> <li>Summary</li> </ul>	Y Y Y Y Partial Y N Y N Y Y I Y Y S Y Y Y Y Y Marked improvement in CGI and ABC – Irritability subscale cf placebo; Statistically significant at p<0.001

Results	<ul> <li>Quantified results (ie,, incidence /1000)</li> <li>Relative risk (RR) and 95% CI</li> <li>Absolute risk reduction (ARR)</li> <li>Number needed to treat (NNT), 95% CI, and time period</li> <li>P values (exact values if possible)</li> <li>Include adverse outcomes</li> </ul>	Significant weight gain and drowsiness in Rx group. No extra-pyramidal symptoms on weekly clinical assessment but parents reported tremor in the Rx group (p= 0.06)
Authors' Conclusions		This study supports the conclusion that Risperidone is effective for short-term management of tantrums, aggression and SIB. Safety data limited and no long-term data on safety.
Reviewer's Summary		Agree with authors' conclusions.

Reference 303: Research Units on Pediatric Psychopharmacology Autism Network. Risperidone treatment of autistic disorder: longer-term benefits and blinded discontinuation after 6 months. *Am J Psychiatry* 2005; 162:1361-1369

Design/Grade	Randomised controlled trial – Grade 1	
Outcomes	<ul> <li>Primary 1) to determine whether the short-term efficacy of risperidone is maintained over time 2) to determine whether the side effect burden of risperidone remains acceptable over a 6 month period of treatment and 3) to examine the feasibility of risperidone discontinuation after 6 months NB: only aim 3 is new to this paper and not already covered in other publications about the same study population.</li> <li>Secondary</li> </ul>	
Design	<ul> <li>N 38 in discontinuation study of whom 38 completed study before it was stopped early</li> <li>Age, sex, race, and other relevant risk factors mean age 8.6 yrs (sd=2.8) for bigger group, of whom discontinuation study was a subset.</li> <li>Inclusion and exclusion criteria; included, autism as defined in DSM-IV, age at entry between 7 and 15 years, wt at least 15kg, and mental age at least 18 months and significant tantrums, and/or self injurious behaviour or agitation.</li> <li>Exclusion criteria – other psychiatric illness, other psychotropic medication</li> <li>Power not stated</li> <li>Method of randomisation not stated</li> <li>Intervention randomised double blind placebo controlled discontinuation of risperidone in children who had shown a sustained response over 6 months.</li> <li>Blinding; double blind</li> <li>Length of follow-up 8 weeks</li> <li>Completeness of follow-up; study stopped early after two interim analyses showed greater relapse rate in placebo treated children.</li> </ul>	
Validity	<ul> <li>Is the study type appropriate for the questions being asked?</li> <li>Was the study population typical of patients with this disease?</li> </ul>	Y

	<ul> <li>Were the treatment/control groups comparable at baseline?</li> <li>Was the intervention compared to placebo and/or best accepted intervention?</li> <li>Was there compliance with the intervention?</li> <li>Was there equal intensity of observation of study and control subjects?</li> <li>Was the process of observation likely to affect the outcome? no</li> <li>Intention to treat analysis?</li> <li>Did conclusions about safety take into account the limited size of the study?</li> <li>Is effectiveness proven? Summary Relapse rate in children who had responded to risperidone was greater as drug withdrawn in a double blind study than in those where drug was not withdrawn. On the other hand, 6 out of 16 or 37.5% of the children who had responded initially did not relapse when drug slowly withdrawn. No factors predicting relapse were identified, but number small.</li> </ul>	Placebo Yes Yes Yes Yes Yes Yes Yes
Results	<ul> <li>Quantified results (ie, incidence /1000)</li> <li>Relative risk (RR) and 95% CI</li> <li>Absolute risk reduction (ARR)</li> <li>Number needed to treat (NNT), 95% CI, and time period</li> <li>P values (exact values if possible)</li> <li>Include adverse outcomes</li> </ul>	
	Discontinuation of risperidone after 6 months in children who had responded was associated with a rapid return of disruptive and aggressive behaviour in most children. No predictors of relapse were identified, but numbers were small.	
	This group of children has been described elsewhere, but the discontinuations described in this paper are new data. Adverse events are mentioned, but probably relate to the larger group of children enrolled in the studies that lead on to this discontinuation study. Weight gain was a problem. No dyskinesia was seen. The authors' comments appear valid.	

Reference 304: Mc Dougle et al. Risperidone for the core symptom domains of autism: results from the study by the autism network of the research units on pediatric psychopharmacology. *Am J Psychiatry* 2005; 162:1142-1148

Design / Grade	Randomised controlled trial – Grade 1	
Outcomes	<ul> <li>Primary: core symptoms of autism as measured by subscale of the Abberant Behaviour Checklist and the Clinical Global Impression improvement scale – not focus of this report.</li> <li>Secondary: scores on the Rivto-Freeman Real Life Rating Scale, the Children's Yale-Brown Obsessive Compulsive Scale, and the Maladaptive behaviour domain of the Vineland Adaptive Behaviour Scales – the focus of this paper.</li> </ul>	
Design	<ul> <li>N: 101 in 8-week double blind placebo controlled trial followed by 8 week open label trial.</li> <li>N= 63 in a 16-week open label continuation study of those who responded to risperidone – for assessing maintenance of improvement – the focus of this paper is maintenance of improvement of secondary outcomes.</li> <li>Age, sex, race, and other relevant risk factors; multicentre North American study. Aged 5 to 17, mean (SD) 8.8 (2.7) 82% male</li> <li>Inclusion and exclusion criteria; for double blind trial inclusion criteria were all met DSM-IV criteria for autistic disorder corroborated by the ADI revised and had impaired behaviour symptoms.</li> <li>Those responding with at least a 25% reduction in the irritability scale and rated as improved or much improved on the CGI improvement scale were counted as responders and enrolled in the 16-week open label continuation study, as were children who had not responded during the double blind trial but who responded as defined above during the following 8 week open label trial.</li> <li>Power; not stated</li> <li>Method of randomisation; random – not described further – but</li> </ul>	
	not all participants selected owing to improvement when on	

	<ul> <li>blinded treatment.</li> <li>Intervention: Risperidone at a mean daily dose of 2mg (SD=1.2) at the start of the 16-week continuation study increasing to a mean of 2.1mg (SD=0.8).</li> <li>Blinding</li> <li>Length of follow-up; 16 weeks at least</li> <li>Completeness of follow-up</li> </ul>	
Validity	<ul> <li>Is the study type appropriate for the questions being asked? Double blind randomised controlled trial of 8 weeks' duration would be expected to be long enough to see improvements, if any, owing to the drug, and continuation study of 16 long enough to show useful length of sustained improvement</li> <li>Was the study population typical of patients with this disease?</li> <li>Were the treatment/control groups comparable at baseline?</li> <li>Was the intervention compared to placebo and/or best accepted intervention?</li> <li>Was there compliance with the intervention?</li> <li>Was there equal intensity of observation of study and control subjects?</li> <li>Was the process of observation likely to affect the outcome?</li> <li>Intention to treat analysis?</li> <li>Did conclusions about safety take into account the limited size of the study?</li> <li>Is effectiveness proven?</li> <li>Summary: this paper adds to an already published report of the double blind study by describing a continuation study of people who had responded to risperidone in the blind study or in the open study that followed. It concentrates on the secondary outcomes and looks at whether improvements were sustained over 6 months of treatment in total.</li> </ul>	Yes Not described here Placebo initially Not stated Not stated No Yes  Yes
Results	<ul> <li>Quantified results (ie, incidence/1000)</li> <li>Relative risk (RR) and 95% CI</li> <li>Absolute risk reduction (ARR)</li> <li>Number needed to treat (NNT), 95% CI, and time period</li> <li>P values (exact values if possible)</li> </ul>	

	Include adverse outcomes. Not here, but in original report	
	Risperidone led to significant improvements in the restricted, repetitive, and stereotyped patterns of behaviour, interests and activities in autistic children. It did not significantly change their deficits in social interaction and communication.	
Reviewer's Summary	Above summary seems fair.	

Reference 305: Shea, S. Risperidone in the treatment of disruptive behavioral symptoms in children and autistic and other pervasive developmental disorders. *Pediatrics* 2004; 114;e634-e641

Design/Grade	Randomised controlled trial – Grade 1	
Outcomes	<ul> <li>Primary:</li> <li>Behaviour assessed on rating scales Aberrant Behavior Checklist (ABC), the parent version of the Nisonger Child Behavior Rating Form (N-CBRF), a Visual Analog Scale (VAS) for the most troublesome symptom, and the Clinical Global Impression-Change (CGI-C).,</li> <li>Safety assessments: looking for side-effects Secondary</li> <li>Not listed.</li> </ul>	
Design	<ul> <li>N =79 (risperidone 40, Placebo 39)</li> <li>Age, sex, race, and other relevant risk factors 5 to 12 years, Canadian multicentre study</li> <li>Inclusion and exclusion criteria; PDD (DSMIV) and CARS =&gt;30. Subjects who had schizophrenia, other psychotic disorders, clinically relevant nonneurologic disease, clinically significant laboratory abnormalities, or a seizure disorder for which they were receiving &gt;1 anticonvulsant or if they had had a seizure in the last 3 months were excluded. In addition, subjects who had a history of hypersensitivity to neuroleptics, tardive dyskinesia, neuroleptic malignant syndrome, drug or alcohol abuse, or human immunodeficiency virus infection were excluded. Subjects were also excluded when they had used risperidone in the last 3 months, had been previously unresponsive or intolerant to risperidone, or were using a prohibited medication.</li> <li>Power</li> <li>Method of randomisation; randomised '1:1' but no details given. No mention of how many children enrolled but never took even one dose.</li> <li>Intervention risperidone or placebo oral solution 1.0 mg/mL was administered once daily in the morning at 0.01 mg/kg/day on</li> </ul>	

	treatment days 1 and 2 and increased to 0.02 mg/kg/day on day 3.  Depending on the therapeutic response at day 8, the dose could be increased by a maximal increment of 0.02 mg/kg/day.  Thereafter, the dose could be adjusted at the investigator's discretion at weekly intervals by increments/decrements not to exceed 0.02 mg/kg/day. The maximal allowable dosage was 0.06 mg/kg/day. In case of drowsiness, the study medication could be
	<ul> <li>administered once daily in the evening, or the total daily dose could be divided and administered on a morning and evening schedule.</li> <li>Blinding said to be double blind</li> <li>Length of follow-up 8 weeks. (91.1%) subjects completed the 8-week study. Seven (8.9%) subjects withdrew before completion; of these, 2 had been randomised to treatment with risperidone and 5 had been randomised to placebo</li> <li>Completeness of follow-up all those taking at least one dose. No mention of how many children enrolled but never took even one dose so not included.</li> </ul>
Validity	<ul> <li>Is the study type appropriate for the questions being asked?</li> <li>Was the study population typical of patients with this disease?</li> <li>Were the treatment/control groups comparable at baseline?</li> <li>Was the intervention compared to placebo and/or best accepted intervention?</li> <li>Was there compliance with the intervention?</li> <li>Was there equal intensity of observation of study and control subjects?</li> <li>Was the process of observation likely to affect the outcome? No Intention to treat analysis?</li> <li>Did conclusions about safety take into account the limited size of the study?</li> <li>Is effectiveness proven?</li> <li>Summary by study endpoint, the mean decrease from baseline in the irritability score experienced by risperidone-treated subjects was almost twice that of placebo-treated subjects: -12.1</li> </ul>

	compared with – 6.5, respectively ( <i>P</i> < .001; Table 2). At study endpoint, risperidone-treated subjects exhibited a 64% improvement over baseline irritability compared with a 30.7% improvement in placebo-treated subjects.  • Risperidone, at a mean dosage of 0.04 mg/kg/day, was well tolerated by the children who participated in this 8-week study. The most common adverse events reported among risperidone-treated subjects were somnolence (72.5%), upper respiratory tract infection (37.5%), rhinitis (27.5%), and increased appetite (22.5%; Table 3). The most common events among placebo-treated subjects were aggressive reaction (20.5%), fever (17.9%), upper respiratory tract infection (15.4%), insomnia (15.4%), vomiting (15.4%), diarrhoea (15.4%), and emotional lability (15.4%).  • 5 (12.5%) risperidone-treated subjects experienced adverse events that were categorised as severe and related to study medication: 1 case of hyperkinesia and somnolence and 1 case each of weight gain, somnolence, aggressive reaction with impaired concentration, and extrapyramidal disorder as a result of an accidental overdose. Two (5.1%) placebo-treated subjects experienced severe events that were considered related to study medication: 1 case of insomnia and sunken eyes and 1 case of accidental medication overdose. Two subjects withdrew from the study because of adverse events: the case of extrapyramidal disorder as a result of accidental overdose in the risperidone group and the case of accidental overdose in the placebo group. Both events subsequently resolved without residual effects.	
Results	<ul> <li>Quantified results (ie, incidence/1000)</li> <li>Relative risk (RR) and 95% CI</li> <li>Absolute risk reduction (ARR)</li> <li>Number needed to treat (NNT), 95% CI, and time period</li> <li>P values (exact values if possible)</li> <li>Include adverse outcomes; yes see above</li> </ul>	
Authors' Conclusion	Risperidone was well tolerated and efficacious in treating behavioural symptoms associated with PDD in children.	

Reviewer's Summary Author's summary appears fair. Study only for 8 weeks, however, so this	
study does not show whether effect maintained, or whether other side	
effects might occur with longer duration of treatment. Only	
extrapyramidal symptoms occurred in accidental overdose.	

Reference 306: Newcomer, J. Second-generation (atypical) antipsychotics and metabolic effects: a comprehensive literature review. *CNS Drugs* 2005; 19(Suppl 1):1-93.

Design/Grade	Systematic review – Grade depends on primary studies used for systematic review		
Outcomes	Primary     Secondary	Adverse effects from second generation (atypical) antipsychotics: Incidence of diabetes, ketoacidosis, hyperglycaemia and lipid dysregulation.	
Design	<ul> <li>Focused on a discrete clinical question</li> <li>Explicit description of literature search</li> <li>State methodological standards used to select studies for inclusion in meta-analysis</li> <li>Demographics of study populations – age, sex, race</li> </ul>	<ul><li>Y</li><li>Y</li><li>N/A</li><li>N</li></ul>	
Validity	<ul> <li>Is the study type appropriate for the questions being asked?</li> <li>Data tested for homogeneity</li> <li>Evidence of publication bias</li> <li>Summary</li> </ul>	<ul> <li>Y</li> <li>N/A</li> <li>N/A</li> <li>Y</li> </ul>	
Results	<ul> <li>Quantified results</li> <li>Odds ratio (OR) and 95%CI</li> <li>Absolute risk reduction (ARR)</li> <li>Number needed to treat (NNT) with 95% CI and time period</li> <li>P values (exact values if possible)</li> </ul>	<ul> <li>Y</li> <li>Yes, where possible</li> <li>N/A</li> <li>N/A</li> <li>Y</li> </ul>	
Authors' Conclusions		Second generation antipsychotic agents differ in their effects on weight and adiposity and on blood glucose and lipid levels (details in study).	
Reviewer's Summary		This is an extensive systematic review assessing the evidence for and against the association between glucose or lipid dysregulation and 8 separate second generation antipsychotics: clozapine, olanzapine, risperidone, quetiapine, zotepine, amisulpride,	

	ziprasidone and aripiprazole.

Reference 307: Ahl, J. et al. Sexual dysfunction associated with neuroleptic-induced hyperprolactinemia improves with reduction in prolactin levels. *Ann NY Acad Sci* 2004; 1032: 289-90

Design/Grade	Randomised controlled trial – Grade 1	
Outcomes	<ul><li>Primary</li><li>Secondary</li></ul>	Sexual function measured by the Global Impressions of Sexual Function (GISF) scale and the Changes in Sexual Functioning Questionnaire (CSFQ).
Design	<ul> <li>N</li> <li>Age, sex, race, and other relevant risk factors</li> <li>Inclusion and exclusion criteria</li> <li>Power</li> <li>Method of randomisation</li> <li>Intervention</li> <li>Blinding</li> <li>Length of follow-up</li> <li>Completeness of follow-up</li> </ul>	<ul> <li>54 (27 remaining on prolactin elevating antipsychotics; 27 switching to prolacting sparing antipsychotic, olanzapine)</li> <li>Schizophrenic patients treated with prolactin elevating antipsychotics that had hyperprolactinemia</li> <li>Hyperprolactinemic</li> <li>NS</li> <li>NS</li> <li>Olanzapine, 5-20 mg/day</li> <li>NS</li> <li>NS</li> <li>NS</li> <li>NS</li> </ul>
Validity	<ul> <li>Is the study type appropriate for the questions being asked?</li> <li>Was the study population typical of patients with this disease?</li> <li>Were the treatment/control groups comparable at baseline?</li> <li>Was the intervention compared to placebo and/or best accepted intervention?</li> <li>Was there compliance with the intervention?</li> <li>Was there equal intensity of observation of study and control subjects?</li> <li>Was the process of observation likely to affect the outcome?</li> <li>Intention to treat analysis?</li> <li>Did conclusions about safety take into account the limited size of the study?</li> <li>Is effectiveness proven?</li> </ul>	<ul> <li>NS</li> <li>NS</li> <li>N</li> <li>NS</li> <li>NS</li> <li>N</li> </ul>

	Summary	to continue with their treatment or switch to olanzapine. The change in sexual function was measured.
Results	<ul> <li>Quantified results (ie, incidence/1000)</li> <li>Relative risk (RR) and 95% CI</li> <li>Absolute risk reduction (ARR)</li> <li>Number needed to treat (NNT), 95% CI, and time period</li> <li>P values (exact values if possible)</li> <li>Include adverse outcomes; yes see above</li> </ul>	After the switch to olanzapine, prolactin levels normalised in more than 90% of the patients (n = 54), and overall sexual functioning improved significantly compared to that in non-switched patients (P = .028). Male patients experienced significant improvement in erectile (P = .028) and ejaculatory function (P = .006), and female patients were significantly less likely to experience painful intercourse (P = .046).
Authors' Conclusions		Sexual dysfunction was associated with hyperprolactinemia in patients treated with conventional antipsychotics and the atypical antipsychotic risperidone. If patients switched from treatment with prolactin-elevating antipsychotics to olanzapine, prolactin levels returned to within normal levels and sexual dysfunction was improved. Minimising treatment-associated sexual morbidity may improve the patient's well-being.
Reviewer's Summary		The participant group was not autistic and results may not be generalisable.

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
308	Yang, P. Tsai J.H. (2004). Occurrence of priapism with risperidone-paroxetine combination in an autistic child. <i>J Child Adolesc Psychopharm</i> 14(3): 342-3.  LETTER – EXPERT OPINION  Level of evidence: x	Case report of one 13-year-old autistic boy.		Priapism occurred about 6 times per day 2 months after treatment with risperidone and paroxetine. This resolved on discontinuation of the treatment.	

Reference 309: Correll, C.U. Leucht, S., Kane, J.M. Lower risk for tardive dyskinesia associated with second-generation antipsychotics: a systematic review of 1-year studies. *American Journal of Psychiatry* 2004; 161(3): 414-425.

Design/Grade	Systematic review — Grade depends on primary studies used for systematic review	
Outcomes	Primary     Secondary	<ul> <li>Risk of tardive dyskinesia associated with second generation antipsychotics compared to first generation antipsychotics.</li> </ul>
Design	<ul> <li>Focused on a discrete clinical question</li> <li>Explicit description of literature search</li> <li>State methodological standards used to select studies for inclusion in meta-analysis</li> <li>Demographics of study populations - age, sex, race</li> </ul>	<ul><li>Y</li><li>Y</li><li>N/A</li><li>Y</li></ul>
Validity	<ul> <li>Is the study type appropriate for the questions being asked?</li> <li>Data tested for homogeneity</li> <li>Evidence of publication bias</li> <li>Summary</li> </ul>	<ul> <li>Y</li> <li>N/A</li> <li>N</li> <li>Y</li> </ul>
Results	<ul> <li>Quantified results</li> <li>Odds ratio (OR) and 95%CI</li> <li>Absolute risk reduction (ARR)</li> <li>Number needed to treat (NNT) with 95% CI, and time period</li> <li>P values (exact values if possible)</li> </ul>	<ul> <li>Y</li> <li>N/A</li> <li>N/A</li> <li>N/A</li> </ul>
Authors' Conclusions		Second generation antipsychotics have a reduced risk for tardive dyskinesia compared to first generation antipsychotics, although the doses of haloperidol used in the comparator studies were relatively high. This finding was true for children, adults and the particularly vulnerable elderly population.
Reviewer's Summary		The identified trials had limitations (only 3 of 8 RCTs of 2 <sup>nd</sup> generation treatments maintained randomisation and were blinded, and comparison with 1 <sup>st</sup> generation

was mostly based on historical data). Also doses of
haloperidol were very high. There are a number of
other limitations with the identified studies. However,
the risk of tardive dyskinesia with 2 <sup>nd</sup> generation
antipsychotics appears to be about 1/5 <sup>th</sup> the risk
observed with first generation antipsychotics. There
are also other side effects of these treatments that
need to be considered. Insufficient information to
assess relative risk estimates.

Reference 310: Anderson, L. T., Campbell, M., Adams, P., & Small, A. M. (1989). The effects of haloperidol on discrimination learning and behavioral symptoms in autistic children. *Journal of Autism & Developmental Disorders*, 19, 227-239.

Design/Grade	Randomised controlled trial – Grade 1		
Outcomes	Primary	Replicate that haloperidol reduces behavioural symptoms	
	Secondary	Assess safety on short term basis & assess effect on discrimination learning.	
Design	• N	45	
	Age, sex, race, and other relevant risk factors	2.02-7.58Y: 35M:10F; Intellectual function profound to borderline MR. All in-patients	
	Inclusion and exclusion criteria	Autism by DSM III criteria & 3 independent psychiatrists. Exclusion criteria in Anderson 1984	
	Power	Not stated	
	Method of randomisation	Not stated	
	Intervention	Haloperidol vs placebo in crossover design – see below. Starting dose of haloperidol 0.5mg per day; max 4mg per day	
	Blinding	Υ	
	Length of follow-up	14/52	
	Completeness of follow-up	Υ	
Validity	<ul> <li>Is the study type appropriate for the questions being asked?</li> </ul>	Υ	
	<ul> <li>Was the study population typical of patients with this disease?</li> </ul>	Υ	
	Were the treatment/control groups comparable at baseline?	Not stated	
	<ul> <li>Was the intervention compared to placebo and/or best accepted intervention?</li> </ul>	Υ	
	Was there compliance with the intervention?	Υ	
	<ul> <li>Was there equal intensity of observation of study and control subjects?</li> </ul>	Υ	
	Was the process of observation likely to affect the	Y – learning tasks too difficult for some children	

	outcome?	
	Intention to treat analysis?	N
	Did conclusions about safety take into account the limited size of the study?	N
	Is effectiveness proven?	Y, in relation to behavioural changes
	Summary	Valid study
Results	Quantified results (ie, incidence/1000)	Y
	Relative risk (RR) and 95% CI	N
	Absolute risk reduction (ARR)	N
	Number needed to treat (NNT), 95% CI, and time period	N
	P values (exact values if possible)	Y
	Include adverse outcomes	None noted
Authors' Conclusions		Effective intervention for behaviour and safe in dosage used with careful titration of dose. No effect on discrimination learning.
Reviewer's Summary		Agree with authors' conclusions.

## Study design:

ctady accigin				
Group 1	2/52 placebo baseline	4/52 haloperidol	4/52 placebo	4/52 placebo
Group 2	2/52 placebo baseline	4/52 placebo	4/52 haloperidol	4/52 placebo
Group 3	2/52 placebo baseline	4/52 placebo	4/52 placebo	4/52 haloperidol

Reference 311: Naruse, H., Nagahata, M., Nakarey, Shirahashi, K., Takesada, M., Yamasaki, K. A multi-center double-blind trial of Pimozide (orap), Haloperidol and placebo. Children with behavioural disorders, using a cross over design. *Aeta Paedopsychiatr*. 1982; 48: 1793-84

Design/Grade	Randomised controlled trial – Grade 1	Crossover double blind
Outcomes	Primary	Clinical effectiveness and safety of pimozide in children with behavioural disorder.
	Secondary	
Design	• N	87
	Age, sex, race, and other relevant risk factors	69M:18F; 3-16 years; race not stated; study carried out in Japan.
	Inclusion and exclusion criteria	In: Behavioural disorders not responding to other treatment. Excl: IQ<20; severe organic brain damage; uncontrollable seizures (not otherwise defined)
	Power	Not stated
	Method of randomisation	Not stated. Drug combinations randomly allocated
	Intervention	8/52 each of placebo; pimozide and haloperidol
	Blinding	Yes. Double blind.
	Length of follow-up	8/52 for each condition
	Completeness of follow-up	80 -82 in comparison groups. Outcome for remaining 5-7 subjects not stated
Validity	<ul> <li>Is the study type appropriate for the questions being asked?</li> </ul>	Yes
	Was the study population typical of patients with this disease?	Mixed group. 34 subjects classified as autistic disturbance. No further detail or demographic data on these subjects. Results for this group provided and analysed separately.
	Were the treatment/control groups comparable at baseline?	Insufficient data, but crossover design
	Was the intervention compared to placebo and/or best accepted intervention?	Yes
	Was there compliance with the intervention?	Not stated
	Was there equal intensity of observation of study and	Yes

I	control subjects?	
	Was the process of observation likely to affect the outcome?	No
	Intention to treat analysis?	No
	Did conclusions about safety take into account the limited size of the study?	Yes. Separate pilot study on endocrine effects was carried out in 10 children by this group and is reported in full in a separate publication.
	Is effectiveness proven?	Yes, within limited study
	Summary	
Results	Quantified results (ie, incidence/1000)	No
	Relative risk (RR) and 95% CI	No
	Absolute risk reduction (ARR)	No
	Number needed to treat (NNT), 95% CI, and time period	No
	P values (exact values if possible)	Yes. Demonstrated both interventions statistical significant improvement in behaviour compared to placebo. When analysed according to diagnostic category, significance only remains for autistic group.
	Include adverse outcomes	Yes.
Authors' Conclusions		Conclude both interventions effective, and that pimozide has some advantages over haloperidol. However, statistical analysis does not support this conclusion.
Reviewer's Summary		Both interventions effective. Small study. This is an old study and more rigorous information about methodology and more rigorous analysis of results would be expected today.

Reference 312: Campbell, M., Armenteros, J. L., Malone, R. P., Adams, P. B., Eisenberg, Z. W., & Overall, J. E. (1997). Neuroleptic-related dyskinesias in autistic children: a prospective, longitudinal study. *Journal of the American Academy of Child & Adolescent Psychiatry*, 36, 835-43.

Design/Grade	Prospective controlled trial – crossover design	
Outcomes	Primary	Report results from a long-term prospective study of haloperidol treatment and prevalence of haloperidol related dyskinesias.
	Secondary	
Design	• N	118
	Age, sex, race, and other relevant risk factors	2.3-8.2Y; 95M:23F;
	Inclusion and exclusion criteria	DSM IIIR criteria for autistic disorder, independently confirmed by three psychiatrists; all requiring pharmacotherapy for behaviour. Excluded: seizure disorder; pre-existing dyskinesia; identifiable cause for autism.
	Power	Not stated
	Method of randomisation	N/A
	Intervention	Periods of treatment with haloperidol, with abrupt cessation to placebo. Design varied with children admitted into study at different times. Dyskinesias evaluated using Abnormal Involuntary Movement Scale (AIMS).
	Blinding	Not stated
	Length of follow-up	25 days to 3,610 days
	Completeness of follow-up	Difficult to determine from data given. Not clear if there were some subjects who exited from the study because of other adverse effects who later developed dyskinesia.
Validity	<ul> <li>Is the study type appropriate for the questions being asked?</li> </ul>	Υ
	Was the study population typical of patients with this disease?	Y
	Were the treatment/control groups comparable at baseline?	Crossover design
	Was the intervention compared to placebo and/or best accepted intervention?	Yes

1		
	Was there compliance with the intervention?	Yes
	<ul> <li>Was there equal intensity of observation of study and control subjects?</li> </ul>	Yes
	<ul> <li>Was the process of observation likely to affect the outcome?</li> </ul>	No
	Intention to treat analysis?	Υ
	Did conclusions about safety take into account the limited size of the study?	Y
	Is effectiveness proven?	N/A
	Summary	Valid study
Results	Quantified results (ie, incidence/1000)	Υ
	Relative risk (RR) and 95% CI	Υ
	Absolute risk reduction (ARR)	N
	Number needed to treat (NNT), 95% CI, and time period	N
	P values (exact values if possible)	Υ
	Include adverse outcomes	Υ
Authors' Conclusions		Drug-related dyskinesias occurred in 33.9% of the children in the study. Risk factors may include female gender; pre/perinatal complications and longer exposure or greater cumulative dose.
Reviewer's Summary		Study provides detailed analysis of dyskinesias in children treated with haloperidol. Study took place over 15 year period, and essentially analyses dyskinesia rate in three studies.

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
313	Campbell, M., Adams, P., Perry, R., Spencer, E.K., Overall, J.E. (1988). Tardive and withdrawal dyskinesia in autistic children: a prospective study. Psychopharmacology Bulletin; 24; 251-255.  CASE SERIES  Level of evidence: x	Participants were children who met DSM-III criteria for infantile autism, full syndrome (diagnosed by 3 child psychiatrists). Children were admitted to the study if they showed clinically significant improvement on haloperidol according to parents and clinical staff. Exclusion criteria were identifiable etiology for autism, seizure disorder, preexisting movement disorder and drug related dyskinesias.	Assessment and videotyping of behavioural symptoms, abnormal movements and other symptoms were made at baseline and at the end of 6 months of haloperidol treatment. Ratings were made on the Childrens Psychiatric Rating Scale, Clinical Global Impressions and Abnormal Involuntary Movement Scale, Abbreviated Dyskinesia Rating Scale and the Timed Stereotypies Rating Scale. After treatment with haloperidol, children were placed on placebo for 4 weeks.	29.3% of the sample developed reversible dyskinesias related to haloperidol treatment – in most cases they were mildly or moderately severe. The length of cumulative haloperidol exposure prior to the onset of a dyskinesia varied from 56 to 1,266 days.  The incidence of dyskinesias calculated from life tables was 85% by 4.2 years.	Authors state that the design of the study (repeated drug withdrawal at 6-month intervals) facilitates the expression of withdrawal dyskinesias and is partly responsible for the high incidence of dyskinesias produced in the study.
314	Committee on the Safety of Medicines. (2000).			Summary of reported adverse effects of	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	Thioridazine: restricted indications and new warnings on cardiotoxicity. London: Committee on the Safety of Medicines.  REPORT  Level of evidence: +			thioridazine.	
315	Medsafe (2001). Prescriber Update. Ministry of Health REPORT Level of evidence: ~	Methodology not reported		Selected articles reviewing current status of medications, including adverse effects.	

Reference 316: Handen, B. L., Johnson, C. R., & Lubetsky, M. (2000). Efficacy of methylphenidate among children with autism and symptoms of attention-deficit hyperactivity disorder. *Journal of Autism & Developmental Disorders*, 30, 245-255.

Design/Grade	Randomised controlled trial: Grade 1	
Outcomes	<ul><li>Primary</li><li>Secondary</li></ul>	
Design	<ul> <li>N</li> <li>Age, sex, race, and other relevant risk factors</li> <li>Inclusion and exclusion criteria</li> <li>Power</li> <li>Method of randomisation</li> <li>Intervention</li> <li>Blinding</li> <li>Length of follow-up</li> <li>Completeness of follow-up</li> </ul>	13 5.6 – 11.2 10♂:3♀ Incl: CARS > 30; Δ by Board Cert Ψ; Conner HI > 15 Not stated – Random assignment of drug order/placebo MPH 0.3mg/kg 0.6 mg/kg Teachers & parents. Not clear that programme staff blinded 3/52 Some missing data
Validity	<ul> <li>Is the study type appropriate for the questions being asked?</li> <li>Was the study population typical of patients with this disease?</li> <li>Were the treatment/control groups comparable at baseline?</li> <li>Was the intervention compared to placebo and/or best accepted intervention?</li> <li>Was there compliance with the intervention?</li> <li>Was there equal intensity of observation of study and control subjects?</li> <li>Was the process of observation likely to affect the outcome?</li> <li>Intention to treat analysis?</li> <li>Did conclusions about safety take into account the limited size of the study?</li> <li>Is effectiveness proven?</li> <li>Summary</li> </ul>	Yes Yes/probably Yes Yes Yes Yes Yes No N/A Yes ± 8/13 'responders'
Results	<ul> <li>Quantified results (ie, incidence/1000)</li> <li>Relative risk (RR) and 95% CI</li> </ul>	Significant response but very small numbers

	<ul> <li>Absolute risk reduction (ARR)</li> <li>Number needed to treat (NNT), 95% CI, and time period</li> <li>P values (exact values if possible)</li> <li>Include adverse outcomes</li> </ul>	Significant adverse effects incl social withdrawal and irritability Y No change on CARS
Authors' Conclusions		
Reviewer's Summary		Very small study indicates that MPH useful, but too small to support recommendation. Further research needed.

 $<sup>\</sup>Psi$  = psychologist HI = Hyperactivity index

Reference 317: Quintana, H., Birmaher, B., Stedge, D., & Lennon, S. (1996). Use of methylphenidate in the treatment of children with autistic disorder. *Annual Progress in Child Psychiatry & Child Development*. (This reprinted article originally appeared in *Journal of Autism & Developmental Disorders*, 1995, Vol 25[3], 283-294.

Design/Grade	Randomised controlled trial – Grade 1	DB crossover
Outcomes	Primary	Evaluate methylphenidate (MPH) efficacy and side effects in children with autism.
	Secondary	
Design	• N	10
	Age, sex, race, and other relevant risk factors	7y – 11y; 6M:4F; mean DQ64.3+/-9.9
	Inclusion and exclusion criteria	DSM IIIR autistic disorder/CARS/off neuroleptics>/= 1/12. Excl: any previous MPH; seizure disorder; major neurological or medical illness.
	Power	NS
	Method of randomisation	NS 'randomly assigned'
	Intervention	2 week baseline/1week 10mg am & 1200 MPH or PLB/I week 20mg am & 1200 MPH or PLB/crossover/1week 10mg am & 1200 PLB or MPH/1week 20mg am & 1200 PLB or MPH
	Blinding	DB
	Length of follow-up	6/52
	Completeness of follow-up	complete
Validity	<ul> <li>Is the study type appropriate for the questions being asked?</li> </ul>	Y
	<ul> <li>Was the study population typical of patients with this disease?</li> </ul>	N: no severe ID; only one mod ID; more females than expected.
	<ul> <li>Were the treatment/control groups comparable at baseline?</li> </ul>	Y
	<ul> <li>Was the intervention compared to placebo and/or best accepted intervention?</li> </ul>	Y
	Was there compliance with the intervention?	Y; observations done in clinical setting following administration of MPH or PLB by nurse.

	<ul> <li>Was there equal intensity of observation of study and control subjects?</li> </ul>	Y
	<ul> <li>Was the process of observation likely to affect the outcome?</li> </ul>	N
	Intention to treat analysis?	N/A
	<ul> <li>Did conclusions about safety take into account the limited size of the study?</li> </ul>	Y
	Is effectiveness proven?	N. Sample too small.
	Summary	Good study design; Valid, but small.
Results	Quantified results (ie, incidence/1000)	Υ
	Relative risk (RR) and 95% CI	Υ
	Absolute risk reduction (ARR)	N/A
	<ul> <li>Number needed to treat (NNT), 95% CI, and time period</li> </ul>	N/A
	P values (exact values if possible)	Υ
	Include adverse outcomes	Υ
Authors' Conclusions		Modest but statistically significant improvement with MPH. Larger studies needed.
Reviewer's Summary		Agree

CARS – Childhood Autism Rating Scale MPH -- methylphenidate PLB -- placebo

Reference 318: Research Units on Pediatric Psychopharmacology (RUPP) Autism network. Randomized controlled crossover trial of Methylphenidate in Pervasive Developmental Disorders with hyperactivity. *Archives of General Psychiatry* 2005; **62**:1266 -1274.

Design/Grade	Randomised controlled trial – Grade 1	DB crossover
Outcomes	Primary	Efficacy and safety of MPH in children with PDD & hyperactivity.
	Secondary	
Design	• N	72
	Age, sex, race, and other relevant risk factors	5.0-13.7Y; 59M:13F; detailed data provided
	Inclusion and exclusion criteria	Autistic disorder, Asperger disorder or PDD-NOS by DSM IV criteria confirmed by ADI-R. Detailed inclusion and exclusion criteria provided.
	Power	60 subjects 99% power to detect moderate effect.
	Method of randomisation	Centrally generated but balanced by site (5 centres)
	Intervention	Test dose phase (1/52); randomised order, PLB controlled phase comparing PLB and 3 different doses of MPH (4/52); open-label continuation phase for MPH responders only (8/52)
	Blinding	Yes
	Length of follow-up	4/52 or 12/52
	Completeness of follow-up	Good
Validity	<ul> <li>Is the study type appropriate for the questions being asked?</li> </ul>	Υ
	Was the study population typical of patients with this disease?	Υ
	Were the treatment/control groups comparable at baseline?	Υ
	Was the intervention compared to placebo and/or best accepted intervention?	Υ
	Was there compliance with the intervention?	Υ
	Was there equal intensity of observation of study and control subjects?	Υ
	Was the process of observation likely to affect the outcome?	No

	Intention to treat analysis?	Υ
	Did conclusions about safety take into account the limited size of the study?	N/A
	Is effectiveness proven?	Υ
	Summary	Study is valid
Results	Quantified results (ie, incidence/1000)	Υ
	Relative risk (RR) and 95% CI	Υ
	Absolute risk reduction (ARR)	N/A
	Number needed to treat (NNT), 95% CI, and time period	Y
	P values (exact values if possible)	Υ
	Include adverse outcomes	Υ
Authors' Conclusions		MPH more effective than PLB in improving inattention, hyperactivity and impulsivity in study population. Response rate lower than in typically developing children with ADHD. Adverse effects more frequent in study group.
Reviewer's Summary		Agree with conclusions. This study is well designed and the paper provides full information.

Reference 319: Tordjman, S., Anderson, G.M., Pichard, N., Charbuy, H., Touitou, Y. Nocturnal excretion of 6-sulphatoxymelatonin in children and adolescents with autistic disorder. *Biological Psychiatry*. 57(2):134-8, 2005 Jan 15.

Design/Grade	Randomised controlled trial – Grade 1	
Outcomes	Primary	Assess nocturnal melatonin secretion in children with autism.
	Secondary	
Design	• N	50 subjects; 88 controls
	Age, sex, race, and other relevant risk factors	11.5Y +/- 4.5; 33M:17F
	Inclusion and exclusion criteria	Autistic disorder by DSM IV; ICD 10; CFTMEA (a French scale) and confirmed by ADI-R and ADOS-G
	Power	Not stated
	Method of randomisation	N/A
	Intervention	Nil
	Blinding	Not stated; no information as to where or by whom lab testing was done
	Length of follow-up	N/A
	Completeness of follow-up	1 subject excluded because incomplete specimen collection
Validity	<ul> <li>Is the study type appropriate for the questions being asked?</li> </ul>	Y
	Was the study population typical of patients with this disease?	Y
	Were the treatment/control groups comparable at baseline?	Matched for age, sex and pubertal status
	Was the intervention compared to placebo and/or best accepted intervention?	N/A
	Was there compliance with the intervention?	N/A
	Was there equal intensity of observation of study and control subjects?	Y
	Was the process of observation likely to affect the outcome?	N
	Intention to treat analysis?	N/A

	Did conclusions about safety take into account the limited size of the study?	N/A
	Is effectiveness proven?	N/A
	Summary	Study is valid. Confounding factors are discussed.
Results	Quantified results (ie, incidence/1000)	Y
	Relative risk (RR) and 95% CI	Υ
	Absolute risk reduction (ARR)	N/A
	Number needed to treat (NNT), 95% CI, and time period	N/A
	P values (exact values if possible)	Υ
	Include adverse outcomes	N/A
Authors' Conclusions		Nocturnal excretion of 6-sulphoxymelatonin (6-SM) is significantly lower in children with autistic disorder than normal controls. Lower excretion more marked in children with more severe impairment and in prepubertal children.
Reviewer's Summary		Conclusions are appropriate for the data. However, 20 of 50 subjects were receiving medication (9 neuroleptics; 7 benzodiazepines; and 12 anticonvulsants). There is no discussion on whether medication could have affected secretion of melatonin. In addition, investigation appears to have involved a single 12 hour urine collection. Repeated collections from each subject would have increased robustness of study. The investigators took care to control for light exposure as much as possible.

Reference 320: Paavonen, J., Nieminen-von Wendt, T., Vanhala, R., Aronen, E., and von Wendt, L.. *Journal of Child and Adolescent Psychopharmacology.* 2003; 13(1) 83-95. Effectiveness of Melatonin in the Treatment of Sleep Disturbance in Children with Asperger Disorder.

Design/Grade	Open clinical trial	
Outcomes	Primary	Effectiveness of melatonin in sleep disorder in children with Asperger Disorder.
	Secondary	
Design	• N	15
	Age, sex, race, and other relevant risk factors	6-17Y; 13M:2F;
	Inclusion and exclusion criteria	AD according to DSM IV criteria
	Power	NS
	Method of randomisation	N/A
	Intervention	Melatonin 3 mg per day 30 mins prior bedtime for 14 days
	Blinding	N
	Length of follow-up	3/52 after discontinuation
	Completeness of follow-up	Good
Validity	<ul> <li>Is the study type appropriate for the questions being asked?</li> </ul>	Υ
	Was the study population typical of patients with this disease?	Y
	Were the treatment/control groups comparable at baseline?	N/A
	Was the intervention compared to placebo and/or best accepted intervention?	N
	Was there compliance with the intervention?	Y Compliance information provided; not quantitative
	Was there equal intensity of observation of study and control subjects?	N/A
	Was the process of observation likely to affect the outcome?	Y
	Intention to treat analysis?	N

	Did conclusions about safety take into account the limited size of the study?	Y
	Is effectiveness proven?	N
	Summary	Essentially a pilot study
Results	Quantified results (ie,., incidence /1000)	Υ
	Relative risk (RR) and 95% CI	Υ
	Absolute risk reduction (ARR)	N/A
	Number needed to treat (NNT), 95% CI, and time period	N
	P values (exact values if possible)	Υ
	Include adverse outcomes	Υ
Authors' Conclusions		Melatonin may be effective. Controlled study needed.
Reviewer's Summary		Agree

Reference 321: Garstang J. Wallis M. Randomised controlled trial of melatonin for children with autistic spectrum disorders and sleep problems. *Child: Care, Health and Development* 2006; 32(5): 585-589.

Design/Grade	Randomised controlled trial – Grade 1	
Outcomes	Primary	Sleep latency, wakings per night, sleep duration
	Secondary	
Design	• N	11
	Age, sex, race, and other relevant risk factors	4-16 years, M/F ratio: 7:4
	Inclusion and exclusion criteria	Diagnosis of ASD (by consultant paediatrician or psychiatrist); difficulties sleeping (sleep latency at least one hour and night wakings that required parental attention; at least 4/7 days over last 6 months; causing distress to participant and family; failure of behaviour management techniques.  Those who had previously used melatonin were excluded and those using sedative medication had to have a washout period of 4 weeks.
	Power	Not stated
	Method of randomisation	Random number tables of hospital pharmacy
	Intervention	Melatonin 5 mg
	Blinding	Double blinded
	Length of follow-up	4 weeks, crossover period of 1 week and 4 weeks on alternative therapy
	Completeness of follow-up	7 completed the trial
Validity	<ul> <li>Is the study type appropriate for the questions being asked?</li> </ul>	Yes
	Was the study population typical of patients with this disease?	Most did not have severe learning difficulties
	Were the treatment/control groups comparable at baseline?	Crossover design
	Was the intervention compared to placebo and/or best accepted intervention?	Yes
	Was there compliance with the intervention?	Not stated

	<ul> <li>Was there equal intensity of observation of study and control subjects?</li> </ul>	Yes
	<ul> <li>Was the process of observation likely to affect the outcome?</li> </ul>	No, although sleep quality was rated by parents.
	Intention to treat analysis?	No
	Did conclusions about safety take into account the limited size of the study?	No.
	Is effectiveness proven?	No
	Summary	A small crossover trial over a duration of 2 months assessing the effectiveness of melatonin 5 mg on 3 measures of sleep quality in children with ASD without severe learning problems.
Results	Quantified results (ie, incidence/1000)	Yes
	Relative risk (RR) and 95% CI	N/A
	Absolute risk reduction (ARR)	N/A
	<ul> <li>Number needed to treat (NNT), 95% CI, and time period</li> </ul>	No
	P values (exact values if possible)	No
	Include adverse outcomes	No
Authors' Conclusions		Melatonin was beneficial for all 3 measures of sleep quality. Further studies needed.
Reviewer's Summary		Further randomised studies are needed to confirm these results.  The high rate of dropout and the low power limits the strength of the findings.

Reference 322: Appleton R. The use of Melatonin in children with Neuro-Developmental disorders and impaired sleep: a randomized double-blind placebo-controlled parallel study (MENDS). Accessed from <a href="http://www.hta.ac.uk/project/1522.asp?src=b08">http://www.hta.ac.uk/project/1522.asp?src=b08</a>, September 10, 2007.

This is an ongoing RCT melatonin vs placebo study of 172 children aged 5 to 18 years with developmental or learning difficulties. It will measure total night time sleep, time taken to fall asleep and number of wakenings during the night. The study started in May 2007 and is expected to be completed in mid 2010.

Reference 323: Jaselskis, C.A., Cook, E.H., et al. Clonidine treatment of hyperactive and impulsive children with autistic disorder. *J of Clin Psychopharmacology*, 1992;12:322-327.

Design/Grade	Randomised controlled trial – Grade 1	
Outcomes	Primary	Examine effects of clonidine in autism.
	Secondary	
Design	• N	8
	Age, sex, race, and other relevant risk factors	5.0yr - 13.4yr; Male; FSIQ 30-75; Race not stated; SE class given
	Inclusion and exclusion criteria	In: ASD meeting DSM IIIR criteria, confirmed independently by 2 psychiatrists. Hyperactive, impulsive behaviour excessive for developmental and language level. Previously failed treatment with MPH, neuroleptic or desipramine.
	Power	Not stated
	Method of randomisation	Random assignment by non-rating clinician
	Intervention	Placebo or clonidine tapered up over 2/52 to 4-10 mcg/kg/day; 4/52 on full dose; 1/52 taper; crossover weeks 8-13 and tapered off in week 14.
	Blinding	Raters, parents and teachers all blinded
	Length of follow-up	14 weeks
	Completeness of follow-up	9th subject dropped because non-compliant with meds and rating scales in week 1
Validity	<ul> <li>Is the study type appropriate for the questions being asked?</li> </ul>	Yes
	Was the study population typical of patients with this disease?	Yes, but no female subjects
	Were the treatment/control groups comparable at baseline?	Crossover design
	Was the intervention compared to placebo and/or best accepted intervention?	Yes
	Was there compliance with the intervention?	Yes (non-compliant subject dropped)

	<ul> <li>Was there equal intensity of observation of study and control subjects?</li> </ul>	Yes
	<ul> <li>Was the process of observation likely to affect the outcome?</li> </ul>	Yes; ratings averaged over 6/52. Does not allow for cumulative effect or tolerance.
	Intention to treat analysis?	No
	Did conclusions about safety take into account the limited size of the study?	No, but described as pilot study.
	Is effectiveness proven?	No
	Summary	Yes
Results	Quantified results (ie,., incidence /1000)	Yes
	Relative risk (RR) and 95% CI	N/A
	Absolute risk reduction (ARR)	N/A
	Number needed to treat (NNT), 95% CI, and time period	No
	P values (exact values if possible)	Yes
	Include adverse outcomes	Yes
Authors' Conclusions		Modest effect demonstrated but usefulness limited by side effects. Further studies needed.
Reviewer's Summary		Agree with authors' conclusions. It is unfortunate that there appear to have been no further RCTs in children with ASD.

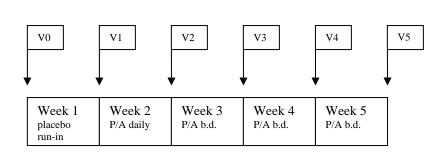
Reference 324: Marrosu, F., Marrosu, G., Rachel, M.G., Biggio, G. Paradoxical reactions elicited by diazepam in children with classic autism. Functional Neurology. 2(3):355-61, 1987 Jul-Sep

Design/Grade	Cohort – Prospective/Retrospective/ Both – Grade 2	
Outcomes	<ul><li>Primary</li><li>Secondary</li></ul>	
Design	<ul> <li>N</li> <li>Age, sex, race, and other relevant risk factors</li> <li>Setting (primary, secondary or tertiary care; or community)</li> <li>Exposure/Intervention</li> <li>Inclusion and exclusion criteria</li> <li>Length of follow-up</li> <li>Completeness of follow-up</li> </ul>	<ul> <li>7</li> <li>7-11Y; 5M:2F; FSIQ 72-104</li> <li>Community (special school)</li> <li>10mg diazepam IM given 'when the anxiety attack of unknown origin interfered seriously with the programme of the class'</li> <li>autism by DSM III criteria</li> <li>3 hours</li> <li>Complete</li> </ul>
Validity	<ul> <li>Is the study type appropriate for the questions being asked?</li> <li>Patients followed from a well-defined point in the course of disease</li> <li>Could selection bias have occurred when patients were identified?</li> <li>If human judgement required to determine outcome, was the assessor blinded to prognostic factors?</li> <li>Results adjusted for extraneous prognostic factors</li> <li>Summary</li> </ul>	<ul> <li>No</li> <li>No</li> <li>Yes</li> <li>No</li> <li>No</li> <li>Not valid</li> </ul>
Results	<ul> <li>Quantified results including both desired and adverse outcomes</li> <li>If length of follow-up varies use actuarial results</li> <li>Relative risk (RR) and 95%CI</li> <li>Absolute annual risk (AAR), (and absolute risk reduction if appropriate)</li> <li>Number needed to treat (NNT) with 95% CI, and the time period</li> <li>P values (exact values if possible)</li> </ul>	<ul> <li>Yes</li> <li>No</li> <li>No</li> <li>No</li> <li>No</li> <li>Yes</li> </ul>

Authors'	Administration of diazepam (10 mg i.m.) to 7 children (2 girls and 5	
Conclusions	boys) affected by infantile autism elicited paradoxical behavioural	
	responses. Mainly, anxiogenic effect, unsocialised aggressive	
	behaviour and explosive aggression were dramatically increased in	
	comparison with the same symptoms present before and after	
	treatment. The results show for the first time that benzodiazepines	
	may elicit paradoxical behavioural response in autistic children. The	
	possible involvement of an altered function at the level of	
	GABA/benzodiazepine receptor complex is discussed.	
Reviewer's	This study is poorly constructed and important information is left	
Summary	out, possibly a result of English not being the authors' first	
	language. A possible assumption is that this treatment was	
	prescribed for all children in this special school setting, but only	
	those who had an adverse reaction have been reported.	
	The children were given an injection of saline '1-2 weeks' after	
	diazepam treatment to assess whether the injection itself was	
	responsible and no behavioural changes were observed. However,	
	no data is reported for this.	
	However, we have not found any other study which addresses the	
	question of paradoxical reaction to benzodiazepines in children with	
	ASD, although many clinicians report having seen such reactions.	
	Clearly a randomised controlled trial is needed to assess response	
	to diazepam (and/or other benzodiazepines) but it is questionable	
	whether this would be ethical.	
	ASD, although many clinicians report having seen such reactions. Clearly a randomised controlled trial is needed to assess response to diazepam (and/or other benzodiazepines) but it is questionable	

Reference 325: King, B. H., Wright, D. M., Handen, B. L., Sikich, L., Zimmerman, A. W., McMahon, W., Cantwell, E., Davanzo, P. A., Dourish, C. T., Dykens, E. M., Hooper, S. R., Jaselskis, C. A., Leventhal, B. L., Levitt, J., Lord, C., Lubetsky, M. J., Myers, S. M., Ozonoff, S., Shah, B. G., Snape, M., Shernoff, E. W., Williamson, K., & Cook, E. H., Jr. (2001). Double-blind, placebo-controlled study of amantadine hydrochloride in the treatment of children with autistic disorder. *Journal of the American Academy of Child & Adolescent Psychiatry*, 40, 658-665.

Amantadine is a non-competitive MNDA (n-methyl-d-aspartate) receptor antagonist. Registered in NZ as Antiviral agent Antiparkinsonian agent Hypothesis: Amantadine HCl is a safe/effective treatment for behaviour disturbance in children with ASD. Study design: 19 Amantadine (15M:4F)43 39 I week placebo run-in 20 control (19M:1F) 3 did not meet continued 1 additional Rx eligibility criteria for pre-existing condition



Week 1 – all placebo

Weeks 2-5 either amantadine or placebo

Observations at V0, V1, V2, V3, V4, V5.

Age: 5-19 Race not stated

Inclusion: ASD by DSM IV or ICD 10 using ADI-R

IQ>35

Idiopathic autism + >p75 for adjusted irritability and hyperactivity

Method of randomisation not stated

Blinding – yes but who not stated

Power adequate

Length of follow up 4/52

Study type appropriate – Y

Population typical – Y problem reflects severe end of spectrum

Comparability of groups – more females in Rx group

Comparison with placebo – Y; observation of both groups equal

Compliance assumed

Results: No difference on parent ratings

Statistically significant improvement on some subscales on investigator ratings especially hyperactivity.

Summary: Insufficient evidence or safety data on which to make any recommendation.

Reference 326: Niederhofer et al. (2003) *Neuropsychopharmacology* 28: 1014-5. Immunoglobulins as an alternative strategy of psychopharmacological treatment of children with autistic disorder.

Design/Grade	Randomised controlled trial – Grade 1	DB crossover
Outcomes	Primary	
	Secondary	
Design	• N	12
	Age, sex, race, and other relevant risk factors	4.2-14.9Y; all male; FSIQ52-84
	Inclusion and exclusion criteria	ICD 10 criteria for autistic disorder. Normal immune and haematological status. Excl: no history of medical or neurologic illness; off medications >1/12 prior
	Power	Not stated
	Method of randomisation	Not stated
	Intervention	IVIG 0.4g/kg or placebo x1 each in crossover study. Interval between injections not stated
	Blinding	Υ
	Length of follow-up	Not stated
	Completeness of follow-up	Υ
Validity	<ul> <li>Is the study type appropriate for the questions being asked?</li> </ul>	Insufficient information
	Was the study population typical of patients with this disease?	Y, but no females
	Were the treatment/control groups comparable at baseline?	Not stated
	<ul> <li>Was the intervention compared to placebo and/or best accepted intervention?</li> </ul>	Υ
	Was there compliance with the intervention?	Υ
	Was there equal intensity of observation of study and control subjects?	Υ
	Was the process of observation likely to affect the outcome?	N
	Intention to treat analysis?	N

	Did conclusions about safety take into account the limited size of the study?	Y
	Is effectiveness proven?	N
	Summary	Insufficient information
Results	Quantified results (ie, incidence/1000)	Υ
	Relative risk (RR) and 95% CI	N
	Absolute risk reduction (ARR)	N
	<ul> <li>Number needed to treat (NNT), 95% CI, and time period</li> </ul>	N
	P values (exact values if possible)	Υ
	Include adverse outcomes	Y
Authors' Conclusions		Parent and teacher ratings improved, but none of the clinician ratings showed significant differences. Further research needed, and authors caution against 'the growing indiscriminate use of intravenous immunoglobulin in treating autistic children'.
Reviewer's Summary		Agree with authors' conclusions.

Reference 327: Willemsen-Swinkels, S. H. N., Buitelaar, J. K., & van Engeland, H. (1996). The effects of chronic naltrexone treatment in young autistic children: A double-blind placebo-controlled crossover study. *Biological Psychiatry*, 39, 1023-1031.

Design/Grade	Randomised controlled trial	
Outcomes	<ul><li>Primary</li><li>Secondary</li></ul>	Assess efficacy of chronic administration of Naltrexone.
Design	<ul> <li>N</li> <li>Age, sex, race, and other relevant risk factors</li> <li>Inclusion and exclusion criteria</li> <li>Power</li> <li>Method of randomisation</li> <li>Intervention</li> <li>Blinding</li> <li>Length of follow-up</li> <li>Completeness of follow-up</li> </ul>	20 (23) 3-7y; 16M:4F; DSM-IIIR criteria for autism NS NS mean dose of 1.0mg/kg/day as od Naltrexone for 4/52 DB PC crossover 20 weeks total (2BL 4Rx 4 Washout) 3 lost (2 did not tolerate taste; 1 parent convinced child had active drug 1st and withdrew)
Validity	<ul> <li>Is the study type appropriate for the questions being asked?</li> <li>Was the study population typical of patients with this disease?</li> <li>Were the treatment/control groups comparable at baseline?</li> <li>Was the intervention compared to placebo and/or best accepted intervention?</li> <li>Was there compliance with the intervention?</li> <li>Was there equal intensity of observation of study and control subjects?</li> <li>Was the process of observation likely to affect the outcome?</li> <li>Intention to treat analysis?</li> <li>Did conclusions about safety take into account the limited size of the study?</li> <li>Is effectiveness proven?</li> <li>Summary</li> </ul>	Y Y No specific data Y Y Y Y Y N N N N
Results	Quantified results (ie, incidence/1000)     Relative risk (RR) and 95% CI	Significant improvement on teacher ratings. Parent and clinical observations did not detect significant differences.

	<ul> <li>Absolute risk reduction (ARR)</li> <li>Number needed to treat (NNT), 95% CI, and time period</li> <li>P values (exact values if possible)</li> <li>Include adverse outcomes</li> </ul>	Includes comment on adverse outcomes.
Authors' Conclusions		Modest and situation-dependent reduction in hyperactivity and irritability. Hypothesis of opioid involvement in core symptoms of ASD not supported. Not recommended for clinical use.
Reviewer's Summary		Small study. Only modest and partial effect. Not recommended for clinical use.

Reference 328: Kolmen, B. K., Feldman, H. M., Handen, B. L., & Janosky, J. E. (1995). Naltrexone in young autistic children: A double-blind, placebo-controlled crossover study. *Journal of the American Academy of Child & Adolescent Psychiatry*, 34, 223-231.

Design/Grade	Randomised controlled trial	
Outcomes	<ul><li>Primary</li><li>Secondary</li></ul>	Evaluation of efficacy and safety of Naltrexone in treatment of autism.
Design	<ul> <li>N</li> <li>Age, sex, race, and other relevant risk factors</li> <li>Inclusion and exclusion criteria</li> <li>Power</li> <li>Method of randomisation</li> <li>Intervention</li> <li>Blinding</li> <li>Length of follow-up</li> <li>Completeness of follow-up</li> </ul>	13 (16) 3.4 – 8.3y (mean5.4); 1F DSM-IIIR criteria for autism >30 on CARS; in stable school or preschool >6mo; normal growth; normal LFTs; exclusion – allergy to acetaminophen (used to make placebo bitter) NS DB PC crossover. Randomisation by pharmacist 1.0mg/kg/day as od Naltrexone Y 6-7 weeks; 13/16
Validity	<ul> <li>Is the study type appropriate for the questions being asked?</li> <li>Was the study population typical of patients with this disease?</li> <li>Were the treatment/control groups comparable at baseline?</li> <li>Was the intervention compared to placebo and/or best accepted intervention?</li> <li>Was there compliance with the intervention?</li> <li>Was there equal intensity of observation of study and control subjects?</li> <li>Was the process of observation likely to affect the outcome?</li> <li>Intention to treat analysis?</li> <li>Did conclusions about safety take into account the limited size of the study?</li> <li>Is effectiveness proven?</li> <li>Summary</li> </ul>	Y Y Data not analysed by authors but groups appear comparable Y Y – non-compliant child dropped from study Y N N Y
Results	Quantified results (ie, incidence/1000)	Authors report 8/13 'responders'

	<ul> <li>Relative risk (RR) and 95% CI</li> <li>Absolute risk reduction (ARR)</li> <li>Number needed to treat (NNT), 95% CI, and time period</li> <li>P values (exact values if possible)</li> <li>Include adverse outcomes</li> </ul>	Improvement documented in 2/3 settings (clinic; home; school) to be classified as responder. Most significant results on parent ratings.
Authors' Conclusions		Modest improvement. Warrants further investigation. Bitter taste a disadvantage.
Reviewer's Summary		Very small, very short-term study. No firm conclusions can be drawn.

Reference 329: Aman MG and Kern RA. *J Am Acad Child Adolesc Psychiat* 1989; 28: 549-65. Review of fenfluramine in the treatment of the developmental disabilities.

Design/Grade	Review article	
Outcomes	<ul><li>Primary</li><li>Secondary</li></ul>	<ul> <li>Review all studies assessing effects of fenfluramine in individuals with developmental disability.</li> <li>Review biochemical studies on whole serotonin metabolism in developmental disability.</li> <li>Review animal literature on neurotoxicity of fenfluramine.</li> </ul>
Design	<ul> <li>Focused on a discrete clinical question</li> <li>Explicit description of literature search</li> <li>State methodological standards used to select studies for inclusion in meta-analysis</li> <li>Demographics of study populations – age, sex, race</li> </ul>	<ul> <li>Review all studies assessing effects of fenfluramine in individuals with developmental disability, to answer question is fenfluramine efficacious.</li> <li>Yes. Visual search of all journals in developmental disabilities field plus prominent pediatric and child psychiatry journals; MEDLARS II search for fenfluramine.</li> <li>Yes</li> <li>Authors refer to having reviewed these, but details not given in this paper.</li> </ul>
Validity	<ul> <li>Is the study type appropriate for the questions being asked?</li> <li>Data tested for homogeneity</li> <li>Evidence of publication bias</li> <li>Summary</li> </ul>	<ul><li>Yes</li><li>Yes</li><li>Not discussed</li><li>Yes</li></ul>
Results	<ul> <li>Quantified results</li> <li>Odds ratio (OR) and 95%CI</li> <li>Absolute risk reduction (ARR)</li> <li>Number needed to treat (NNT) with 95% CI and time period</li> <li>P values (exact values if possible)</li> </ul>	<ul> <li>Yes</li> <li>No</li> <li>No</li> <li>No</li> <li>No</li> <li>No</li> </ul>
Authors' Conclusions		Fenfluramine may cause improvement in social behaviour, stereotypic behaviour, excessive motor activity and attention span in some autistic children.  Animal literature raises concern about neurotoxicity, but not clear

	if these concerns are relevant to use in children with developmental disorders.
Reviewer's Summary	Agree. Fenfluramine withdrawn from market in 1997 because of concerns of toxicity in adults (cardiac and pulmonary hypertension).



Reference 330: Stern, L. M., Walker, M. K., Sawyer, M. G., & Oades, R. D. (1990). A controlled crossover trial of fenfluramine in autism. *Journal of Child Psychology & Psychiatry & Allied Disciplines*, 31, 569-585.

Design/Grade	Randomised controlled trial: Grade 1	
Outcomes	Primary     Secondary	Efficacy of fenfluramine in ASD  To meet parent demand for fenfluramine use in a controlled setting.
Design	<ul> <li>N</li> <li>Age, sex, race, and other relevant risk factors</li> <li>Inclusion and exclusion criteria</li> <li>Power</li> <li>Method of randomisation</li> <li>Intervention</li> <li>Blinding</li> <li>Length of follow-up</li> <li>Completeness of follow-up</li> </ul>	20 M:F 14:6; 4.9-17.3Y; ASD by DSM-III criteria NS Randomisation by pharmacist Fenfluramine 1.5 mg/kg/day Y 12/12 19/20 completed study (1 moved out of area)
Validity	<ul> <li>Is the study type appropriate for the questions being asked?</li> <li>Was the study population typical of patients with this disease?</li> <li>Were the treatment/control groups comparable at baseline?</li> <li>Was the intervention compared to placebo and/or best accepted intervention?</li> <li>Was there compliance with the intervention?</li> <li>Was there equal intensity of observation of study and control subjects?</li> <li>Was the process of observation likely to affect the outcome?</li> <li>Intention to treat analysis?</li> <li>Did conclusions about safety take into account the limited size of the study?</li> <li>Is effectiveness proven?</li> <li>Summary</li> </ul>	Y NS but DB/PC crossover Y Y – checked by parent diaries Y N – but different measures and scales used according to IQ of subject N Y N

Results	<ul> <li>Quantified results (ie, incidence/1000)</li> <li>Relative risk (RR) and 95% CI</li> <li>Absolute risk reduction (ARR)</li> <li>Number needed to treat (NNT), 95% CI, and time period</li> <li>P values (exact values if possible)</li> <li>Include adverse outcomes</li> </ul>	Significant improvement in more able children on IQ measure (BAS).
Authors' Conclusions		Fenfluramine may result in modest improvements in a subgroup of children with ASD.
Reviewer's Summary		A well designed study with a long period of observation. However, wide variation within group (esp IQ) and results need to be interpreted with caution.

Reference 331: Coplan, J., Souders, M.C., Mulberg, A.E., et al. (2003), *Archives of Disease in Childhood* 88: 737-9. Children with autistic spectrum disorders. II: Parents are unable to distinguish secretin from placebo under double-blind conditions.

Design/Grade	Randomised controlled trial – Grade 1	
Outcomes	Primary	To determine ability of parents to guess whether child has received secretin or placebo. Standardised measures may have failed to detect improved behaviours that are observed by parents.
	Secondary	
Design	• N	62
	Age, sex, race, and other relevant risk factors	Data reported separately
	Inclusion and exclusion criteria	Familes of children participating in DB crossover trial of secretin infusion vs saline placebo.
	Power	Not stated
	Method of randomisation	Not stated
	Intervention	Parents asked to guess which group their child had been in before unblinding.
	Blinding	Υ
	Length of follow-up	N/A
	Completeness of follow-up	60/62
Validity	<ul> <li>Is the study type appropriate for the questions being asked?</li> </ul>	Υ
	<ul> <li>Was the study population typical of patients with this disease?</li> </ul>	Υ
	Were the treatment/control groups comparable at baseline?	Y
	<ul> <li>Was the intervention compared to placebo and/or best accepted intervention?</li> </ul>	Y
	Was there compliance with the intervention?	Υ
	<ul> <li>Was there equal intensity of observation of study and control subjects?</li> </ul>	Y

	Was the process of observation likely to affect the outcome?	N
	Intention to treat analysis?	N
	Did conclusions about safety take into account the limited size of the study?	N/A
	Is effectiveness proven?	N
	Summary	Valid study
Results	Quantified results (ie, incidence/1000)	Υ
	Relative risk (RR) and 95% CI	N
	Absolute risk reduction (ARR)	N
	Number needed to treat (NNT), 95% CI, and time period	N
	P values (exact values if possible)	Υ
	Include adverse outcomes	N/A
Authors' Conclusions		Parents cannot distinguish short term behavioural effects of secretin from placebo. One family guessed correctly based on generalised flush post infusion.
Reviewer's Summary		Agree with conclusions of authors. Note that data only analysed for parents who perceived improvement on either secretin or placebo as other groups were too small for analysis.

Reference 332: Levy, S. E., Souders, M. C., Wray, J., Jawad, A. F., Gallagher, P. R., Coplan, J., Belchic, J. K., Gerdes, M., Mitchell, R., & Mulberg, A. E. (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.

Design/Grade	Randomised controlled trial: Grade 1	
Outcomes	<ul><li>Primary</li><li>Secondary</li></ul>	Effect of a single dose of human synthetic secretin on behaviour and communication
Design	<ul> <li>N</li> <li>Age, sex, race, and other relevant risk factors</li> <li>Inclusion and exclusion criteria</li> <li>Power</li> <li>Method of randomisation</li> <li>Intervention</li> <li>Blinding</li> <li>Length of follow-up</li> <li>Completeness of follow-up</li> </ul>	61(62) 3-8yr; race not fully stated – no significant difference between groups ASD – by ADI without other significant disability; other neurological disorder; previous Rx with secretin Computerised randomisation assessment See above Parents; Personnel involved in clinical and neurodevelopmental assessments Good, but assessment at 2 weeks post infusion
Validity	<ul> <li>Is the study type appropriate for the questions being asked?</li> <li>Was the study population typical of patients with this disease?</li> <li>Were the treatment/control groups comparable at baseline?</li> <li>Was the intervention compared to placebo and/or best accepted intervention?</li> <li>Was there compliance with the intervention?</li> <li>Was there equal intensity of observation of study and control subjects?</li> <li>Was the process of observation likely to affect the outcome?</li> <li>Intention to treat analysis?</li> <li>Did conclusions about safety take into account the limited size of the study?</li> <li>Is effectiveness proven?</li> <li>Summary</li> </ul>	Y – but follow-up very short Y Y Y Y Y Y Y N N N (but crossover design therefore not required) N

Results	<ul> <li>Quantified results (ie, incidence/1000)</li> <li>Relative risk (RR) and 95% CI</li> <li>Absolute risk reduction (ARR)</li> <li>Number needed to treat (NNT), 95% CI, and time period</li> <li>P values (exact values if possible)</li> <li>Include adverse outcomes</li> </ul>	Significant on one measure only Yes but information is not clear
Authors' Conclusions		Secretin is an ineffective treatment.
Reviewer's Summary		Agree, but longer tem follow-up would have added to the robustness of findings.

Companion paper not reviewed – reports parents unable to distinguish short-term behavioural effects.

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
333	Levy, S.E., Hyman, S.L. (2005). Novel treatments for autistic spectrum disorders. Mental Retardation and Developmental Disabilities 11: 131-142.  NON SYSTEMATIC REVIEW  Level of evidence: x	No methodology stated.	Summary of measures used in studies.	Individual results for studies reported.	Summary of the evidence for 'novel' treatments for ASD but not reviewed systematically or graded for quality of evidence. Plea from authors for parents of children with ASD to await confirmatory studies when faced with anecdotal reports of success with various 'novel' therapies. Also a plea for more rigorous scientific studies of treatments of ASD so that valid conclusions can be reached.

Reference 334: Nye C, Brice A. Combined vitamin B6-magnesium treatment in autism spectrum disorder. *Cochrane Database of Systematic Reviews* 2005, Issue 4. Art. No. CD003497. DOI: 10.1002/14651858.CD003497.pub2.

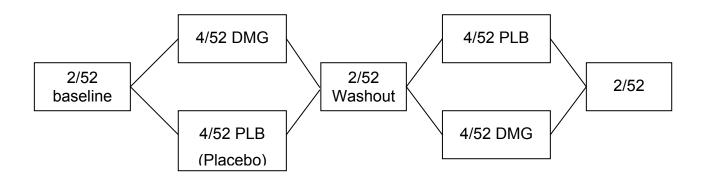
Design/Grade	Meta-analysis — Grade depends on primary studies used for meta-analysis
Outcomes	<ul> <li>Primary to determine the efficacy of vitamin B6 and magnesium for treating social, communication, and behavioural responses of children and adults with autism spectrum disorder. The major outcome included measures of:</li> <li>1. Verbal Behaviour, eg, increased language use</li> <li>2. Non-verbal Behaviour, eg, improved response to environmental stimuli</li> <li>3. Social interaction: eg, increased response to people</li> <li>Secondary</li> </ul>
Design	<ul> <li>Focused on a discrete clinical question; yes – does treatment with B12 and Mg affect any of the outcomes of interest.</li> <li>Explicit description of literature search; yes. Databases listed, as are keywords. No language restrictions were applied.</li> <li>State methodological standards used to select studies for inclusion in meta-analysis; these clearly stated, including only studies with adequate or unclear concealing of blinding were included, and those not reporting a randomisation procedure were excluded. Only those with a 20% or less rate of attrition were included. Authors were contacted for further data if insufficient data were included in the publication.</li> <li>Demographics of study populations – age, sex, race; 2 studies from the USA, one from Japan. A total of 23 boys and 10 girls took part.</li> <li>Administration of the intervention varied from 4 to 20 weeks.</li> <li>Dosage varied from 100mg B6 rising to 200mg/kg/day after two weeks (Kuriyama 2002) (no magnesium use reported) to 200mg/70kg of B6 plus 100gm/70kg magnesium (Tolbert 1993); to the higher doses of 30mg/kg body weight (maximum 1g/day) and 10mg/kg (maximum 350mg/kg/day) (Findling 1997).</li> </ul>
Validity	<ul> <li>Is the study type appropriate for the questions being asked? Yes</li> <li>Data tested for homogeneity? No meta-analysis was possible owing to lack of reported data (Findling 1997) and differences in both clinical populations and outcome measures between Kuriyama 2002 and Tolbert 1993.</li> <li>Evidence of publication bias? Not commented on.</li> <li>Summary; rigorous procedure employed in this systematic review. Lack of extractable data precluded inclusion of Findling 1997 in the analysis.</li> </ul>
Results	Quantified results     Intelligence quotient (IQ) B6 vs placebo, Weighted mean difference (fixed) 95% CI 5.25 [-20.13, 30.63]     Verbal intelligence quotient B6 vs placebo, Weighted mean difference (fixed) 95% CI 2.00 [-18.22, 22.22]

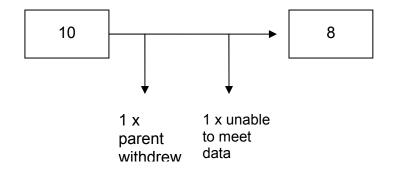
	Performance IQ B6 vs placebo, Weighted mean difference (fixed) 95% CI -6.75 [-26.85, 13.35] Social quotient B6 vs placebo, Weighted mean difference (fixed) 95% CI -12.50 [-30.35, 5.35] Odds ratio (OR) and 95% CI Absolute risk reduction (ARR) Number needed to treat (NNT) with 95% CI, and time period P values (exact values if possible)
Authors' Conclusions	Owing to the small number of studies, the methodological quality of studies, and small sample sizes, no recommendations can be advanced for autism. There is simply not sufficient evidence to demonstrate treatment efficacy.
Reviewer's Summary	The authors identified a large number of studies, but only 3 were of sufficient quality to be included. Even then, data from one were in a format that made inclusion in a meta-analysis impossible. A further problem with this study was that the control group was not randomly assigned. The two studies with useable data covered time periods of only a few weeks. The authors of this review note that longer treatment periods may be necessary. B6 has potentially severe side effects such as neuropathy. The main conclusion, however, is that much larger numbers are needed to provide useful data, probably as multiple smaller sample studies by way of multi-centre trials that would allow aggregation of data. The authors' conclusions are reasonable.

Reference 335: Bolman, W. M., & Richmond, J. A. (1999). A double-blind, placebo-controlled, crossover pilot trial of low dose dimethylglycine in patients with autistic disorder. *Journal of Autism & Developmental Disorders*, 29, 191-194.

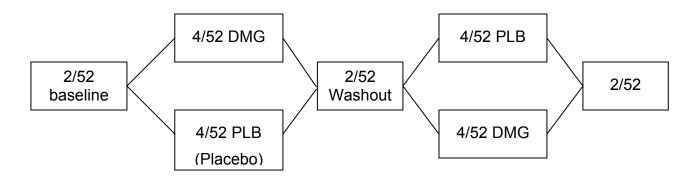
Design/Grade	Randomised controlled trial – Grade 1		
Outcomes	Primary	To assess effectiveness of dimethylglycine in double-blind controlled trial.	
	Secondary		
Design	• N	10	
	Age, sex, race, and other relevant risk factors	Age: 4.5 – 30.8Y (7 < 10yr Others 13/21/30); All ♂; Race not stated. Intelligence not evaluated. No high-functioning or Asperger	
	Inclusion and exclusion criteria	Autism by DSM IIIR criteria; both authors concur	
	Power	Not stated; not adequate	
	Method of randomisation	Crossover; allocation to order not stated	
	Intervention	Low dose DMG (125 -375 mg per day based on subject's weight). See study design diagram below	
	Blinding	Double blind	
	Length of follow-up	14/52	
	Completeness of follow-up	8/10 completed. 1 x parent withdrew. 1 x unable to meet data collection	
Validity	<ul> <li>Is the study type appropriate for the questions being asked?</li> </ul>	Υ	
	Was the study population typical of patients with this disease?	Y, severe end of spectrum	
	Were the treatment/control groups comparable at baseline?	No significant differences between groups	
	<ul> <li>Was the intervention compared to placebo and/or best accepted intervention?</li> </ul>	Y	
	Was there compliance with the intervention?	Υ	
	Was there equal intensity of observation of study and control subjects?	Y	

	<ul> <li>Was the process of observation likely to affect the outcome?</li> </ul>	N
	Intention to treat analysis?	N
	<ul> <li>Did conclusions about safety take into account the limited size of the study?</li> </ul>	Y
	Is effectiveness proven?	N
	Summary	Small but valid study
Results	Quantified results (ie, incidence/1000)	N
	Relative risk (RR) and 95% CI	N
	Absolute risk reduction (ARR)	N
	<ul> <li>Number needed to treat (NNT), 95% CI, and time period</li> </ul>	N
	P values (exact values if possible)	Y
	Include adverse outcomes	Υ
Authors' Conclusions		No significant effect of DMG, but acknowledge need for larger study.
Reviewer's Summary		Very small study. Authors comment on the widespread use of DMG and anecdotal evidence cited in support of this. However, they could find no controlled trials, therefore initiated this trial.





Age 4.5 - 30.87 < 10yr Others 13/21/30 All  $\circlearrowleft$ Race not stated Intelligence not evaluated No high-functioning or Asperger



No significant differences between groups

Reviewer summary: Very small study Some methodological issues

- No information on how Δ ASD made
- No information on randomisation

Reference 336: Millward, C., Ferriter, M., Calver, S., Connell-Jones, G. Gluten- and casein-free diets for autistic spectrum disorder. *Cochrane Database of Systematic Reviews* 2004, Issue 2. Art No.: CD003498. DOI: 10.1002/14651858.CD003498.pub2. The Cochrane Library, 2006, Issue 3.

Design/Grade	Meta-analysis – Grade depends on primary studies used for meta-analysis
Outcomes	<ul> <li>Primary; improvements in behaviour, cognitive and social functioning in individuals with autism as measured by Behavioural Observations and standardised assessments of autistic behaviours; Communication and Linguistic ability; Cognitive functioning; and or Motor Ability.</li> <li>Concentration of peptides in urine samples</li> <li>Secondary</li> </ul>
Design	<ul> <li>Focused on a discrete clinical question: yes – to determine the efficacy of a gluten-and or casein-free diet as an intervention to improve behaviour, cognitive and social functioning in individuals with autism.</li> <li>Explicit description of literature search: yes. Databases searched are listed, as are key words. References of all studies identified from electronic and hand searches were inspected for further studies, and experts in the field as well as research and consumer groups with an interest in autism and nutrition were contacted.</li> <li>State methodological standards used to select studies for inclusion in meta-analysis: Studies that reported more than 30% attrition would have been reported but not included in the analysis. Concealment of treatment allocation was assessed. Only one trial was included. Another study is awaiting assessment as information concerning randomisation has been unobtainable from the authors.</li> </ul>
Validity	<ul> <li>Is the study type appropriate for the questions being asked? Yes.</li> <li>Data tested for homogeneity: N/A as only one study found</li> <li>Evidence of publication bias: insufficient studies to assess this</li> <li>Summary: only one study met the criteria for inclusion, and this was a small scale single-blinded randomised trial of combined gluten-and casein-free diet versus a 'normal' diet. The participants were from Norway. The treatment period was 12 months; mean age 91 (range 62-120) months for intervention group, 86 (range 59-127) for control group. Norwegian children</li> <li>Inclusion: diagnosed as having autism and having raised urinary peptides</li> <li>Power: very low owing to small numbers</li> <li>Method of randomisation; random within pairs matched for autistic symptoms</li> <li>Intervention – gluten-and casein-free diet</li> <li>Blinding – single blind (method: coin tossing), with adequate concealment of allocation</li> <li>Length of follow-up, 12 months</li> </ul>
Results	<ul> <li>Quantified results: Post treatment reduction in Autistic traits (measured by DIPAB, a Danish instrument for measuring autistic traits) in treatment group vs control of mean (SD) 5.6 (2.42) vs 11.20 (5.00) weighted mean</li> </ul>

Authors' Conclusions	difference (95%CI) of -5.60 [-9.04; -2.16] favouring treatment. No effect seen on Linguistic Age, Cognitive Functioning, or Motor Ability, which is not surprising given the small number of subjects and low power to detect a difference.  Odds ratio (OR) and 95% CI see above Absolute risk reduction (ARR) Number needed to treat (NNT) with 95% CI and time period P values (exact values if possible)  Extensive literature review identified only one randomised controlled study of gluten-and/or casein free diet as an intervention to improve behaviour, cognitive and social functioning in individuals with autism. Results indicate that a combined gluten-and casein-free diet may reduce some autistic traits. This is an important area of study and large scale, randomised control trials are needed.
Reviewer's Summary	This research found only one study of 20 children that met their criteria. (Knivsberg, 2002). The authors are awaiting information on randomisation of another study before being able to consider it. This study deals with the effect on learning of a gluten-and cassin-free diet. There is also another relevant study under way which should finish in 2008. The authors' conclusions appear justified.

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
337	Metz, B., Mulick, J.A., Butter, E.M. (2005). Autism: a late 20 <sup>th</sup> century magnet. In: Jacobson, J.W., Foxx, R.M., Mulick, J.A. (eds). Controversial therapies for developmental disabilities: Fad, fashion and science in professional practice. Mahwah, N.J. Erlbaum.  NON SYSTEMATIC REVIEW – EXPERT OPINION  Level of evidence: x	Review of the evidence for fad treatments proposed for ASD.		Results from individual studies reported.	This is a non systematic appraisal of the evidence for 'fad' treatments for ASD.

Reference 338: Sinha, Y., Silove, N., Wheeler, D. et al. Auditory integration training and other sound therapies for autism spectrum disorders. *Cochrane Database of Systematic Reviews* 2004; Issue 1.

Design/Grade	Systematic review – Grade depends on primary studies used for systematic review	
Outcomes	Primary Secondary	<ul> <li>Cognitive ability</li> <li>Core features of autism</li> <li>Hyperacusis</li> <li>Auditory processing</li> <li>Behavioural problems</li> <li>Attention and concentration</li> <li>Activity level</li> <li>Quality of life in both school and home environments</li> <li>Adverse events</li> </ul>
Design	<ul> <li>Focused on a discrete clinical question</li> <li>Explicit description of literature search</li> <li>State methodological standards used to select studies for inclusion in meta-analysis</li> <li>Demographics of study populations – age, sex, race</li> </ul>	• Y • Y • Y
Validity	<ul> <li>Is the study type appropriate for the questions being asked?</li> <li>Data tested for homogeneity</li> <li>Evidence of publication bias</li> <li>Summary</li> </ul>	<ul> <li>Y</li> <li>N/A</li> <li>NR</li> <li>Y</li> </ul>
Results	<ul> <li>Quantified results</li> <li>Odds ratio (OR) and 95% CI</li> <li>Absolute risk reduction (ARR)</li> <li>Number needed to treat (NNT) with 95% CI, and time period</li> <li>P values (exact values if possible)</li> </ul>	<ul> <li>Y</li> <li>N</li> <li>N</li> <li>N</li> <li>Y, for some results</li> </ul>
Authors' Conclusions		Further research is required to determine the

	effectiveness of sound therapies, as the included studies were limited. In the absence of evidence, the treatment must be considered experimental and care must be taken not to risk hearing loss. Parents also need to be aware of the cost involved in pursuing these treatments.
Reviewer's Summary	Data synthesis of the 6 included trials (n=171) was limited by statistical and clinical heterogeneity. The methodology and size of the included studies did not allow for definitive conclusions.

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
339	Committee on Children with Disabilities. (1998). Auditory Integration Training and Facilitated Communication for Autism. Pediatrics 102(2): 431-433.  EXPERT OPINION Level of evidence: x	No methodology described.		Recommendations given:  • AIT may help some children with autism but there are as yet no good controlled studies to support its use. Thus, the use of this treatment is not warranted at this time, except within research protocols. Paediatricians should obtain current data on AIT as they become available.	Conclusions appear to be based on a consensus of an expert committee on children with disabilities.
340	Tinbergen, N., Tinbergen, E.A. (1983). Autistic children: new hope for a cure. London: Allen Unwin  BOOK – EXPERT OPINION  Level of evidence: x	Ethology approach taken.		Claims made for holding therapy as a successful therapy for children with ASD.	Not possible to exclude the possibility of bias in the approach taken.
341	Romanczyk, R.G,, Arnstein, L., Soorya, L.V., et al. (2003). The myriad of controversial treatments of autism. In: Lilienfeld, S.O., Lynn, S.J., Lohr, J.M.	No methodology stated.		The authors conclude that there is substantial evidence for the efficacy of ABA but evidence is lacking for other popular therapies for autism.	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	(eds). Science and pseudoscience in clinical psychology. New York: The Guilford Press. Chapter in book  EXPERT OPINION  Level of evidence: x				
342	Kaplan, M., Edelson, S.M., Seip, J.L. (1998). Behavioral changes in autistic individuals as a result of wearing ambient transitional prism lenses. <i>Child Psychiatry and Human Development</i> 29: 65-76.  OBSERVATIONAL STUDY  Level of evidence: x	Before and after double-blind crossover design study  N=18 Range from 7 to 18 years (mean=11.5yrs); 13 males, 5 females; no other demographic factors reported primary or secondary diagnosis of autism by an independent clinician or psychologist.  Half the participants wore ambient prism lenses and half wore clear lenses for 3 months, then the groups were crossed over for 4 months (lenses were indistinguishable).	Behaviour assessed using the Aberrant Behaviour Checklist (this has been shown to be a valid measure of behavioural problems) (assessed by parents of the participants.  Four performance tasks to assess both attention and orientation simultaneously (scored by first author).	<ul> <li>Summary scores indicated a decrease in behaviour problems in the experimental group for the 1 ½ and 2 month assessment periods and a small increase in behaviour problems during the 3<sup>rd</sup> and 4<sup>th</sup> month assessments. There were no changes in the placebo group (clear lenses).</li> <li>At month 2, t(8)=2.057, p&lt;0.05.</li> <li>No significant differences between groups on the performance tasks.</li> </ul>	The authors speculated that the decrease in behaviour problems at 2 months was consistent with the phenomenon termed 'visual capture'.  The findings of the study are limited by the study design, which did not provide for independent assessments of changes.
343	Morgan H. (2003).	N/A	N/A	N/A	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	Adults with autism. Cambridge University Press.				
	воок				

## **EVIDENCE TABLES FOR PART 5: LIVING IN THE COMMUNITY**

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
344	Morgan, H. (1996). Attachment and loss: a focus on transition and bereavement. In Morgan, H. (Ed.) Adults with Autism, Cambridge; Cambridge University Press. BOOK CHAPTER Level of evidence: x	Book chapter: includes case vignettes.		<ul> <li>Explores significance of attachment and loss for adults with autism.</li> <li>Applies theory and research on attachment, bereavement, and psychosocial transition to autism, and develops models.</li> <li>Suggests that autistic trait of inflexibility of thought affects attachment, transition, loss and bereavement.</li> <li>Implications for practitioners identified. Practitioners need to understand how and why attachments are formed, to plan the timing, sequencing, synchronisation of transitions based on this understanding and that of the individual circumstances, and to anticipate the problems that may occur based on this underlying knowledge.</li> </ul>	
345	Coates, S. (1996). Issues relating to the further education and support of students with autism. <i>Skill Journal</i> , 54(April), 11-14.	Anecdotal report.		Transitioning students into higher education requires careful selection and planning, precise timing of funding, flexibility, and problemsolving.	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	EXPERT OPINION  Level of evidence: x				
346	Held, M. F., Thoma, C. A., & Thomas, K. (2004). "The John Jones Show": how one teacher facilitated self-determined transition planning for a young man with autism. Focus on Autism & Other Developmental Disabilities, 19(3), 177-188.  OBSERVATIONAL STUDY	Qualitative study involving special education teacher and a 17-year-old man with ASD.	Participatory action research.	Findings: Successful education and employment outcomes after combining strategies designed to develop self-determination skills into transition planning.  Strategies included:  Person-centred planning  self-determination curriculum and self-instructional model  use of technology to support the student in having a voice in the process, integration of instruction across the day.	
347	Level of evidence: +  Meyer, R. N. (2001).  Asperger Syndrome  Employment  Workbook: An  Employment  Workbook for Adults  with Asperger  Syndrome. London:  Jessica Kingsley  Publishers Ltd.  EXPERT OPINION	Book.		Findings  • Long periods of unemployment are common, as is 'underemployment', or working below one's skills level.  • Transition planning required.  • Employment prospects improve if ASD characteristics are taken into account.  • Recommends supported employment.	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	Level of evidence: x				
348	Morgan, H., Edwards, G. & Mason, L. (1996). Developing a support model, within a further education college, for adults with autism. In Morgan, H. (Ed.) Adults with Autism, Cambridge; Cambridge University Press. BOOK CHAPTER Level of evidence: x	Book chapter: described Oakfield House/Matthew Boulton College Project, and includes case vignettes.		Where access to further education has been achieved, adults with autism have been provided with a general service for people with additional learning needs, rather than an autism-specific service and the educational infrastructure and support necessary for successful placement has often been lacking. Result: failed opportunities for people with autism, and in some cases, profoundly damaging effects.  Variables within the further education system which adults with autism can find anxiety provoking:  • content of the curriculum  • methods of teaching  • context of teaching environment  • out of class activities  • relationships with staff and peers  • short induction period  • structure of sessions.  Successful outcomes for 2 adults supported by the Oakfield House. Matthew Boulton College Project  Recommendations  • Training in autism for lecturers, classroom assistants and	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				<ul> <li>Adequate preparation</li> <li>Information sharing</li> <li>Staggered start time of courses</li> <li>Consistency of approach and staffing</li> <li>Support worker from host organisation.</li> </ul>	
349	Ridley, J., Hunter, S., & Infusion Cooperative. (2005). "Go For It!": Supporting People with Learning Disabilities and/or Autistic Spectrum Disorder in Employment. Edinburgh: Scottish Executive Social Research.  EVIDENCE-BASED GUIDELINE Level of evidence: +	Evidence-based guideline.		Recommendations: Features of best practice in supported employment include:  • individuals controlling their own vocational destinies through self-determination, facilitated by person-centred planning, and a career based approach  • employment specialists acting as facilitators, not experts  • taking account of employers' as well as individuals' needs  • using 'natural supports' and supplementing jobs in ways that are 'typical' for each setting  • using intentional strategies to enhance social integration  • supporting self-employment  • post or follow-up support  • ensuring that people with severe disabilities can access supported employment  • quality outcomes result when services adopt a principles and values-led approach to	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				supported employment.	
350	National Advisory Committee on Health and Disability. (2003). To Have an 'Ordinary Life'. Community membership for adults with an intellectual disability. (No. ISBN 0478- 25239-X). Wellington. EVIDENCE-BASED GUIDELINE Level of evidence: +	Evidence-based guideline.		Recommendations for people with an intellectual disability were:      careful and long-term planning for transition into retirement     people must be able to access existing income support, employment and training opportunities     people must be able to pursue personally meaningful lives, in which vocational services and non-vocational community participation are available as part of a range of supported living options.	
351	Minister for Disability Issues (2001) The New Zealand Disability Strategy: Making A World Of Difference: Whakanui Oranga, Wellington, Ministry of Health. Avaliable from <a href="http://www.odi.govt.nz">http://www.odi.govt.nz</a> Z REPORT Level of evidence: +	Strategic plan of NZ government, based on wide consultation.		Underpinning the NZ Disability Strategy is a vision of a fully inclusive society.  Achieving this vision will involve ensuring that disabled people have a meaningful partnership with government, communities and support agencies, based on respect and equality.  To advance NZ towards a fully inclusive society, the Strategy includes 15 objectives, underpinned by detailed actions. The objectives are to:	

Ref Reference No Type and	•	d Participants	Measures	Outcomes/Results	Notes
				<ol> <li>Encourage and educate for a non-disabling society</li> <li>Ensure rights for disabled people</li> <li>Provide the best education for disabled people</li> <li>Provide opportunities in employment and economic development for disabled people</li> <li>Foster leadership by disabled people</li> <li>Foster an aware and responsive public service</li> <li>Create long-term support systems centred on the individual</li> <li>Support quality living in the community for disabled people</li> <li>Support lifestyle choices, recreation and culture for disabled people</li> <li>Collect and use relevant information about disabled people and disability issues</li> <li>Promote participation of disabled Mäori</li> <li>Promote participation of disabled Pacific peoples</li> <li>Enable disabled children and youth to lead full and active lives</li> <li>Promote participation of disabled women in order to improve their quality of life</li> <li>Value families, whänau and</li> </ol>	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				people providing ongoing support.  Two of the specific actions regarding education are:  • promote appropriate and effective inclusive educational settings that will meet individual educational needs  • improve post-compulsory education options for disabled people, including: promoting best practice, providing career guidance, increasing lifelong opportunities for learning and better aligning financial support with educational opportunities.	
352	Howlin, P. (2000). Outcome in adult life for more able individuals with autism or Asperger syndrome. <i>Autism</i> , 4(1), 63-83. SYSTEMATIC REVIEW Level of evidence: +	Systematic review.		<ul> <li>Findings</li> <li>Comparison of outcome in mixed-ability groups of adults with ASD indicates some increases in employment opportunities over time (1960 to 2000).</li> <li>Appropriately structured educational programmes may influence later academic and occupational attainments.</li> <li>Access to specialist supported employment schemes could significantly improve chances of individuals finding and maintaining suitable employment.</li> </ul>	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				Few specialist support systems exist and most individuals have to rely heavily on the support of their families in finding jobs or accommodation.	
353	The National Autistic Society. (2004). Guidelines for	Web-based information.		Describes common presentations of ASD symptoms in educational settings.	
	teaching students with Asperger syndrome in further education colleges.			Advice on how to support students with ASD, with the example of preparing for an exam.	
	Retrieved 3/12/04,			Details 'everyday considerations':	
	2004, from http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=129&a=2232			<ul> <li>teacher as positive role model</li> <li>diagnostic disclosure</li> <li>problems in teaching settings (eg, group work, lack of</li> </ul>	
	EXPERT OPINION - WEB-BASED INFORMATION			comprehension, lack of empathy, problems with motivation, distress caused by lack of information, social chameleons).	
	Level of evidence: x			,	
354	Glennon, T. J. (2001). The stress of the university experience for students with Asperger syndrome. Work, 17, 183-190.	Overview of literature (no search criteria) and presentation of case vignettes of people with Asperger Syndrome (AS).		Recommendation: in order to comprehend the extent and types of supports needed for people with AS, the intricacies between the person with AS and the college experience must be explored.	
	NON SYSTEMATIC			Stressful situations within the	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	REVIEW Level of evidence: x			university environment include:     the transition process     social relationships and activities     academic stressors     new life of independence.  The author demonstrates supports that may assist people with AS in managing the stressful situations, with specific references to preparation, familiarisation, peers mentors, course development and organisation, and cognitive behaviour therapy.	
355	Aoraki Polytechnic. (2004). Good Practice Guidelines for Aoraki Polytechnic Students Who Have Asperger Syndrome, from http://www.aoraki.ac. nz/support/ WEB-BASED INFORMATION – EXPERT OPINION Level of evidence: x	Web-based information.		Described support requirements for students with AS at Aoraki Polytechnic. Adapted from Powell (2002) (ref 39).	
356	Massey University. (2005). Disability Services. Retrieved	Web-based information.		Information on services for students with a disability.	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	3/10/05, 2005, from http://student-services.massey.ac.n Z EXPERT OPINION – WEB-BASED INFORMATION Level of evidence: x				
357	University of Otago. (2005). Disability Information and Support. Retrieved 3/10/05, from http://www.otago.ac.nz/services/disabilities-office  EXPERT OPINION – WEB-BASED INFORMATION Level of evidence: x	Web-based information.		Information on services for students with a disability.	
358	University of Canterbury. (2005). Disability Support Service. Retrieved 3/10/05, from http://canterbury.ac.n z/disability/about.sht ml  EXPERT OPINION – WEB-BASED	Web-based information.		Information on services for students with a disability.	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	INFORMATION Level of evidence: x				
359	Victoria University of Wellington. (2005). Disability Support Services. Retrieved 3/10/05, from http://www.vuw.ac.nz/st_services/disability  EXPERT OPINION – WEB-BASED INFORMATION  Level of evidence: x	Web-based information.		Information on services for students with a disability.	
360	Lones, J. (1996). Autism and Asperger syndrome: implications for examinations. <i>Skill Journal</i> , 56, 21-24.  EXPERT OPINION Level of evidence: x	Advice based on experience.		Describes common presentations of ASD symptoms in the classroom.  Considerations for examinations include:  separate examination room object of comfort in examination room extra time presentation of examination papers on plain paper and in one colour language of examination questions as clear as possible prompt candidate when it is time to move on to the next question use of word processing or	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				<ul> <li>exemption for the assessment of handwriting</li> <li>papers scrutinised by someone familiar with ASD and aware of the candidate's diagnosis</li> <li>Performance in oral tests may be affected by other symptoms.</li> </ul>	
361	University of Waikato. (2004, 21/9/04). Disability Support Services, 3/10/05, from http://www.waikato.a c.nz/sasd/health/disa bility/  EXPERT OPINION – WEB-BASED INFORMATION Level of evidence: x	Web-based information.		Information on services for students with a disability.	
362	Muller, E., Schuler, A., Burton, B. A., & Yates, G. B. (2003). Meeting the vocational support needs of individuals with Asperger syndrome and other autism spectrum disabilities. Journal of Vocational Rehabilitation, 18,	Qualitative pilot study of the views of 18 high-functioning adults with ASD.	Semi-structured interview.	Findings Three main themes identified, as below.  Workplace experiences:  • diverse vocational interests  • unemployment and underemployment  • generally negative work experiences.  Obstacles to successful	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	163-175. OBSERVATIONAL STUDY – QUALITATIVE Level of evidence: +			<ul> <li>employment:</li> <li>mastering the application process</li> <li>adapting to new job routines</li> <li>communication</li> <li>navigating social interactions with employers and co-workers.</li> </ul> Recommendations: <ul> <li>job matching</li> <li>individualised ASD-specific supports</li> <li>communication supports</li> <li>autism awareness training</li> <li>attitudinal supports</li> </ul>	
363	Hurlbutt, K., & Chalmers, L. (2004). Employment and adults with Asperger syndrome. Focus on Autism & Other Developmental Disabilities, 19(4), 215-222.  OBSERVATIONAL STUDY – QUALITATIVE Level of evidence: ~	Qualitative study of 6 adults with Asperger Syndrome.	Initial and follow-up interviews, in person, by telephone or via e-mail.	Findings: Frequent unemployment and underemployment.  Difficulties interfering with employment success included:  • social difficulties  • communication issues  • stress and anxiety.  All had difficulty maintaining jobs.  Recommendations for aiding success in the workplace included:  • use of job coaches  • clear explanation of duties, responsibilities, expectations	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				<ul> <li>and rules ahead of time</li> <li>considered disclosure of diagnosis</li> <li>employers considering the advantages of having an employee with ASD (eg, on time, attention to detail, satisfaction with repetitive work, loyalty, stability)</li> <li>educating employers and coworkers about ASD.</li> </ul>	
364	Gilson, S. F. (1998). Case management and supported employment: a good fit. Journal of Case Management, 7(1), 10-17. NON SYSTEMATIC REVIEW Level of evidence: x	Overview of literature (no search criteria) and presentation of case study of a man with severe intellectual disability.		Recommendations:  • supported employment schemes are beneficial to people with disabilities, including ASD  • case management assists supported employment  • potential roles of case manager outlined.	
365	Keel, J. H., Mesibov, G. B., & Woods, A. V. (1997). TEACCH - supported employment program. <i>Journal of</i> <i>Autism &amp;</i> <i>Developmental</i> <i>Disorders</i> , 27(1), 3-9. OBSERVATIONAL	Descriptive paper on TEACCH services to 'over 100' persons with ASD since 1989.		Findings Prior to TEACCH providing supported employment in 1989, 37% of individuals were without any placement, 31% had sheltered work settings, and 23% were at school.  Since TEACCH supported employment services began, 96 individuals have achieved	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	STUDY Level of evidence: ~			community job placements.  Three models of supported employment were used:  • individual placement – job coach works with individual with ASD to locate job, train and fade out support (72% of people with jobs)  • dispersed enclave – job coach supports several people with ASD employed by one business (21% of people with jobs)  • mobile crew – job coach 2 – 3 individuals and provide a service in the community (eg, house cleaning) (7% of people with jobs).  Jobs were in food services (38%), clerical (15%), stocking (11%), custodial (11%) lab/technical (9%), manufacturing (4%), and other (12%).	
366	Mawhood, L., & Howlin, P. (1999). The outcome of a supported employment scheme for high-functioning adults with autism or Asperger syndrome. Autism, 3(3), 229-	Descriptive paper of the outcome of a supported employment project for 30 high-functioning people with ASD (27 male, 3 female). Control group of 20 high-functioning men with ASD living outside the area covered but meeting all	Psychometric battery of tests of cognitive and linguistic skills, academic attainment and social understanding.	Findings Over the 2-year evaluation period, 19 (63.3%) subjects were found employment. Only 5 (25%) of the control group found paid work.  No group differences in the proportion of time in work during thepre-intervention period, but at the	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
<b>No</b> 367		Book chapter: description of the Gloucestershire Group Homes Employment Training Unit (ETU). Includes case vignettes.	Information on educational, employment and residential histories.  Rosenberg Self Esteem Inventory.  Interview.  Work Personality Profile.	end of the evaluation period the supported group spent significantly more time in employment.  9 people in the supported group found permanent employment, and 10 had temporary or seasonal contracts. 3 of the control group had permanent contracts, and 2 had temporary contracts.  14/15 managers reported satisfaction with the scheme.  The ETU model is described, under the following sections:  key elements of a specialist employment service outlining the pathway to employment basic skills training and personal development assessment (ETU individual	
	Group Homes Model. In Morgan, H. (Ed.) Adults with Autism, Cambridge; Cambridge University Press.			assessment and Placing Assessment and Counselling Team assessment)  career guidance enclave work  ETU business model	
	BOOK CHAPTER Level of evidence: x			<ul> <li>mobile crew work experience</li> <li>work experience with a job coach</li> <li>role of job coach supporting an individual in employment</li> </ul>	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
		Methods and Participants	Measures	supportive employment services in the UK.  Case vignettes presented, no data.  Chapter concludes that:     successful specialist employment services need to understand the specific difficulties a person who experiences ASD has in accessing mainstream employment     must address these needs and provide necessary skills and support     service would benefit from working with mainstream services     provide continuum of provision, catering for people who can and can't progress to open employment     teaching methods need to reflect trainer's understandings of the individual     emphasis on clear, direct unequivocal, instruction, supplemented by visual material     at the pace of the individual     continual assessment and	Notes
				<ul><li>liaison with support network</li><li>gradual progression from ETU–</li></ul>	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				based training allows for comprehensive training to take place	
368	Unger, D. D., Parent, W., Gibson, K., Kane-Johnston, K., & Kregel, J. (1998). An analysis of the activities of employment specialists in a natural support approach to supported employment. Focus on Autism and Other Developmental Disabilities, 13(1), 27-38.  OBSERVATIONAL STUDY  Level of evidence: +	Descriptive paper of the outcome for 36 individuals served by the Natural Supports Transition Project from June 1992 until November 1996. Most were intellectually disabled. Some (an unspecified number) had ASD.	Questionnaire – Community and Workplace Support Form.	Findings 36 individuals with severe disabilities were placed in 54 jobs.  57 different types of support needs wereidentified. 590 support needs identified for whole group.  Six categories of support needs were:  • finding a job  • learning how to do the job  • obtaining assistance with completing the job  • addressing work-related issues  • addressing non-work-related issues  • transportation.  Employment specialists have primary responsibility for arranging the support for work-related issues.  Once an individual is employed, assistance is predominately provided by supervisors or other workplace personnel. Rarely was this role identified as belonging to the employment specialist.	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
369	Nesbitt, S. (2000). Why and why not? Factors influencing employment for individuals with Asperger syndrome. Autism, 4(4), 357- 369.  OBSERVATIONAL STUDY — QUALITATIVE  Level of evidence: ~	Qualitative study of 41 organisations employing people with ASD through a supported employment scheme, and 40 organisations not employing an individual with ASD.	Questionnaire.	Findings The 5 items found to be significantly more important to organisations using the employment scheme were related to the organisation's understanding of ASD, and of the supported employment scheme.  The 7 items found to be more important to organisations not employing people with ASD focused on the ability of the individual to behave in certain ways rather than their ability to do the job, and the ability of the individual to adapt to the organisation. These organisations did not see provision of information about the disorder as an important factor, nor did they acknowledge the importance of an employment support worker in supporting the individual.	
370	Waleski, G. (Undated). Services Needed for Teens and Adults on the Autism Spectrum. Retrieved 3/12/04, from <a href="http://www.isn.net/~jypsy/gary3.htm">http://www.isn.net/~jypsy/gary3.htm</a> EXPERT OPINION – WEB-BASED	Web-based opinion.		Teenagers with ASD have difficulties performing successfully at school and entering employment.  Assistance to teenagers with ASD includes:  • counsellors providing vocational assistance  • intensified tutoring needed in schools  • vocational assistance.	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	INFORMATION Level of evidence: x			Adults with ASD need career planning and vocational assistance.	
371	Bray, A. (2003). Work for adults with an intellectual disability: review of the literature prepared for the National Advisory Committee on Health and Disability to inform its project on services for adults with an intellectual disability. Dunedin: Donald Beasley Institute.  SYSTEMATIC REVIEW  Level of evidence: +	Systematic review.		Supported employment is available in many countries, with variable success.  There are not enough supported employment services to meet the needs of all adults with an intellectual disability who want to work in the community.	
372	Lattimore, L.P., Parsons, M.B., Reid, D.H. (2002). A prework assessment of task preferences among adults with autism beginning a supported job. Journal of Applied Behavior Analysis; 35(1):85-8.	Single case study design with 3 male clients aged 25, 26 and 29. All had autism and severe or profound intellectual disability. None communicated vocally.	Cumulative number of choices	Reports supported the assessment for identifying single task preferences, but did not reveal preferences of 2 workers for alternate tasks.  Further research needed.	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	OBSERVATIONAL STUDY – CASE STUDY Level of evidence: x				
373	Hagner, D., & Cooney, B. F. (2005). "I do that for everybody": supervising employees with autism. Focus on Autism & Other Developmental Disabilities, 20(2), 91-97. OBSERVATIONAL STUDY Level of evidence: +	Qualitative evaluation of the supervisors of 14 successfully employed people with ASD.	Semi-structured interview.  Worksite observations.	Findings Supervisors evaluated employees with ASD highly.  Supervisory strategies linked with success included:  • maintaining a consistent schedule and set of job responsibilities  • using organisers to structure the job  • reducing idle or unstructured time  • being direct when communicating with the employee  • providing reminders and reassurances.  Supervisors believed assistance from rehabilitation agency was crucial to successful employment.	
374	Department of Recreation and Leisure University of North Carolina	Consensus/ Expert Opinion. Project Autism was a three-	Two nationally recognised programmes collaborated on the	A manual was created to prepare school and therapeutic personnel (teachers, families, residential staff, recreation providers, school	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	Chapel Hill. (2000). Project autism. Retrieved 5/04/2004, from http://www.unc.edu/d epts/recreate/crds/au tism/  EXPERT OPINION Level of Evidence: ~	year effort to address the recreation needs of people with autism.	project – University of North Carolina, Chapel Hill, Department of Recreation and Leisure Studies and Division TEACCH, Department of Psychiatry.	counsellors and recreation specialists) to serve children and youth with autism, with a focus on social and recreational skills.	
375	UK Department of Health. (2004). National service framework for children, young people and maternity services, standard 8: Disabled children and young people and those with complex health needs. UK Department of Health REPORT  Level of Evidence: ~	UK Government Policy National standards for children across health and social services ensure needs of children, young people and pregnant women have services that meet identified needs. The standards outline the vision, standards, markers of good practice and rationale, including performance indicators against which progress towards standards will be measured.	Eight external working groups (over 250 members from health professionals, service users and carers, health managers, agencies and key advocates for children) worked on reports and recommendations for over 1 year. Consultation meetings with children, young people and families held. Professional groups consulted. Emergent findings	The UK National Framework establishes 11 standards for promoting the health and well-being of children and young people and for providing high quality services to meet their needs. Standard 8 focuses on 'Disabled Children and Young People and Those with Complex Health Needs'.	P16, 5.7 refers to inclusive leisure, inclusive of children with ASD.

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
			published and responses called for.		
376	Bray, A., & Gates, S. (2003). Community participation for adults with an intellectual disability. A review of the literature. Dunedin, NZ: Donald Beasley Institute for Research and Education on Intellectual Disability.  NON SYSTEMATIC REVIEW  Level of Evidence: ~	Literature review of studies about adults with an intellectual disability.	Literature Review included:  • exploring experience of community participation  • social relationships and networks  • role of staff  • personal experiences  • leisure activities  • physical activity.	Findings Study outlined strategies for promoting community inclusion including implications for NZ communities and disability support services.	Information on participation in leisure activities is found on pp 23-35.
377	Bray, A., & Robertson, S. (2005). Discussion document for the Auckland ASD project. A report to the Ministry of Health. New Zealand: Wellington: Ministry of Health.  QUALITATIVE STUDY	Discussion document that reviewed previous reports and New Zealand-based services for people with ASD.  Analysis of data on the number of children and young people (0-21 years) known to access services and known to NASC. Analysis of responses from	Reviewed current services in Auckland based on information from the NASC.  Analysed 15 structured focus groups involving parents, carers and individuals with ASD to support	Findings:  Revealed a range of services provided through public, private and community organisations.  Identified current gaps or limitations in services for ASD children, young people and their families. Combined with services prioritised by the focus groups, a range of possible services were identified for development or	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	Level of Evidence: ~	155 parents, carers and individuals who participated in 15 focus groups.  A report prepared by Tainui MAPO informed the Auckland ASD Project of some of the key issues facing Maori children who have ASD and family/whānau.	prioritisation for service development in the Auckland region.	improvement.  • Supported the decisions of the Auckland ASD Advisory Group to identify services for 2 pilot projects and to develop a service framework for children, young people with ASD and their families in the Auckland region.	
378	Attwood, T. (2004). Using special interests and repetitive behaviour. Paper presented at the Autism Conference: unlocking the potential within, Christchurch.  EXPERT OPINION Level of Evidence: x	Conference Paper Extract. Text adapted from: 'Understanding and managing circumscribed interests'. In: Learning and behaviour problems in Asperger syndrome, edited by Margot Prior and published by The Guilford Press, 2003.	Referenced extract. Based on surveys, clinical experience, personal contact.	Explanation of ASD/special interests; how interests can change with age; triggers; common characteristics; consequence and function of special interests including barriers to community participation; ASD perspective; enjoyment and anxiety reduction; impaired executive function.  Strategies for constructive support include interests leading to income and employment; making friends.	
379	Orsmond, G. I., Krauss, M. W., & Seltzer, M. M. (2004). Peer relationships and social and recreational activities among adolescents	Research study.  Investigated peer relationships and participation in social and recreational activities among 235 adolescents and adults	Sub-sample of 235 people (10-47 years) with ASD, who were living with their parents. Sub-sample taken from 407	Prevalence of friendships, peer relationships and participating in social and recreational activities all low. Comparable to previous research. Greater participation predicted by greater functional independence, less impaired social	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	and adults with autism. Journal of Autism and Developmental Disorders, 34(3), 245-256.  OBSERVATIONAL STUDY  Level of Evidence: ~	with autism, who lived at home.  Study limitations included:  • participants were volunteers and may not be representative of all people with ASD  • all lived with their families and results may not have reflected experiences of those living in services  • all data obtained from the mothers.	adolescents and adults with ASD who are participating in a longitudinal study. Mothers provided all the data, based on ADI-R, a standardised investigator-based interview, based on ICD-10; World Health Organisation, 1992 and parallels the DSMIV criteria.	interaction skills, higher internalising behaviours and environmental support from maternal participation in social and recreational activities, greater number of services received and inclusion in integrated settings. Supporting the family to maintain social relationships may have an important effect for individual with ASD.	
380	Whitehouse, R., Chamberlain, P., & O'Brien, A. (2001). Increasing social interactions for people with more severe learning disabilities who have difficulty developing personal relationships. <i>Journal of Learning Disabilities</i> . 5(3), 209-220.  OBSERVATIONAL STUDY	Based on findings from a social contact group set up for four men with severe learning disabilities.	Measures included  • Sue Spence Social Skills Assessment (Spence 1986)  • Ager Life Experiences Checklist (Ager 1990).	For people with severe disabilities, the opportunity to build social networks does not depend on the person's cognitive abilities or social skills but on the physical opportunities for meeting others, in a supportive environment.	Participants assessed as having a severe learning disability (IQ less than 55); severe social skill deficits and few meaningful relationships; ASD not identified.

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	Level of evidence: ~				
381	Coventry, Warwickshire, & Neurodiversity Group (2000). UK. The all parliamentary group on autism manifesto. Retrieved from <a href="http://www,geocities.com/CapitolHill/7138/rights/manifesto.htm">http://www,geocities.com/CapitolHill/7138/rights/manifesto.htm</a> 6/10/2004  EXPERT OPINION Level of Evidence: ~	All Party Manifesto. Members came from all political parties and agreed to work together to promote the interests of people with ASD and their carers. This resulted in a Manifesto, which also included extensive consultation with the autism movement in the UK.	Manifesto sets out the goals and principles the group is working to.  A specific objective in the Manifesto related to meaningful activity and leisure that promotes social inclusion.	Key agreement that multi-agency collaborative planning needed to promote social inclusion and person- centred planning for people with ASD. Central Goverment should provide guidance to local Authorities and provide the financial resources for consistent service provision.	
382	Howlin, R. (2003). Asperger syndrome in the adolescent years. In: Holliday Willey, L. (ed) Chapter 1. Asperger syndrome in adolescence. London & New York: Jessica Kingsley Publishers.  BOOK CHAPTER	Book/Expert Opinion. Chapter 1 summarises how children form social groups; explains the confusion adolescents with Asperger syndrome experience and the implications arising from these challenges.	Richard Howlin (PhD) is a clinical child and adolescent psychologist.	Outlines the objectives for therapeutic support, components for a treatment plan; the role of parents and schools for providing support to maximise learning and to encourage a sense of social competence.	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	Level of Evidence: ~				
383	Klin, A., & Volkmar, F. R. (1995).  Asperger syndrome: Some guidelines for assessment, diagnosis, and intervention. Connecticut: Yale-LDA Social Learning Disabilities ProjectYale Child Study Center.  GUIDELINES  Level of Evidence: ~	Website/Expert opinion Published article		Provides guidelines for assessment and diagnosis including brief recommendations for treatment and interventions.	
384	Pyles, L. (2003). Education and the adolescent with Asperger syndrome. In: Holliday Willey, L. (ed). Chapter 11. Asperger syndrome in adolescence. London: Jessica Kingsley Publishers.  BOOK CHAPTER Level of Evidence: x	Book/Expert opinion. Covers ideas to support children at school; information for parents; practical ideas for transition support; identifies a range of education facilities and approaches and preparation for life after school.	Lise Pyles is a parent of a person with Asperger Syndrome and an author of 2 books (ASD).	Provides contacts for information and support including NZ reference.	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
385	Foley, D. (2003). Starting from scratch: Being innovative in finding interventions for your adolescent with Asperger syndrome. In Holliday Willey, L. (ed). Chapter 10. Asperger syndrome in adolescence.  BOOK CHAPTER Level of Evidence: x	Book/Expert Opinion. Chapter 10 written by a parent. Personal account of finding interventions for an adolescent with Asperger Syndrome.	DeAnn Foley has a Masters of Education, is a co-author of several articles and is a teacher in special education.	Emphasises the need to incorporate a social component to interventions and therapies, and to be as innovative as possible, while relying on the skills and expertise of trusted professionals.	
386	Department of Labour. (2004). Achieving balanced lives and employment. What New Zealanders are saying about work- life balance.:Work- Life Balance Project, Department of Labour.  QUALITATIVE STUDY  Level of Evidence: +	NZ Government project Consultation process included over 700 responses from individuals and organisations, meetings, media articles, research articles and projects.	Consultation process resulted in policy and other actions to improve work-life balance. Appendices contain copies of submission response forms, information about people and organisations who responded and a list of meetings held with interested groups.	The project was established to develop policies and practices promoting better balance between paid work and life outside of work. Three key components identified for work-life balance: paid work, unpaid work and personal time.  Disability was identified as an obstacle to achieving work-life balance for some people, related to mobility. A range of problems were identified for parents of children with disabilities.	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
387	Autistic Association of New Zealand. (2001). The needs and gaps in services for families and individuals with an autistic disorder. Christchurch.  OBSERVATIONAL STUDY – SURVEYS  Level of Evidence: ~	Data drawn from 2 surveys, 2000-2001:  • 932 families and  • 979 people with ASD. Detailed breakdown of employment status of participants. Survey also covered diagnosis, specialist and welfare guardianship, carer support needs, Needs Assessment, health, education.	Telephone survey.	931 members had ASD diagnoses. 274 were 16 years and above. Majority reliant on government for income with many still in the education system.	
388	Stanton, M. (2003). How do I be me? In: Holliday Willey, L (ed). Asperger syndrome in adolescence. Chapter 13. London: Jessica Kingsley Publishers.  BOOK CHAPTER Level of Evidence: x	Book/Expert Opinion. Explores the concept of how to support people with ASD and respecting their right to be autistic.	A teacher of children with severe learning disabilities, including autism, in the UK. Parent of a young man with ASD and author of 1 published book (ASD).	Small but useful list of references to support approach and philosophy.	
389	Debbaudt, D., & Rothman, D. (2001). Contact with	Information article.		Describes symptoms of ASD for law enforcement officials.	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	individuals with autism: effective resolutions. FBI Law Enforcement Bulletin, 70(4), 20 - 25.  EXPERT OPINION  Level of evidence: x			Identifies situations in which police might meet a person with ASD.  Suggests appropriate responses for police in general, and, in particular, when a crime has been committed.	
390	Petersilia, J. A. (2001). Crime victims with developmental disabilities: a review essay. Criminal Justice and Behavior, 28(6), 655-694.  NON SYSTEMATIC REVIEW Level of evidence: ~	Review. Search not described. Covers people with developmental disabilities, including autism.		Findings Very little research exists on victims with disabilities. The current state of knowledge is seriously inadequate.  Simple changes to standard intake forms, police reports, and other data collection would assist research.  More research is needed on victim risk factors, but likely to include:  • misinterpretation of social cues  • difficulties recognising danger  • poor self-protection skills  • no or poor 'keeping safe' education  • acquiescing to behaviour they do not like in order to have a social contact  • dependency on others  • limited access to resources.  Vulnerability to crime may be related to offender characteristics	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				(personality, occupation), characteristics of the interactions between offender and victim (legitimate authority and power), social control, the environment in which the offence occurs, and the culture of society (attitudes towards people who are different). System changes are required to better meet the needs of people with developmental disabilities who are victims.	
391	Debbaudt, D. (2002b). Avoiding unfortunate situations: Section B: Avoiding unfortunate situations. Retrieved 4/11/04, 2004, from: http://policeandautism.cjb.net/ml  EXPERT OPINION  Level of evidence: x	Booklet originally written in 1994, on the interactions between children and adults with autism and law enforcement professionals.		<ul> <li>Makes suggestions to families to lessen police interactions.</li> <li>Gives advice to people with ASD on how to behave when in contact with police.</li> <li>Provides information on ASD for police.</li> </ul>	
392	Debbaudt, D. (2003). Safety issues for adolescents with Asperger syndrome. In Holliday Willey, L. (Ed.), Asperger Syndrome in Adolescence: Living	Book chapter.		Prevention is first step. Parents should ensure that anyone in regular contact with the person with ASD is considered to be safe and appropriately supported and supervised. Social skills, education in sexual safety strategies, community safety,	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	with the Ups, the Downs, and Things in Between. London: Jessica Kingsley Publishers.  BOOK CHAPTER – EXPERT OPINION  Level of evidence: x			strategies to keep safe when out at night, and what to do if they are abused, are important. Preventative measures include:  • giving neighbours information on the person with ASD  • Developing good relationships with neighbours  • intervening early on in the life of the person with ASD to ensure that the obsessional interests, social deficits and communication problems of childhood do not become behaviours that expose the person to risk of victimisation or criminal offending.  • establishing firm and consistent rules in childhood, so that people with ASD will accept limits on their behaviour in adulthood.	
393	Taylor, B.A., Hughes, C.E., Richard, E. et al. (2004). Teaching teenagers with autism to seek assistance when lost. Journal of Applied Behaviour Analysis 37(1): 79-82.	Three teenagers with autism (ages 17, 13 and 14 years) were taught to respond to a vibrating pager to seek assistance in community settings when physically separated from their parents and teachers. A multiple baseline probe design was used.	The dependent measure was the percentage of correct responses to being paged for each teaching trial.	Upon being paged, the participants successfully handed a communication card to a community member indicating that they were lost (after teaching sessions). Generalisation was assessed in non-training community sites and on outings with the participants' parents.	A limitation of the study was that responses to the pager were not measured at baseline (prior to being taught how to respond to the pager).

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	CASE SERIES Level of evidence: ~				
394	Howlin, P., & Clements, J. (1995). Is it possible to assess the impact of abuse on children with pervasive developmental disorders? Journal of Autism & Developmental Disorders, 25(4), 337-354.  OBSERVATIONAL STUDY — QUALITATIVE  Level of evidence: +	Retrospective investigation of the behaviour of 12 children with pervasive developmental disorders who attended a particular school where significant abuse was discovered. All children had significant communication problems.	Structured parental interview covering social-communicative skills, behaviour problems associated with stressful experiences, problems related more specifically to autism, self-help skills, and general health.	<ul> <li>Findings</li> <li>No significant differences detected across time in social-communicative skills, self-help skills, and general health.</li> <li>Most children had shown a marked deterioration in behaviour associated with stressful experiences and problems related more specifically to autism during the time abuse was known to have occurred at the school.</li> </ul>	
395	The Law Commission. (1996). The evidence of children and other vulnerable witnesses: a discussion paper (No. NZLC PP26). Wellington: The Law Commission.  EXPERT OPINION	Discussion paper.		Describes NZ provisions and practices to manage situations in which people with intellectual disability are complainants and/or witnesses in criminal cases.	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	Level of evidence: x				
396	Clare, I. (2001). Witnesses with learning disabilities. British Journal of Learning Disabilities, 29, 79-80.	Editorial.		Research has led to improved processes when people with an intellectual disability are complainants and witnesses.	
	EXPERT OPINION  Level of evidence: x				
397	Milne, R., & Bull, R. (1999). Investigative Interviewing: Psychology and Practice. Chichester: John Wiley & Sons Ltd.  EXPERT OPINION	Book.		Summarised research and procedures on investigative interviewing. Chapters include police interviews, false testimony, and interviewing vulnerable people.	
	Level of evidence: x				
398	Beversdorf, D. Q., Smith, B. W., Crucian, G. P., Anderson, J. M., Keillor, J. M., Barrett, A. M., et al. (2000). Increased discrimination of "false memories" in	Study of diagnostic accuracy. Subjects were 8 high-functioning adults with ASD, and 16 non-autistic adults, matched for age, gender, IQ and educational level.	False Memory Test.	Findings Subjects with ASD performed significantly better than controls at discriminating true items from index (false) items.	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	autism spectrum disorder.  Proceedings of the National Academy of Sciences of the United States of America, 97(15), 8734-8737.  OBSERVATIONAL STUDY  Level of evidence: +				
399	Konstantareas, M. (1998). Allegations of sexual abuse by nonverbal autistic people via facilitated communication: testing of validity. Child Abuse and Neglect, 22(10), 1027-1041.  CASE STUDY  Level of evidence: ~	Case study test of a protocol developed to assess the validity of facilitated communication. Subject was a 19-year-old non-verbal man with ASD.	Protocol comprised of:  • psychological testing  • message-passing tasks  • analysis of allegations.	<ul> <li>Findings</li> <li>Subject's responses through         Facilitated Communication were         at a significantly higher level than         psychological testing indicated         his level of functioning.</li> <li>Subject unable to give correct         answers to questions that the         communicator did not know of in         advance.</li> <li>Police report included information         at developmental and adaptive         levels far beyond that established         for the client, and inconsistent         with symptoms of ASD.</li> </ul>	
400	Loynes, F. (2002). Autism and the Criminal Justice System. Retrieved	Web-based information.		No figures on prevalence of people with ASD in the prison system, or rates of offending. Police are generally sympathetic,	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	24/11/04, 2004, from http://www.faaas.org/articles/appga0402.html  EXPERT OPINION  Level of evidence: x			but ASS may be a 'hidden' disorder. Reasons that people with ASD offend include: exploitation by others	
401	O'Brien, G. (2002). Dual diagnosis in offenders with intellectual disability: setting research priorities: a review of research findings concerning psychiatric disorder (excluding personality disorder) among offenders with intellectual disability.  Journal of Intellectual and Developmental Disability, 46 (Supplement 1), 21-30.  NON SYSTEMATIC REVIEW	Review (titled a 'mini-review' in journal). Search criteria not described. Eight publications identified addressing autism and offending.		Findings Pressing need for research on autism in ID and offending.	
	Level of evidence: ~				

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
402	Harem, D.J., Gould, J., Mills, R. et al. A preliminary study of individuals with autistic spectrum disorders in three special hospitals in England. Accessed at www.nas.org.uk/content/1/c4/38/68/3hospitals.pdf. 6 September 2007.  CROSS SECTIONAL STUDY  Level of evidence: x	The population of 3 Special Hospitals in the UK was screened using a screening questionnaire for ASD in psychiatric patients (developed by Nylander). Inter-rater agreement was assessed with a 10% sample. Clinical information on participants scoring 5 or more positive responses was collected using a modified version of the Handicaps, Behaviours and Skills schedule. Prevalence of autistic conditions was estimated.	Nylander screening scale Handicaps, Behaviours and Skills schedule.	A total of 1,305 patients were screened. The Nylander questionnaire had high sensitivity but low specificity (when the cut-off score of 5 or more is considered) – ie, there were a large number of false positives. 31 patients had definite ASD and 31 patients had possible ASD, giving a prevalence rate between 2.4% and 5.3%.	Authors concluded that a better screening questionnaire is required. Among offenders detained under mental health legislation in secure psychiatric hospitals, there is a small prevalence of ASD. The implications of this are discussed.
403	Myers, F. (2004). On the Borderline? People with Learning Disabilities and/or Autistic Spectrum Disorders in Secure, Forensic and Other Specialist Settings. Edinburgh: Scottish Executive Social Research.  OBSERVATIONAL STUDY	Scoping and prevalence study.		<ul> <li>Findings</li> <li>Within secure settings, people with intellectual disabilities (ID) and/or ASD are identified through information available prior to or at referral, information collected in the course of routine assessments following admission, and information collected or assessments undertaken in response to problems of concerns arising.</li> <li>Prevalence could not be clearly established, but characteristics of people identified are</li> </ul>	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	Level of evidence: +			summarised.  Issues identified in need assessment, care planning, meeting assessed needs, through care and after care.	
404	Morgan, H. (2004). Research commissioned by Autism Cymru in prevalence of people with ASD in prisons in South Wales. In Breen, T. (Ed.). Cardiff.  EXPERT OPINION Level of evidence: x	E-mail correspondence		Autism Cymru have commissioned research on prevalence of people with ASD in prison in Wales.	Hugh Morgan is the Chief Executive Officer of Autism Cymru.
405	Murrie, D., Warren, J., Kristiansson, M., et al. (2002). Asperger syndrome in forensic settings. International Journal of Forensic Mental Health 1(1): 59-70.  CASE STUDIES Level of evidence: x			Discussion of 6 case studies that give suggestions on the implications of AS for forensic clinicians. The studies show ways in which people with AS differ from most individuals in forensic settings – there is a commonality of deficient empathy.	
406	Palermo, M. T.	Three case studies: 19-year-		Findings:	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	(2004). Pervasive developmental disorders, psychiatric comorbidities, and the law. International Journal of Offender Therapy and Comparative Criminology, 48(1), 40-48.  CASE STUDIES  Level of evidence: x	old man with PDD-NOS, 33- year-old man with Asperger Syndrome (AS), and 30- year-old man with AS.		The hypothesis that delinquent behaviour resulted from co-morbid psychopathology and not from the developmental disorder was supported in all case studies.	
407	Seattle Community Network. (2002). Until Proven Innocent. Retrieved 24/11/04, 2004, from http://www.scn.org/pe ople/autistics/process .html  EXPERT OPINION Level of evidence: x	Web-based information.		Information developed to prepare people with ASD for encounters with the criminal justice system. Advice given on confessions, disclosures, investigative and interrogation procedures, prosecution, plea bargain, pleading, and prison.	
408	Debbaudt, D. (2002a, 2/12/02). Avoiding unfortunate situations: Section A: A definition and a law enforcement handout. Retrieved	Booklet originally written in 1994 on the interactions between children and adults with autism and law enforcement professionals.		Lists symptoms of ASD as they may be experienced by police (eg, may not recognise police vehicle, badge or uniform, or understand what is expected of them if they do). Lists suggested police behaviour when encountering a person with	Dennis Debbaudt was a professional investigator and journalist for 27 years, is the father of a young

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	4/11/04, 2004, from http://policeandautism.cjb.net/handout.html  EXPERT OPINION  Level of evidence: x			ASD (eg, talk in short, direct phrases, such as 'Stand up now. Go to the car).'	man who has autism. Mr. Debbaudt presents to law enforcement agencies in the United States, Canada and United Kingdom. His materials are in use by police departments around the world.
409	The National Autistic Society. (2004). Information for criminal justice professionals. Retrieved 4/11/04, 2004, from http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=471  EXPERT OPINION  Level of evidence: x	Web-based information.		Information for criminal justice professionals covering definitions, characteristics of people with ADD, theories on offending, what to do if they think a person has an ASD, and communication with a person with ASD.	
410	Warren,A. (2006). Asperger's Syndrome and Autistic Spectrum Disorders in the Courts. Paper presented at National			Summary of the disorder and practical suggestions for interactions with people with ASD within the judicial system.	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
	Judicial College of Australia Conference: Science, Experts and the Courts; Sydney 2006.				
	EXPERT OPINION				
	Level of evidence: x				

## **EVIDENCE TABLES FOR PART 6: PROFESSIONAL LEARNING AND DEVELOPMENT**

Ref No	Reference, study type and rating	Methods and Participants	Measures	Outcomes/Results	Notes
411	Scheuermann, B., Webber, J., Boutot, E.A., et al. (2003). Problems with personnel preparation in autism spectrum disorders. Focus on Autism and Other Developmental Disabilities 18: 197-206.  REVIEW – EXPERT OPINION  Level of evidence: x	No methodology described.		An examination of problems with the preparation of school personnel who serve children with ASD. Some of the areas of concern include: current teacher shortage and attrition among special education teachers, non-categorical vs categorical teacher training and the impact of each on teacher preparedness, lack of scope and depth of most autism training models, clashes in theoretical orientation that may negatively affect teacher training and issues that may arise when undertrained teachers interact with parents.	Recommendations are made.
412	Freschi, D.F. (1999). Guidelines for working with one-to- one aides. <i>Teaching Exceptional Children</i> 31: 42-45.  REVIEW – EXPERT OPINION  Level of evidence: x			This article explores what educators can do to facilitate effective collaboration and success for children in education.	
413	Godfrey, R., Moore,	11 children with mild to	Pre and post test	Study 1: Precision teaching and	In Study 1 a group

Ref No	Reference, study type and rating	Methods and Participants	Measures	Outcomes/Results	Notes
	D., Fletcher-Flinn, C., Anderson, A. (2002). An evaluation of some programmes for children with autism spectrum disorder in Auckland: Opportunities, contingencies and Illusions. A report prepared for the Ministry of Education Wellington.  PROGRAMME EVALUATION  Level of evidence: ~	moderate ASD who were 8 years old or younger. Their language levels varied from well below chronological age, to age appropriate. Teacher aide support varied from 50 to 100% of the time they were in a mainstream setting.  The programmes:  • 5 children were in the Autism Action Precision Teaching programme and a mainstream situation  • 3 children were in a mainstream situation only (one pre-school and two school age)  • 3 children were in home- based therapy (ABA) (2 of the children were pre-schoolers and 1 was school age) 2 were also in mainstream settings for part of the week. Four studies were conducted Study 1: description of services, cost and effectiveness. Study 2: further analysis of data on classroom learning and behaviour. Study 3: social skills analysis of social interactions and play behaviour.	measures:	<ul> <li>higher levels of instruction, praise and feedback</li> <li>greater amounts of on-task behaviour and no stereotypical behaviours.</li> <li>Study 2: Precision teaching:         <ul> <li>more complete units of instruction, praise, feedback sequence than other settings</li> <li>Study 3: Social skills in free play in mainstream settings:                 <ul> <li>there was no difference in play skills between the three groups</li> <li>teacher aides and support workers appeared unclear whether their role was a teaching or caretaking one. Facilitative interactions by the adults were associated with more peer interactions for the children than compensatory interactions. Teacher aides and support workers and teachers in mainstream settings need more training</li></ul></li></ul></li></ul>	of children who were mainstreamed and received early intervention or inclusive services support from SES were withdrawn.

Ref No	Reference, study type and rating	Methods and Participants	Measures	Outcomes/Results	Notes
		Study 4: an investigation of stereotypic behaviour in 3 of the children.		behaviour.	

## **EVIDENCE TABLES FOR PART 7: MAORI PERSPECTIVES**

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
414	Shek, D.T.L., Tsang, S.K.M., Lam, L.L., et al. (2005). Psychometric properties of the Chinese version of the psycho-educational profile-revised (CPEP-R). Journal of Autism and Developmental Disorders 35(1): 37-44.  CROSS-SECTIONAL STUDY  Level of evidence: ~	A reliability and validity study of the Chinese version of the Psycho-educational Profile-Revised (CPEP-R). This tool was administered to 63 preschool children with symptoms of autistic disorder recruited from special childcare centres in Hong Kong	CPEP-R.	The scales of the CPEP-R were internally consistent, reliable across raters and temporally stable. Regarding validity, the developmental score and developmental age assessed by CPEP-R were significantly correlated with the Merrill-Palmer Scale of Mental Tests and the Hong Kong Based Adaptive Behaviour Scale. The Behavioural Scale of the CPEP-R was also significantly related to the Childhood Autism Rating Scale.	Limitations of the study were:  only generalisable to Chinese children in Hong Kong based on a small sample, boys with a restricted range of intellectual level were overrepresented. norms of the Merrill Palmer Scale are out of date limited to concurrent validity only.
415	Mandell, D.S., Novak, M. (2005). The role of culture in families' treatment decisions for children with autism spectrum disorders. Mental Retardation and Developmental Disabilities Research Reviews 11: 110-115.	No methodology described but other research cited.		Review of literature regarding cultural influences on decisions regarding ASD and the implications for the study and treatment of ASD from literature on culture and other health conditions of childhood. Discussion of the interpretation of symptoms and beliefs about the cause, course and treatment of ASD. Suggestions presented for	

NON SYSTEMATIC	specific language for clinicians to
REVIEW	use in discussion with families with different cultural beliefs about
Level of evidence: x	the use of less traditional treatment strategies.

## **EVIDENCE TABLES FOR PART 8: PACIFIC PEOPLES' PERSPECTIVES**

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
416	Ministry of Health (2005). Te Orau Ora: Pacific Mental Health Profile. Wellington: Ministry of Health REPORT Level of evidence: ~		Demographic and socioeconomic data drawn from the Census, Mental Health Information Collection and NZHIS.	A descriptive overview of mental health status of Pacific peoples in New Zealand.	
417	Ministry of Health (2006). The Pacific Health and Disability Action Plan. Wellington: Ministry of Health REPORT Level of evidence: ~		Extensive consultations and community forums with Pacific providers, health professionals and communities.	A report of the strategic direction and actions for improving health outcomes for Pacific peoples and reducing inequalities between Pacific and non-Pacific peoples. The aim is to provide and promote affordable, effective and responsive health and disability services for all New Zealanders.  6 priority areas highlighted where improvements can be made to health and disability services for Pacific peoples.	This report is directed at the health and disability sectors and Pacific communities.
418	Statistics New Zealand (2006). Pacific Profiles.  REPORT  Level of evidence: ~		Data based on the 2006 census.	Descriptive profile of each of the 7 largest Pacific ethnic groups in NZ. Information provided on demographics, language, religion, families and households, education, the labour force, income, housing, access to	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
				amenities, smoking behaviour and number of children born.	
419	Ministry of Pacific Affairs (2001). Pacific Consultation Guidelines. Wellington: Ministry of Pacific Island Affairs.			Discussion of the issue of consultation in relation to policy making for Pacific peoples.	
	REPORT Level of evidence: x				
420	Anonymous (2004). Living with disability in New Zealand. Wellington: Ministry of Health. REPORT Level of evidence: ~		Data derived from a household disability survey post the 2001 census and comparisons made with disability surveys undertaken in 1996.	A resource on the status of people with disability in NZ, developed for a wide range of users, including people with disability, policy analysts, funders, service providers and other interested parties, both inside and outside government.	
421	Anae, M., Coxon, E., Mara, D. et al. (2002). Pasifika Education Research Guidelines: Final Report. Auckland: Uniservices.  REPORT  Level of evidence: ~	Extensive methodology described incorporating both quantitative and qualitative aspects.	Fono, literature review of Pacific education and combined experiences of the research team.	Discussion of the issues that Pacific researchers should be aware of when conducting research on Pacific peoples. Recommendations for the research process includes:  • selection of research topic, research questions and methodological approach	

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
422	Agnew, F., Pulotu- Endemann, K., Robinson, G., et al. (2004). Pacific models of mental health service delivery in New Zealand project. Auckland: HRC. REPORT Level of evidence: ~	Methodology included:  qualitative grounded theory methodology  literature search, review and collation of published and unpublished material  primary structured interviews etc.	Data collected from interviews, literature review and personal correspondence and focus groups.	<ul> <li>instrument design</li> <li>information gathering</li> <li>analysis of data</li> <li>drafting of final report</li> <li>dissemination of findings.</li> </ul> A description at a particular point in time of Pacific peoples' mental health history, taken from a variety of points of view: <ul> <li>Pacific service provider</li> <li>Pacific mental health consumer</li> <li>family member</li> <li>relevant literature</li> <li>indigenous and/or ethnic minority health specialists overseas.</li> </ul>	
423	King, A. (2002). The Pacific Health and Disability Plan (see above, reference no. 417 – duplicated ref).				

## **EVIDENCE TABLES FOR APPENDICES**

Ref No	Reference, Study Type and Rating	Methods and Participants	Measures	Outcomes/Results	Notes
424	Agree Collaboration. Appraisal of Guidelines for Research and Evaluation (AGREE) Instrument. www.agreecollaboratio n.org. 6 October 2007.  EVALUATION INSTRUMENT  Level of evidence: +	An instrument designed to appraise guidelines, Appraisal of Guidelines Research and Development (AGREE), developed by a group of researchers from 13 countries.	The instrument contains 23 key items categorised in 6 domains:  • scope and purpose  • stakeholder development  • rigour of development  • clarity and presentation  • applicability  • editorial independence.	The objectives of the project were to provide a framework to create a coordinated international approach to the appraisal of clinical guidelines and to identify potential areas for harmonisation of guideline development.	Used extensively internationally to appraise guidelines for quality.
425	Tuchman R. (2003). Autism. Neurologic Clinics 21(4): 915-932.  NON SYSTEMATIC REVIEW  Level of evidence: x	Expert opinion. No methodology or search described.		General review of autism.	
426	Gabriels, R.L., Hill, D.E., Pierce, R.A., et al. (2001). Predictors of treatment outcome in young children with autism: a retrospective study. <i>Autism</i> 5(4):	Retrospective prognostic study of 17 children diagnosed with autism or PDD-NOS who received generic treatment (combination of treatments) over a mean period of 37 months.	Pre-treatment evaluations occurred at a mean age of 31 months with follow-up evaluations at a	Significantly different developmental trajectories were observed among the participants at follow-up, separating the participants into 2 distinct groups (high and low outcome).	The range and intensity of interventions varied widely across participants, making it difficult to determine how

	407-429.  RETROSPECTIVE CASE SERIES  Level of evidence: x		mean age of 67 months.		outcomes related to interventions used.
427	Research Autism. Research Autism. http://www.researchautism.net. 26 September 2007.  EVIDENCE-BASED WEBSITE Level of evidence: ~	Website, established in 2003 by the Autism Intervention Research Trust, dedicated exclusively to research into interventions in autism. Methodology described.	Documented process for searching of primary, secondary and tertiary sources, with appraisal process and grading of research studies and development of evidence tables.		
428	Wigram, T. & Gold, C. (2006). Music therapy in the assessment and treatment of autistic spectrum disorder: clinical application and research evidence. Child: Care, Health & Development Sep; 32(5): 535-42  NON SYSTEMATIC REVIEW  Level of evidence: ~	A review (of published reports, systematic reviews, controlled studies and clinical case reports) of the value and effectiveness of music therapy, an intervention for children with ASD.	The review included one meta-analysis on the broader field of music therapy but only one of the studies addressed ASD specifically. Two systematic reviews focused specifically on ASD have had conflicting results and shortcomings in design.	Generalisation of studies to clinical practice is limited. Larger RCTs examining interventions that are closer to clinical practice are needed to confirm positive results of available studies. Existing studies provide good rationale for developing more rigorous research.	

			Whipple (2004) – non-randomised and blinding design features not transparent; Ball, (2004) – effects of music therapy unclear.	
429	Barnaby, R. (2003).  Developing peer friendships among adolescents with an intellectual disability using dramatherapy. In partial fulfillment of the requirements of the Master of Arts in Arts Therapy. Whitecliffe College of Arts and Design.  UNPUBLISHED THESIS  Level of evidence: ~	The study explored whether 6 adolescents with an intellectual disability between 12-18 years of age were able to make changes and acquire social skills that would enable them to develop friendships.	The study included a non-systematic literature search that outlined the importance of friendship to adolescents with an ID. Pre and post programme tests were completed by participants and parents. Findings demonstrated that participants had improved their ability to use social skills and showed a willingness to continue their friendships beyond the group.	Only 1 participant was identified as being diagnosed with autism.
430	Silove, N. Autistic Spectrum Disorder,	Guide to prescribing. No methodology described.		

Clinician's Guide to		
Psychotropic		
Prescribing in Children		
and Adolescents.		
http://www.camhsnet.or		
g/editLevel3.asp?subs		
ectionID=28&SectionID		
=7&SectionName=Publ		
ications&SubSectionTit		
le=Reference+Material		
<u>s</u> . 6 November 2005.		
WEBSITE		
INFORMATION		
Level of evidence: x		