

A Review of the Research to Identify the Most Effective Models of Practice in Early Intervention for Children with Autism Spectrum Disorders

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2011

**This report was funded by the Australian Government
Department of Families, Housing, Community Services and
Indigenous Affairs (FaHCSIA).**

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This review was prepared for the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), by Professor Margot Prior, Professor Jacqueline Roberts, Professor Sylvia Rodger and Professor Katrina Williams on behalf of the Australian Autism Research Collaboration (AARC), with assistance from Dr Greta Ridley, Rebecca Sutherland and Susan Dodd.

Acknowledgments

This review is a follow up and extension of Roberts J. M. A. and Prior M. A, *Review of the Research to Identify the Most Effective Models of Practice in Early Intervention for Children with Autism Spectrum Disorders*, (2006) Australian Government Department of Health and Ageing.

The authors would like to acknowledge the contribution of the advisory group for this review: Dr Natalie Silove, Professor Valsamma Eapen, Dr Angelika Anderson and Mrs Judy Brewer Fischer. We would also like to thank the organisations across Australia for completing surveys and providing information: Australian Advisory Board on Autism Spectrum Disorders (AAB), Autism Advisors, Parenting Research Centre (PRC), Speech Pathology Australia (SPA), Occupational Therapy Australia, Australian Psychological Society and The Royal Australian College of Physicians, Division of Paediatrics and Child Health.

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Suggested Format for Citation

Prior, M., Roberts, J. M.A., Rodger, S., Williams, K. & Sutherland, R. (2011). *A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders*. Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, Australia.

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List of shortened forms

AAB	Australian Advisory Board-on-Autism Spectrum Disorders
AAC	Alternative and Augmentative Communication
AARC	Australian Autism Research Collaboration
ABA	Applied Behavioural Analysis
ABI	Autism Behavioural Intervention
ACT	Australian Capital Territory
AD	Autistic Disorder
ADI-R	Autism Diagnostic Interview – Revised
ADOS	Autism Diagnostic Observation Schedule
ADOS-G	Autism Diagnostic Observation Schedule – Generic
AIT	Auditory Integration Training
APA	American Psychiatric Association
ASD	Autism Spectrum Disorders
CAMs	Complementary and Alternative Medicines
CBT	Cognitive Behaviour Therapy
CCT	Clinical Controlled Trial
CTM	Comprehensive Treatment Model
DIR	Developmental Individual-Difference, Relationship Intervention
DoHA	Department of Health and Ageing
DSM	<i>Diagnostic and Statistical Manual</i> (III: Third; IV: Fourth; V: Fifth Edition)
DSP	Developmental Social-Pragmatic model
DV	Dependent variable
EBSCO	E lton B Stephens C ompany
ED	Eclectic developmental
EI	Early Intervention
EIBI	Early Intensive Behavioural Interventions
ERIC	Education Resources Information Center

ES	Effect Size
ESDM	Early Start Denver Model
FaHCSIA	Australian Government Department of Families, Housing, Community Services and Indigenous Affairs
FC	Facilitated Communication
FCT	Functional Communication Training
FFW	Fast ForWord Program
HAPP	Hodson Assessment of Phonological Patterns
HCWA	Helping Children with Autism Package
IBI	Intensive Behavioural Intervention
ICD-10	WHO International Classification of Diseases
IEP	Individual Education Program
IFSP	Individual Family Service Plan
IOA	Inter Observer Agreement
IP	Individual Plan
IQ	Intelligence Quotient
IR	Inter-rater
IS	Interpersonal Synchrony
ISP	Individual Service Plans
IV	Independent Variable
Ix	Intervention
LEAP	Learning Experiences: an Alternative Program for Preschoolers and their Parents
MT	Magnitude of Treatment
NAC	National Autism Council
NAS	National Autistic Society
NLP	Natural Language Paradigm
Non-IS	Non-interpersonal synchrony
NSW	New South Wales

OT	Occupational Therapy
PACT	Preschool Autism Communication Trial
PALS	Playing and Learning to socialise
PBS	Positive Behaviour Support
PDD	Pervasive Developmental Disorders
PDD-NOS	Pervasive Developmental Disorder - Not Otherwise Specified
PECS	Picture Exchange Communication System
PEP-R	Psycho-educational Profile-Revised
PLAY	Play and Language for Autistic Youngsters
PLS	Preschool Language Scale
PP	Personal Plan
PRC	Parenting Research Council
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PROMPT	PROMPTs for Restructuring Oral Muscular Phonetic Targets
PRT	Pivotal Response Training
R&P	Roberts and Prior
RCN	Raising Children Network
RCT	Randomised Control Trial
RDI	Relationship Development Intervention
RPMT	Responsive Education and Prelinguistic Milieu Teaching
SARRAH	Services for Australian Rural and Remote Allied Health
SCERTS	Social-Communication, Emotional Regulation, and Transactional Support
SERVAM	Sensory considerations, Environmental management, Routines and planned change, Visual supports, Autism friendly communication, Motivation
SGD	Speech Generating Device
SI	Sensory Integration
SIT	Sensory Integration Therapy
SM	Scientific Merit
SMRS	Scientific Merit Rating Scale

SP	Speech Pathology
SP	Symbolic Play (Intervention)
SPA	Speech Pathology Australia
TEACCH	Treatment and Education of Autistic and related Communications Handicapped Children
UCLA	University of California, Los Angeles
Tx	Treatment
VM	Video Modelling
WHO	World Health Organization

Context of the Review

This review is a follow up and extension of Roberts J.M.A., and Prior, M. (2006) *A review of the research to identify the most effective models of practice in early intervention services for children with Autism Spectrum Disorders (ASD)*, Australian Government Department of Health and Ageing (DoHA). Since then, the Helping Children with Autism (HCWA) Package has been set up by the Australian Federal Government. The package is multifaceted and includes funding provided through the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) for early intervention for children with autism.

Controversy exists internationally about the most effective early intervention for children with ASD. There has been a rapid increase in the types of programs and interventions available over the past 6–7 years, along with a substantial increase in the amount of research into the outcomes of interventions. The reviews of evidence are of varying quality. This report reviews the latest research evidence, and includes a discussion of what is currently understood about principles of good practice in autism early intervention, and the application of those principles in practice. In addition, the report summarises the results of a survey of key stakeholders involved in the implementation of this component of the HCWA package. Sections of this report address matters that have arisen since the implementation of the FaHCSIA Early Intervention Services component of the HCWA Package.

FaHCSIA commissioned this report to provide up-to-date information about the evidence for the efficacy of interventions for young children with ASD up to the age of 7 years, including ratings of the scientific merit of the intervention research. In addition, FaHCSIA requested an update of current understanding of what constitutes good practice in autism intervention.

Recommendations from this report are designed to inform processes used to assess the eligibility of interventions, and the suitability and capacity of potential providers to deliver effective autism early interventions under the HCWA Package.

Evidence-based treatment guidelines are particularly important in the field of autism where there has been considerable controversy surrounding the effectiveness of various treatments, including those which are well promoted but lack scientific evidence for their perceived effectiveness. Parents, professionals and government need information to help them evaluate claims of the success of treatments, particularly those treatments that claim or promise to cure children with ASD. Although some of these interventions might be helpful to children, others might be ineffective or even harmful. Research evidence is needed to address these claims and also to prevent limited resources from being invested in non-productive programs.

Previous syntheses of evidence have found that only a small number of autism treatment programs have direct research evidence that supports their effectiveness, and that this research is limited. In other words, previous reviews have found that very few outcomes of particular autism interventions are sufficiently robust to allow confident recommendations about their efficacy or otherwise. Most treatments have not been evaluated adequately and many have not been evaluated at all. In the absence of direct evidence, parents and professionals must also consider how well an intervention meets guidelines for good practice in autism intervention and the extent to which the rationale for the intervention is based on research evidence about autism.

The information described in this report is based on reputable peer-reviewed reviews that have rated the scientific merit of research evaluating a large number of interventions. In the case of study reports that had not previously been rated, the research was rated by the review team using a Scientific Merit Rating Scale (SMRS) developed by the United States' National Autism Center, for the *National Standards Report* (National Autism Center, 2009). In addition, overall findings from several international reviews of the research evidence for treatments for children with ASD have been summarised and included. A list of these reviews is provided in Appendix A, and our current evidence reviews are summarised in Tables 1–4.

This review includes:

- a summary of the research findings pertinent to assessing eligibility and non-eligibility of early intervention program proposals
- a summary of the feedback coming from consultations with stakeholders and peak bodies, and a synthesis of their views and suggestions
- a proposal of strategies for the future to enhance the choice of valid programs and providers (carried out through FaHCSIA)
- advice on methods to keep up to date with the emerging literature on early intervention for ASD
- guidelines to underpin decision making on program/provider approval and recommendations for the process to achieve this aim, including guidelines to enhance understanding of the approval standards.

Key Considerations and Scope of Review

Age range

The focus of this report is early intervention (EI) for children with ASD up to the age of 7 years, which is the age limit for eligibility for receiving access to early intervention funding and services under the HCWA EI Services Provider Panel. Research into interventions for older age groups of children and adults with ASD has not been reviewed.

Interventions reviewed

This review focuses on learning-based interventions for children under 7 years old, as these are the interventions funded through the HCWA EI Provider Panel. Hence interventions that are medically based and interventions involving Complementary and Alternative Medicines (CAMs) are not addressed in this report.

Interventions for young children with autism and their families that are based on learning can be described as:

- primarily behavioural
- primarily developmental
- combined
- primarily therapy based
- family based, and/or
- other.

See Appendix B for a description of the classification system used to group learning-based interventions, with examples.

Intensity

The 'intensity' of a program refers to the number of hours of treatment the child receives per week as well as the intensity of training, curriculum, evaluation, planning, and coordination. A total of 15–25 hours per week over 2–3 years is generally recommended for autism early intervention in the research literature (Roberts & Prior 2006) with some programs recommending as much as 40 hours per week.

The concept of intensity, as discussed in the research, is complex and not necessarily conveyed solely by the 'number of hours of intervention per week'. Quality is as important as quantity and more challenging to measure. Focusing exclusively on the number of hours per week detracts from the amount of actual meaningful engagement, which is the key factor (Marcus, Garfinkle & Wolery 2001).

Note that there is no reliable evidence that 'recovery' or 'cure' occurs as a result of treatments or interventions for children with ASD. However it is clear and well supported by the evidence base, that with appropriate intervention, children with autism continue to develop and to learn behaviours that will better equip them for life.

Part 1 – Review

1.1. Introduction

Autism spectrum disorders (ASD) are characterised by qualitative impairments in social interaction and communication skills, as well as stereotypic behaviours and limited activities and interests. While ASD has become a commonly used term in clinical practice, this nomenclature is not officially recognised by current mainstream disease classification systems, such as the *Diagnostic and Statistical Manual of Mental Disorders* fourth edition or fourth edition text revision (DSM-IV, DSM-IV-TR) (APA 1994, APA 2000), and the *International Classification of Diseases* (ICD-10) (WHO 1993). However the concept of a spectrum of autistic disorders is proposed to be integral to the next iteration of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM), the DSM-V.

ASD is generally considered to include autism, defined in the DSM, third edition (DSM-III) (APA 1980) as 'infantile autism', in the third edition revised (DSM-IIIR) (APA 1987) and fourth edition (DSM-IV) (APA 1994) as Autistic Disorder and in ICD-10 (WHO 1993) as Classical Autism. Also included in the term ASD are the diagnoses:

- Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS)
- 'other pervasive developmental disorders'
- 'pervasive developmental disorder, unspecified'
- Asperger's syndrome or Asperger's disorder
- atypical autism.

It is expected that with the release of DSM-V in 2013 (www.dsm5.org) the term 'ASD' will become the official diagnostic term and all the other diagnostic labels listed above are unlikely to be part of that classification system and therefore will not be commonly used in diagnosis or reporting.

1.1.1 Heterogeneity of ASD

Autism is a spectrum disorder encompassing a range of individuals with characteristics varying in severity across domains of cognitive, communication and social development, and restricted interests/repetitive behaviour. At an individual level this means that children diagnosed with autism are as different from each other as are children who are developing typically. There is an obvious tension between describing children who are similar in their needs and outcomes versus ensuring all children with problems of a similar type are identified. Another tension exists between the requirements of a classification system to provide diagnostic labels versus a dimensional description of strengths, weaknesses and function that is thought useful in developmental disability internationally (World Health Organisation 2007). This tension is unlikely to be resolved while the aetiology of autism is uncertain and while the observation of behaviour and assessment of function remains the mainstay of diagnosis. However, classifications are of great relevance to those organisations funding intervention services for children with ASD and other disabilities, as they impact upon both the numbers of children identified and the type and duration of interventions that need to be available (Szatmari 2011).

The range of autism increased significantly with the addition of Asperger's Disorder in the 1990s and now includes a greater proportion of cognitively able individuals. Several established interventions for autism, e.g. 'The Me Program' (Lovas 1981) and TEACCH, (Schopler, Mesibov & Baker 1982), were developed for what is now a sub-group on the autism spectrum (Autistic Disorder). Each child with an ASD is an individual. Hence in addition to variation across developmental domains there is variation depending on age, maturity and variation of family background and cultural expectations. The challenge for intervention is to be flexible enough to take into account individual patterns of cognitive and language skills, social abilities, degree of rigidity and stereotyped behaviour, restricted interests, co-morbid conditions and family and environmental factors.

1.1.2 Diagnosis and assessment

Though diagnosis is clearly important, it is not the primary focus of the Early Intervention (EI) component of the HCWA Package. Children need to be diagnosed as having an ASD in order to access EI funding under the HCWA Package. Diagnostic assessment needs to be conducted by suitably qualified teams of professionals working collaboratively with families and utilising accepted good practice in autism diagnosis. Diagnostic assessment is funded under the Medicare component of the HCWA Package.

Assessment of strengths and needs across the core domains of autism for the purpose of program development and evaluation needs to be conducted for each child as part of a tailored, individualised approach to intervention. This is not the same as a diagnostic assessment, although one should inform the other. Individual assessment for program development purposes may involve the completion of checklists—most established interventions for children with autism have instruments available for this purpose. Good practice dictates that:

- an individualised approach is central to intervention for children with autism
- goals for intervention need to be developed and prioritised via an Individual Plan (IP)
- when the program is implemented it must be reviewed and revised as required. A useful tool for this purpose, a planning matrix, is described in Appendix C.

1.1.3 Incidence and prevalence

Estimates of the prevalence of ASD using the DSM-III, DSM-III-R, DSM-IV or ICD-10 diagnostic classification systems, from published synthesised literature up to April 2004 varied between 3 and 82 per 10,000 (Williams & Brayne 2006) and from 2000–07 between 16 and 181 per 10,000 (Fombonne 2009) and are still subject to change. Males are affected about four times more frequently than females.

Most recent published national data for Australia, estimated the prevalence of children accessing Centrelink funding with a diagnosis of autism as 47.2 per 10,000 in 2005 in 6–12 year olds, and with a diagnosis of Asperger Disorder of 15.3 per 10,000 (Williams et al. 2008). Centrelink prevalence estimates probably do not include children with other ASDs (PDD-NOS, Atypical autism and other related diagnoses).

1.1.4 Collaborative multidisciplinary practice

Autism Spectrum Disorders are multifaceted conditions encompassing a range of core features as well as a number of associated features (intellectual disability in some children, sensory processing difficulties, anxiety and challenging behaviours). A single discipline or approach is unlikely to address all the intervention needs of the child and their family in a holistic and appropriate way. Similarly, accessing a number of therapists (such as speech pathologists or occupational therapists) in isolation, without coordination and cooperation between professionals and families, may lead to lack of program coordination, more stress for parents, and reduced opportunities for generalisation of intervention across people and settings. Conversely, collaborative multidisciplinary approaches result in more effective outcomes for clients and the ability to focus on the 'whole child' and their individual characteristics and needs, rather than a single area of functioning (Nicholson, Artz, Armitage & Fagan 2000). This is particularly the case in complex difficulties such as ASD, as described by Jordan (2001): "Autism ... is a condition that straddles so many different disciplines in its definitions, education and care that it is inevitably best approached in a multidisciplinary way" (p.5).

Ideally, children with autism should be able to access intervention that is individualised to all their areas of strengths and needs. Generally, this will be best developed and delivered by a collaborative, multidisciplinary team, or in some cases, by utilising a trans disciplinary model where interventions are developed and supported by a team but delivered by one or two professionals who work across all developmental areas. A collaborative multidisciplinary team may consist of a number of professionals including educators, speech pathologists, occupational therapists and psychologists, who provide collaborative assessments, jointly set goals and develop Individual Plans, provide intervention, and review progress. The Planning Matrix described in Appendix C is a useful tool to facilitate multidisciplinary program development and for including input from families.

1.1.5 Working with families

Working with families and ensuring they are integrally involved with goal setting, planning, intervention and evaluation of any program or intervention is crucial. To do this, parents require emotional support, information, advice, and training in working with their children. Families are the most significant constant in a child's life and it is important that they are engaged in the process, to the level they desire, to reduce stress, increase family functioning, and to maximise children's skills in a meaningful social context (Keen 2007; Beatson 2005). The following points require consideration:

- **Stress and grief:** It is recognised that families of children with autism may experience greater stress than families of children with other disabilities and families of children without a disability (Honey, Hastings & McConachie 2005). Grief also impacts on families, particularly after a diagnosis has been made, and may resurface as children grow older and during transition points, such as school entry. Service providers should be aware of the physical and psychological impact of long-term stress and grief on parents.
- **Supporting decision making:** Families require support to make good decisions about which services to access, as well as the content of the intervention as it relates to their child. Historically, professionals alone were seen as having the expertise to make decisions about the needs of a child with autism. In contrast, the expertise and wishes of the family are now seen as central to the decision-making process (Keen 2007). It is clear, however, that making decisions about services can be difficult and distressing and many parents feel that, while

they are experts about their children, they do not have the knowledge to make decisions about which course of intervention to take (Valentine 2010). Other parents may become very active and engaged in seeking intervention, and in decision making, but will continue to require support to engage with service providers and develop effective partnerships. Effective service delivery must accommodate the differing needs of families (Valentine 2010).

- **Cultural diversity:** Cultural differences need to be considered by all those working with the family as this will impact on their decision-making process, the choices that are made, and the way they engage with the interventions provided (Mandell & Novak 2005; Trembath, Balandin & Rossi 2005; Vigil & Hwa-Froelich 2004). The needs of families from culturally and linguistically diverse backgrounds must be considered when providing intervention programs and family support.
- **Family centred practice:** Family centred practice is an essential element of good practice in early intervention provision. Family centred practice includes acknowledging the uniqueness of each family, enhancing parental competencies, involving families in programming decisions, and developing collaborative relationships between parents and professionals (Beatson 2006).

1.1.6 Program fidelity and outcomes

'Fidelity' refers to the confidence with which we can say that the program delivered was the one that was described in the application for funding support, and that all program features have been applied consistently, as specified. Firstly, a detailed description of the program needs to be available, sufficient to allow replication of the intervention. This is often found in a treatment manual. Secondly, checks need to be built into the research to establish that the program was carried out in a manner consistent with the manual.

1.1.7 Challenges inherent in measuring outcomes

Variability in the reported outcome measures makes it difficult to compare studies of different treatment evaluations. It is also problematic to disentangle clinical significance versus statistical significance, and to be sure that positive changes reported are not due to chance or to confounding factors when multiple outcome measures are used.

The extent to which sound research criteria are met, in particular the replication of the research findings by different researchers, is an indication of the confidence one can have in the findings. Unfortunately in the field of autism there is a tendency for research containing major errors in the selection and interpretation of the evidence to be used to substantiate claims for a particular intervention, or in some cases claims are made with a "flagrant perversion or disregard for evidence" (Schopler et al. 2001, p.13).

The challenges in this review are to summarise the available research evidence, to consider the quality and fidelity of the evidence, and where possible, to suggest how the evidence relates to the programs available in Australia.

1.1.8 Issue of timing of intervention

The recent growth in research and knowledge about intervention practice and progress reinforces the importance of intervention in early childhood development. While there is no doubt that appropriate intervention can improve outcomes for children and adults with autism at any age, the sooner an intervention commences the better. One advantage of starting intervention early is the prevention of the development of secondary characteristics of autism such as

challenging behaviours and co-morbid mental health problems like anxiety. The target group for the early intervention funding provided by FaHCSIA through the HCWA Package is children under 7 years old.

1.2 Membership of the HCWA EI Provider Panel

There are a myriad of proposed treatments for autism, many of which have little or no scientific evidence to guide decision-making. The quality of proposals seeking service provider status has been highly variable and poses significant challenges for those responsible for making decisions about eligibility for membership of the HCWA EI Provider Panel.

The process for evaluation of applications for service provider status involves consideration of the following criteria for assessing program proposals:

- Scientific Merit, including both:
 - Type 1 research evidence. This is research directly evaluating outcomes of specific programs, and
 - Type 2 research evidence. This is research into the characteristics of ASD which informs us about how likely it is that the intervention will be effective, based on our knowledge of the condition.
- Evidence of adherence to principles of good practice for early intervention generally and for autism intervention more specifically. These are particular characteristics of interventions that contribute to successful outcomes for children with ASD and their families.

More detail is provided in the following section.

1.2.1 Scientific merit

In order to identify the best outcomes as evidenced in the literature and also best value for money, we have reviewed research on treatments published from 2005 to 2011, from a scientific point of view to identify and assess evidence about what is likely to work.

A study is described as having scientific merit when the design and execution of the research is of a sufficient quality to enable independent scholars to draw firm conclusions about treatment efficacy from the results.

Methodology for Scientific Merit Rating Scale

In this review we have used the Scientific Merit Rating Scale (SMRS) developed by the United States' National Autism Center for the *National Standards Report* (2009). The SMRS involves rating the research into outcomes of interventions along five critical dimensions of experimental rigour. These ratings are then combined and an overall scientific merit score is obtained which indicates the extent to which interventions can be considered to be effective. The five critical dimensions considered when determining the SMRS score are:

- research design
- measurement of the dependent variable
- measurement of the independent variable or procedural fidelity
- participant ascertainment
- generalisation.

For detail about the SMRS and process followed for this review see Appendices D and E.

Limitations

There are two key limitations to the SMRS process as applied in this review. These are:

- **Amount of evidence**

There is some reliable evidence for a small number of interventions (see summary of systematic reviews, Appendix A, and our own SMRS tables, Appendix E). However the clear majority of interventions rated under this review do not have a scientific evidence base. As a result, Type 2 evidence (i.e. “Does the proposed intervention make sense in light of what is known about autism?”) needs to be considered. Consideration needs to be given as to how well the intervention addresses principles of good practice in early intervention and autism. In order to do this, reliable objective information about the intervention is required. This is not always available. Therefore one of the recommendations of this review is to clarify the extent of the information that should be provided in provider panel applications to enable evaluation of the application.

- **Intensity**

The second limitation concerns the intensity of the interventions described as established in the research literature. These are almost all designed to be delivered at higher levels of intensity and have been evaluated at higher levels of intensity than is probably possible with public funding alone. As a result, the level of intensity at which an ‘established’ intervention is implemented and evaluated needs to be considered. It cannot be assumed that the same findings would be made if the intervention is implemented at lower levels of intensity.

1.2.2 Principles of good practice

The previous review (Roberts & Prior 2006) and the subsequent *Good Practice Guidelines* (Prior & Roberts 2006) provide the core criteria for judgement of the suitability of interventions (along with any modifications stemming from this review).

These guidelines will remain as core criteria for judgement of the suitability of interventions along with any modifications stemming from this review.

Key elements of effective interventions

The *Good Practice Guidelines* lists the following as key elements of effective interventions.

- autism specific program content providing highly supportive teaching environments and generalisation strategies
- supporting the need for predictability and routine
- a functional approach to challenging behaviours
- transition support
- use of visual supports
- sufficient intensity
- multidisciplinary collaborative approach
- inclusion of typically developing peers
- focus on independent functioning
- addressing obsessions and rituals.

These principles of good practice and elements of effective intervention are explained more fully in Appendix F.

The objectives of this review process are that:

- families should be in a better position to obtain the best possible available interventions for their children given the constraints of geographic location and service availability
- FaHCSIA has up-to-date information and guidance about the evidence for efficacy of interventions and about interventions based on current best practice for children with ASD and their families.

Part 2 – Research Evidence for Treatment Efficacy

2.1 Introduction

Decisions about implementation of interventions should be informed by research evidence about the intervention. Evidence varies in quality and quantity so it is important to establish how much evidence there is and how reliable the findings are. In order to do this we search research data bases and then review and rate the articles that are found relating to a particular intervention. This is direct evidence and is referred to as **Type 1 research evidence**.

It is also important to consider whether the intervention makes sense in relation to what we know about autism. In order to do this we consider research about the condition and whether or not the intervention makes sense in relation to our research-based knowledge of autism. This is referred to as **Type 2 research evidence**.

The final consideration we make when evaluating the evidence for an intervention, is the extent to which the intervention addresses criteria for good practice in autism intervention. These are referred to as **principles of good practice**. (Appendix F provides a detailed description and operationalisation of principles of good practice in autism intervention as used in this report.)

Ideally an intervention will have both types of evidence and will also address principles of good practice in autism intervention; however this is often not the case. Many interventions have not been directly evaluated (Type 1), in which case we need to make decisions based on research-based information about autism (Type 2 evidence) and evaluate how well the intervention adheres to the principles of good practice in autism intervention.

This section includes:

- Summary of research searches and rating methodology. Detailed description of findings can be found in Appendix E
- A review of recent (April 2005–May 2011) research literature evaluating outcomes of early intervention for autism. Where studies have been assessed and findings documented in reliable recent comprehensive reviews the findings of these reviews have been summarised. Relevant research published from April 2005–May 2011 which had not been included in existing comprehensive reviews, was reviewed for the purposes of this report using the Scientific Merit Rating Scale (SMRS) described in the United States 2009 National Autism Center (NAC) review (see www.nationalautismcenter.org/nsp/ for details).
- A table summarising available information about interventions that have one or fewer published trials available, including existing direct (Type 1) and indirect (Type 2) evidence and best practice assessment where information is available.
- Summary table showing recommended eligibility rating based on results for nominated interventions incorporating Type 1 and Type 2 direct research evidence and principles of good practice in autism intervention.

2.2 Summary of Research Search and Rating Methodology

2.2.1 Research search

General literature

Literature searches of Medline, PsychInfo, Cochrane Central and ERIC were conducted using combinations of the following search terms: (intervention, treatment outcome or therapy) AND (autism, pervasive developmental disorders or Asperger's syndrome) AND (randomised controlled trial, controlled clinical trial or between group comparisons). Searches were limited to publication dates ranging from 2005 to 2011 and to young children up to the age of 12 years (See Appendix D for full search strategy). Bibliographies of key reviews were hand searched to identify additional publications. Finally, publications known to authors of this review were also taken into account.

Abstracts of articles identified were examined to determine whether studies met key criteria (described below).

Study quality was assessed by one of three reviewers using the Scientific Merit Rating Scale (SMRS) as described in the *National Standards Report* (National Autism Center 2009). Studies that had already been reviewed and described in the *National Standards Report* were not reviewed as the findings of this report were considered to be reliable.

Specific interventions

Specific interventions were also searched in order to determine any research that may not have been elicited via the comprehensive search. This included a list of interventions provided by FaHCSIA. In these cases, the databases Medline and PsychInfo were searched using the following terms: (Specific intervention) AND (autism OR autism key word).

Websites of specific interventions were also searched for key research.

Abstracts of articles identified were examined by reviewers to determine whether studies met key criteria. The amount of information available for these interventions varied and in some cases there was insufficient information on which to base recommendations.

Inclusion criteria

Abstracts of articles identified through the electronic database searches and website searches were examined to determine whether studies met the following key criteria:

- published original research
- children aged from 0–7 years with ASD (Autism, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), Asperger's syndrome)
- studies with 10 participants or more
- any study design except single subject designs having less than 10 participants
- children experiencing educational and behavioural interventions, not biomedical or psychodynamic interventions.

2.2.2 Assessing methodological quality of individual studies

Study quality was assessed by one of three reviewers using the Scientific Merit Rating Scale (SMRS) as described in the *National Standards Report* (National Autism Center 2009). Studies that had already been reviewed and described in the *National Standards Report* were not reviewed as the findings of this report were considered to be reliable.

The *National Standards Report* (National Autism Center 2009) examines five critical dimensions of experimental rigour:

- research design
- measurement of the dependent variable
- measurement of the independent variable or procedural fidelity
- participant ascertainment
- generalisation of results.

For each of the five dimensions of scientific merit, a score between zero and five (0–5) was assigned, with 0 representing a poor score and 5 representing a strong score. The dimension scores were combined to yield a composite score that was rounded to the nearest whole number; this was called the SMRS score. The formula for combining these dimensions is as follows:

Research Design (0.30) + Dependent Variable (0.25) + Participant Ascertainment (0.20) + Procedural Integrity (0.15) + Generalisation (0.10) = 1

SMRS scores of 3, 4, or 5 indicate that sufficient scientific rigor has been applied.

SMRS scores of 2 provide initial evidence about treatment effects. However, more rigorous research must be conducted to confirm these same effects would be more likely to occur when more rigorous procedures are applied to other individuals with an ASD.

SMRS scores of 0 or 1 indicate that insufficient scientific rigor has been applied to allow for generalization to the population of individuals with ASD.

Findings from the search, quality assessment and data extraction were summarised according to the type, quality and quantity of evidence found. (See Appendix E for tabulated data from each article).

2.3 Summary of Studies Grouped by Type

This section includes a summary of all studies identified through the literature search described previously, along with recent systematic reviews relevant to each category.

2.3.1 Comprehensive interventions

This category of interventions includes a range of services that aim generally to provide a comprehensive model of intervention. Results of individual studies and systematic reviews are presented in Table 1. These interventions vary widely in intensity, direct focuses on the child, and treatment philosophy but are similar in terms of breadth of goals across areas of functioning. Studies included in this section include research on the following interventions:

- behavioural interventions that are grounded in learning theory such as applied behavioural intervention (ABI), early intensive behavioural intervention (EIBI)
- developmental interventions that focus on child development and building positive relationships
- combined interventions, sometimes known as ‘eclectic interventions’ that combine elements of behavioural and developmental models and take account of evolving knowledge about autism and typical development.

Table 1: Review of recent (2005–May 2011) research literature into outcomes of early intervention for autism – comprehensive interventions

Studies evaluated for this review	
Author/s	Quality and outcomes
New research	
Dawson, G., Rogers, S., Munson, J., Smith, M., Winter, J., Greenson, J. et al. (2010). Randomized, controlled trial of an intervention for toddlers with autism: the Early Start Denver Model. <i>Pediatrics</i> , 125(1), e17–23.	Good quality study (4.025) of the Early Start Denver Model (ESDM), compared with eclectic intervention. EDSM blends ABA principles with developmental and relationship-based approaches for young children, and is generally delivered intensively. Found significant improvements in IQ, language, adaptive behaviour, and autism diagnosis. This study needs replication to strengthen conclusions.
Lydon, H., Healy, O. & Leader, G. (2011). A comparison of Video Modelling and Pivotal Response Training to teach pretend play skills to children with Autism Spectrum Disorder. <i>Research in Autism Spectrum Disorders</i> , 5, 872–884.	Pivotal Response Training (PRT) vs. video modelling. Good quality study (3.675) though very small numbers. Measured 'play actions' and verbalisations. Significant increase in play actions pre-post for both conditions, but greater increase for PRT. No difference between groups for verbalisations.
McConkey, R., Truesdale-Kennedy, M., Crawford, H., McGreevy, E., Reavey, M. & Cassidy, A. (2010). Preschoolers with autism spectrum disorders: Evaluating the impact of a home-based intervention to promote their communication. <i>Early Child Development and Care</i> , 180(3), 299–315.	Low quality study (SMRS 2.61), some beneficial outcomes reported. Eclectic approach including TEACCH, + PECS + Hanen delivered over 9 months in home visits. Treatment group showed improvements on Psycho-Educational Profile (PEP-R) across many developmental areas; however data were not collected on the control group. Significant improvements on communication and daily living scales on Vineland. Poorly reported parental outcomes. Both groups increased in autism severity.

<p>Peters-Scheffer, N., Didden, R., Mulders, M. & Korzilius, H. (2010). Low intensity behavioural treatment supplementing preschool services for young children with autism spectrum disorders and severe to mild intellectual disability. <i>Research in Developmental Disabilities</i>, 31(6), 1678–1684.</p>	<p>Good quality study (SMRS 3.54) of combined intervention (a group program using TEACCH principles, plus individual treatment using Lovaas style ABA), compared with no treatment (normal preschool program). Significant positive outcomes for developmental age and adaptive skills. No difference for ASD severity or for behaviour.</p>
<p>Roberts, J., Williams, K., Carter, M., Evans, D., Parmenter, T., Silove, N., Clark, T. & Warren, A. (2011). A randomised controlled trial of two early intervention programs for young children with autism: Centre-based with parent program and home-based. <i>Research in Autism Spectrum Disorders</i>, 5, 1553–1566.</p>	<p>Good quality random clinical trials (RCT) (SMRS 3.65) comparing an eclectic home based treatment with centre based, and a control group (waitlist, treatments as usual). Mixed outcomes: centre based outcomes generally slightly better than home-based but the need for range of programs to suit different families/children noted.</p>
<p>Smith, I.M., Koegel, R.L., Koegel, L.K., Openden, D.A., Fossum, K.L. & Bryson, S.E. (2010). Effectiveness of a novel community-based early intervention model for children with autistic spectrum disorder. <i>American Journal on Intellectual & Developmental Disabilities</i>. 115(6), 504–523.</p>	<p>Good quality study (SMRS 4.19), though with no comparison group so outcomes are difficult to interpret. Both higher and lower functioning children were included. The intervention combines parent training and naturalistic one-to-one behaviour intervention employing PRT. Outcomes included: significant improvements in communication (measured on formal assessment), for all children, with greater improvement for children with IQ greater than 50. Significant gains in cognitive age for cohorts combined, decrease in autism symptoms for group with higher IQ scores.</p>
<p>Zachor, D.A, Itzchak, E.B., Rabinovich, A.-L., Lahat, E. (2007). Change in autism core symptoms with intervention.</p>	<p>Good quality study (SMRS 3.88) comparing ABA with an eclectic developmental program. Autism outcomes (measured by ADOS) = improvement in communication domain significant for ABA group, not significant for the ED group. Both groups improved on the social domain but the</p>

<p><i>Research in Autism Spectrum Disorders</i>, 1(4), 304–317.</p>	<p>ABA group had a larger clinical effect. No differences in cognitive ability between groups.</p>
<p>Zachor, D.A. & Itzchak, E.B. (2010). Treatment approach, autism severity and intervention outcomes in young children. <i>Research in Autism Spectrum Disorders</i>, 4(3), 425–432.</p>	<p>Good quality study (SMRS 3.36) comparing centre-based ABA with centre-based eclectic program. Non-randomised but groups were similar pre-treatment. Both treatments provided similar hours and intensity but differed in philosophy, model, and parent involvement. Groups both showed improvements with no difference between groups.</p>
<p>Summary of systematic reviews of treatments</p>	
<p>Eikeseth, S. (2009). Outcome of comprehensive psycho-educational interventions for young children with autism. <i>Research in Developmental Disabilities</i>, 30(1), 158–178.</p>	<p>Overall outcome: Twenty studies evaluated behavioural treatment, 3 studies evaluated TEACCH and 2 studies evaluated the Colorado Health Sciences Project. ABA treatment was demonstrated to be effective in enhancing global functioning in pre-school children with autism when treatment is intensive and carried out by trained therapists (one Level 1 study, four Level 2 studies).</p>
<p>Eldevik, S., Hastings, R.P., Hughes, J.C., Jahr, E., Eikeseth, S. & Cross, S. (2010). Using participant data to extend the evidence base for intensive behavioural intervention for children with autism. <i>American Journal on Intellectual & Developmental Disabilities</i>, 115(5), 381–405.</p>	<p>Overall outcomes:</p> <p>Behavioural intervention can achieve reliable change in IQ and adaptive behaviour compared with less intensive interventions.</p> <p>IQ and adaptive behaviour at intake predict gains in adaptive behaviour. Intensity of intervention can predict gains in both IQ and adaptive behaviour.</p>
<p>Makrygianni, M.K. & Reed, P. (2010). A meta-analytic review of the effectiveness of behavioural early intervention programs for children with autistic spectrum disorders. <i>Research in Autism</i></p>	<p>Overall outcomes:</p> <p>Behavioural early intervention programs can improve children’s language comprehension, communication skills, and socialisation, as well as intellectual abilities.</p> <p>Behavioural early intervention programs are much more effective than eclectic (control)</p>

<p><i>Spectrum Disorders</i>, 4(4), 577–593.</p>	<p>programs in improving intellectual, language, and adaptive behaviour abilities of children with ASD.</p> <p>Factors found to be correlated with the effectiveness of the behavioural programs were: intensity and duration of the programs; inclusion of parental training, as well as the age and the adaptive behaviour abilities of the children at intake.</p> <p>Intensity of 25 hours/week was associated with a strong effect size (0.7) for all outcomes but no further effect was found for interventions of more than 25 hours/week.</p>
<p>Magiati, I., Moss, J., Charman, T. & Howlin, P. (2011). Patterns of change in children with Autism Spectrum Disorders who received community based comprehensive interventions in their pre-school years: A seven year follow-up study. <i>Research in Autism Spectrum Disorders</i>, 5(3), 1016–1027.</p>	<p>Overall outcome: Review aimed at tracking patterns of change longitudinally, as a result of a broad range of interventions. There are no comparisons of intervention groups against control groups, or against each other. Does not shed any light on the efficacy of particular interventions.</p>
<p>Peters-Scheffer, N., Didden, R., Korzilius, H. & Sturmey, P. (2011). A meta-analytic study on the effectiveness of comprehensive ABA-based early intervention programs for children with Autism Spectrum Disorders. <i>Research in Autism Spectrum Disorders</i>, 5(1), 60–69.</p>	<p>Overall outcomes: EIBI group out-performed the control group on all dependent variables.</p> <p>Interpret results cautiously as there was publication bias identified with the expressive language outcome studies and quite high statistical heterogeneity. This was possibly due to differences in characteristics of the treatment (setting, amount of supervision), participants (age at treatment onset, IQ at treatment onset, diagnosis) and methodological problems (small sample sizes, non-randomised approaches, non-uniform assessment tools, quasi-experimental designs, lack of equivalent groups, lack of adequate fidelity, selection bias, and comparison group differences).</p>
<p>Odom, S.L., Boyd, B.A., Hall, L.J. & Hume, K. (2010). Evaluation of comprehensive treatment models for individuals with autism spectrum</p>	<p>Thirty comprehensive treatment models (CTM) were identified, the majority based on an applied behaviour analysis framework, although a substantial minority followed a developmental or relationship-based model. As a group, CTMs were strongest in the operationalisation of their models, although relatively weaker in measurement of implementation, and with some notable</p>

<p>disorders. <i>Journal of Autism and Developmental Disorders</i>, 40(4), 425–436.</p>	<p>exceptions, weak in evidence of efficacy.</p>
<p>Virues-Ortega, J. (2010). Applied behaviour analytic intervention for autism in early childhood: meta-analysis, meta-regression and dose-response meta-analysis of multiple outcomes. <i>Clinical Psychology Review</i>, 30(4), 387–99.</p>	<p>Overall outcomes: Long-term, comprehensive ABA intervention leads to (positive) medium to large effects in terms of intellectual functioning, language development, and adaptive behaviour of individuals with autism. Although favourable effects were apparent across all outcomes, language-related outcomes (IQ, receptive and expressive language, communication) were significantly superior to non-verbal IQ, social functioning and daily living skills outcomes, with effect sizes approaching 1.5 for receptive and expressive language and communication skills.</p>

2.3.2 General summary of current research evidence for comprehensive interventions

The findings of the current literature review support the findings of previous reviews.

Behaviourally based interventions, and specifically those that are intensive (often referred to as applied behavioural analysis (ABA) or early intensive behavioural intervention (EIBI)), continue to indicate some positive outcomes for some children in a range of areas including cognitive skills, communication, and adaptive behaviour. It is important to note, however, that outcomes vary among studies and between individual children, and that there is still limited information about which children with an ASD are most likely to benefit from behavioural interventions. Recent studies comparing intensive behavioural interventions with eclectic interventions that were delivered with similar levels of intensity, found that children in both groups made significant improvements and that the groups did not differ significantly. A study of an intensive developmental approach also indicated significant improvements in IQ, language, adaptive behaviour, and autism diagnosis for some young children with autism, though more studies of this model are required.

The current research also included a number of studies evaluating a range of eclectic programs and interventions, such as TEACCH and Building Blocks, which measured a range of outcomes. Findings from new research and systematic reviews generally indicated positive outcomes. These outcomes included improvements in developmental age and adaptive skills for children involved in a combined TEACCH and ABA program, though no differences were found in ASD severity or behaviour, and there were mixed outcomes for a randomised controlled trial that compared centre-based, home-based and control groups, with centre-based outcomes generally slightly better than home-based. These findings show similarities to those of the Comparative Effectiveness Review (Warren et al. 2011) in the small number of studies of mixed quality, though with generally positive outcomes in a range of areas.

It is likely that intensity of intervention and parental involvement play a role in the effectiveness of intervention programs. The need for a range of programs to suit the needs of different children and families is also noted, given that no single intervention resulted in the same outcomes for all children studied. Results of this up-to-date review, incorporating the most recent research findings extend and are essentially consistent with findings from the previous review of Roberts and Prior (2006).

2.4 Family Based Interventions

This category includes interventions that are primarily aimed at equipping families with the skills, knowledge and support they need to facilitate positive outcomes for their children. This category includes programs such as Hanen 'More than Words', Earlybird programs and other parent training interventions. Results of individual studies and systematic reviews are presented in Table 2.

Table 2: Review of recent (2005–May 2011) research literature on family based studies and autism

Studies evaluated for this review	
New research	
Author/s	Quality and outcomes
Whittingham, K.S.K., Sheffield, J. & Sanders, M.R. (2009). Stepping Stones Triple P: an RCT of a parenting program with parents of a child diagnosed with an autism spectrum disorder. <i>Journal of Abnormal Child Psychology</i> , 37(4), 469–480.	Stepping Stones Triple P, randomised controlled trial. This was a good quality study (SMRS = 3.95) with significant reductions in child behaviour problems, improvement in parenting styles, greater parental efficacy at follow up.
Keen, D., Couzens, D., Muspratt, S & Rodger, S. (2010). The effects of a parent-focused intervention for children with a recent diagnosis of autism spectrum disorder on parenting stress and competence. <i>Research in Autism Spectrum Disorders</i> , 4(2), 229–241.	Good quality study (3.72) comparing parent supported intervention (workshops & visits) with self-directed video based activities. Greater social communication skills reduced parenting stress levels.
Osterling, I., Visser, J., Swinkels, S., Rommelse, N., Donders, R., Woudenberg, T., et al. (2010). Randomized controlled trial of the focus parent training for toddlers with autism: 1-year outcome. <i>Journal of Autism & Developmental Disorders</i> , 40(12), 1447–	Good quality study (3.76) comparing groups of children accessing good quality intervention, with one group receiving additional focused parent training. No difference was found between parent training group and care as usual (though 'care as usual' was very comprehensive).

1458.	
Carter, A., Messinger, D.S., Stone, W.L., Celimli, S., Nahmias, A.S. & Yoder, P. (2011). A randomized controlled trial of Hanen's 'More Than Words' in toddlers with early autism symptoms. <i>Journal of Child Psychology and Psychiatry</i> 52(7), 741–752.	Hanen More Than Words, good quality study (4.15). No main effect for child outcomes (compared with control group) but results indicated better outcomes for children with lower interest in toys and other play objects at time 1.
Pillay, M., Alderson-Day, B., Wright, B., Williams, C. & Urwin, B. (2011). Autism Spectrum Conditions – Enhancing Nurture and Development (ASCEND): An evaluation of intervention support groups for parents. <i>Clinical Child Psychology and Psychiatry</i> , 16(1), 5–20.	Parent training course, low quality study (2.26). All data parent self-report. No comparison group. Reported improvements in parent knowledge and child behaviour but interpret with caution.
Summary of systematic reviews of treatments	
McConachie, H. & Diggle, T. (2007). Parent implemented early intervention for young children with autism spectrum disorder: a systematic review. <i>Journal of Evaluation in Clinical Practice</i> , 13(1), 120–129.	Overall outcome: Due to a number of methodological shortcomings in all studies and small sample sizes, it was not possible to establish the effectiveness of parent-mediated intervention for young children with autism at this time. Both randomized and controlled studies tended to suggest that parent training leads to improved child communicative behaviour, increased maternal knowledge of autism, enhanced maternal communication style and parent child interaction, and reduced maternal depression. All studies included were performed before 2005 (outside this review's criteria).

2.4.1 Summary of current research evidence for family based interventions

The current review identified a small number of good quality studies indicating some positive outcomes of family based interventions on a number of outcomes. These outcomes included significant reductions in child behaviour problems, improvement in parenting styles, and

greater parental efficacy following the Triple P 'Stepping Stones' parent training, and greater social communication, reduced parenting stress levels for parent intervention group compared when compared to a video training group. However a further two good quality studies found no positive effects compared to their comparison groups. Of note, each of the studies evaluated different interventions so caution is required in interpreting overall outcomes and more research is required.

The recent Comparative Effectiveness Review by Warren et al (2011) also identified a small number of studies of parent training and low intensity interventions, including the recent 'PACT' (Preschool Autism Communication Trial) research (Green et al., 2010) and concluded that "Less intensive interventions to provide parent training for bolstering social communication skills and managing challenging behaviours may be useful for younger children with ASDs, particularly to improve social communication, language use, and potentially symptom severity and family functioning. However, while parent training programs can modify parenting behaviours during interactions, data are limited about their contribution to specific child improvements in the short- and long-term beyond simple language gains for some children" (p.101).

2.5 Therapy Based Interventions

This category of interventions tends to focus on development of skills in specific areas such as communication, cognition, social and motor and include those generally (though not exclusively) associated with speech pathology and occupational therapy.

Results of individual studies and systematic reviews are presented in Table 3.

Table 3: Review of recent (2005–May 2011) research literature on therapy based interventions and autism

Studies evaluated for this review	
New research	
Author/s	Quality and outcomes
Gulsrud, A.C., Kasari, C., Freeman, S. & Paparella, T. (2007). Children with autism's response to novel stimuli while participating in interventions targeting joint attention or symbolic play skills. <i>Autism</i> , 11(6), 535–546.	Good quality study (4.49) comparing children's responses to novel stimuli while participating in two different interventions targeting joint attention skills versus symbolic play skills, no control group. Children in the intervention targeting joint attention responded significantly better socially, and engaged in coordinated joint looks when an unexpected stimulus was put in front of them compared to children in the symbolic play intervention.
Landa, R.J., Holman, K.C., O'Neill, A.H. & Stuart, E.A. (2011). Intervention targeting development of socially synchronous engagement in toddlers with autism spectrum disorder: A randomized controlled trial. <i>Journal of Child Psychology and Psychiatry</i> , 52(1), 13–21.	Good quality study (4.57) with positive outcomes for both groups. The study compared 2 treatments. The interventions provided identical intensity (10 hours per week in classroom), student-to-teacher ratio, schedule, home-based parent training (1.5 hours per month), parent education (38 hours), and instructional strategies, except the Interpersonal Synchrony (IP) condition provided a supplementary curriculum targeting socially engaged imitation, joint attention, and affect sharing; measures of these were primary outcomes. The treatment group (IP) increased in engaged imitation (significant difference), and approached significance on formal measures of joint attention and affect sharing.
Wong, V.C. & Kwan, Q.K. (2010). Randomized controlled trial for early intervention for autism: a pilot study of the Autism 1-2-3 Project. <i>Journal of Autism & Developmental Disorders</i> , 40(6), 677–688.	Good quality study (3.69) of 'Autism 1-2-3' program – group, child and parent involvement. Significant change for communication and social interaction measured on ADOS. Limitations due to sample size, reporting of data.
Whalen, C., Ilan, A.B., Vaupel, M., Fielding, P., Macdonald, K., Cernich, S.	Reasonable quality study (3.09) compared comprehensive program with comprehensive program + computer program (40 mins/day for 3 months). Significant improvements seen in

<p>& Symon, J. (2010). Efficacy of TeachTown: Basics computer-assisted intervention for the Intensive Comprehensive Autism Program in Los Angeles Unified School District. <i>Autism: the international journal of research and practice</i>, 14(3), 179–197.</p>	<p>receptive language for younger children only, no change in expressive language or developmental assessment.</p>
<p>Yoder, P.J. & Lieberman, R.G. (2010). Brief Report: Randomized test of the efficacy of picture exchange communication system on highly generalized picture exchanges in children with ASD. <i>Journal of Autism & Developmental Disorders</i>, 40(5), 629–632.</p>	<p>Good quality study (4.67) that looked at generalisation of PECS training. Compared PECS with 'Responsive education, pre-linguistic milieu' teaching and measured whether children used picture exchange in a generalised way post intervention. The PECS group showed significantly more picture exchange in a setting involving novel adults, toys and setting.</p>
<p>Summary of systematic reviews of treatments</p>	
<p>Kagohara, D.M. (2010). Is video-based instruction effective in the rehabilitation of children with autism spectrum disorders? <i>Developmental Neurorehabilitation</i>, 13(2), 129–140.</p>	<p>Overall outcome: Video modelling studies. Difficult to draw conclusions due to only 1–3 participants in any one included study having ASD. Also mean age of included sample was 7.6 years although 55% were school age (6–12 years) and 30% were 3–5 years. Most studies reported positive results, but the certainty of evidence was not strong for all of the studies due to reliance on pre-experimental research designs.</p>
<p>Preston, D. & Carter, M. (2009). A Review of the Efficacy of the Picture Exchange Communication System Intervention. <i>Journal of Autism and Developmental Disorders</i>, 39, 1471–1486</p>	<p>Overall outcome: based on 3 RCT studies of PECS, but nature and quantity of data arising from RCTs at this point in time is insufficient to draw firm conclusions regarding the PECS interventions</p>

<p>Stephenson, J. & Carter, M. (2009). The use of weighted vests with children with autism spectrum disorders and other disabilities. <i>Journal of Autism & Developmental Disorders</i>, 39(1), 105–114.</p>	<p>Overall outcome: Weighted vests are ineffective. Six studies were identified in this area, all with weak study design and methodological weaknesses.</p>
<p>Kokina, A. & Kern, L. (2010). Social Story interventions for students with autism spectrum disorders: a meta-analysis. <i>Journal of Autism & Developmental Disorders</i>, 40(7), 812–826.</p>	<p>Overall outcome: Social Stories is in the low/questionable category of effective interventions. No significant changes in outcomes are confirmed. All are single subject design studies covering a sample of 47 children. Studies were of low methodological quality.</p>
<p>van der Meer, L.A. & Rispoli, M. (2010). Communication interventions involving speech-generating devices for children with autism: a review of the literature. <i>Developmental Neurorehabilitation</i>, 13(4), 294-306.</p>	<p>Overall outcome: Only 4 /23 studies had ‘conclusive’ single-subject study designs comprising a total of 13 children. Two small studies had small positive effects, non-RCT studies. Despite this, the review identified several trends, including (a) a clear tendency for targeting requesting as the main communication skill taught, (b) that instructional approach reflects the communication skill being taught, (c) the need to incorporate generalisation and maintenance strategies into treatment procedures, and (d) the predominance of single-case designs and resulting limitation to individual outcomes.</p>
<p>Sinha, Y., Silove N., Williams, K.J. & Hayan, A. (2011). Auditory integration training and other sound therapies for autism spectrum disorders. Cochrane Database of Systematic Reviews. 1, 2011. No.: CD003681. 00075320-100000000-02670</p>	<p>Overall outcome: A recently updated Cochrane Systematic Review (highest level of evidence) reviewed 7 randomised controlled trial (RCT) studies of auditory integration therapies (AIT). The authors suggest that there is no evidence that auditory integration training or other sound based therapies are effective as a treatment for autism and state that AIT cannot be recommended for use at this time.</p>

2.5.1 Summary of current research evidence for therapy based interventions

The current review adds little information to previous findings regarding therapy based interventions. Limitations still exist in the research literature regarding the effectiveness of social stories and communication interventions such as PECS and there is only a small amount of information regarding the use of speech generating devices. Despite documented sensory differences in people with autism and the need to consider sensory processing difficulties, there remains very limited evidence regarding sensory integration therapy with the early intervention age group. Systematic reviews of sensory based interventions including weighted vests and auditory integration therapy (AIT, also known as therapeutic listening or sound therapy) indicate that these interventions show no benefit to young children with autism. More intervention research across this field is required.

2.6 Other Interventions

This category can potentially include a range of interventions; however, the only studies to emerge from the current literature review were evaluations of the effects of music therapy and physiotherapy.

Results of individual studies and systematic reviews are presented in Table 4.

Table 4: Review of recent (2005–May 2011) research literature on other interventions and autism

Studies evaluated for this review	
New research	
Author/s	Quality and outcomes
Lim, H.A. (2010). Effect of 'Developmental Speech and Language Training Through Music' on speech production in children with Autism Spectrum Disorders. <i>Journal of Music Therapy</i> , 47(1), 2–26.	Good quality study (3.975) comparing music training, speech training and control using appropriate videos over 3 days. Music and speech groups both increased verbal production compared with controls (significant differences, large effect size); low functioning participants showed greater improvement with music training than with speech training.
Summary of systematic reviews of treatments	
Petrus, C., Adamson, S.R., Block, L., Einarson, S.J., Sharifnejad, M. & Harris, S.R. (2008). Effects of exercise interventions on stereotypic behaviours in children with autism spectrum disorder. <i>Physiotherapy Canada</i> , 60 (1), 134–145.	Overall outcome: This review incorporated 7 studies, 4 single subject design with weak methodology, 1 case study with weak methodology and two group design studies assessed to have moderate quality. The two group studies included one repeated measures study (no control group) with only 5 children aged 14–15 years. The other study was a case series with 5 children aged 9–11 years. Both these studies fall outside this review's criteria. The method for identifying children with ASD was based on a statement only rather than using standardized tools. Based on the weakness in study design and method to identify children with ASD, along with the small sample sizes and broad sage groups of children being assessed, no strong conclusions can be drawn from this review.

2.6.1 Summary of current research evidence for other interventions

This review identified one study regarding music therapy that involved videos rather than more traditional, interaction based music therapy. A positive outcome was found (increased verbal production) but it is unlikely that this particular intervention is representative of music therapy more broadly. The Comparative Effectiveness Review (2011) identified two studies that described some positive results regarding music therapy but described the quality of both as 'poor'.

One review study of physiotherapy and autism was identified which looked at the effect of exercise on stereotypical mannerisms often seen in autism. Some short-term reductions were observed in some children; however the studies included were generally of low quality with a small number of children and a wide age range.

2.7 Summary of Named Interventions

Table 5 provides a summary of named interventions in terms of direct evidence and indirect evidence or principles of good practice for known treatments with some direct evidence. An evaluation of compliance with principles of good practice is shown if sufficient information was available about an intervention to enable an assessment to be completed. For an explanation of the principles of good practice see Appendix F.

Table 5: Summary of named interventions

Interventions	Type 1 direct evidence (current review, National Autism Centre, Roberts and Prior 2006)	Type 2 indirect research evidence about autism &/or rationale (principles of good practice)	Comment
Known treatments for ASD with some evidence			
Developmental Social-Pragmatic (DSP) model:	Single subject design, n = 3. Variable outcomes measured using observation, no levels of significance reported (Ingersoll et al 2005).	See Roberts & Prior (2006) for discussion. See Raising Children Network < http://raisingchildren.net.au > for summary.	Model of engaging parent and child using a developmental approach, well grounded in child development theory and in relation to autism. Limited direct evidence but strong theoretical basis.
DIR/Floortime approach	Limited direct evidence; single study low quality (Solomon et al. 2007; cited in Comparative Effectiveness Review, 2011) used a DIR/Floortime approach in a parent training model.	See Roberts & Prior (2006) for discussion. Based on developmental theory, focuses on individual strengths and needs, takes into account sensory needs, follows child's lead, developing reciprocal relationships. Emphasis on parent	Limited direct evidence, addresses core features of autism utilising a developmental approach.

Interventions	Type 1 direct evidence (current review, National Autism Centre, Roberts and Prior 2006)	Type 2 indirect research evidence about autism &/or rationale (principles of good practice)	Comment
		training to allow for high intensity program in the natural setting.	
The PLAY Project®	Limited direct evidence; single study low quality (Solomon et al. 2007; cited in Comparative Effectiveness Review, 2011)	As above	Uses DIR/Floortime theoretical approach, home based, parent training to play with children Limited direct evidence, addresses core features of autism utilising a developmental approach.
Preschoolers with Autism	Manualised parent training program. One study, RCT, high quality (4.85). Compared program with counselling program and no treatment. Better outcomes for parents compared with no treatment, similar outcomes for parents in counselling intervention. Greater outcomes for parents with pre-existing mental health difficulties.	Program focuses on key areas of autism, including features of autism, communication and behaviour support.	Developed at Monash University by Tonge & Brereton (2005). Parent training researched with good outcomes for parents. No measures reported for child outcomes. Addresses core features of autism.
Social, Communication, Emotional Regulation Transactional Support	No research based direct evaluation found	Program focuses on key areas of autism – social communication, emotional regulation and providing transactional supports (including	SCERTS is a model of service provision, rather than a specific program. No research regarding the effectiveness as a whole but

Interventions	Type 1 direct evidence (current review, National Autism Centre, Roberts and Prior 2006)	Type 2 indirect research evidence about autism &/or rationale (principles of good practice)	Comment
(SCERTS)		<p>visual supports and other communication aides).</p> <p>Very strong basis in research for all components of the model.</p>	all components are grounded in well-established research.
TEACCH	See Roberts & Prior (2006) for discussion of early research. Comparative Effectiveness review identified 4 newer studies, 2 of reasonable quality, 1 of these with young children (3–5 years) (Tsang 2007). Significant improvements in motor and cognitive domains, control group also made gains.	<p>Components of program strongly based in established understanding of autism, utilising:</p> <ul style="list-style-type: none"> • autism specific curriculum • structured teaching • routines and organisation • communication support • use of visual supports • strengths based content and teaching • individualisation 	Involves structured teaching and a ‘whole of life’ approach to support and education. Strong use of organisation and visual supports to structure learning.

Interventions	Type 1 direct evidence (current review, National Autism Centre, Roberts and Prior 2006)	Type 2 indirect research evidence about autism &/or rationale (principles of good practice)	Comment
Triple P – Stepping Stones adaptation	Good quality (3.95) study (see literature table) with significant reductions in child behaviour, improvement in parenting styles, greater parental efficacy at follow up.	Program specifically adapted for parents of children with a developmental disability. Targets associated features of autism (specifically challenging behaviour) and aims to reduce parent stress. Functional approach to challenging behaviour.	Parenting program modified for parents of children with a developmental disability. Some good quality research evidence and good practice principals (single component address a specific area of need to be used within a comprehensive program.
Building Blocks	One good quality study (3.65) comparing Building Blocks® home based program with the Building Blocks® centre based program and a waiting list control group. Mixed outcomes, centre based outcomes generally slightly better than home-based but the need for range of programs to suit different families/children noted.	Comprehensive approach including: naturalistic play-based intervention <ul style="list-style-type: none"> • behavioural and developmental theory • structured teaching • functional communication skills • positive behaviour support • assessment of sensory processing issues • use of visual supports 	Good quality research though with mixed outcomes, the need to provide centre-based and/or home-based programs depend on family and child characteristics is recognised. Approach meets good practice guidelines and key effective elements.

Interventions	Type 1 direct evidence (current review, National Autism Centre, Roberts and Prior 2006)	Type 2 indirect research evidence about autism &/or rationale (principles of good practice)	Comment
Speech generating devices/ high tech Augmentative and Alternative Communication (AAC) devices	No large scale RCT of speech generating devices but some single subject design suggesting efficacy.	Speech generating devices address core feature of autism (communication and social interaction) as part of comprehensive program. Matches some learning style features of ASD including visual skills.	Assessment and provision of high tech communication devices. Relevant to autism as one part of a comprehensive intervention plan.
Known interventions with limited or no evidence base			
Miller Method	<p>From Roberts & Prior (2006):</p> <ul style="list-style-type: none"> • Jordan, Jones, and Murray (1998) conducted a review of research evidence for the effectiveness of the Miller Method • one study of outcomes of the program, which failed to evaluate the direct effects of the independent variable (i.e. the treatment program) • further research is required...the program must be considered pre- 	<p>From Roberts & Prior (2006):</p> <ul style="list-style-type: none"> • based on 'Cognitive-developmental systems theory', assumes that typical development depends on the ability of the children to form systems and organised 'chunks' of behaviour • claims to transform the child's 'aberrant systems (lining up blocks, driven reactions to stimuli, etc.) into functional behaviours' 	<p>Very limited research evidence (type 1)</p> <p>Limited type 2 evidence</p> <p>Limited evidence for 'elevated platform' rationale</p> <p>Unknown best practice elements, including predictability and routine, autism specific curriculum, intensity and transition support</p>

Interventions	Type 1 direct evidence (current review, National Autism Centre, Roberts and Prior 2006)	Type 2 indirect research evidence about autism &/or rationale (principles of good practice)	Comment
	experimental in nature.	<ul style="list-style-type: none"> strategies employed include narrating the children's actions while they are a metre above the ground on an 'Elevated Square' <p>From website:</p> <ul style="list-style-type: none"> focus on sign AAC while narrating elevated activities, philosophy mentions social interaction, communication and behaviour but it is unclear how these are addressed. 	
<p>Multi-sensory Environment (Snoezelen room)</p> <p>Also known as Snoezelen rooms, provides sensory stimuli across the range of sensory modalities within a specially built room. Initially designed for institutionalised</p>	<p>Total 6 studies (autism + Snoezelen, autism + multisensory environment)</p> <ul style="list-style-type: none"> one study of 3 adults with autism found no effect on challenging behaviour one study of children 5–17, 2 with ASD, no stats, not quality reviewed no studies found with children under 5 no studies found with children with 	<p>Limited evidence for rationale, limited evidence of any good practice principles or elements of effective interventions (ASD content, teaching, generalisation, functional approach to challenging behaviours).</p>	<p>Limited Type 1 evidence</p> <p>Limited evidence for rationale</p> <p>Does not meet best practice criteria as a stand-alone intervention</p>

Interventions	Type 1 direct evidence (current review, National Autism Centre, Roberts and Prior 2006)	Type 2 indirect research evidence about autism &/or rationale (principles of good practice)	Comment
patients. Also used with elderly population with dementia.	autism		
<p>Sensory Integration Therapy (SIT)</p> <ul style="list-style-type: none"> • Sensory Diet • Weighted Vests • Wilbarger Brushing Protocols 	<p>Roberts & Prior (2006) found no supporting evidence for SIT</p> <p>Comparative Effectiveness Review (2011) indicated that studies of SI were of poor quality.</p> <p>Rodger et al. (2010) describe “no robust evidence supporting its efficacy in achieving functional outcomes by correcting underlying sensory integrative dysfunction” (p.2).</p>	<p>Sensory processing differences are widely reported in autism but no quality evidence that SI changes sensory responses in ASD.</p> <p>Studies have not shown evidence of impact of weighted vests (Stephenson & Carter, 2009).</p> <p>Very limited published research on effectiveness of sensory diets or brushing protocols.</p>	<p>Children with autism may have marked responses to sensory information; however there is currently no evidence that SIT, sensory diets, brushing programs or weighted vests can correct underlying sensory problems.</p>
Auditory Integration Therapy	<p>Limited evidence of effectiveness (see Roberts & Prior 2006 for review).</p> <p>Comparative Effectiveness Review (2011) described two fair quality studies with no effect of treatment.</p>	<p>Sound sensitivities often reported but limited evidence of physiological differences (Stiegler & Davis 2010).</p> <p>No evidence that AIT changes physiological level or behavioural response.</p>	<p>Also known as ‘Tomatis therapy’, listening therapy and therapeutic listening. No research evidence of effectiveness. Not currently listed by FaHCSIA as an eligible therapy.</p>

Interventions	Type 1 direct evidence (current review, National Autism Centre, Roberts and Prior 2006)	Type 2 indirect research evidence about autism &/or rationale (principles of good practice)	Comment
Alert Program for Self-Regulation	<p>Program evaluated for students with 'emotional disturbances' in mainstream schools and a modified program for school aged children with foetal alcohol spectrum disorder.</p> <p>No other empirical research found.</p>	Based on theories of self-regulation and self-management use of sensory strategies to manage self-regulation issues.	Aims to teach children (and/or their parents) to identify their state of arousal (high, low, alert) and to use appropriate cognitive and or sensory strategies to self-regulate.
Cognitive Behaviour Therapy	<p>Some direct evidence of effectiveness for school aged children with high-functioning autism or Asperger syndrome (ages 7+).</p> <p>No apparent evidence for early intervention population.</p>	Anxiety can be associated with autism but unclear whether principles and practice of CBT would match the language and cognitive level of young children with an ASD.	CBT is an established treatment for anxiety disorders (which can be associated with ASDs) but even adapted CBT relies on adequate language and cognitive skills. Unlikely to be appropriate for the EI population.
Single element components addressing one aspect of ASDs			
<p>PALS Social Skills Program (Playing and Learning to Socialise)</p> <p>www.palsprogram.com.au</p>	One RCT found, good quality study (2.85) though not specific to autism.	<p>Based on rationale that children with an ASD have difficulties learning and using social skills. Program targets skills:</p> <ul style="list-style-type: none"> greeting others 	Well established program for typically developing, some use in autism, though no empirical research. Rationale, teaching methods and program elements suggest appropriate for some

Interventions	Type 1 direct evidence (current review, National Autism Centre, Roberts and Prior 2006)	Type 2 indirect research evidence about autism &/or rationale (principles of good practice)	Comment
		<ul style="list-style-type: none"> • taking turns: talking and listening • taking turns at play • sharing • asking for help • identifying feelings • empathy • overcoming fear and anxiety • managing frustration • calming down and speaking up. <p>Uses video modelling, puppets, role play, songs to teach skills.</p>	<p>children.</p> <p>Single element addressing one aspect of ASDs. For use combined with other ASD specific elements only.</p>
<p>Sleepwise©: Positive Sleeping Practices for Young Children with Developmental Delay</p>	<p>One empirical study found (O'Connell & Vannan 2008), 23 families, mixed diagnoses, all developmental disability ages 1–7 years.</p> <p>Treatments varied according to child</p>	<p>Increased prevalence of sleep disturbance in children with developmental delay that requires professional intervention (cited in O'Connell & Vannan, 2008)</p>	<p>Sleep is a particular issue for children with autism. Sleepwise© has some Type 1 evidence and the rationale is consistent with current understanding of autism and best practice intervention to</p>

Interventions	Type 1 direct evidence (current review, National Autism Centre, Roberts and Prior 2006)	Type 2 indirect research evidence about autism &/or rationale (principles of good practice)	Comment
	<p>characteristics and parental preferences</p> <p>General gains, though outcomes and level of success were determined according to individual goals</p>	<p>High rates of sleep problems reported in children with autism (Richdale 1999)</p> <p>Sleepwise© is used by therapists to help families/carers of young children (under six) with developmental delay in supporting children's sleep, including individual sleep plans and family support</p> <p>Techniques include social stories, visual supports, positive behaviour supports, sensory supports, appropriate for children with an ASD</p> <p>Family based, working with parents</p>	<p>address a particular issue.</p> <p>Single element addressing one aspect of ASDs. For use combined with other ASD specific elements.</p>
SoSAFE!	No direct evidence found.	Based on addressing social skills issues, relevant to autism but applicable to older age group regarding relationships, sexuality and protective behaviours.	<p>So Safe pages on www.shfpact.org.au/index.php?option=com_content&view=article&id=141:sosafe-user-training&catid=25:for-disability-workers&Itemid=128</p> <p>Sexuality program for adults – no</p>

Interventions	Type 1 direct evidence (current review, National Autism Centre, Roberts and Prior 2006)	Type 2 indirect research evidence about autism &/or rationale (principles of good practice)	Comment
			evidence of efficacy for children.
Toilet Time©: Toilet Training for Young Children with Developmental Delay	One small study on the effects of traditional toilet training (operant conditioning) plus video modelling. Some impact of training plus video modelling compared with training alone. Carers reported that support was important (Keen et al. 2007.)	Evidence that toilet training can be delayed in children with an ASD. Limits opportunities for integration (e.g. preschool). Parent training and support, use of visual supports, use of video modelling, behaviour analysis techniques are consistent with needs of children with autism.	Addresses an issue for children with autism documented in the research, likely difficulties attributable to intellectual disability/delay, communication and socialisation difficulties, differences in sensory processing. Program is consistent with autism learning needs, one small research study providing some supporting evidence. Single element addressing one aspect of ASDs. For use combined with other ASD specific elements.
'Social Eyes'	No reference in the literature	Rationale based on social interaction difficulties seen in people with an ASD. Developed for adults.	Developed by NAS but for adults www.autism.org.uk/socialeyes.aspx Need to look at whether any modifications have been made for

Interventions	Type 1 direct evidence (current review, National Autism Centre, Roberts and Prior 2006)	Type 2 indirect research evidence about autism &/or rationale (principles of good practice)	Comment
			<p>young children.</p> <p>Current format would suggest that it is unsuitable.</p>
Pragmatic Language Group / Pragmatics for Prep	Service based; no direct evidence.	Pragmatics is an area of communication that is particularly affected by autism. Relevant to higher functioning young children with autism. Will need to check that good practice principles are met.	<p>Service based; no direct evidence but matches particular area of need for some children with autism.</p> <p>Single element addressing one aspect of ASDs. For use combined with other ASD specific elements.</p>
Music Therapy	<p>Good quality study (Lim, 2010; SMRS score of 3.975) comparing music training, speech training and control using appropriate videos over 3 days. Music and speech groups both increased verbal production compared with controls (significant differences, large effect size); low functioning participants showed greater improvement with music training than speech training.</p> <p>2 low quality studies identified in</p>	Aims to address core autism features of social interaction and communication. Would need to be used in conjunction with other treatments, rather than as a stand-alone intervention.	Some limited research evidence of effectiveness for communication. Would need to be used in conjunction with other treatments, rather than as a stand-alone intervention. Would need to meet best practice guidelines.

Interventions	Type 1 direct evidence (current review, National Autism Centre, Roberts and Prior 2006)	Type 2 indirect research evidence about autism &/or rationale (principles of good practice)	Comment
	Comparative Effectiveness Review (2011) describing outcomes for joint attention and communication skills.		
Service based and/or not specific to ASDs			
'Super-nanny' – whole family support provided by a mental health nurse in the family home using a DSP approach	No direct evidence for or against 'super-nanny' approach. DSP is an approach supported by some limited evidence; however, it would need to be operationalised appropriately to meet key effective elements and principles of good practice.	Unclear whether any core features of autism are addressed. Not multi-disciplinary, appears to be delivered by nurse, rather than psychologist.	Limited information about components. No information about how good practice principles or key effective elements are addressed. Not multidisciplinary. Query whether this service is specific to autism.
Phonological Awareness Groups, Literacy groups	Phonological awareness relates to development of literacy skills. No evidence that children with high functioning autism (i.e. those with good verbal language skills) have literacy difficulties greater than the typical population.	Not addressing core features of autism or established associated features.	Limited relevant rationale, not related to functional language and/or communication development. Need to question whether groups were run by a speech pathologist, teacher, OT or psychologist, rather than a therapy aide (unqualified).

Interventions	Type 1 direct evidence (current review, National Autism Centre, Roberts and Prior 2006)	Type 2 indirect research evidence about autism &/or rationale (principles of good practice)	Comment
Aquatic OT 10 Week Program	<p>One small survey regarding clinicians' perceptions of the benefits of aquatic therapy, though within a Sensory Integration (SI) framework (Vonder Hulls et al. 2006).</p> <p>One conference abstract (Daniels & Mahmic 2006) relating to this specific intervention, aim of the program to foster interaction and communication between child and parent in a natural setting rather than swimming, sensory or motor skills.</p> <p>Children made gains in goals, parents were able to identify many areas of benefit for both their children and themselves.</p> <p>Very limited study.</p>	<p>Limited evidence that general aquatic interventions are relevant to the core features of autism.</p> <p>In this service, however, the weekly pool sessions focused on developing: movement in the water; play skills; communication; independence and consistent routines, parent interaction and education, various communication aides.</p> <p>Potential to meet some good practice/effective elements guidelines, would need to be part of a more comprehensive service and thoroughly checked for effective elements</p>	<p>Abstract of Aquatic Therapy Program www.icms.com.au/apc2005/abstract/36.htm</p> <p>Limited direct or indirect evidence for rationale, however, in this service, the focus on communication, routines and interaction mean that it may be part of an overall comprehensive program.</p>
Aquatic OT School Holiday Intensive Program	As above	As above	As above

Interventions	Type 1 direct evidence (current review, National Autism Centre, Roberts and Prior 2006)	Type 2 indirect research evidence about autism &/or rationale (principles of good practice)	Comment
<p>Fast ForWord Program</p> <p>Computer based, intensive</p> <p>Designed to improve oral language and literacy</p>	<p>Strong et al. (2011) meta-analysis, PRISMA protocol. Included only RCT, had to include standardised measures of language, oral or written. All included studies were school aged. Not specific to autism. Conclusion: There is no evidence from this review that the program is effective as a treatment for children's reading or expressive or receptive vocabulary weaknesses.</p> <p>Russo et al. (2010) – study of ASD children and FFW, n=5, mean age 9 years, there is a control but it is non-randomised, biological outcome measures but no measure of language, behaviour, adaptive functioning or school performance. There is no verification of diagnosis, a variety of diagnoses (autism, Asperger's and ASD) and restrictive inclusion criteria (normal IQ and language abilities). Not relatable to an EI population.</p> <p>SMRS score 1.51 (SMRS scores of 0 or 1 indicate that insufficient scientific rigor has</p>	<p>Intensive computer program designed to improve literacy and oral language. No relationships to good practice principles for young children with autism (i.e. not autism specific, does not address the core features of autism, not multidisciplinary, not functional approach to challenging behaviours, limited family involvement etc.)</p>	<p>The best available meta-analysis of randomised controlled trials suggests there is no evidence that Fast ForWord (FFW) is an effective treatment for typically developing children with language or literacy difficulties</p> <p>The only study found of ASD and FFW is of poor quality with no measures of functioning</p> <p>There is no Type II evidence or rationale that would suggest that FFW would match the learning strengths/deficits of children with ASD</p> <p>FFW does not match the best practice guidelines set out in Prior & Roberts (2006)</p>

Interventions	Type 1 direct evidence (current review, National Autism Centre, Roberts and Prior 2006)	Type 2 indirect research evidence about autism &/or rationale (principles of good practice)	Comment
	<p>been applied to the population of individuals with ASD. There is insufficient evidence to even suggest whether a treatment may or may not have beneficial, ineffective, or harmful effects.)</p>		
<p>PROMPT PROMPTs for Restructuring Oral Muscular Phonetic Targets</p>	<p>One study of PROMPT with children with autism (Rogers et al. 2006). Study design single subject design (5 participants), meaning that each child acted as their own control, scattered results (1 child showed improvement on formal assessment, 2 of 5 increased their spoken words, 1 child regressed).</p>	<p>PROMPT is a treatment designed to impact on motor aspects of speech production, originally designed for children with significant motor speech disorders (e.g. childhood apraxia of speech).</p> <p>Limited evidence of efficacy with children with motor speech disorders</p> <p>Limited evidence that childhood apraxia of speech is prevalent within the autism population (Shriberg et al. 2011)</p>	<p>Limited evidence for rationale for use.</p>

Interventions	Type 1 direct evidence (current review, National Autism Centre, Roberts and Prior 2006)	Type 2 indirect research evidence about autism &/or rationale (principles of good practice)	Comment
Parent and family support			
Early Bird Advanced training	<p>Parental needs for emotional support, education and training are well established (see Roberts & Prior, 2006 for discussion). Family involvement is one of the key effective elements of early intervention and appropriate consideration of family needs is a component of good practice. Current research indicates that there is preliminary empirical support for parent training on child outcomes:</p> <p>From the Comparative Effectiveness Review (2011)</p> <p>“Less intensive interventions focusing on providing parent training for bolstering social communication skills and managing challenging behaviours have been associated in individual studies with short-term gains in social communication and language use. The current evidence base for such treatment remains” <i>insufficient, with current research lacking consistency in interventions and outcomes assessed (p.ES-7).</i></p> <p>Any training provided for parents by approved service providers must adhere to the key elements of effective early intervention identified in Roberts & Prior (2006) and the current review, particularly with regard to:</p> <ul style="list-style-type: none"> • autism specific curriculum, addressing the core features of ASDs and/or associated features • functional approach to challenging behaviours 		
Individual Parent Counselling			
Family Camp			
ABA Parent Training			
Individual Family Psychological Therapy			
Intensive Family Support – Family Therapists			
Parent/Family Workshops and Sibling Workshops			

Interventions	Type 1 direct evidence (current review, National Autism Centre, Roberts and Prior 2006)	Type 2 indirect research evidence about autism &/or rationale (principles of good practice)	Comment
		<ul style="list-style-type: none"> • predictability and routine • visual supports • multidisciplinary team involvement wherever appropriate 	
Teacher/centre support			
Parent/teacher training	Teacher training is not an approved service under the current guidelines.		
Advanced Behaviour Management teacher training	Consideration should be given to funding services that allow for collaborative planning (e.g. Individual Education Program (IEP) meetings) and individual visits to children's everyday settings (such as preschools and childcare) to facilitate generalisation of skills, appropriate behaviour support, use of visual supports and transition, as per the established principles of good practice.		
Coaching for preschool / childcare staff			
Educational Services. Training for teachers			
Let's Link: Mainstream child care setting support for staff			
Other			
Physiotherapy / motor skills	Limited research evidence regarding physiotherapy in autism. Consideration may be given to children with Rett's syndrome.		

2.8 Interventions Rated According to Research

This section reviews the evidence regarding the intervention and evaluates the research supporting underlying rationales and evaluation according to application of principles of good practice in 0–7 year olds.

Table 6 presents an evaluation of the intervention research supporting the underlying rationale, and the application of principles of good practice in 0–7 year olds. It provides recommendations regarding the eligibility of early intervention services for children aged 0–7 years, based on the list of interventions provided by FaCSHIA and including treatments.

Interventions that are service based and which have not provided information about their philosophy and service provision, and about which no other information could be found, have not been provided with a rating. In order to assess the eligibility of these services further information is required.

Table 6: Interventions rated according to research

Key

E = Established/Eligible based on evidence

EE = Emerging evidence

BP = Eligible based on best practice approach. Evidence awaited.

SE = Single element, eligible based on evidence or best practice, must be used with other eligible interventions

NEI = Not eligible, insufficient information regarding best practice or evidence

NEE = Not eligible based on best practice guidelines or evidence that indicate the intervention is not effective

A number of programs have been given a rating of both EE (Eligible based on emerging evidence) and SE (Single element that must be used with other eligible treatments). This recognises that a number of treatments, particularly some therapy based interventions, have some emerging evidence but that they support only one part of a child’s overall needs. These ratings further highlight the need for collaborative multidisciplinary practice.

Type of Intervention	Named interventions within that type of intervention	Established/ Eligible based on evidence	Eligible based on emerging research	Eligible based on best practice approach. Evidence awaited.	Eligible element based on evidence or best practice, must be used with other eligible Tx	Not eligible as insufficient info re best practice and/or evidence	Not eligible as not based on best practice and/or evidence that not effective

Type of Intervention	Named interventions within that type of intervention	Established/ Eligible based on evidence	Eligible based on emerging research	Eligible based on best practice approach. Evidence awaited.	Eligible element based on evidence or best practice, must be used with other eligible Tx	Not eligible as insufficient information re best practice and/or evidence	Not eligible as not based on best practice and/or evidence that not effective
Comprehensive programs, including EIBI, ABA, combined approaches, developmental approaches	Applied behavioural analysis (ABA) or early intensive behavioural intervention (EIBI)	E					
	Early Start Denver Model (ESDM)		EE				
	TEACCH (Treatment and education of autistic and related communication handicapped children)		EE				
	LEAP (Learning Experiences – An Alternative Program for Pre-schoolers and Parents)		EE				
	PACT		EE				
	Building Blocks (centred based and home-based)		EE				
	SCERTS (Social-Communication, Emotional Regulation and Transactional Support)				BP		
	DIR/Floortime Approach				BP		

Type of Intervention	Named interventions within that type of intervention	Established/ Eligible based on evidence	Eligible based on emerging research	Eligible based on best practice approach. Evidence awaited.	Eligible element based on evidence or best practice, must be used with other eligible Tx	Not eligible as insufficient information for best practice and/or evidence	Not eligible as not based on best practice and/or evidence that not effective
	Developmental Social-Pragmatic (DSP) model			BP			
	Relationships Development Intervention (RDI)			BP			
	The PLAY Project®			BP			
	Miller Method					NEI	
Service based treatments specific to autism – more information required	Learn & Grow Group			BP			
	HAPP Approach			BP			
	SERVAM (Sensory considerations, Environmental management, Routines and planned change, Visual supports, Autism friendly communication, Motivation)			BP			
	Play Links			BP			
	Autism Specific Long Day Care (Supported placement in inclusive long-day care setting.			BP			

Type of Intervention	Named interventions within that type of intervention	Established/ Eligible based on evidence	Eligible based on emerging research	Eligible based on best practice approach. Evidence awaited.	Eligible element based on evidence or best practice, must be used with other eligible Tx	Not eligible as insufficient information re best practice and/or evidence	Not eligible as not based on best practice and/or evidence that not effective
	Regular IEPs, IFSPs, regular therapy sessions and consultations)						
Family based including parent training	Hanen 'More than Words'		EE				
	Hanen 'It takes two to talk'					NEI	
	Pre-schoolers with Autism		EE				
	Triple P – Stepping Stones adaptation		EE				
	Other parent training programs Any training provided for parents under by approved service providers must adhere to the key elements of effective early intervention: Autism specific curriculum, addressing the core features of ASDs and/or associated features Functional approach to challenging behaviours			BP			

Type of Intervention	Named interventions within that type of intervention	Established/ Eligible based on evidence	Eligible based on emerging research	Eligible based on best practice approach. Evidence awaited.	Eligible element based on evidence or best practice, must be used with other eligible Tx	Not eligible as insufficient information re best practice and/or evidence	Not eligible as not based on best practice and/or evidence that not effective
	Predictability and routine Visual supports Multidisciplinary team involvement wherever appropriate						
Therapy based	Provision of SGD and other Augmentative & Alternative Communication (AAC)		EE				
	PECS		EE				
	Signing/other AAC		EE				
	Alert Program for self-regulation			BP			
	Social Stories				SE		
	Pragmatic Language Groups / Pragmatics for Prep				SE		

Type of Intervention	Named interventions within that type of intervention	Established/ Eligible based on evidence	Eligible based on emerging research	Eligible based on best practice approach. Evidence awaited.	Eligible element based on evidence or best practice, must be used with other eligible Tx	Not eligible as insufficient information re best practice and/or evidence	Not eligible as not based on best practice and/or evidence that not effective
	Aquatic OT 10 Week Program				SE		
	Aquatic OT School Holiday Intensive Program				SE		
	Cognitive Behaviour Therapy					NEI	
	Phonological Awareness/Literacy groups					NEI	
	Sensory Integration Therapy					NEI	
	Sensory diet					NEI	
	Auditory Integration Therapy						NEE
	Fast ForWord Program						NEE
	PROMPT (PROMPTs for Restructuring Oral Muscular Phonetic Targets)					NEI	
	Multi-sensory Environment (Snoezelen room)						NEE

Type of Intervention	Named interventions within that type of intervention	Established/ Eligible based on evidence	Eligible based on emerging research	Eligible based on best practice approach. Evidence awaited.	Eligible element based on evidence or best practice, must be used with other eligible Tx	Not eligible as insufficient information re best practice and/or evidence	Not eligible as not based on best practice and/or evidence that not effective
Single element components addressing one aspect of ASDs	Sleepwise©: Positive Sleeping Practices for Young Children with Developmental Delay				SE		
	PALS Social Skills Program (Playing and Learning to Socialise)				SE		
	Toilet Time©: Toilet Training for Young Children with Developmental Delay				SE		
	Music therapy				SE		
	SoSAFE!					NEI	
	'Social Eyes'					NEI	
Not specific to autism	'Super-nanny' - whole family support provided by a mental health nurse in the home using a DSP approach					NEI	

Type of Intervention	Named interventions within that type of intervention	Established/ Eligible based on evidence	Eligible based on emerging research	Eligible based on best practice approach. Evidence awaited.	Eligible element based on evidence or best practice, must be used with other eligible Tx	Not eligible as insufficient information re best practice and/or evidence	Not eligible as not based on best practice and/or evidence that not effective
Services identified as requiring more specific information via details given to FaHCSIA. These could not be provided with a rating.	Narrative therapy					NEI	
	Circles of support (inclusion program encourage other children to help the child participate in activities)				SE		
	Next Step program						
	Sensory and perceptual motor therapy						
	Jump Start						
	'I can do it'						
	Busy Hands group						
	Solution focussed brief therapy						
	AUSPsych						
	'Communication Sensation'						

Type of Intervention	Named interventions within that type of intervention	Established/ Eligible based on evidence	Eligible based on emerging research	Eligible based on best practice approach. Evidence awaited.	Eligible element based on evidence or best practice, must be used with other eligible Tx	Not eligible as insufficient information re best practice and/or evidence	Not eligible as not based on best practice and/or evidence that not effective
	Discover and Learn						
	Travelling teacher' – intensive live in (5 days)						
	Equipment Purchase						
Teacher/ centre support	Teacher training					NEI	
	Collaborative planning services Consideration should be given to funding services that allow for collaborative planning (e.g. IEP meetings) and individual visits to children's everyday settings (such as preschools and childcare) to facilitate generalisation of skills, appropriate behaviour support, use of visual supports and transition, as per the established principles of good practice.			BP			
	Transition visits			BP			

Type of Intervention	Named interventions within that type of intervention	Established/ Eligible based on evidence	Eligible based on emerging research	Eligible based on best practice approach. Evidence awaited.	Eligible element based on evidence or best practice, must be used with other eligible Tx	Not eligible as insufficient information re best practice and/or evidence	Not eligible as not based on best practice and/or evidence that not effective
Other	Physiotherapy / motor skills (with exceptions made for children with Rett's Syndrome)					NEI	

2.9 Summary

Evidence from high quality trials that is consistent across studies is lacking. There are also few studies with enough power to show whether real improvements have been made as a result of the interventions studied. Further, limited studies exist that have well documented information about potential adverse outcomes, and there are few studies that rigorously assess cost benefit of treatments. There are limited data about the effectiveness of interventions that have been shown to be effective in small trials, when implemented in service settings, where ensuring treatment fidelity and compliance are more problematic.

Nonetheless, high intensity interventions which address the child and family's needs using a behavioural, educational and/or developmental approach have been shown to be the best of currently available early interventions. In addition a few interventions have now been proven to be ineffective.

The summary of recommendations provided in Table 6 incorporates the findings of reviews, evidence syntheses and an update of evidence as available by May 2011. It pertains to interventions that we recommend be considered eligible or ineligible for HCWA Early Intervention funding, based on what we know today. As more is learnt about autism, new evidence is published, and best practice models are evaluated, it is likely that listed interventions will have their eligibility modified (either up or down graded), and that new interventions will emerge. It is therefore recommended that ongoing literature monitoring and reviews are conducted.

Part 3 – Stakeholder Surveys

3.1 Background and Methodology

After discussions with FaHCSIA, the project team undertook two surveys and one consultation to gather information about views of professionals involved with the HCWA Package. The surveys were sent to:

- key autism peak bodies and professional groups whose constituents are service providers for the HCWA Package
- Autism Advisors.

The consultation was with the Parenting Research Centre (PRC) who developed the Raising Children's Network website. Extensive surveys with parents were beyond the scope of this evaluation. The importance of gaining parents' views is acknowledged and recommended for further evaluation studies.

3.1.1 Peak Bodies Survey

Peak Bodies representing members/professionals who are registered as Autism Panel Providers (professionals approved by FaHCSIA to provide eligible interventions) for the HCWA Package; or practitioners who refer families to such providers, were invited to provide written submissions based on a series of questions developed by the treatment review project team. The organisations/peak bodies were requested to seek the views of their membership in order to provide a representative submission to the project team. In consultation with FaHCSIA, the following peak bodies were contacted: Occupational Therapy Australia, Speech Pathology Australia, the Australian Psychological Society, The Royal Australian College of Physicians Division of Paediatrics and Child Health, the Royal Australian and New Zealand College of Psychiatrists, and the Autism Advisory Board. (See letter to peak bodies in Appendix G.)

Survey Instrument and Procedure

The project team, in consultation with FaHCSIA, developed a list of open-ended questions of relevance to these peak bodies. The Survey was developed to enable peak organisations to comment on a number of key issues designed to help improve the current service provision and funding package for young children with autism.

Organisations were asked to comment on the current administration of the Early Intervention (EI) Provider Panel component of the HCWA Package, specifically in relation to the approval process of panel providers, the approval process of specific interventions, and the interaction between panel providers and FaHCSIA.

Organisations were invited to comment on the adequacy of the EI services of the HCWA Package, including the amount of funding available per family, the breadth of intervention currently available, and the overall quality of the service.

Organisations were also invited to comment on currently approved interventions and their views about any additional services that should be funded.

Questions were asked about issues raised by parents including their access to services, possible improvements in implementation, their satisfaction, and suggestions on how to improve the *EI Operational Guidelines*.

A pilot version of the survey questions was sent to three autism panel providers, one each from occupational therapy, speech pathology and psychology for comment. Minor modifications to the questions were made in response to feedback from these panel providers. As the letter of invitation for submissions was sent to the Chief Executive Officer or Chair of these organisations, the project team left it up to this person to email their membership and seek comments/suggestions. These were compiled by the peak body or organisation and a summary of comments was forwarded by way of a written submission to the project team. Hence it is not possible to determine how many individual professionals were consulted.

Submissions were received from five of the six organisations contacted, namely the Australian Advisory Board, Speech Pathology Australia, Australian Psychological Society, Occupational Therapy Australia Limited, and the Royal Australasian College of Physicians Division of Paediatrics and Child Health. In addition unsolicited submissions were received from Services for Rural and Remote Allied Health (SARRAH), A4, and an individual professional. The latter was sent to the appropriate peak body for inclusion in its response.

Analysis

All written responses to the open-ended questions were read by two members of the project team and summarised. Subsequently key points were distilled in relation to each question asked. There was strong agreement between project team members and across peak bodies in relation to the key points raised. A final overarching summary of themes was consensually developed and is presented here.

Results

The key recommendations from the 5 Peak Body organisations, to each of the survey questions, is summarised below. After analysing the completed surveys, it was clear that there was a general consensus among the organisations as to their major concerns and also their recommendations to improve service delivery.

Q.1 (a): Views of the administration of the HCWA Package in relation to approval of panel providers

The general consensus among the 5 organisations indicated a definite preference for all approved services to provide a multi-disciplinary approach to intervention. All approved providers should be monitored and have guidelines in place ensuring multidisciplinary collaborative practice. The present lack of experience and expertise in autism among some service providers needs to be addressed. Approved services should have a strong commitment to providing evidence-based interventions.

Q.1 (b): Views on the administration of the HCWA Package in relation to approval of specific types of intervention

It was agreed that there is a need for clear procedures for the assessment and ongoing evaluation of panel providers. It was recommended that independent consultants with expertise and experience in autism should work/collaborate with FaHCSIA. Organisations surveyed also agreed on the need for clear standards to ensure quality and consistency of

service providers, and that approval should only be given to services providing evidence-based interventions. Eligible services should also have a focus on providing collaborative planning between families and multi-disciplinary team members.

Q.1 (c): Views on the administration of the HCWA Package in relation to panel providers' interaction with FaHCSIA

Revision of the current fee structure was suggested, including of the fees charged by providers for intervention. Organisations surveyed indicated that the current fee schedule template could be made easier to work with. Also, changes to Guidelines need to be well disseminated to either providers or parents. A quality assurance framework is required.

Q.2 (a): Adequacy of service provision of HCWA funded services in terms of amount allocated per family

An optimal aim among the organisations surveyed is consistency of service provision across all geographical areas. It is proposed that funding be indexed annually to reflect increases in the cost of most services. Public funding levels are not sufficient to fully cover intensive intervention. Organisations recommended guidance for families to assist them to best utilise their funding allocations.

Q.2 (b): Adequacy of service provision of HCWA funded services in terms of breadth of intervention provided

There is a limited range of services in some rural and remote areas. The approval in rural and regional areas of some sole providers who lack multidisciplinary team input has negatively impacted on the plan for a multi-disciplinary intervention focus among providers. According to some organisations surveyed, there are often delays in the availability of certain interventions in some areas. One concern expressed was the conflict of interest where Autism Advisors are also service providers. There is not additional funding available for assistance for Indigenous families, non-English speaking families or other families who may have additional needs.

Q. 2 (c): Adequacy of service provision of HCWA funded services in terms of quality of advice to parents from autism advisors

It has been suggested that the role of Autism Advisors be expanded to include brokerage advice and support for families. However Advisors must have enhanced knowledge, experience and expertise to ensure consistency of information to families. Conflict of interest issues arise when Advisors are also service providers.

Q.2 (d): Adequacy of service provision of HCWA funded services in terms of time frame for service provision

The present cut-off date for EI funding (7 years) means children who are not diagnosed until older ages are ineligible for this funding. It was suggested that funding be provided for two years following diagnosis, for children who are diagnosed at older ages. There is a lack of awareness of the funding package among some parents and the package needs to be more widely publicised.

Q.3: Specific concerns about currently funded interventions

Of major interest to all organisations surveyed, was a desire for increased supervision, ongoing monitoring and evaluation of approved service providers. All approved service providers must be accountable and transparent in the selection and delivery of services.

Some service providers are believed to lack specific autism expertise and experience and this needs to be addressed. In addition, all funded services should be evidence-based and provide consistency and transparency in fee structures and fee collection across services.

Q.4: Interventions that you consider should be funded that currently are not

Services that are funded should be evidence-based. There were suggestions by some respondents for physiotherapy and music therapy to be included as approved services if they form part of a multi-disciplinary approach. Further, consideration should be given to providing more funding for families living a long distance from services.

Q.5: Currently funded interventions that should no longer be funded

There was consensus across all organisations that funding should only be provided for services that are evidence-based, goal-directed and collaborate with families in determining priorities and goals. Therefore FaHCSIA needs to establish best practice guidelines and audit services, as well as introducing a process to remove non-conforming services.

Q.6: Parents' issues in accessing HCWA funded early intervention services

There are a number of issues raised with organisations by parents in accessing the early intervention services. These issues included the difficulties for some families to access appropriate services and the travel costs imposed on families to access service, especially in rural and remote areas. There are long waiting lists and limited services in rural and remote regions, which leads to lack of choice and higher fees. The cost of certain therapies is prohibitive to many families. Parents want greater access to experienced, knowledgeable service providers.

Q.7: Suggestions for improvements in implementation of the HCWA package

There was consensus on the need for clear communication between FaHCSIA, advisors, service providers and families, especially around any changes to guidelines. Parents also recommended a stronger complaints process and more accountability for service providers. Parents would like clearer funding guidelines, with some changes to funding process recommended, and extension of funding to include children diagnosed later and those with other disabilities. Organisations surveyed recommended an updated website and a way of centralising records for better access for families and service providers. Mechanisms for ensuring accountability of service providers were also recommended.

Q.8: Parents' satisfaction with the current eligible interventions available through the HCWA as reported to survey groups

While most parents were satisfied to some extent with the current approved services, they also suggested changes to guidelines and extra funding for rural and remote families. Families and advisors want to be kept informed about the range of services available through the HCWA funding to assist them to make informed choices. More services in rural and remote areas are wanted to meet demand.

Q.9: Suggested improvements to the early intervention operational guidelines

According to the surveys, the current Guidelines are beneficial and should be updated regularly. The guidelines should provide clarity around development of service plans and guidelines around purchase of resources and information about alternative models for EI services. It has been suggested that the role of advisors be expanded to provide brokering support to families. The information on the FaHCSIA website should be regularly updated.

Overall Summary of Findings

After summarising the input from the Peak Bodies, a number of recommendations were found to be common among the organisations. There was general agreement across all organisations on a number of key points. There was general consensus that all potential panel providers must meet certain standards and requirements in order to meet the eligibility criteria. These requirements included:

- a multi-disciplinary approach to service provision, with a focus on collaboration with families
- a system of ongoing monitoring and evaluation of service providers and services,
- a commitment to providing evidence-based interventions,
- a commitment to employing staff members with at least 2 years' experience and expertise in autism, and to providing ongoing training about autism to panel providers and Autism Advisors.

Another key issue raised by all Peak Bodies was the need to develop the current procedures for the assessment and ongoing evaluation of eligible panel providers. This is an essential requirement in order to ensure the quality and consistency of service provision. There was consensus that any evaluation and monitoring process would be most effective if undertaken by independent consultants, with experience and expertise in autism.

Peak Bodies wish to have consistency of service provision for families across different geographical areas, especially early intervention services in particular rural and remote areas. Families who have to travel long distances to access services, often incur additional costs. The current fee structure was widely discussed, with suggestions for improved consistency in fees and more funding for very intensive intervention. It was proposed that the cut-off age of 7 years for funding be increased to include older children who have not been diagnosed early enough to access the early intervention funding packages.

There was also discussion about the role of Autism Advisors. It was felt that the role could be expanded to include more of a brokering role, enabling advisors to offer guidance to families and to offer family support. There was also concern that some Autism Advisors were also service providers, presenting a conflict in interest and therefore potential inability to offer unbiased advice or information to families. It was felt among the Peak Bodies that the current Guidelines were clear but should be regularly updated.

3.1.2 Consultation with the Raising Children's Network (Autism)

Discussions were held with Mr Derek McCormack, Manager, Science Communication Content Manager, Raising Children Network (RCN) about the role and function of the PRC Raising Children Network (Autism) Internet based services for families of children with ASD in relation to Early Intervention Therapies. The RCN provides a suite of resources on the internet to inform families and professionals about autism, and to offer education and guidance on a range of aspects of ASD. The four main entry points to further information on the website are: (1) Learning about autism, (2) Guide to therapies, (3) Service pathfinder and (4) Parent forum. McCormack reports that there have been more than 156,000 visits to the website in total since launching in 2009, with an average of 200 visits per day. The two resources of particular relevance for the current review are:

- Reviews of treatment and interventions which are posted on the Guide to Therapies Site:
http://raisingchildren.net.au/parents_guide_to_therapies/parents_guide_to_therapies.html
- The online Parent Discussion Forum which is the most popular parent forum in the RCN suite:
<http://raisingchildren.net.au/forum/Forum133-1.aspx>

Reviews of Treatment and Interventions

The RCN autism website is now in its third year of operation. It is one component of the HCWA package which focuses on internet delivery of information to families and provides sections as noted above which include a guide to therapies and interventions for autism. This component sets out the features of each of a wide range of interventions. It incorporates a research rating scale of the status of each one, which is based on the scientific evidence for its effectiveness using accepted rating scales for quality of research evidence from the literature. Each entry concludes with a list of references and web-based information possibilities for readers to follow up to access further information if they wish. This site is kept current with updates of the latest research every 6 months.

The RCN has a team of science communication experts (writers and editors) working with partner experts on this site to identify and review current evidence and to translate and present the findings in easily consumable language for families. This team is very focused on the rigour of the evidence they provide but also emphasizes the need for family context and treatments to fit closely together in making treatment decisions. For the selection of interventions to be researched and reported on the site, the RCN relies on information from a variety of sources to identify proposed treatments requiring review. These sources include conference attendance, media stories about ASD, parent feedback on what is circulating 'out there', what is being talked about in communities, and watching and listening in order to tune in to what is attracting attention in the autism field. On this site, an email address is provided for families to contact the RCN if they wish.

Feedback to RCN on the site is not substantial (but see below for a recent survey in progress to seek feedback), and mostly comes in the form of parents reporting their own family stories. Feedback from professionals working in the field has also been limited but the site is well known and some professionals at least, check the material presented in the intervention reviews to assess its fit with their practice. Some autism bodies (e.g. Autism Victoria) have reported to the RCN staff how valuable this site is for them.

In answer to the question of how the adequacy of current provision of funded interventions is viewed, McCormack noted that it is hard to answer this question because there is insufficient knowledge in the community on what is being funded, and what might be on a list of approved interventions. In some cases Autism Advisors do not have this knowledge either. He also noted that the same comments apply to attempts by the RCN team to access state based information on providers of assessment and diagnosis. The RCN has begun to build a list of providers but is finding it difficult to get information about who is available for this work. McCormack commented that parents have been requesting more technology to support interventions for their children.

It is important to explore and review technological developments which could enhance learning and social networking for children with autism (e.g. use of iPads), although this area will probably address an older age group than that covered by the Early Intervention package.

Autism Online Discussion Forum

This is an online space for peer support, where parents share ideas and stories about their experiences. So far, this forum has seen more than 4,000 new conversations begun by parents, drawing over 28,000 replies and comments from others. The popularity of this forum has led the team to expand it, and to break it into a few 'sub-forums' on request from dedicated forum users. See the online forums here:

<http://raisingchildren.net.au/forum/Forum133-1.aspx>

This is the most popular RCN internet resource and attracts a great deal of discussion. McCormack described it as 'a great case study on the need for peer support' in the ASD field. It incorporates topics for discussion suggested by and engaged in by parents. One example cited was 'how to deal with birthday events'. The high level of good positive support given by parents to other parents in this forum is notable. The RCN team also provides suggestions on topics for discussion. A three person RCN staff team moderates this forum and reads every post. They contact users only if the terms of use have been breached or scanning of a post indicates that there may be a major problem for a particular respondent which indicates that they might need help or advice. If it is considered that help is needed for a particular case, they consult with experts to garner ideas and strategies to underpin feedback to that correspondent. A website evaluation survey was recently launched to ask parents about how they feel about RCN information and whether they feel further support is needed.

<http://raisingchildren.net.au/survey/TakeSurvey.asp?SurveyID=30K493216891G>

It will be useful to follow up on this initiative for further feedback.

Further comments and discussion with McCormack revealed that there may be a need for more clarity around what the HCWA Package offers. Choices are difficult if consumers do not know what is available. For some families the paperwork and personal research required to make use of the resources and available funding may be a barrier. Parents often need a dedicated advisor or mentor to help them through this process. While this role may be filled by an Autism Advisor, advisors themselves are not always clear and fully informed about resources and availability.

3.1.3 Survey of Autism Advisors

Background

In order to obtain the views of Autism Advisors about the HCWA package and their experiences with providing advice to parents, a purpose-designed electronic survey was developed specifically for Autism Advisors.

Survey Instrument

The survey was developed by the project team to focus on the key questions asked of the peak bodies and to obtain more specific information on the experiences of Autism Advisors who have regular contact with parents of newly diagnosed children who are accessing the HCWA funding. The first section of the survey obtained demographic information from the

advisors regarding their location, length of time as an advisor, professional background, specific training and affiliations. Closed questions with fixed responses were used in this section.

The second section elicited information about their roles and experiences as Autism Advisors. Specifically, information was sought about the time spent with parents, adequacy of their preparation for the role, adequacy of the HCWA funding, knowledge of evidence behind the interventions provided, concerns about any current eligible interventions, need for other interventions currently not funded, issues experienced by parents in accessing services, and operationalisation of the package, funding, and criteria for service eligibility. Both closed questions with fixed responses and open ended questions were used in this section.

In the final section Advisors were asked their perspectives about parents' needs, and about satisfaction with panel providers, and about parents' informational needs and concerns. Both closed and open ended questions were utilised. See Appendix H for copy of the survey. The survey was piloted with several Advisors prior to finalisation and deployment.

Procedure and Analysis

A link to the survey was emailed to the people on the list supplied to the project team of Autism Advisors across all states/territories in Australia, and to the state autism associations, who were asked to forward this to their advisors. This dual pronged approach aimed to capture as many advisors as possible. While it is not clear how many people received the survey, we understand there are 58 Autism Advisors across the country. Advisors were asked to follow a link to the electronic survey using the Zoomerang electronic survey software www.zoomerang.com. Advisors were asked to complete the survey within two weeks. A follow up email was sent two weeks later to encourage further completion. There were 53 visits to the site while the survey was open. In total, responses were received from 29 Advisors, revealing a 50% response rate. Data collected from these surveys were anonymous. Descriptive statistics (frequencies and percentages) only were used to summarise the data. Open-ended questions were analysed using content analysis after two researchers read and summarised key findings and identified emergent themes.

Results

Of the 29 responses to the survey received from Advisors across all 8 States and Territories, the majority of responses were from New South Wales (25%) and Victoria (25%), with 14% each from South Australia and Western Australia, and 7% each from Queensland and ACT. We acknowledge that a 50% response rate to the survey is less than optimal and that this may limit the reliability of the results.

Demographics

In the first section of the Survey, Autism Advisors provided information about their experience and expertise in autism. According to the completed surveys, the majority of Advisors come from backgrounds such as teaching and psychology, occupational therapy and early childhood education. However, 46% of the Advisors come from other training backgrounds including counselling, social science, disability studies, speech pathology, human geography and community development, family support, communications, art therapy, information management and a parent. See Table 7.

Table 7: Professional backgrounds of Autism Advisors survey respondents

Professional Background	Number	Percentage
Teaching	9	32
Early childhood	2	7
Occupational therapy	1	4
Speech pathology	0	0
Psychology	8	29
Social work	0	0
Other	13	46

NB: some respondents indicated they had more than one profession

Autism Advisors were also asked to provide information about their experience and expertise in the field of autism. One of the major concerns about the eligibility criteria for Autism Advisors was the perceived limited expertise and experience of many of the staff members employed by panel providers. According to the survey results, over 50% of the Advisors surveyed had more than 2 years' experience as an Autism Advisor and over 90% had been working in the field of autism for more than 2 years. This implies that the majority of the professionals who completed the survey have at least a basic understanding and knowledge of the disorder. Almost all of the Advisors surveyed have been involved in professional development activities related to autism, including specific workshops, seminars and conference and were affiliated with state-based autism organisations. The majority of Advisors felt very well prepared (64%) or prepared (36%) for their role as Autism Advisors.

Service Provision

The majority of Advisors (54%) felt that the needs of the children with autism were being well or very well met by the current funding packages, while 43% felt the HCWA package was only adequate in meeting parents' needs. They felt that urban families have access to a range of services and their needs are generally well met. However the needs of some rural and remote families were perceived to be inadequately met. They reported that for these families there is a lack of services, limited choices for service and long waiting lists. Advisors felt that additional funding needed to be allocated to provide home visits, workshops or group work, information and training for parents, as well as respite and crisis support.

Many Advisors felt that children diagnosed at a later age are disadvantaged and their needs are not being adequately met. There is concern about the length of time taken for parents to obtain a diagnosis because waiting lists for paediatricians are too long and GPs need more training to recognise symptoms. The quality of some services offered to families was considered inadequate, especially some questionable treatments, poorly trained and inexperienced panel providers, with some families being described as being 'ripped off'. One of the major concerns about the eligibility criteria for Autism Advisors was the perceived limited expertise and experience of many of the staff members employed by panel providers. More rigorous standards for eligibility of panel providers were suggested, especially in terms of their staff qualifications and experience and closer monitoring of services once they are approved, to ensure consistent quality of intervention.

Advisors were asked to comment on whether current eligible interventions reflect evidence-based intervention practices in early intervention for children with autism. Most Advisors felt that the majority of current eligible interventions reflected current guidelines for evidence-based intervention adequately or well. However, only one Advisor felt that current services reflected these guidelines very well. Perhaps more effort needs to be made to address this issue. See Table 8.

Table 8: Effectiveness of eligible interventions in reflecting current best evidence on outcomes of early intervention for children with ASD

Evidence-based intervention	Number	Percentage
Very well evidenced	1	4
Well evidenced	16	57
Adequately evidenced	10	36
Inadequate evidence	1	4
Very lacking in evidence	0	0

Advisors were also asked to comment on whether parents were kept informed about the level of evidence for eligible interventions. Advisors overall felt that parents are sufficiently provided with information about the level of evidence-base for eligible services. However, the amount of information provided is often dictated by the level of parent interest, and dependent on the questions parents ask. They also considered that it was the responsibility of service providers (i.e. Panel Providers) to advise parents on this matter, rather than this being something that Autism Advisors necessarily provided.

Over 50% of advisors indicated specific concerns over some of the currently eligible services, especially the way in which some services provide intervention that was not in accordance with their original agreement with FaHCSIA. According to one advisor, some services ‘lure’ families with eligible services and then market non-eligible interventions. Advisors would like to see stricter reviews and guidelines with service providers having to meet certain standards, qualifications, and to demonstrate evidence behind their practices. This is in line with a request from peak bodies.

Advisors were invited to suggest additional interventions they believe should be considered by FaHCSIA for eligibility for funding. The most commonly requested additional services were physiotherapy and music therapy, especially if presented as part of a multi-disciplinary program. In terms of programs that should no longer be funded, advisors felt the need for all services provided by panel providers to be closely monitored to ensure that they meet current research standards in providing evidence-based intervention.

Autism Advisors were asked to comment on possible issues that made it difficult for parents to access eligible services. The major concerns included locality of services and the distance parents sometimes have to travel to access these, the availability of trained and experienced professionals and the waiting lists attached to some services. In addition, advisors indicated

that language barriers, lack of appropriate case management, social issues and poor time management also impacted on how parents are able to access appropriate services. See Table 9.

Table 9: Issues that impede access to eligible services

Issues	Number	Percentage
Locality/distance	27	96
Cost	20	71
Waiting lists	25	89
Availability of providers	26	93
Lack of adequate resources	5	18
Family finances	17	61
Other	5	18

NB some respondents indicated they had more than one issue impeding access.

There was general consensus among the Autism Advisors that families should be able to access a range of service options and that the current list of interventions is adequate for most families and adheres to the necessary criteria outlined by FaHCSIA. The criteria outlined by FaHCSIA suggest that eligible services should be well structured, organised, regular and predictable and focused on specific objectives. Services should have an ASD specific content and focus and be well managed and focus on children’s attention, compliance, imitation, language and social skills and provide a supportive teaching environment to maximise early learning. Over 70% of advisors felt that the majority of eligible services adhere to these criteria well or very well. More than 70% felt that the eligible services provided ASD specific content and focus, 64% felt that eligible services provided appropriate functional approaches to problem behaviour, and attention to communication skills and collaborative planning with families.

Parent Needs

According to the Autism Advisors survey, the majority (96%) of parents make contact with Autism Advisors within two months of diagnosis. Once referred, families have a range of needs to be addressed. All families require information about services within their local areas, with most families also wanting information about how to choose the most appropriate services, cost of services, general information on autism and how to access government services. In addition, under the ‘other’ category some families wanted access to resources, such as information on financial support, preschools, respite, and information about how to access grief counselling. See Table 10.

Table 10: Parent needs from the Autism Advisors on initial contact

Parent Needs	Number	Percentage
Emotional support	22	79
Information about ASD	23	82
Information about government support	22	79
Information about parent support groups	15	54
Just need to chat	22	79
Information about accessing right services	24	86
Information about services available	28	100
Other	7	25

In addition, Advisors reported that parents' information needs reflected need for knowledge about services in their locality (93%); which intervention is right for their child (86%); cost of services (56%); local autism associations/support groups (52%); other parents' experiences with services (52%); websites (48%) and evidence base of interventions (30%).

The majority of Autism Advisors (85%) felt that parents are typically able to find the services they want in their local area and that parents are 'somewhat satisfied' (70%) with the list of eligible interventions currently available. Most parents are very satisfied with speech therapy services, occupational therapy, home-based interventions and services offering a multidisciplinary approach. Families are most satisfied when they feel that they are getting value for money and are supported by therapists who have their child's interest at heart.

However, rural families reported problems accessing services, a lack of choice and long waitlists, having to travel long distances to find appropriate interventions. Some parents are frustrated that their preferred therapists are not recognised as eligible service providers and so they are unable to spend their HCWA funding on these services. Some families have expressed dissatisfaction with the cost of the services charged to clients with funding packages.

Advisors felt that parents' needs post diagnosis were being met adequately (67%) or very adequately (19%) by the HWCA eligible interventions. A number of possible improvements to the Early Intervention Operational Guidelines were suggested by autism advisors, in consultation with parents. These included:

- a focus on collaboration between all service providers and parents to ensure each child maximises potential,
- improved complaints process,
- regular update of all information in Guidelines
- all documentation to be simplified and less ambiguous
- monitoring the costs of funded services
- clarification of relationship between providers and individual members of consortiums who work together to provide a multi-disciplinary approach to intervention for some families.

Overall, Advisors felt that interventions currently funded and the whole funding process met the needs of children with ASD and that families are generally satisfied with services provided. Most dissatisfaction stems, and problems arise, from service providers who do not provide the quality of intervention they claim, or who do not adhere to the current guidelines for service provision. Advisors felt strongly that there should be stronger ongoing monitoring or auditing of all panel providers to ensure quality service provision according to the guidelines.

While there was considerable agreement between feedback from Peak Bodies and Autism Advisors on a number of matters, there was a mismatch in the perception by Autism Advisors that the interventions available to parents were evidence based, and the feedback from Peak Bodies many of whom were concerned at the lack of evidence base in many of the interventions being provided by Provider Panels. This suggests a poor awareness among Autism Advisors about the research evidence underpinning many of the programs provided by panel members.

Part 4 – Issues raised by FaHCSIA for consideration during the development of the review

As this review was being developed, FaHCSIA raised several specific issues that were relevance to the review. These are outlined below.

Use of funds for diagnosis

Diagnostic assessment is not the same as assessment for program development and is therefore not to be funded as part of this package (see page 5). Intervention programs are to be developed on the basis of already completed diagnostic assessments.

One to one versus group interventions

Small group interventions may be effective; however staff:child ratios should not exceed 2:6 and each child must have an Individual Plan (IP). Generally group session fees would be expected to be less than 1:1 session fees.

Individual plans, assessment, goal setting, evaluation and review

Individual plans are fundamental to effective intervention. See Appendix C for a resource that may be useful for planning (Planning Matrix). Services should be able to specify the process they have in place for individual collaborative planning and review.

Interventions targeting one domain only, versus comprehensive interventions

Services should make clear to families whether an intervention is specific to one domain of children's functioning (e.g. communication or play), or is more comprehensive.

Comprehensive or domain specific inputs may both be appropriate, provided the family is making an informed choice.

Generic early intervention versus autism specific INTERVENTION (a)

It cannot be assumed that generic early intervention will meet principles for good practice in autism unless evidence for efficacy for ASD has been demonstrated. Unless research indicates that a generic intervention has been shown to be effective for autism it should not be considered an appropriate intervention for a child with ASD. FaHCSIA may wish to consider exceptions in particular circumstances, (e.g. isolated families where no ASD specific intervention is available).

Generic allied health versus autism intervention (b)

It is important to note that training in speech pathology, psychology or occupational therapy per se does not in and of itself ensure therapists have expertise required to work with children with autism. In addition, these services when provided by sole providers (rather than as part of a consortium or multidisciplinary team providing EI) are unlikely to meet guidelines for good practice. Individual allied health services may more appropriately be funded through Medicare. Practitioners need to provide evidence of continuing professional development in autism, or experience gained through previous work settings that enables them to provide evidence-based EI interventions for children with ASD.

Part 5 – Conclusions and Recommendations

On the basis of the evidence review (Part 2), and the input from Stakeholders (Part 3), and incorporating discussions with staff from FaHCSIA (Part 4) we have developed a set of recommendations in relation to:

- improved communication and information sharing between all components and personnel involved in the HCWA Package
- decisions about eligible and ineligible treatments (Table 6)
- processes for regularly updating the evidence base
- operationalisation of principles of good practice
- revisions pertaining to evaluating and managing provider applications in a revised process for the future
- need for monitoring and follow up of services
- need for innovations or changes to address identified problems.

As we present these recommendations in this section, we note supporting data and the sources of these data, as derived from the review, and which underpin the rationale for the suggestions

1. Improved communication and information sharing between all components and personnel involved in the HCWA Package

Stakeholder feedback clearly indicated the need for improved communication and information sharing regarding the HCWA Package and the Early Intervention funding in particular.

Recommendations and suggestions arising from this feedback include the following:

- Regular updating of the guidelines and the FaHCSIA website
- Improved clarity regarding the development of service plans, purchasing resources and other issues
- Improved communication between all stakeholders, particularly regarding guideline changes
- Continued dissemination of information regarding all aspects of the Package, including access to information and services to assist decision making.

2. Eligible and ineligible treatments

Clarity about approved interventions

Table 6 in Part 2 informs stakeholders of eligible and ineligible interventions.

The decisions in this table take into account requests from stakeholders for approval of funding only for services that are evidence-based, goal-directed, and collaborative with families.

It is recommended that FAHCSIA circulates a list of approved interventions meeting criteria, and posts this on the internet in the interests of clearer and more universal communication to all stakeholders. Similarly, a brief outline of review methods and findings of the current review should also be on the internet site in plain language, with hard copy available on request.

The table indicates that flexibility is needed as very few of the recommended treatments have a strong evidence base and hence their eligibility rating may change as further evidence becomes available. Recommendations for processes to ensure this occurs are described in the following points.

Relevant criteria for evidence-based interventions and for good practice guidelines need to be made specific within the application process. (See operationalisation of good practice guidelines Appendix F, and recommendations for revision of panel provider application format below 6b).

3. Processes for regularly updating information about evidence of effectiveness and best practice

Evidence and information that allows assessment of best practice will continue to emerge over time. Thus, regular updating of the eligibility list of treatments will be required. We note that from 1995 there have been marked increases in publication about treatments for autism. Using the sensitive (broad) clinical queries treatment filter in PubMed we found that between 1995–2004 on average, 100 papers were published each year, while in 2010 over 280 were published. PubMed would not include many psychological and educational treatment publications that are relevant to autism, but we use this information to illustrate the growth rate of literature in this area and the need for strategies to keep abreast with emerging literature.

Some options for keeping up to date with the emerging literature on early intervention for ASD are:

- Set-up automatic links to data bases (e.g. PsychInfo, PubMed and ERIC) to trigger notification of new/current autism intervention related publications.
- Engage a research officer to review intervention studies retrieved and rate them in accordance with the evidence and good practice rating mechanisms established in this review.
- Engage a panel of experts (from a range of professions) to review the intervention literature and its ratings (as generated in a) and b) above) and review whether this new information changes the eligibility rating as per Table 6.

4. Reinvigoration of operationalisation of principles of good practice

The principles of good practice and the need for eligible services to meet these principles are outlined in Appendix F. In particular, attention is drawn to two principles:

- emphasis on services providing collaborative planning between families and multi-disciplinary teams
- family involvement, which is essential for good practice (see page 15 should be specifically addressed in applications by panel providers.

The initial requirement that providers form a multidisciplinary collaboration, in line with recommended principles of good practice, was relaxed in 2010 because of the difficulty this presented to families in remote/ rural areas of Australia. Feedback suggests this change has not been helpful and re-confirms the importance of a multidisciplinary approach. Therefore we recommend that the requirement for providers to be multidisciplinary be restated with possible exceptions for isolated families in remote rural areas on a case by case basis

Particular questions have been raised concerning physiotherapy, and music therapy. Physiotherapy does not have an evidence base for autism. A special case may be made for individuals with Rett's Disorder requiring physiotherapy. Music Therapy has some evidence to suggest it may be effective as a component of a program only (see page 43). We support the latter only if it is part of an eligible multi-disciplinary EI approach.

5. Employment of panel staff members with at least two years' experience and expertise in autism, along with provision of ongoing training

The lack of experience and expertise among some service providers is a recurrent theme in stakeholder feedback. In line with principles of good practice, staff personnel delivering the programs need to have demonstrated substantial experience and expertise in autism, plus engagement in ongoing training and support/supervision. Changes in staff skill and experience profile subsequent to approval are to be reported on in the revised monitoring and evaluation process.

Employment of non-qualified staff was also noted as a stakeholder concern.

6. Revisions pertaining to evaluating provider applications

6(a) Decision making on provider panel approvals

Submitted applications must conform to published guidelines, and must clearly demonstrate how conformity to guidelines will be shown throughout the intervention, and how this will be monitored.

Criteria need to be clear for panel provider applicants that intervention must have valid scientific evidence (Type 1 and/or Type 2) and must meet principles of good practice indicating that this treatment will make a difference to autism in cognitive, adaptive, social, behavioural, and communicative development etc., as listed in modified current sections in FaHCSIA application document and seen in 5, above, in this section.

Full details of all providers regarding the status, professional experience, and competence in the autism field required. (Note that both the intervention program and the provider(s) have to be scrutinised.)

Full details of the program offered including all personnel, all components of intervention, time frame, setting, fees/charges, multidisciplinary input, and details of adherence to clinical guidelines should be provided.

We recommend that independent senior consultants with expertise and experience in autism should work with FaHCSIA to provide advice on unclear or doubtful applications.

6(b) We recommend changes to the application form as follows:

- Applications to include reference to research evidence, direct evidence of intent to cover measurable outcomes, direct evidence of relevance to ASD and application of principles of good practice in ASD EI.

Revision of criteria relating to the goals of intervention is required. We recommend stating the required goals of “documented gains in development in social, communicative, cognitive, adaptive, play, self-care areas, and in improvement in problem behaviour areas”.

Providers should incorporate information on what measures will be used to demonstrate change within and across those core domains, and how improvement will be measured and quantified for individual children.

6(c) Provision of consistent advice to potential service providers seeking to join the panel:

Consistent responses are important for potential providers seeking information, to draw attention to the methods and rationale leading to approval standards for stakeholders who contact the department.

In problematic or unclear cases, the submission could be referred to experts for advice on treatment effectiveness.

7. Roles of Autism Advisors

An expanded role for Autism Advisors including service brokerage and case management assistance for families was a dominant theme in the feedback data.

This could involve further guidance for some families to help them to complete paperwork and to assist them to best utilise their funding allocations.

8. A system of ongoing monitoring and evaluation of services

Stakeholder feedback has indicated a need for more supervision and ongoing monitoring and evaluation of service providers, suggesting strongly that there need to be processes in place to ensure that services are being delivered as originally proposed.

Many respondents considered that once treatment has been funded, there is not sufficient follow up surveillance to ensure that interventions are proceeding as proposed, that approved provider staff have remained consistently engaged, that the program is multidisciplinary, and that the progress of the children in the domains specified for attention have been assessed to monitor improvements.

We recommend ongoing monitoring and reporting from providers covering the above noted principles, along with submission of regular reports to FaHCSIA. This could be monitored in vivo by a person on the ground, or via a questionnaire, or parent survey focused on the assessment of change in the domains targeted for improved adjustment.

We recommend the monitoring and follow-up of provider programs to ensure fidelity of treatment and to check any changes to staff or programs from the original granting of eligible provider status.

An important component of this recommendation is for clear and consistent fee schedules, e.g. for single versus group interventions, single providers in remote areas, changes in interventions; and particular components of interventions.

9. Innovation or changes to address identified problems

Stakeholder feedback highlights different service experiences across the different geographical areas, especially longer waiting lists, extra travel costs and a lack of appropriate early intervention services, which means families have to accept what is available, including multidisciplinary services and services with higher fees than those in metropolitan areas.

We strongly recommend consideration of the advantages and feasibility of tele-health methods where this could provide a better service to assist families.

10. Other issues raised by stakeholders included:

- **Fees and funding process:** The current fee structure was widely discussed with suggestions for revision including improved consistency in fees and more funding for intensive intervention. The cut-off age for funding at age 7, was considered to disadvantage children who are not diagnosed early enough to access the early intervention funding packages.
- **Funding levels are not high enough to fully cover the intensive intervention programs which are most strongly supported by the evidence.** The level of Government funding available to go towards the costs of intensive interventions needs to be made clear to families and service providers.
- **Conflict of interest:** There was concern that some Autism Advisors were also service providers, presenting a clear conflict of interest and therefore potential inability to offer unbiased advice or information to families. This supports the importance of having clear guidelines about service provision and the need to ensure that all services follow these best-practice guidelines.
- **Delays in availability of some interventions**
- **Some families are disadvantaged including non-English speaking, indigenous families, socio-economically and educationally poorer families.**
- **There may be a need for a process to remove non-conforming services**

Limitations of the review

- The scope of the survey was limited by our brief to primarily survey stakeholders about their experience, together with the processes for determining eligibility or otherwise of early intervention providers in a defined section of the HCWA package.
- Feedback from a representative sample of consumers (parents) or from people with autism was not obtained due to time and resource constraints.
- A significant number of the interventions requiring rating had insufficient research evidence and/or available information to enable us to rate eligibility.

Appendices

- Appendix A: Selected research evidence for treatments of children with ASD**Error! Bookmark not defined.
- Appendix B: Classification system used to group and discuss interventions based on learning**..... Error! Bookmark not defined.
- Appendix C: Planning Matrix**..... Error! Bookmark not defined.
- Appendix D: Research strategy and scientific merit rating scale**Error! Bookmark not defined.
- Appendix E: Scientific merit rating scale and outcome data ...** Error! Bookmark not defined.
- Appendix F: Application of principles of good practice to interventions**Error! Bookmark not defined.
- Appendix G: Copy of peak bodies' letter and submission request**Error! Bookmark not defined.
- Appendix H: Autism Advisor Survey** Error! Bookmark not defined.

Appendix A: Selected research evidence for treatments of children with ASD

M.K. Makrygianni, P. Reed / *Research in Autism Spectrum Disorders* 4 (2010) 577–593-589 Sys Review

Goals:

- Comparing the baseline and follow-up assessment with one another
- Comparing behavioural EIPs with those in any eclectic-control programs (the most commonly employed control condition)
- Identify effectiveness of the EIPs on children’s age, intellectual abilities, language skills, and adaptive behaviour, and of the programs, such as: the intensity and the duration of the program, the staff number and training and the parental training.

Overall outcomes:

1. Behavioural EIPs can improve children’s language comprehension, communication skills, and socialization. Also improve the intellectual abilities of the children.
2. Behavioural programs are effective in improving behavioural EIPs and are much more effective than the eclectic (control) programs in improving the intellectual, language, and adaptive behaviour abilities of children with ASD.
3. Factors that were found to be correlated with the effectiveness of the behavioural programs were the intensity and the duration of the programs, the parental training, as well as the age and the adaptive behaviour abilities of the children at intake.

Inclusion criteria:

1. Only peer-reviewed journals, longitudinal studies (all published between 1984 and 2007). Studies confirmed with funnel plot to not be biased. Search engines not identified
2. Assessed an ABA program or a program based on Young Autism Project or it was a replication of Lovaas study.
3. Diagnosis of autism, ASD, AD, PDD-NOS, PDD.
4. Young children (nursery school, or first classes of primary school)
5. Only quantitative data

<p>Study methodology assessed:</p> <p>Published 11 item scale: randomisation, IO agreement over 0.80, precise description of independent variable (e.g., treatment) and dependent variable, comparison group, fidelity, independent raters, reported effect sizes, participant characteristics, link between research question and data analysis, and appropriate statistical analysis with adequate</p>	<p>Studies > 9 criteria: High quality</p> <p>Studies 6–8 criteria: Low</p>
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power (n > 10)	
Outcomes assessed: <ul style="list-style-type: none"> • Intellectual • Language • Adaptive behaviour abilities (communication, daily living skills, and socialization) • Number of participants, the age of the children at intake. 	Pre-post treatment Effect Sizes in relation to methodological quality: <ul style="list-style-type: none"> • >0.9 (high) for both low and high qual. grps • >0.9 (high) for both low and high qual. grps • 0.4–0.5 (medium) for both low and high qual. grps 38 months (mean), mental age 53 months
Outcomes assessed: <ul style="list-style-type: none"> • Intellectual • Language • Adaptive behaviour abilities (communication, daily living skills, and socialization) • Number of participants, the age of the children at intake 	Behavioural vs. Control group Effect Sizes in relation to methodological quality: <ul style="list-style-type: none"> • 0.4–0.5 (medium) for both high and low qual. grps • Medium for high qual. grp; high for low qual. grp • High for high qual. grp; medium for low qual. grp 38 months (mean), mental age 53 months
<ul style="list-style-type: none"> • Intensity and the duration of the EIP 	<ul style="list-style-type: none"> • 25hrs/week: ES >0.7 (High) for all outcomes; >25hrs/week no further effect • <25hrs/week: ES variable • Intensity not correlated with progress in language ability. Effectiveness of the program varies independently from the programs' duration.
<ul style="list-style-type: none"> • Parent training 	10/20 programs implemented parent training so conclusions could not be drawn
<ul style="list-style-type: none"> • Child's age at intake 	<ul style="list-style-type: none"> • Children <53 months at intake: ES medium • Children >53 months at intake: ES variable Effectiveness of program not dependent on child's age at intake.

<ul style="list-style-type: none"> • Child's developmental ability 	<p>Effectiveness of program not dependent on child's intellectual or language ability. Higher adaptive ability more effective the Behavioural EIP program vs eclectic program</p>
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Peters-Scheffer 2010 A meta-analytic study on the effectiveness of comprehensive ABA-based early intervention programs for children with ASD Research in ASD 5(1): 60-69

Inclusion criteria:

- comprehensive search performed (Medline, PsychInfo, ERIC), manual search of journals and search of bibliographies
- intervention to address all 3 core deficits in autism using ABA
- studies with a pre-test post-test control group only
- ASD (using DSM III, III-R, IV) or AD and PDD-NOS via ICD 10
- children <10 yr at onset
- standardized measures and quantitative outcomes, standardized mean differences compared.
- published in English between 1980–2009.

11 studies included; one RCT; rest non-randomised with rep-test post-test control grp.

Two independent reviews selecting studies (IOA 100%).

Study quality (Downs and Black checklist, 1998), independent reviewers. Mean quality score 24.65/32 (sd= 1.29; range 23-27).

Overall Outcome:

EIBI group out performed control group on all dependent variables. Full scale on non-verbal IQ improved in EIBI grp 11.98 and 11.09 points more than control groups, respectively. In receptive and expressive language average increases were 1394 and 15.21 points more, respectively. EIBI surpassed control group on composite adaptive behaviour, comm., daily living skills and socialization subscales by 5.92, 10.44, 5.48, 4.96 points more, respectively. Effect sizes (ES) were medium for adaptive behaviour: daily living subscale (0.68) and high for IQ (2) , non-verbal IQ (0.98), adaptive behaviour (0.91), receptive (2.91) and expressive language (1.1), adaptive behaviour: communication subscale (1.32) and adaptive behaviour: socialization scale (1.49). These large effect sizes reflect clinical significance.

Interpret results cautiously as there was publication bias identified with the expressive language outcome studies and quite high statistical heterogeneity possibly due to differences in characteristics of the treatment (setting, amount of supervision), participants (age at Tx onset, IQ at Tx onset, diagnosis) and methodology (small sample sizes, non-randomised

approaches, non-uniform assessment tools, quasi-experimental designs, lack of equivalent groups, lack of adequate fidelity, selection bias, comparison group differences).

<ul style="list-style-type: none"> • Children’s age • Diagnosis • IQ at intake 	<ul style="list-style-type: none"> • 33.56 to 65.68 months • ASD (47%), AD (12.8%); PDD-NOS (40%) • 27.52 to 76.53
- Intervention duration	<ul style="list-style-type: none"> • Exp grps: ~12.5–38.6 hrs/week of EIBI for 10months to more than 2 yrs • Control grps: <ul style="list-style-type: none"> ○ less intensive EIBI (<10hr/week) ○ eclectic grp (12.5–29.08 hrs/week) ○ parent-directed ABA <p>or Treatment as usual (public EI, nursery provision, Portage, school based intervention)</p>

Virues-Ortega 2010: Applied Behavior analytic intervention for autism in early childhood: meta-analysis, meta-regression and dose response meta-analysis of multiple outcomes

Comprehensive lit search (Medline, PsychINfo, Cochrane Centre). Search strategy provided (1985-2009). References lists of reviews searched.

Exclusion criteria:

- non-peer reviewed studies
- ABA not implement according to major features of approach (referenced)
- Focus of intervention was specific rather than general
- Intervention did not meet >10hours/wk and no less than 45 weeks duration
- Not formally diagnosed according to ADIR, ADOS, DSM IV
- Single subject design or intervention less than 5 subjects
- study was epidemiological
- reported non-standardised outcomes
- no pre-test measurement
- subject selection bias evident
- mean and SD not available

Independent screener of papers, IR agreement 90%. Twenty-two studies included.

Independent screening of methodological quality (Downs and Black 1989); IR agreement 95%.

Overall outcome: long-term, comprehensive ABA intervention leads to (positive) medium to large effects in terms of intellectual functioning, language development, and adaptive behaviour of individuals with autism. Although favourable effects were apparent across all outcomes, language-related outcomes (IQ, receptive and expressive language, communication) were distinctively superior to non-verbal IQ, social functioning and daily living skills, with effect sizes approaching 1.5 for receptive and expressive language and communication skills.

<p>Participants:</p> <p>age</p> <p>diagnosis</p> <p>Setting of intervention & duration</p> <p>Type of study</p>	<ul style="list-style-type: none"> • 323 participants • 22.6 to 66.3 months • 15 studies exclusively autism; 7 studies autism and PDD-NOS • 13 UCLA model, 9 general ABA • 18 school- or clinic-based (two of these home-based) & 48 to 407 weeks • 4 parent managed programs & 12–45 weeks • 8 studies within subject design and 13 studies had a control group
<p>Outcomes:</p> <p>IQ</p>	<ul style="list-style-type: none"> • ABA: ES 1.19 for 18 studies (113 subjects) <p>Clinic-based: ES 1.23</p> <p>Parent-managed: ES 1.02</p> <ul style="list-style-type: none"> • Studies with a control grp (10: 169 subjects) <p>ES: 1.31</p>
<p>- non-verbal IQ</p>	<ul style="list-style-type: none"> • ABA: ES 0.65 for 10 studies (146 subjects) <p>Clinic-based: ES 0.65</p> <p>Parent-managed: ES 0.65</p> <ul style="list-style-type: none"> • Studies with a control grp (8: 123 subjects) <p>ES 0.76</p>
<p>- receptive language</p>	<ul style="list-style-type: none"> • ABA: ES 1.48 for 11 studies (172 subjects)

<p>- expressive language</p>	<ul style="list-style-type: none"> • Studies with a control grp (7: 116 subjects) <p>ES: 0.99</p> <ul style="list-style-type: none"> • ABA: ES 1.47 for 10 studies (164 subjects) • Studies with a control grp (7: 116 subjects) <p>ES: 0.99</p>
<p>-adaptive behaviour domains:</p> <p>- Communication</p> <p>Daily living skills</p> <p>Socialisation</p> <p>Composite</p>	<p>ABA for 11 studies (170 subjects);</p> <p>ES: 1.45</p> <ul style="list-style-type: none"> • 6 studies using UCLA model; ES = 1.73 • 4 studies using general ABA = 1.17; ES: 0.62 • 8 studies with a control grp; ES = 0.68 <p>ES: 0.95</p> <ul style="list-style-type: none"> • 8 studies with a control grp; ES= 0.68 • 15 studies (232 subjects); ES=1.09 <p>ES no different for clinic based vs parent managed programs or when limited to 10 studies with a control (165 subjects).</p> <p>ES increased with intensity but not duration</p>

All meta-analysis subject to statistical heterogeneity ($I^2 = 68-88\%$) and publication bias ($p < 0.02$).

Kagorah D. Is video-based instruction effective in the rehabilitation of children with autism spectrum disorders? 2007. *Developmental Neurorehabilitation* 13(2):129-140.

Reviewed intervention studies on the use of video-based instruction for teaching adaptive behaviours to children with autism spectrum disorders (ASD).

Forty-four studies encompassing 49 experiments met the inclusion criteria. The studies targeted a range of adaptive behaviours and academic skills.

1. Adequate search strategy searching four known databases, no year range specified and three manual search strategies employed as well
2. Inclusion criteria appropriate though only needed one participant in study to have ASD for study to be included and included all children <18yrs.

3. Some quality assessment performed in studies but not clear to what degree. No formal quality assessment process used.

Outcomes:

Difficult to draw conclusions due to only 1–3 participants in any one included study having ASD. Also mean age of included sample was 7.6 years although 55% were school age (6–12 years) and 30% (3–5 years).

Most studies reported positive results, but the certainty of evidence was not strong for all of the studies due to reliance on pre-experimental designs. Most studies assessed outcomes of social and communication skills, not adaptive behaviours. Most studies performed video based instruction in home or school settings, not community settings where instruction is required. A wide range of models were used for video instruction making it difficult to determine which model works best in which setting. Furthermore few studies looked at video-based instruction independent of additional strategies making it difficult to determine effects specific to video-based instruction.

Karkhaneh M. Social stories to improve social skills in children with autism spectrum disorder. *Autism* 14(6): 641-662.

Followed systematic reviews methods (Higgins 2006).

Comprehensive search strategy used (all key databases) plus hand searches of bibliographies

Two independent reviewers of search and for quality assessment with a validated scale (Jadad, 1996, Chalmers, 1981, Smith 2007).

Inclusion criteria:

- Six Controlled trials (4 RCT, 2 CCT) published between 2006–2009
- 135 participants, median sample size 20
- variable control groups
- quality criteria (0 low, 5 high): 1 study 2/5, 2studies 1/5, 3 studies 0/5

Participants:	
Age	10 years (4–14 years)
Diagnosis	not clear if independently diagnosed in any studies
Treatment duration	same day to 6 weeks
Treatment intensity	2 trials within a session to 10 readings in a day for 30 consecutive days

Majority of children in this review were >7yrs, therefore will exclude at this stage. The one study that had children with mean age 6 yrs (4–8) had a quality score of 0/5 and therefore will not offer any further information to this review.

Preston D. A Review of the Efficacy of the Picture Exchange Communication System Intervention. *J Autism Dev Disord* (2009) 39:1471–1486

- Descriptive review; 27 studies
- comprehensive lit search strategy using all databases and manual searching of bibliography references.

Inclusion criteria:

- journal articles in English from 1992 to July 2007;
- used PECS (Bondy & Frost 1994; Frost & Bondy 1994, 2002) as whole or part of an intervention strategy as indicated by reference to program documentation and description of implementation (Phases I–VI)
- presented group or individual data on the results of the intervention.

Overall outcome based on RCT studies (3): nature and quantity of data arising from RCTs at this point in time is insufficient to draw firm conclusions regarding the PECS interventions.

Single subject designs:	<p>14 single subject studies:</p> <ul style="list-style-type: none"> • 4 used alternating design • 8 used multiple baseline across participants, settings, descriptors taught and activities. • 2 ABAB design • 2 within subject changing criteria design <p>poor quality for single subject designs (not discussed further)</p>
<p>Group experimental design:</p> <p>Number</p> <p>Diagnosis</p> <p>Age</p>	<p>RCT: Howlin et al. 2007; Yoder and Stone 2006a, quasi-experimental: Carr and Felce 2007a, b.</p> <p>161 subjects (35% of the total sample): 98 in PECS and 92 in control or other treatment groups.</p> <p>Autism or PDD-NOS and little or no speech.</p> <p>20 months to 11 years</p> <p>IO reliability reported in <20% sessions (Howlin 2007); procedural</p>

Quality	<p>fidelity only reported by Yoder 2006 in <20% of sessions)</p> <p>Social validity reported by Yoder 2006</p>
Outcomes for 3 RCT studies	<p>Yoder and Stone (2006a):</p> <ul style="list-style-type: none"> • 36 children with autism, aged 21–54 months • randomly assigned to PECS (phases I–VI) or Responsive Education and Prelinguistic Milieu Teaching (RPMT) intervention groups • PECS group showed a significantly greater increase in frequency of speech ($d = 0.63$) and in number of different words used ($d = 0.50$) after 6 months of intervention, but by 6 months post-intervention the difference was no longer evident. • children who were low in initial object exploration benefited more from the RPMT intervention, while those who were higher benefited more from PECS, these effects being evident 6 months post-intervention. <p>Overall, a significant increase in non-imitative spoken acts over 1 year, though increase could be attributed to maturation.</p> <p>Yoder and Stone (2006b):</p> <ul style="list-style-type: none"> • 36 children with autism, Aged 20–53 months • examined effect of the PECS vs RPMT on initiating joint attention, requesting, and turn-taking • all 3 functions increased significantly, but RPMT increased turn-taking more than PECS. Children who were higher in initiating joint attention before treatment had greater increases in both initiating joint attention and requesting following RPMT intervention, while those who were initially lower in initiating joint attention had greater increases following PECS intervention. <p>Howlin et al. (2007):</p> <ul style="list-style-type: none"> • group RCT of 84 children with autism, aged 4–11 years • examined effectiveness of a consultancy model to deliver PECS (phases I–VI), rather than the efficacy of PECS per se. • rates of communicative initiations and PECS usage were significantly increased immediately following intervention, but that these effects were not maintained once the intervention ceased. • no significant increase in frequency of speech.

	no increase in most ADOS-G ratings, with the exception of a decrease in the severity score for the Reciprocal Social Interaction domain at the 10 month follow-up. Unfortunately no data was provided on the fidelity of implementation of the PECS program, or indeed on the fidelity of the teacher training.
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Wallace & Rogers, Intervening in infancy: implications for autism spectrum disorders. *J Child Psychology & Psychiatry*. 2010. 51(12): 1300-1320.

- Comprehensive search strategy including search of PsychInfo and Pub Med databases, hand search of reviews
- 32 controlled, high-quality experimental studies.

Inclusion criteria:

- article published in a peer-reviewed journal
- article described a well-designed, controlled intervention efficacy study involving infants or toddlers with significant risk of prematurity, developmental delay including Down syndrome, risk of intellectual disability
- study participants were in the age range of 0–3 years
- paper reported sufficient data to calculate effect sizes.

Two independent reviewers of studies including rating of studies by level of evidence type 1-type 6 (Nathan and Gorman, 2002):

- Type 1 Studies are randomized, prospectively designed clinical trials which use randomly assigned comparison groups and all critical design requirements.
- Type 2 Studies are clinical trials using a comparison group to test an intervention. These have some significant flaws but not critical design flaws that would prevent one from using the data to answer a study question. This category also includes single-subject designs.

Overall outcome:

- Most efficacious interventions routinely use a combination of four specific intervention procedures, include:
 1. parent involvement in intervention, including ongoing parent coaching that focused both on parental responsiveness and sensitivity to child cues and on teaching families to provide the infant interventions
 2. individualization to each infant's developmental profile
 3. focusing on a broad rather than a narrow range of learning targets
 4. temporal characteristics involving beginning as early as the risk is detected and providing greater intensity and duration of the intervention.

Study design	<ul style="list-style-type: none"> • type 1 studies (6) • type 2 studies (26) • 24 studies looking at prematurity; 6 type 1, 18 type 2 • 5 studies looking at Dev. Delay incl. Down syndrome; all type 2 • 3 studies looking at intellectual disability; all type 2 • 23/32 studies used randomization • 3/32 partial randomisation
Premature group outcomes:	<ul style="list-style-type: none"> • two randomized controlled studies demonstrated large effect sizes (0.7-0.8) in cognitive ability following intervention up to 36months and effect was sustained well into early childhood and beyond. Intervention started with parent training in hospital and at home from when child was an infant (study 1: long-lasting and intensive intervention carried out for 36 months and study 2: a very brief intervention lasting only 3 months and carried out by a visiting nurse. Common elements include an individualized developmental curriculum for children, a strong focus on parent training and parent delivery of the intervention, and emphasis on supporting parents. • overall ES for group was 0.44; key strategy involved parent training
Developmental delay group outcomes:	<ul style="list-style-type: none"> • intervention involved teaching parents developmental activities to share with their children. Ix was broad-based and individualized, and provided in a mixed one-to-one and group setting. Families were provided with additional support in the form of parent groups and therapy. • overall ES for group was 0.44; key strategy parent training and continued support for parents over the long term
Intellectual disability group	<ul style="list-style-type: none"> • key RCT: full-day intervention was delivered in specialized daycare centres beginning when the infants were 6–12 weeks of age and continued until age 5 years. The infant curriculum consisted of activities designed to stimulate language, motor, social, and cognitive skills and was delivered by the daycare staff. Families receive support throughout intervention. Intense (40hrs/wk for 60 months) • most of them delivered in high-quality child care settings • overall ES for group was 1.26

Communication interventions involving speech-generating devices for children with autism: A review of the literature. LJ van Der Meer. *Developmental Neurorehabilitation*, August 2010; 13(4): 294–306

Comprehensive search strategy using 6 different databases including CINAHL, MEDLINE, ERIC plus manual searches of reference lists. 23 studies identified between 1998–2009. Two Independent reviewers to identify included studies.

Inclusive criteria:

- children (<18 years of age) with ASD (9.8%), autism, (66.7%), PDD-NOS (23.5%)
- intervention involving SGDs defined as implementing one or more therapeutic/ teaching procedures for the purpose of trying to increase or improve the child’s communication skills or abilities through the use of a SGD. Examples could include teaching a child to use an SGD to (a) make requests, (b) spell words or (c) repair a communicative breakdown
- quality assessment criteria not clear
- 51 children aged 3–16 years (mean 7.7 yrs)

Overall outcome:

- Only 4 /23 studies had ‘conclusive’ single-subject study designs comprising a total of 13 children.

<p>Trembath D., Balandin S., Togher L., Stancliffe R. Peer- mediated teaching and augmentative and alternative communication for preschool-aged children with autism. <i>Journal of Intellectual and Developmental Disability</i> 2009;34: 173–186.</p>	<p>To assess the effectiveness of peer-mediated naturalistic teaching, with and without an SGD (Talara-32; digitized) on the communicative behaviours of children with autism (3 boys aged 3–5 yrs)</p> <p>Used multiple baseline design</p>	<p>Following the SGD intervention there were immediate increases in the communicative behaviours of all three children. Increases were statistically significant. Interactions generalized to mealtime activities, however, only one child maintained these increases</p>
<p>Olive M, de la Cruz B, Davis T, Chan J, Lang R, O’Reilly M, Dickson S. The effects of enhanced milieu teaching and a voice output communication aid on the requesting of three children with autism.</p>	<p>To evaluate the effects of enhanced milieu teaching combined with a SGD (Cheap Talk 4 Inline Direct; digitized) on the requesting skills of 3 boys aged 45–66 months</p> <p>Used multiple probe</p>	<p>All participants demonstrated an increase in SGD use as well as an increase in total spontaneous independent requests</p>

<i>Journal of Autism and Developmental Disorders</i> 2007;37:1505–1513.	across participants design	
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- No RCTs have been performed in this area.

Outcome of comprehensive psycho-educational interventions for young children with autism

- Eikeseth. S. 2009. *Research in Developmental Disabilities* 30 (2009) 158–178.
- Evaluated comprehensive psycho-educational research on early intervention for children with autism. Twenty-five outcome studies were identified.
- Twenty studies evaluated behavioural treatment, 3 studies evaluated TEACCH and 2 studies evaluated the Colorado Health Sciences Project.
- Looked at scientific merit (Highest 1, lowest 3) and magnitude of treatment (Highest 1; lowest 4)
- Scientific merit: (only 1 study with scientific merit 1: Smith, 2000)
- Studies relevant to current review see below: all *scientific merit 2*, *criteria* include:
 - diagnosis by independent diagnostician using DSM IV criteria plus standardised tools (ADOS, ADIR)
 - study design not random
 - dependent variable (standardized assessments of IQ and adaptive functioning and other assessments)
 - treatment fidelity (performed or if not, provided in a treatment manual)
- Magnitude of treatment criteria:
 - significant differences between groups on IQ and adaptive functioning (IQ measure must be based on language/ communication skills in addition to visual spatial or performance skills) as a minimum
 - significant differences between groups on IQ or adaptive functioning as a minimum.

Study	Study outcomes	Scientific merit (SM) Magnitude of Treatment (MT)	Magnitude of results
Eikeseth, S. 2007	Compared effects of ABA and eclectic treatment for children with autism. Mean intake age was 5.5 years. ABA group received 28/week of one-to-one ABA treatment during the first year of intervention with a gradual reduction of treatment hours over the next 2 years. Eclectic group received 29 h/ week of one-to-one eclectic treatment with a gradual reduction of treatment hours over the next 2 years.	SM =; MT = 1 Group assignment to either an ABA treatment group (n = 13) or to an eclectic treatment group (n = 12) was based on availability of ABA supervisors and performed by a person who was independent of the study	Follow-up assessment—~3 years after the treatment begun—ABA group scored significantly higher as compared to the eclectic treatment group on intelligence, language, adaptive functioning, maladaptive functioning and on two of the subscales on the socio-emotional assessment (social and aggression). The ABA treatment group gained an average of 25 IQ points, ES = 2.21; 12 points in adaptive functioning ES = 1.35. By comparison, the eclectic treatment group obtained Average change of +7 points in IQ, +10 points in Adaptive Functioning. Seven of 13 children in the ABA group who scored within the range of mental retardation at intake scores within the average range (0.85) on both IQ and verbal IQ at follow-up, compared to 2 of 12 children in the eclectic treatment group.
Remington 2007	Compared effects of ABA with treatment as usual for children with autism. Mean	ES = 2; MT = 2 Group assignment to	There were no significant differences at intake on any of the measures. Follow-up assessment showed that the ABA treatment group scored significantly higher as compared to the comparison

	intake age was 37 months.	either an ABA treatment group (n = 23) or to a treatment as usual group (n = 21) was based on parental choice. Participants in the ABA treatment group received 25.6 h per week of one-to-one ABA for 2 years. Participants in the comparison group received standard provision from the local education authorities. Hours not unspecified.	<p>group on intelligence, but not on language functioning or adaptive behaviour (ABA treatment group gained an average of 12 IQ points, ES = 0.72, whereas children in the comparison group lost, on average, two IQ points). Children in the ABA group showed an advantage over the comparison group in language functioning at follow-up, as more children in the ABA group reached basal on the Reynell comprehension and expression scales post treatment.</p> <p>The ABA group showed significantly better score on responding to joint attention as compared to the comparison group, but not in initiating joint attention. No other significant changes were reported in child outcome.</p>
Cohen 2006	Compared effects of ABA with special education provided at local public schools for children with autism or PDD-NOS. Participants' mean age at diagnosis was 31.2 months (range 18–48) and all <48 months by the onset of treatment.	SM: 2; MT = 1 Group assignment to either an ABA treatment group (n = 21, 20 with autism and 1 with PDD-NOS) or to an eclectic treatment group (n = 21, 14 with autism and 7 with PDD-NOS) was based on	At intake, ABA group had significantly more children with autism (less with PDD-NOS) as compared to the comparison group. Follow-up assessment ~3 years after the treatment begun –ABA group scored significantly higher as compared to the two comparison groups on IQ and adaptive functioning, though not on visual IQ and language (language comprehension was marginally significant with p = 0.06). The ABA group gained an average of 25 IQ points, ES = 1.52, 10 points in adaptive functioning, ES = 1.23. By comparison, the eclectic treatment group obtained average change of 4 points in IQ, □3 points in Adaptive Functioning. Six of the 21 ABA treated children were fully included into regular education without assistance, and 11 others were

		<p>parental preference.</p> <p>ABA group received 35–40 h per week of one-to-one ABA treatment provided in a community setting. Participants in the comparison group received public community Services. The child/teacher ratios varied from 1:1 to 3:1. Classes 3–5 days/week, for up to 5 h per day.</p>	<p>included with support; in contrast, only 1 comparison child was placed primarily in regular education.</p>
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ABA treatment is demonstrated effective in enhancing global functioning in pre-school children with autism when treatment is intensive and carried out by trained therapists (one Level 1 study, four Level 2 studies, Cohen et al. 2006; Eikeseth et al. 2002, 2007; Howard et al. 2005; Remington et al. 2007; nine Level 3 studies, Andersen et al. 1987; Birnbrauer & Leach 1993; Eldevik et al. 2006; Lovaas 1987; and Sallows & Graupner 2005; Sheinkopf & Siegel 1998; Smith, Buch, & Gamby 2000; McEachin et al.1993; Magiati et al. 2007; Weiss 1999).

Odom 2010: Evaluation of comprehensive treatment models (CTMs) for individuals with ASD. *J Autism Dev Disord* 40(4):425-436.

CTMs:

- identified by literature search (PsychInfo and EBSCO)
- surveyed well known books and literature review
- incorporated models from NAC report
- experts in the field

Defined by 6 criteria:

- model description published in a refereed journal article
- a single procedural guide, manual to define model
- clear theoretical or conceptual framework that is published
- address multiple developmental or behavioural domains that represent core features of autism
- model must be intensive (25hrs/week or more), extends for 9–10 months, and planned engagement consistent with mode.
- implemented at least at one site in the US.

Evaluation

Four evaluators with extensive training and experience related to ASD. Standard telephone 1x to CTM director (30–90min) and summarised outcomes according to evaluation criteria. Used American Evaluation Association guidelines combined with guidelines from leaders in ASD Tx field. Polit testings of evaluation performed. Inter rater agreement 83%

Operationalisation: Interventions documented and published such that others can use them

Implementation measures: Fidelity implementation measure developed plus some evidence of reliability and validity.

Replication: Model adopted and replicated by others, provided with initial training but otherwise independent of CTM developer

Type of empirical evidence: Evidence of efficacy must appear in different venues, strongest being a peer-reviewed journal, then book chapters or reports from CTM developers

Quality of research methodology: SMRS system

Complementary evidence from studies of focused interventions: provide evidence from peer reviewed journals of focused interventions that are used as part of the models.

Scored 0 lowest to 5 highest

Program	Operation-alisation	Fidelity	Replication	Outcome data	Quality	Additional studies
Denver	5	4	5	5	2	0
DIR	5	3	5	4	2	0
Douglass	5	3	0	5	3	5
Hanen	2	0	1	3	0	0

Case-Smith, J., & Arbesman, M. (2008). Evidence-based review of interventions for autism used in or of relevance to occupational therapy. *American Journal of Occupational Therapy*, 62, 416–429.

Inclusion criteria

1. Performance area or intervention approach used in occupational therapy
2. Included children and adolescents
3. Peer reviewed
4. Study design (Level 1: RCTs, sys reviews, meta-analysis); (Level 2: nonrandomized controlled trials such as cohort studies; (Level 3: before-after one group designs)
5. Searches (1986–2007) Medline, CINAHL, ERIC, PsycINFO, Social Sciences Abstracts, Sociological Abstracts, Linguistics and Language Behavior Abstracts, Rehab Data, Latin American and Caribbean Health Sciences Literature and EBSCO Host, Cochrane Database of Systematic Reviews, Campbell Collaboration.

Overall outcome

Overall this was a descriptive review of studies (Level I to III) that looked at a range of interventions which fall in the domain of occupational therapy. Majority of studies described were performed before 2005, outside this review’s study criteria. Also as no clear independent standardised quality assessment was performed on included studies, the level of scientific rigour is likely to vary among studies making it difficult to make comparisons or draw clear conclusions. Few studies were completed by occupational therapists, rather the author has attempted to interpret the outcomes and apply to occupational therapy practice.

Study design & methodology	Reported: 49 studies
Published criteria used for Law 2002	<ul style="list-style-type: none"> • 18 Level 1 • 17 level 2

	<ul style="list-style-type: none">• 14 level 3• (no clear evidence of assessment of study quality or which research design elements are assessed).
Outcomes:	<ul style="list-style-type: none">• Descriptive review, no objective measures examined.

Appendix B: Classification system used to group and discuss interventions based on learning

Behavioural Interventions	Applied Behaviour Analysis (ABA) (Early) Intensive Behavioural Interventions (EIBI/IBI) Contemporary ABA e.g. NLP
Developmental Interventions	Developmental Social-Pragmatic Model (DSP) Floor time Relationship Development Intervention Play therapy
Combined Interventions	SCERTS(Social-Communication, Emotional Regulation and Transactional Support) TEACCH (Treatment and education of autistic and related communication handicapped children) LEAP (Learning Experiences – An Alternative Program for Preschoolers and Parents)
Family Based Interventions	The Hanen Program The Early Bird Program
Therapy Based Interventions Tend to focus on development of skills in specific areas such as communication, cognition, social and motor	Communication Focused Interventions Visual Supports/Alternative and Augmentative Communication (AAC) Picture Exchange Communication System (PECS) Social Stories Facilitated Communication (FC) Functional Communication Training (FCT) Social Skills Interventions Sensory/Motor Interventions Sensory Integration Auditory Integration Training Doman-Delacato method

Other Interventions	Higashi/Daily Life Therapy The Option Method Music Intervention Therapy Spell The Camphill Movement Miller Method
Interventions for co-morbid conditions associated with autism such as anxiety, challenging behaviour	CBT PBS

Appendix C: Planning Matrix

This is a useful tool to facilitate multidisciplinary program development and for including input from families.

This information and more is available on the Positive Partnerships website:

www.autismtraining.com.au

Positive Partnerships Planning Matrix

The characteristics of autism affect all aspects of a person's life. Even when children with autism share characteristics, the impact of these will be different and will depend on the age, developmental stage and individual strengths. To be effective, strategies need to be designed to reflect the individual's strengths and needs. The Positive Partnerships Planning Matrix can help those involved with the student to develop a shared understanding these strengths and needs.



The image shows a table titled "Positive Partnerships Planning Matrix". The table has a header row with five columns: "Communication", "Social Interactions", "Restricted Interests Repetitive behaviour", "Sensory Processing", and "Information processing & learning styles". The first column is labeled "Characteristics", "Implications", and "Strategies" in its respective rows. The table is empty, intended for user input. At the bottom left, it says "copyright 2011 Positive Partnerships" and at the bottom right, it says "Planning Matrix".

	Communication	Social Interactions	Restricted Interests Repetitive behaviour	Sensory Processing	Information processing & learning styles
Characteristics					
Implications					
Strategies					

What is the Planning Matrix?

The planning matrix enables parents, teachers and others working with a student with autism to create a snapshot of the individual. It clearly identifies the characteristics of autism and how these impact on the life of the student. The planning matrix also outlines key strategies that work for that student.

The planning matrix is completed by a child's support team. This could include parents or carers, school personnel, allied health professionals or others working with the child. A matrix can be completed at any time and will be particularly useful when a child is transitioning between classes, schools or settings.

How can the Planning Matrix be used?

The Planning Matrix is a way to gather and record information about the characteristics and impact of autism, relevant to the student. For this reason, no two matrices will be exactly alike.

A completed Planning Matrix:

- will be a 'snapshot' of the student – as the child develops and changes, adapt and update your planning matrix so that it grows with the individual
- allows you to easily describe how the characteristics of an ASD present for the student, the impact of these characteristics and what the team can do to support the individual
- will be useful when reviewing or auditing – if the impact changes or the strategies require adjustment
- can be used to support annual review of students needs by paediatricians and allied health professionals
- can be used to support planning and transition
- can be used to communicate the important information about the impact of autism to siblings, extended family members, baby sitters, sports coaches, future employers.

Completing a Planning Matrix

The planning matrix consists of five columns (communication, social interaction, repetitive behaviours and restricted interests, sensory processing and information processing/learning styles. With the child's team, provide concise information in these areas:

- **Communication:** How the student communicates with others, including how they express themselves and their ability to comprehend what is communicated to them.
- **Social interaction:** The student's understanding of social rules along with their ability to make and maintain friendships, understand emotions, read and respond to other people.
- **Repetitive behaviours & restricted interests:** How the student responds to routines and change, the presence of unusual movements or vocalisations and any special interests.
- **Sensory processing:** The student's response to sensory information - touch, taste, smell, sight, sound, proprioception (knowing where their body is in space) and vestibular processing (balance) information.
- **Information processing / learning styles:** How the child processes information including their learning strengths and difficulties and how they prefer to learn (e.g. better understanding of visual input compared to auditory input). It also includes the capacity to plan and organise, impulsivity, self-regulation, concrete and literal thinking and attention difficulties.

There are three rows to complete for each of the areas above – What are the characteristics of autism for this student? What are the impacts of these? What strategies will be useful?

- **Characteristics:** The features, difficulties, strengths and differences that the student displays in each of the areas above.
- **Impact:** The effect a particular characteristic has on the student at home, at school and/or in the community.
- **Strategies:** Modifications, adjustments and activities to support the student. This will include strategies to minimise negative impacts and enhance the positive impact of the student's identified challenges and characteristics. In an educational setting, this will include adjustments and accommodations.

A completed planning matrix will be a 'snapshot' of the student – as the child develops and changes, adapt and update your planning matrix so that it grows with the individual.

Appendix D: Research strategy and scientific merit rating scale

Literature Review Methods and Literature Search and Retrieval Process

Databases

The following search terms were used to retrieve references from four databases:

MEDLINE, PsycINFO, Cochrane Central (randomized controlled trials) and Education Resources Information Center (ERIC), Hand-searches of reference lists were also performed to identify additional studies.

Search terms

Database	Medline (1966-April 2011)	PsychInfo (1872-April 2011)	Cochrane Central (April 2011)	ERIC (-April 2011)
Autism terms	Exp. child development disorders, pervasive asperger.tw kanner.tw	Exp. pervasive developmental disorders/ or exp. autism/ or exp. Asperger's syndrome asperger.tw kanner.tw	Exp. child development disorders, pervasive asperger.tw	Pervasive developmental disorders/ or Asperger's syndrome/ or autism asperger.tw kanner.tw
Study design	Randomized controlled trial.pt controlled clinical trial.pt random.tw control.tw intervention.tw	Exp. between groups/ or clinical trials Random.tw Control\$.tw	Randomized controlled trial.pt controlled clinical trial.pt random.tw control.tw intervention.tw	
Treatment	Early intervention therapeutics treatment outcome	Exp. school based intervention/ or exp. group intervention/ or exp. family intervention/ or exp. early intervention Exp. treatment (treatments or		Exp. outcomes of treatment Exp. intervention/ or early intervention Therapy Special education

		therapy or interventions).tw		(treatment or therapy or intervention).tw
Limits	Exp, animals/ not humans.sh 'all infant birth to 23 months') or 'preschool child (2 to 5 years)' or 'child (6 to 12 years)' Year: 2005-2011	Childhood <birth to age 12 yrs> Year: 2005–2011	Exp, animals/ not humans.sh 'all infant birth to 23 months') or 'preschool child (2 to 5 years)' or 'child (6 to 12 years)' 10. Year: 2005–2011	Childhood education or grade 1 or grade 2 or kindergarten Year: 2005–2011
Total (duplicates removed)	225	398	166	107

NB. Text words (tw) were extended using the symbol '\$'

Article selection process

Abstracts of articles identified through the electronic database searches were examined to determine whether studies met the following key criteria:

- published original research
- children aged between 0–7 years with ASD (autism, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), Asperger syndrome)
- studies with 10 participants or more
- any study design except single subject designs with less than 10 participants
- children experiencing educational interventions, not biomedical or psychodynamic interventions,

Two reviewers evaluated each abstract for inclusion or exclusion.

Searches of bibliographies, internet and grey literature sources identified a further seven research articles including six reviews.

Data abstraction process

Three reviewers assessed the full text of each included article. The staff members and clinical experts who conducted this review jointly developed the evidence tables from the abstracted data. The type of data abstracted included: study design, descriptions of the study populations (for applicability), description of the intervention, appropriateness of comparison groups and outcome data.

Assessing methodological quality of individual studies

We used the Scientific Merit Rating Scale as described in the *National Standards Report* (ref) which examines five critical dimensions of experimental rigour:

- research design
- measurement of the dependent variable
- measurement of the independent variable or procedural fidelity
- participant ascertainment
- generalisation of results.

For each of the five dimensions of scientific merit, a score between zero and five (0–5) was assigned with 0 representing a poor score and 5 representing a strong score. The dimension scores were combined to yield a composite score that was rounded to the nearest whole number; this was called the SMRS score. The formula for combining these dimensions is as follows: Research Design (0.30) + Dependent Variable (0.25) + Participant Ascertainment (0.20) + Procedural Integrity (0.15) + Generalization (0.10).

SMRS scores of 3, 4, or 5 indicate that sufficient scientific rigor has been applied.

SMRS scores of 2 provide initial evidence about treatment effects. However, more rigorous research must be conducted to confirm these same effects would likely occur when more rigorous procedures are applied to other individuals with ASD.

SMRS scores of 0 or 1 indicate that insufficient scientific rigor has been applied to the population of individuals with ASD.

Results

Literature review

Of 896 references identified through electronic database searches, 107 references met inclusion criteria. Seventeen of the included references were in the National Autism Center Standards Report (2009) and had already been assessed for quality using the SMRS system. The remainder underwent quality assessment using the SMRS system (Appendix E). Fourteen of the references were systematic reviews which represent the highest level of evidence.

Appendix E: Scientific merit rating scale and outcome data

The following tables present the raw data providing analysis of the scientific merit of the studies included in the review. Scores can fall between 0 and 5, with scores of 3, 4 or 5 indicating that sufficient scientific rigour has been applied to the study and that we can draw conclusions about the treatment effects. The following data are presented alphabetically.

Please refer to the Reference list for further details of the information presented in the tables.

Study: Carter, A.S., Messinger, D.S., Stone, W.L. & Celimli, S., Nahmias, A.S. & Yoder, P. (2011)

Intervention type: Hanen (RCT)

Criteria	Research Design	Measurement of DV (Direct Behavioural Observation)	Measurement of IV	Participant Ascertainment	Generalisation
	No. of groups Design No. of participants Data loss	Type of measurement Reliability %age of sessions Conditions	Implementation accuracy Implementation accuracy data collection IOA for treatment fidelity	Who diagnosed (professional; independent; blind) How diagnosed (instrument; DSM ICD)	Objective Maintenance data &/or Across settings / stimuli / responses / persons
Score Per Criteria	5; 5; 5; 4 = 4.75	5; 5; 3; 4 = 4.25	5; 5; 5 = 5	3; 3 = 3	5; 3 = 4
Weighted Score	$4.75 \times 0.3 = 1.425$	$4.25 \times 0.25 = 1.0625$	$5 \times 0.2 = 1$	$3 \times 0.15 = 0.45$	$4 \times 0.1 = 0.4$
Total Score	4.3375				

Comment: No main effect on parent responsiveness or child outcome, however improved outcomes for children with initially lower object interest (played with fewer toys). Children were all under 2 years of age.

Study: Gulsrud, A.C., Kasari, C., Freeman, S. & Paparella, T. (2007)

Intervention type: 'Joint attention intervention' vs. 'Symbolic play intervention'

Criteria	Research Design	Measurement Of DV (Direct Behavioural Observation)	Measurement Of IV	Participant Ascertainment	Generalisation
	No, of Groups Design No. of Participants Data Loss	Type of Measurement Reliability %Age Of Sessions Conditions	Implementation Accuracy Implementation Accuracy Data Collection IOA For Treatment Fidelity	Who Diagnosed (Professional; Independent; Blind) How Diagnosed (Instrument; Dsm Icd)	Objective Maintenance Data &/Or Across Settings / Stimuli / Responses / Persons
Score Per Criteria	5; 5; 5; 4 = 4.75	5; 5; 5; 5 = 5	1; 1; 1 = 1	3; 3 = 3	5; 2 = 3.5
Weighted Score	4.75 X 0.3 = 1.425	5 X 0.25 = 1.25	1 X 0.2 = 0.2	3 X 0.15 = 0.45	3.5 X 0.1 = 0.35
Total Score	3.675				

Comment: Compared two interventions, no control group. Joint attention>symbolic play for shared interactions, and proportion of time spent sharing coordinated joint looks.

Study: Klayva, E. & Avramidis, E. (2005)

Intervention type: 'Circle of Friends'

Criteria	Research Design	Measurement of DV (Direct behavioural observation)	Measurement of IV	Participant Ascertainment	Generalisation
	No of groups Design No of participants Data loss	Type of measurement Reliability %age of sessions Conditions	Implementation accuracy Implementation accuracy data collection IOA for treatment fidelity	Who diagnosed (professional; independent; blind) How diagnosed (instrument; DSM ICD)	Objective Maintenance data &/or Across settings / stimuli / responses / persons
Score Per Criteria	5; 4; 3; 4 = 4	4; 5; 3; 3 = 3.75	1; 1; 1 = 1	1; 1 = 1	2; 2 = 2
Weighted Score	4 x 0.3 = 1.2	3.75 x 0.25 = 0.938	1 x 0.2 = 0.2	1 x 0.15 = 0.15	2 x 0.1 = 0.2
Total Score	2.688				

Comment: Outcomes for communication (response and initiation rates). NB: N=5 and SMRS rating low. Interpret with caution

Study: Keen, D., Couzens, D., Muspratt, S. & Rodger, S. (2010)

Intervention type: Professionally supported parent focused intervention vs. Self-directed video based parent focused intervention

Criteria	Research Design	Measurement of DV	Measurement of IV	Participant Ascertainment	Generalisation
	No. of groups Design No. of participants Data loss	Type of measurement Protocol Psychometric properties Evaluators	Implementation accuracy Implementation accuracy data collection IOA for treatment fidelity	Who diagnosed (professional; independent; blind) How diagnosed (instrument; DSM ICD)	Objective Maintenance data &/or Across settings / stimuli / responses / persons
Score Per Criteria	5; 5; 5; 4 = 4.75	5; 5; 5; 4 = 4.75	1; 1; 1 = 1	3; 5 = 4	5; 1 = 3
Weighted Score	$4.75 \times 0.3 = 1.43$	$4.75 \times 0.25 = 1.19$	$1 \times 0.2 = 0.2$	$4 \times 0.15 = 0.6$	$3 \times 0.1 = 0.3$
Total Score	3.72				

Comment: No control group. Professionally supported significantly better outcomes than parent directed in children's' social communication, adaptive behaviour; parents' stress, self-efficacy

Study: Landa , R.J., Holman K.C., O'Neill, A.H. & Stuart, E.A. (2011)

Intervention type: Interpersonal Synchrony (IS) vs. Non-interpersonal synchrony (Non-IS) - both school and home based interventions, but IS provided supplementary curriculum targeting socially engaged imitation, joint attention, and affect sharing.

Criteria	Research Design	Measurement of DV	Measurement of IV	Participant Ascertainment	Generalisation
	No. of groups Design No. of participants Data loss	Type of measurement Protocol Psychometric properties Evaluators	Implementation accuracy Implementation accuracy data collection IOA for treatment fidelity	Who diagnosed (professional; independent; blind) How diagnosed (instrument; DSM ICD)	Objective Maintenance data &/or Across settings / stimuli / responses / persons
Score Per Criteria	5; 5; 5; 4 = 4.75	5; 5; 5; 4 = 4.75	3; 3; 5 = 3.7	5; 5 = 5	5; 4 = 4.5
Weighted Score	$4.75 \times 0.3 = 1.43$	$4.75 \times 0.25 = 1.19$	$3.7 \times 0.2 = 0.74$	$5 \times 0.15 = 0.75$	$4.5 \times 0.1 = 0.45$
Total Score	4.57				

Comment: No control group. IS > Non-IS (see 'Intervention Type' above). Significant Outcomes (endpoint and follow up): socially engaged imitation. Similar gains for joint attention and affect sharing, but figures did not reach significance.

Study: Lim, H. (2010).

Intervention type: Music Training vs. Speech Training vs. controls

Criteria	Research Design	Measurement of DV (Direct Behavioural Observation)	Measurement of IV	Participant Ascertainment	Generalisation
	No. of groups Design No. of participants Data loss	Type of measurement Reliability %age of sessions Conditions	Implementation accuracy Implementation accuracy data collection IOA for treatment fidelity	Who diagnosed (professional; independent; blind) How diagnosed (instrument; DSM ICD)	Objective Maintenance data &/or Across settings / stimuli / responses / persons
Score Per Criteria	5; 5; 5; 4 = 4.75	5; 5; 5; 5 = 5	1; 1; 1 = 1	5; 5 = 5	5; 2 = 3.5
Weighted Score	$4.75 \times 0.3 = 1.425$	$5 \times 0.25 = 1.25$	$1 \times 0.2 = 0.2$	$5 \times 0.15 = 0.75$	$3.5 \times 0.1 = 0.35$
Total Score	3.975				

Comment: Music Training, Speech Training both had better outcomes than controls. Outcomes: Verbal production (semantics, phonology, pragmatics, prosody). Music Training had greater outcomes than Speech Training for low functioning ASD children.

Study: Lydon, H., Healy, O. & Leader, G. (2011).

Intervention type: Pivotal Response Training (PRT) vs. Video Modelling (VM)

Criteria	Research Design	Measurement of DV (Direct Behavioural Observation)	Measurement of IV	Participant Ascertainment	Generalisation
	No of groups Design No of participants Data loss	Type of measurement Reliability %age of sessions Conditions	Implementation accuracy Implementation accuracy data collection IOA for treatment fidelity	Who diagnosed (professional; independent; blind) How diagnosed (instrument; DSM ICD)	Objective Maintenance data &/or Across settings / stimuli / responses / persons
Score Per Criteria	5; 4; 2; 4 = 3.75	5; 5; 5; 5 = 5	1; 1; 1 = 1	5; 5 = 5	5; 2 = 3.5
Weighted Score	$3.75 \times 0.3 = 1.125$	$5 \times 0.25 = 1.25$	$1 \times 0.2 = 0.2$	$5 \times 0.15 = 0.75$	$3.5 \times 0.1 = 0.35$
Total Score	3.675				

Comment: No control group, PRT greater numbers of play actions than VM

Study: McConkey, R. Truesdale-Kennedy, M., Crawford, H., McGreevy, E., Reavey, M., Cassidy, A. (2011)

Intervention type: Keyhole (TEACCH + PECS + Hanen)

Criteria	Research Design	Measurement of DV	Measurement of IV	Participant Ascertainment	Generalisation
	No. of groups Design No. of participants Data loss	Type of measurement Protocol Psychometric properties Evaluators	Implementation accuracy Implementation accuracy data collection IOA for treatment fidelity	Who diagnosed (professional; independent; blind) How diagnosed (instrument; DSM ICD)	Objective Maintenance data &/or Across settings / stimuli / responses / persons
Score Per Criteria	5; 3; 5; 3 = 4	4; 4; 3; 2 = 3.25	1; 1; 1 = 1	1; 1 = 1	4; 1 = 2.5
Weighted Score	4 x 0.3 = 1.2	3.25 x 0.25 = 0.81	1 x 0.2 = 0.2	1 x 0.15 = 0.15	2.5 x 0.1 = 0.25
Total Score	2.61				

Comment: Treatment vs. control (home visits with parental psycho-education and educational toys and equipment). Significant outcomes: child communication, parental health. Low total score due to several design limitations, need to be cautious in interpreting results.

Study: Oosterling, I. Visser, J., Swinkels, S., Rommelse, N., Donders, R., Woudenberg, T., Roos, S., van der Gaag, R., Buitelaar, J. (2010)

Intervention type: Focus Parent Training (for Toddlers)

Criteria	Research Design	Measurement of DV	Measurement of IV	Participant Ascertainment	Generalisation
	No. of groups Design No. of participants Data loss	Type of measurement Protocol Psychometric properties Evaluators	Implementation accuracy Implementation accuracy data collection IOA for treatment fidelity	Who diagnosed (professional; independent; blind) How diagnosed (instrument; DSM ICD)	Objective Maintenance data &/or across settings / stimuli / responses / persons
Score Per Criteria	5; 4; 5; 4 = 4.5	5; 5; 4; 3 = 4.25	1; 1; 1 = 1	5; 5 = 5	4; 4 = 4
Weighted Score	4.5 x 0.3 = 1.35	4.25 x 0.25 = 1.06	1 x 0.2 = 0.2	5 x 0.15 = 0.75	4 x 0.1 = 0.4
Total Score	3.76				

Comment: No greater outcomes reported when compared with 'treatment as usual'. Both intervention and control participants were enrolled in comprehensive interventions.

Study: Peters-Scheffer, N., Didden, R., Mulders, M., & Korzilius, H. (2010)

Intervention type: 'low intensity behavioural treatment' – group & on-on-one; elements of TEACCH, elements of Lovaas' discrete trial format

Criteria	Research Design	Measurement of DV	Measurement of IV	Participant Ascertainment	Generalisation
	No. of groups Design No. of participants Data loss	Type of measurement Protocol Psychometric properties Evaluators	Implementation accuracy Implementation accuracy data collection IOA for treatment fidelity	Who diagnosed (professional; independent; blind) How diagnosed (instrument; DSM ICD)	Objective Maintenance data &/or Across settings / stimuli / responses / persons
Score Per Criteria	5; 4; 5; 4 = 4.5	5; 3; 4; 3 = 3.75	1; 1; 1 = 1	5; 5 = 5	5; 1 = 3
Weighted Score	4.5 x 0.3 = 1.35	3.75 x 0.25 = 0.94	1 x 0.2 = 0.2	5 x 0.15 = 0.75	3 x 0.1 = 0.3
Total Score	3.54				

Comment: Intervention and control (control group poorly defined, no treatment). Significant outcomes: developmental age; adaptive skills, Non-Significant outcomes: autistic symptom severity; emotional and behavioural problems.

Study: Pillay, M., Alderson-Day, B., Wright, B., Williams, C., & Urwin, B. (2011) **Intervention type:** ASCEND

Criteria	Research Design	Measurement of DV	Measurement of IV	Participant Ascertainment	Generalisation
	No. of groups Design No. of participants Data loss	Type of measurement Protocol Psychometric properties Evaluators	Implementation accuracy Implementation accuracy data collection IOA for treatment fidelity	Who diagnosed (professional; independent; blind) How diagnosed (instrument; DSM ICD)	Objective Maintenance data &/or Across settings / stimuli / responses / persons
Score Per Criteria	2; 2; 2; 2 = 2	2; 2; 3; 2 =2.25	1; 1;1 = 1	5; 5 = 5	2; 1 = 1.5
Weighted Score	2 x 0.3 = 0.6	2.25 x 0.25 = 0.563	1 x 0.2 = 0.2	5 x 0.15 = 0.75	1.5 x 0.1 = 0.15
Total Score	2.263				

Comment: Study has no control group. All data is self-report from parents, pre and post 11 session programme.

Study: Russo, N.M., Hornickel, J., Nicol, T., Zecker, S. & Kraus, N. (2010)

Intervention type: Fast ForWord

Criteria	Research Design	Measurement of DV	Measurement of IV	Participant Ascertainment	Generalisation
	No of groups Design No of participants Data loss	Type of measurement Protocol Psychometric properties Evaluators	Implementation accuracy Implementation accuracy data collection IOA for treatment fidelity	Who diagnosed (professional; independent; blind) How diagnosed (instrument; DSM ICD)	Objective Maintenance data &/or Across settings / stimuli / responses / persons
Score Per Criteria	2; 5; 1; 2 = 2.5	5; 1; 1; 3 =2.5	0; 0; 0	2; 2 = 2	0; 0 = 0
Weighted Score	2.5 x 0.3 = .75	2.5 x .25 = 0.625	0 x 0.2 = 0	2 x 0.15=0.3	0
Total Score	1.675				

Comment: non-RCT, 5 participants, mixed group of diagnoses (ASD, autism, Asperger's), biological markers only measured.

Study: Smith, I. M., Koegel, R. L., Koegel, L. K., Openden, D. A., Fossum, K. L., & Bryson, S. E. (2010)

Intervention type: NS EIBI (Nova-Scotia early intensive behaviour intervention model) – includes Pivotal Response Treatment

Criteria	Research Design	Measurement of DV	Measurement of IV	Participant Ascertainment	Generalisation
	No of groups Design No of participants Data loss	Type of measurement Protocol Psychometric properties Evaluators	Implementation accuracy Implementation accuracy data collection IOA for treatment fidelity	Who diagnosed (professional; independent; blind) How diagnosed (instrument; DSM ICD)	Objective Maintenance data &/or Across settings / stimuli / responses / persons
Score Per Criteria	5; 4; 5; 4 = 4.5	5; 4; 4; 4 = 4.25	5; 1; 5 = 3.67	5; 5 = 5	5;1 = 3
Weighted Score	4.5 x 0.3 = 1.35	4.25 x 0.25 = 1.06	3.67 x 0.2 = 0.73	5 x 0.15 = 0.75	3 x 0.1 = 0.3
Total Score	4.19 NB: No Control Group				

Comment: no control group. Improved outcomes: Expressive and receptive language; behaviour problems; autism symptoms

Study: Tonge, B., Brereton, A., Kiomall, M., McKinnon, A., King, N. & Rinehart, N. (2006)

Intervention type: Parent training

Criteria	Research Design	Measurement of DV	Measurement of IV	Participant Ascertainment	Generalisation
	No of groups Design No of participants Data loss	Type of measurement Protocol Psychometric properties Evaluators	Implementation accuracy Implementation accuracy data collection IOA for treatment fidelity	Who diagnosed (professional; independent; blind) How diagnosed (instrument; DSM ICD)	Objective Maintenance data &/or Across settings / stimuli / responses / persons
Score Per Criteria	5; 5; 5; 5 = 5	5; 5; 5; 5 = 5	5; 5; 2 = 4	5; 5 = 5	3; 1 = 2
Weighted Score	5 x 0.3=1.5	5 x 0.25= 1	4 x 0.2=0.8	5 x 0.15 = 0.75	2 x 0.1= 0.2
Total Score	4.25				

Comment: Measured parent outcomes only, beneficial outcomes reported compared with controls and alternative treatment group.

Study: Whalen C, M. D., Ilan, A.B., Vaupel, M., Fielding, P., Macdonald, K., Cernich, S.& Symon J. (2010).

Intervention type: Teachtown Basics (Computer Assisted Instruction)

Criteria	Research Design	Measurement of DV	Measurement of IV	Participant Ascertainment	Generalisation
	No. of groups Design No. of participants Data loss	Type of measurement Protocol Psychometric properties Evaluators	Implementation accuracy Implementation accuracy data collection IOA for treatment fidelity	Who diagnosed (professional; independent; blind) How diagnosed (instrument; DSM ICD)	Objective Maintenance data &/or Across settings / stimuli / responses / persons
Score Per Criteria	5; 4; 5; 4 = 4.5	5; 3; 4 ;3 =3.75	1;1;1 = 1	2;2 = 2	5;1 = 3
Weighted Score	4.5 x 0.3 = 1.35	3.75 x 0.25 = 0.94	1 x 0.2 = 0.2	2.5 x 0.15 = 0.3	3 x0.1 = 0.3
Total Score	3.09				

Comment: Beneficial outcomes compared with control group (i.e. regular school curriculum) in receptive language for younger children only, no change in expressive language or developmental assessment.

Study: Zachor, D. A., Ben-Itzhak, E., Rabinovich, A.-L., & Lahat, E. (2007)

Intervention type: Eclectic-Developmental (ED) vs. Applied Behavioural Analysis (ABA)

Criteria	Research Design	Measurement of DV	Measurement of IV	Participant Ascertainment	Generalisation
	No. of groups Design No. of participants Data loss	Type of measurement Protocol Psychometric properties Evaluators	Implementation accuracy Implementation accuracy data collection IOA for treatment fidelity	Who diagnosed (professional; independent; blind) How diagnosed (instrument; DSM ICD)	Objective Maintenance data &/or Across settings / stimuli / responses / persons
Score Per Criteria	5; 5; 5; 5 = 5	5; 5; 5; 3 = 4.5	1; 1; 1 = 1	5; 5 = 5	5; 1 = 3
Weighted Score	5 x 0.3 = 1.5	4.5 x 0.25 = 1.13	1 x 0.2 = 0.2	5 x 0.15 = 0.75	3 x 0.1 = 0.3
Total Score	3.88				

Comment: No control group, ABA group greater outcomes than ED group in communication, social interaction and changes to diagnostic classification

Study: Zachor, D. A., & Itzchak, E. B. (2010)

Intervention type: Eclectic-Developmental (ED) vs. Applied Behavioural Analysis (ABA)

Criteria	Research Design	Measurement of DV	Measurement of IV	Participant Ascertainment	Generalisation
	No. of groups Design No. of participants Data loss	Type of measurement Protocol Psychometric properties Evaluators	Implementation accuracy Implementation accuracy data collection IOA for treatment fidelity	Who diagnosed (professional; independent; blind) How diagnosed (instrument; DSM ICD)	Objective Maintenance data &/or Across settings / stimuli / responses / persons
Score Per Criteria	5; 5; 5; 5 = 5	5; 5; 5; 4 = 4.75	0 (no description)	5; 4 = 4.5	0 (not measured)
Weighted Score	$5 \times 0.3 = 1.5$	$4.5 \times 0.25 = 1.13$	0	$4.5 \times 0.15 = 0.675$	0
Total Score	3.30				

Comment: Outcomes included high diagnostic stability with both groups showed similar stability and change (ABA – 6.7% improved, 4.4% deteriorated; EC – 6% improved). Both groups improved, no difference between groups.

Appendix F: Application of principles of good practice to interventions

Consideration of the extent to which intervention reflects principles of good practice for early intervention and for autism early intervention

Principles of good practice

This section addresses two areas:

- good practice guidelines that are common to most generic early intervention, education or therapy based services
- key elements of effective interventions that are specific to autism and drawn from the current literature on autism spectrum disorders.

Good Practice Guidelines

There are a number of basic, good practice principles that are fundamental to working with young children and their families. It would be anticipated that services on the provider panel would be able to demonstrate their adherence to the majority of the following:

- **Individualised Assessment for Intervention Planning:** This refers to assessments carried out with individual children to determine their strengths and needs in a range of core autism areas, such as communication and social interaction, along with developmental skills. This assessment guides the content of intervention while providing information about the best techniques to use with an individual child. The process should not be confused with assessment for diagnosis of autism. Assessment for intervention planning may take a range of forms including parent questionnaires, formal assessments or structured observations in play.
- **Individualised programming based on strengths and needs:** Programming for intervention should be individualised and based on the findings of the intervention planning assessment. Programs should be designed to address the child's needs while acknowledging, drawing on and encouraging their areas of strength and talent.
- **Individual Plan (IP):** Individual Plans (IP) go by many names, including Individual Education Plans (IEP), Individual Family Service Plan (IFSP), Personal Plans (PP), Individual Service Plans (ISP). For simplicity, the term 'Individual Plan' (IP) will be used in this document to refer to these plans. The basic goals of an Individual Plan are to document:
 - the child's areas of strengths and needs
 - goals for intervention, identified through a collaborative process with those involved with the child , including the family
 - information about how these goals will be addressed
- All children in early intervention services should have an IP that is developed by all those involved with the child, including family, early intervention providers, preschools or childcare services. IPs should be developed at least annually and reviewed at least every 6 months.
- **Review, evaluation and adjustment of program:** Intervention programs need to be evaluated regularly to ensure that they continue to meet the needs of the child. This process involves a review of the IP goals, review of the child's skills and needs to ensure that the program is addressing skills and needs, i.e., the child is showing improvement and the goals are still relevant and development of revised and if required new goals, as appropriate, and in collaboration with the family and other key people in the child's life.
- **Collaboration with other professionals:** The importance of multidisciplinary and/or trans disciplinary teams to early intervention for children with autism is described in full in the following section.
- **Family centred practice:** The importance of family centred practice is described in Section 1.

Key elements of effective interventions for children with autism

Program Content

Within this element there are five basic skill domains; ability to attend to elements of the environment, ability to imitate others, ability to comprehend and use language, ability to play appropriately with toys (Howlin 1997), and ability to socially interact with others (Dawson & Osterling 1997). Marcus, Garfinkle and Wolery (2001) suggested that effective programs utilise the following intervention strategies based on the learning characteristics of children with autism:

- clarifying meaningful information, organisation and scheduling
- teaching across settings and people
- active directed instruction
- individualisation of teaching materials and curriculum
- provision of visual supports
- teaching imitation at a developmentally appropriate level
- using strengths and interests to help with weak areas of development.

The service should address one or more of the key features of autism spectrum disorders:

- communication
- social interaction
- repetitive behaviour and/or restricted interests.

Associated features of autism can include:

- consideration of sensory processing difficulties (though this is not adequately addressed via sensory integration therapy or multi-sensory rooms)
- anxiety
- intellectual disability/learning difficulties.

Questions to ask include:

- Which of the key features does this intervention address?
- Which of the associated features does this intervention address?
- How does the intervention cater to the learning characteristics of children with an ASD, including need for organisation and scheduling, teaching across settings and people, individualisation of teaching materials and curriculum, use of visual supports and using strengths and interests?

Highly Supportive Teaching Environments and Generalisation Strategies

The core skills outlined above are taught in a highly supportive teaching environment and are then systematically generalised to more complex, natural environments. Howlin (1997) stressed the need for behaviourally oriented strategies. Highly supportive teaching environments utilise appropriate environmental supports, structured teaching, visual supports and systematically help children to generalise content of the intervention to other settings (e.g. parent training and information, sharing information with childcare providers, providing services outside traditional clinic based settings). It is also important to consider staffing ratios, especially in group interventions. Implementation of individual child goals in a small group context is not feasible with a less than 2 adults for 6 children.

The interventions provided should include an appropriate staff to child ratio (no more than 6 children with 2 staff). Service providers should be able to describe how they systematically help children to generalise content of the intervention to other settings (e.g. parent training and information, sharing information with childcare providers, providing services outside traditional clinic based settings).

Questions to ask include:

- What is the staff to child ratio for group programs?
- How do you ensure that skills taught in one setting are generalised to the home and community settings?

Predictability and Routine

Research shows that children with autism become more socially responsive and attentive when information is provided in a highly predictable manner and, conversely, that their behaviour is severely disruptive when the same stimuli are presented in an unpredictable manner. Service providers can address this area by establishing routines within sessions supported visually where appropriate and by supporting families and other settings to maximise the use of visually supported routines, social interactions, communication and behaviour strategies.

Service providers should address the need for predictability and routine by establishing routines within sessions supported visually where appropriate and by supporting families and other settings to maximise the use of visually supported routines, social interactions, communication and behaviour strategies.

Questions to ask include:

- How is predictability and routine supported during sessions?
- How are parents and other carers supported to establish routines and predictability in other settings?

A Functional Approach to Challenging Behaviours

Most programs focus on the prevention of problem behaviour by means of increasing the child's interest and motivation, structuring the environment and increasing positive reinforcement for appropriate behaviour. Should the problem behaviour persist despite ecological management, the behaviour is analysed to determine the function of the behaviour for the child. The environment is then adapted in specific ways to avoid triggers and

reinforcers for the problem behaviour and appropriate behaviour is taught to give the child an alternative more acceptable behaviour. Howlin (1997) stressed the importance of recognising the communicative function of problem behaviour and the need to teach the child more appropriate alternative means of communication. Punitive measures, such as exclusionary time out, withdrawal of privileges and other forms of punishment are not appropriate behaviour support techniques for children with autism.

Service providers should use a functional approach to challenging behaviours, including ecological management and analysis to determine the communicative function of the behaviour and teaching appropriate alternative behaviours. Punitive measures, such as exclusionary time out, withdrawal of privileges and other forms of punishment are not appropriate behaviour support techniques for children with autism. Obsessions and rituals may be an underlying function of some challenging behaviours, however these behaviours may have a positive function for the child in regulating anxiety and may also act as a powerful source of motivation and reward.

Questions to ask include:

- How are challenging behaviours addressed during intervention sessions?
- What methods are used to support parents and other carers to prevent challenging behaviours and to support alternative appropriate behaviours?
- How are obsessions and rituals addressed?

Transition Support

Most programs recognise that transition to school is a time when children with autism need a great deal of support. Effective programs actively teach school skills to enable the child to be as independent as possible. Programs frequently take an active role in finding school placements that will best suit the child and then actively integrate the child with autism into the new setting. Transition supports for children with autism can include assisting the child to learn appropriate school readiness skills, collaboration and communication with new settings (e.g. schools) about the child's current skills and needs, and actively supporting transition to a new environment through visits, visual supports and stories where appropriate.

Service providers should adequately address transition where appropriate. Transition supports for children with autism can include assisting the child to learn appropriate school readiness skills, collaboration and communication with new settings (e.g. schools) about the child's current skills and needs, and actively supporting transition to a new environment through visits, visual supports and stories where appropriate.

Questions to ask include:

- How does the service support transitions to new settings? Family Involvement

Effective programs recognise that parents are a critical component in early intervention for children with autism. Most programs support parents to choose the type and intensity of their involvement in their child's program. Effective programs are sensitive to the stresses encountered by families of children with autism and provide parent groups and other types of emotional support (e.g. Dawson & Osterling, 1997; Tonge & Brereton, 2005). Families should also be supported to utilise strategies taught as part of the interventions at home and to be

empowered to encourage their children's communication, social interaction and to manage behaviour effectively at home and in the community.

Service providers should utilise a family centred practice approach wherever appropriate and that families are as fully engaged in decision making, goal setting, planning and implementing strategies as possible.

Questions to ask include:

- How does the service ensure families are involved in assessment, planning, goal setting and strategy implementation for their child?
- How do services support parents to learn about autism and appropriate strategies?
- How do services support families in times of stress?

Use of visual supports

Dawson and Osterling (1997) noted that the provision of augmentative communication methods is a characteristic of many programs reviewed. In addition, both Howlin (1997) and Quill (1997) stressed the importance of visually cued instruction to provide the child with a predictable and readily understood environment.

Services should use highly supportive teaching strategies and supporting predictability and routine during intervention settings and that these strategies are also encouraged and supported in other environments. One of these strategies is the use of visual supports and this should be encouraged in most settings.

Questions to ask include:

- What strategies are used to provide a supportive teaching environment and to encourage predictability and routine?
- What role do visual supports play?

Multi-disciplinary collaborative approach

Autism requires a multi-disciplinary approach to assessment and service provision (Jordan, 2001). The team is likely to include speech pathologists, teachers, psychologists, occupational therapists and parents. Children with autism should access services that are multidisciplinary and collaborative (assessments and programs are provided by a number of individual service providers, such as speech pathologists or teachers, who communicate and collaborate with each other to develop goals, provide intervention and evaluate progress) or trans disciplinary (assessments and programs are holistic, developed by a team of professionals but delivered by a single provider working across disciplines). Collaborative multidisciplinary and trans disciplinary approaches ensure that all areas of need seen in children with autism can be adequately addressed.

HCWA Early Intervention assistance funding is recommended for services that are multidisciplinary and collaborative (programs are provided by a number of individual service providers, such as speech pathologists or teachers, who communicate and collaborate with each other to develop goals, provide intervention and evaluate progress) or trans disciplinary (programs are holistic, developed by a team of professionals but delivered by a single provider working across disciplines). Collaborative multidisciplinary and trans disciplinary

approaches ensure that all areas of need seen in children with autism can be adequately addressed.

Questions to ask include:

- Which disciplines (SP, educator, OT, psychologist) are directly involved in service provision for individual children?
- If the service is a single discipline service, how are collaborative links made with other disciplines providing services for the child?

Additional elements

In addition to the elements listed above, a high level of intensity is recommended (see page 3).

Interventions reflecting good practice are also characterised by the following:

- inclusion of typically developing peers
- promotion of independent functioning throughout the intervention programs
- incorporation of obsessions and rituals as part of structured teaching and positive behaviour support.

Appendix G: Copy of peak bodies' letter and submission request

FaHCSIA Review of Autism Interventions by Australian Autism Research Collaboration (AARC)

Working group: Professors Prior, Roberts, Williams and Rodger

10 April 2011

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The Australian Government has committed \$190 million for the four years up to June 2012 to deliver the Helping Children with Autism package. The package will help address the need for support and services for children with Autism Spectrum Disorders (ASDs). All initiatives include support for parents, families, carers and children from Indigenous backgrounds, Culturally and Linguistically Diverse (CALD) backgrounds and those living in rural and remote areas. The package includes:

- Autism Advisors
- Funding for early intervention services
- PlayConnect Playgroups
- Early Days family workshops
- An ASD website

If you wish to know more about the package, please follow www.fahcsia.gov.au/sa/disability/progserv/people/HelpingChildrenWithAutism/Pages/default.aspx

The Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) has commissioned a review of autism interventions funded by the Helping Children with Autism Package (HCWA). This review is being undertaken by a multidisciplinary group of researchers from Psychology (Professor Margot Prior), Paediatrics (Professor Katrina Williams), Speech Pathology (A Professor Jacqueline Roberts) and

Occupational Therapy (Professor Sylvia Rodger) from the Australian Autism Research Collaboration (AARC).

This review seeks to: (1) provide a comprehensive list of autism interventions based on the latest evidence based research, (2) provide a basis for appropriate assessment by FaHCSIA of provider applications; (3) note concerns raised by families and practitioners, based on feedback from peak bodies, about current practices and ineligible interventions and (4) develop a process to be applied by FaHCSIA designed to ensure that children are receiving effective evidence based interventions and that families are able to make more informed decisions about available interventions.

FaHCSIA have requested that the Working Group consult with a range of stakeholders including the Peak Bodies who represent members who are registered as Autism Panel Providers (professionals accredited by FaHCSIA to provide remunerated interventions) for the HCWA package or practitioners who refer families to such providers. As your organisation is such a Peak Body, we are requesting that you seek the views of your membership in order to provide a submission to the Working Party. We are contacting Occupational Therapy Australia, Speech Pathology Australia, the Australian Psychological Society, The Royal Australian College of Physicians Division of Paediatrics and Child Health and the Royal Australian and New Zealand College of Psychiatrists.

We are interested in a submission from your organisation that addresses the following:

What are your members' views about the way the HCWA package is administered in relation to: approval of panel providers; approval of specific types of interventions; panel providers' interaction with FaHCSIA?

How adequate do your members consider the current provision of eligible early interventions in the HCWA package in terms of: the amount allocated per family; the breadth of interventions provided; quality of advice given to parents by autism advisors; time frame for service provision (i.e. only for children less than 7 years of age)?

What specific concerns (if any) do you have about any of the currently funded interventions? Please see url below for more information on these and attached Appendix A

www.fahcsia.gov.au/sa/disability/funding/earlyintervention/operation_guidelines/Pages/default.aspx

Are there interventions you are aware of that you consider should be funded that currently are not? Please provide comments.

Please list any currently funded interventions that you consider should no longer be funded, and explain why.

What issues (if any) are you aware of that parents may have in accessing HCWA funded early intervention services?

Are there any aspects of FaHCSIA's implementation of the HCWA package that could be improved for your members and parents?

How satisfied are parents are with the current list of eligible interventions available through the HCWA? If not satisfied, what are parents' main issues?

The Early Intervention Operational Guidelines outline the therapies eligible for funding under the HCWA package. Does your organisation refer to these guidelines and do you have any suggested improvements for the guidelines? Please see url below for more information on these and attached Appendix A
www.fahcsia.gov.au/sa/disability/funding/earlyintervention/operation_guidelines/Pages/default.aspx,

Please email your written submission as an email attachment as Word Document by Tuesday 3rd May 2011 to Sue Dodd (suedodd1@bigpond.net.au). If you have any questions please contact Sylvia Rodger s.rodger@uq.edu.au or phone 07 33651664 or Sue Dodd suedodd1@bigpond.net.au.

We thank you very much for your assistance in obtaining the views of your membership. This will assist us to provide comprehensive advice to FaHCSIA and to improve service provision for children with ASD and their families in Australia.

Yours sincerely,



Professor Sylvia Rodger

On behalf of Professors Prior, Roberts and Williams

AARC Working Group.

Appendix H: Autism Advisor Survey

Review of Autism Interventions Survey

Created: May 02 2011, 10:34 PM

Last Modified: May 22 2011, 5:45 PM

Design Theme: Basic Blue

Language: English

Button Options: Custom: Start Survey: 'Start Survey!' Submit: 'Submit'

Disable Browser 'Back' Button: False

Review of Autism Interventions Survey

Page 1 - Question 1 – Choice - One Answer (Bullets)

SECTION 1: DEMOGRAPHICS

Where is your service located?

- Queensland
- New South Wales
- Victoria
- Australian Capital Territory
- Tasmania
- South Australia
- Northern Territory
- Western Australia

How long have you been working as an autism advisor?

- 0-6 months
- 6-12 months
- 1-2 years
- More than 2 years

What is your professional background?

- Teaching
 - Early childhood
 - Occupational therapy
 - Speech pathology
 - Psychology
 - Social work
 - Other, please specify
-

How long have you been working in the area of Autistic Spectrum Disorder?

- Less than 2 years
- 2-5 years
- 6-10 years
- More than 10 years.

What training if any have you received in ASD specifically?

Is your service affiliated with?

- A state based autism association
- Another autism provider
- or you are sole provider
- Other, please specify

SECTION 2: ABOUT YOUR ROLE AND EXPERIENCES AS AN AUTISM ADVISOR

When parents first make contact, approximately how long do you spend on the phone or in person with them?

- Less than 30 minutes
- 30-60 minutes
- 1-2 hours
- More than 2 hours.

Did you feel adequately prepared to undertake your role?

- Very well prepared
- Prepared
- Neither prepared or not prepared
- Not prepared
- Not at all well prepared

How well do you feel the needs of children with ASD are catered for by the current HCWA package eligible interventions?

- Very well
- Well
- Adequately
- Somewhat poorly
- Very poorly

Please comment on how well you feel the needs of children with ASD are being met from your experience

Do you think that most eligible interventions (ie. more than 70%) reflect current best evidence on effective early intervention for children with ASD?

- Very well evidenced
- Well evidenced
- Adequately evidenced
- Inadequate evidence
- Very lacking in evidence.

From your experience please comment on whether (if any) information is provided to parents about the level of evidence for eligible interventions?

Do you have any specific concerns about current eligible interventions?

- Yes
- No
- If you answered yes, please tell us about these concerns

Are there any interventions that you feel should be funded which are not currently?

- Yes
 - No
 - If yes, please provide the name of the intervention and why you feel it should be funded
-

Are there any interventions which are currently funded which you feel should not be?

- Yes
 - No
 - If yes, please provide the name of the intervention and why your feel it should not be funded.
-

What are the issues which impede parents from accessing eligible services?

You may choose more than one response

- Locality/distance
- Cost
- Waiting lists
- Availability of providers
- Lack of adequate resources

- Family finances
- Other, please specify

Page 2 - Question 17 - Rating Scale - Matrix

How adequate do you consider?

	More than adequate	A d e q u a t e	I n a d e q u a t e	Totally inadequate
The current provision of eligible interventions in the HCWA package in terms of the amount of funding allocated per family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The range of interventions offered to families	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The quality of the interventions offered	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The time frame for service provision (ie. only children less than seven years of age)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Page 2 - Question 18 - Choice - One Answer (Bullets)

There are a number of criteria that FAHCSIA requires of eligible interventions. These are that the interventions

are well structured, organised, regular and predictable and focused on specific objectives;

are consistently managed;

focus on attention, compliance, imitation, language and social skills;

provide a highly supportive teaching environment to maximise learning;

have a low child/staff ratio for centre based programs with a maximum of 2-4 children per adult

How well do you feel the majority of services (ie. more than 70%) adhere to these criteria?

- Very well
- Well
- Unsure
- Not well
- Not at all well
- Don't know

Page 2 - Question 19 - Choice - One Answer (Bullets)

Early intervention services must have an ASD specific content and focus including the practices below:

teaching joint attention skills, play and imitation skills; building functional communication skills. This may include language and Alternative and Augmentative Communication (AAC) such as picture systems, gestures and signing;

teaching social interaction skills in a supported environment;

daily living skills, e.g. toileting, washing hands, eating;

management of sensory issues;

generalisation of learning strategies to new situations and with new people;

management of undesirable or challenging behaviors; and

early engagement and recognising emotions.

How well do you feel the majority of services (i.e. more than 70%) adhere to these practices?

- Very well
- Well

- Unsure
- Not well
- Not at all well
- Don't know

Page 2 - Question 20 - Choice - One Answer (Bullets)

Early Intervention services for children under the HCWA strategy must:

have a functional approach to problem behaviours including teaching alternative appropriate skills and positive behaviour support, and communication skills to replace the behaviours of concern.

be designed in collaboration with the family and include family involvement. Through advice and information, families are supported to help their child with play, social and communication skills development, and with the management of challenging and repetitive behaviours.

families, teachers and therapists are to collaborate in preparing the child for transition to school or to another setting.

must provide systematic connection and integration between the early intervention program and the next stage for the child, whether this transition is to school or to another therapeutic or special education setting.

ensure that the child's social, cognitive and/or adaptive functioning before, during and at the end of their treatment plan is systematically evaluated and reported according to the requirements of the Deed of Agreement.

How well do you feel the majority of services (ie. more than 70%) adhere to these guidelines?

- Very well
- Well
- Unsure

- Not well
- Not at all well
- Don't know

Page 3 - Question 21 - Choice - One Answer (Bullets)

SECTION 3: YOUR PERSPECTIVES ABOUT PARENTS' NEEDS, SATISFACTION WITH PANELS AND ELIGIBLE INTERVENTIONS

On average, how long is it between when parents have received a diagnosis for their child and when they make contact with you as an Autism Advisor?

- Less than a month
- 1-2 months
- 3-5 months
- 6 months or more

Page 3 - Question 22 - Choice - Multiple Answers (Bullets)

What are parents' main needs when they make contact with you as an Autism Advisor?

You can choose more than one option.

- Emotional support
- Information about ASD
- Information about services available
- Information about government support
- Information about parent support groups
- Just need to chat
- Information about how to choose the right services/interventions for their child/family

- Other, please specify
-

Page 3 - Question 23 - Choice - Multiple Answers (Bullets)

What type of information do parents typically want?

You can choose more than one option.

- Services/interventions in their locality
 - Cost of interventions
 - Evidence behind interventions
 - Other parents experiences with interventions
 - Websites
 - Local autism associations/parent groups
 - Which intervention is right for their child
 - Other, please specify
-

Page 3 - Question 24 - Choice - One Answer (Bullets)

Do parents typically find the intervention they want in their locality?

- Yes all of the time
- Yes most of the time
- Not usually
- Never

How satisfied are parents with the current list of eligible interventions available?

- Very satisfied
- Somewhat satisfied
- Neither satisfied nor dissatisfied
- Dissatisfied
- Very dissatisfied.

If parents are dissatisfied, please comment on their main issues

Generally, how satisfied are parents with the interventions they receive?

- Very satisfied
- Somewhat satisfied
- Neither satisfied nor dissatisfied
- Dissatisfied
- Very dissatisfied.

Are there any particular interventions which parents are most satisfied with?

- Yes
 - No
 - If yes, please provide details of the interventions and why parents are satisfied with them
-

Are there any interventions which parents are least satisfied with?

- Yes
 - No
 - If yes, please provide details of the interventions and why parents are dissatisfied
-

Are parents' needs post diagnosis being met with the HWCA eligible interventions?

- Yes very well
- Adequately
- Not well
- Not at all well

The Early Intervention Operational Guidelines outline the therapies eligible for funding under the HCWA package. See the url below for more information on these http://www.fahcsia.gov.au/sa/disability/funding/earlyintervention/operational_guidelines/Pages/default.aspx

Do you have any suggested improvements for the guidelines?

Are you aware of any specific concerns that the parents you engage with have about any of the eligible interventions?

Please provide details if there are any concerns.

Are there any interventions that parents would like access to, that they currently do not have access to?

Please provide details.

Page 3 - Question 34 - Open Ended - Comments Box

Do you have any other comments?

Thank You Page

Thank you for taking the time to complete this survey. Your responses will assist in the review of the HCWA funded interventions to ensure that they are comprehensive and in keeping with latest evidence based research and best practice standards

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