A Review of the Research to Identify the Most Effective Models of Practice in Early Intervention for Children with Autism Spectrum Disorders. & Recommendations for determination of good practice.

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July 2011

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

~~AUTISM TREATMENT~~ REVIEW OF EARLY INTERVENTION THERAPIES

This review was prepared by Professor Margot Prior, Associate Professor Jacqueline Roberts, Professor Sylvia Roger and Professor Katrina Williams representing t~~T~~he Australian Autism Research Collaboration (AARC).
The AARC was requested by the ~~THE~~ Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) to undertake this review.

The review was completed with assistance from Dr Greta Ridley, Rebecca Sutherland and Susan Dodd. ~~for the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs~~

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Acknowledgments

This review is a follow up and extension of a 2006 report commissioned by the Australian Government Department of Health and Aging.

The authors would like to acknowledge the contribution of the following people to this review: Advisory group members; Dr Natalie Silove, Professor Valsa Eapen, Dr Angelika Anderson, and Mrs Judy Brewer Fischer, for their contribution to this review. Organisations across Australia for completing surveys and providing information.; Australian Advisory Board -on-Autism Spectrum Disorders (AAB), Autism Advisors, Parenting Research Centre (PRC), professional bodies; Speech Pathology Australia (SPA) Occupational Therapy Australia, the Australian Psychological Society, The Royal Australian College of Physicians Division of Paediatrics and Child Health.

Disclaimer

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~~Housing, Community Services and Indigenous Affairs (the Department) has financially supported the production of this review. Whilst every effort has been made to ensure that the information contained in the review is accurate and up-to-date at the time of publication, the Department does not accept any responsibility for any errors, omissions or inaccuracies in this review. The views expressed by the authors do not necessarily represent the views of the Department or Australian Government policy.~~

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Suggested Format for Citation

Prior, M, Roberts, J. M. A., Rodgers S., Williams, K. Ridley, G., Sutherland, R., Dodd, S., (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.

The Context of the R~~r~~eview

This report presents an update and extension of the results and recommendations arising from a review of early intervention services for children with Autism Spectrum Disorder (ASD) ~~autism~~ completed for t~~T~~he Department of Health and Aging (DOHA) by Jacqueline Roberts and Margot Prior in 2006. The report also contains a discussion of what is currently understood about principles of good practice in autism early intervention and the application of those principles in practice. Sections of this report address issues that have arisen as a result of the ~~roll-out of funding for autism~~implementation of the Ea~~-~~rly i~~I~~ntervention Services component of the~~through the~~ Department of Families, Housing, Community Servoices and Indigenous Affairs' (FaHCSIA) Helping Children with Autism (HCWA) P~~p~~ackage.

Comment [cw1]: Either autism or ASD but consistent throughout

~~The current~~This report was commissioned by FaHCSIA to provide up to date information about the evidence base for interventions for young children with autism up to 7 years, including rating of scientific merit and an update of current understanding of what constitutes good practice in autism intervention. Recommendations from the report will ~~to~~ inform the process used by FaHCSIA ~~of~~to assessing the eligibility of proposed interventions and the suitability and capacity of potential providers to deliver effective ~~of~~ autism early interventions~~ for eligibility for funding as providers~~.

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 effectiveness. Parents and professionals, including government, need information to help them evaluate claims of successful treatments, particularly those treatments with~~in~~ which practitioners have claimed to have 'cured' children

with autism, or promise to do so. Although these interventions might be helpful to children, they might also be ineffective or even harmful. Research evidence is needed to address these claims.

There is limited direct research evidence to support the effectiveness of a small number of treatment programs. T~~,t~~hat is, research into outcomes of particular interventions which is robust enough to allow for confident recommendations about the efficacy or otherwise of the intervention. However, most treatments have not been ~~the~~ evaluated adequately and some have not been evaluated at all. Consequently, parents and professionals must also consider how well interventions meet 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 review is based on reputable reviews that have rated the scientific merit of research evaluating the intervention. If research evidence was found that had not previously been rated, the research was rated by the team using a scientific merit rating scale (SMRS) developed by the United States' National Autism Center for the National Standards report (2009). In addition, overall findings from several international reviews of the research evidence for treatments for children with autism have been summarised and included.
A list of these reviews is provided in Appendix X.

This review will include:

- A summary of the research findings pertinent to assessing eligibility and non-eligibility of early interventions;
- A summary of the feedback from consultations with stakeholders and peak bodies, and a synthesis of their views and suggestions.
- 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, and recommendations for the process to achieve this aim including a proposed script for FaHCSIA staff to refer to in explaining the approval standards to stakeholders who contact the department.
- Rules and guidelines to underpin decision making on program/provider approval.

Deliverables:

1. Updated review of the evidence base for interventions for young children with autism (0-7 years) including rating of scientific merit and an update of current understanding of what constitutes good practice in autism intervention.

2. Surveys of stakeholders focusing on issues arising for them from the Early Intervention ~~EI p~~Provider P~~p~~anel.

3. Process for evaluating applications for provider status updated if necessary as a result of literature review and survey.

4. A table of eligible and ineligible interventions arising from the evaluative reviews which can be used by FaHCSIA to make decisions regarding programs proposed by providers.

5. Guidelines and recommendation re process for future evaluation of applications by FaHCSIA (see dot point above).

Key Cconsiderations and Scope

Age range:
The focus of this report is the early intervention (EI) for children with autism up to the age of 7yrs which is ~~,~~ the age limit for eligibility for receiving access to early intervention funding and services ~~as a provider~~ under the HCWA EI ~~provider~~ Services ~~program~~Provider Panel. Research into interventions for older age groups of children and adults with autism has not been reviewed.

Which Interventions:
This review focuses on interventions based on learning for ~~young~~ children under 7 years old as these are the interventions funded ~~as part of~~through the HCWA EI provider ~~program~~panel. There is a range of other interventions for autism including medical/biological and complimentary and alternative medicine/treatment (CAMS) interventions. H~~,~~ however, in general, there is minimal positive research evidence for CAMS and only limited evidence for some medications that may assist with behaviour management or with co-morbid mental and physical health conditions (e.g. anxiety). Interventions that are medically based and interventions involving ~~complimentary and alternative treatment (~~CAMS~~),~~ are therefore not addressed in this report.

~~**Intervention based on learning:**~~
~~The primary focus of this review is i~~Interventions for young children with autism and their families that are based on learning~~. These~~ can be described as:

- ~~-~~primarily B~~b~~behavioural,
- primarily ~~developmental~~Developmental,
- C~~c~~ombined,
- primarily ~~t~~Therapy B~~b~~ased,
- F~~f~~amily B~~b~~ased and/or
- O~~o~~ther including interventions for commonly occurring co-morbid conditions such as anxiety.

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Please see **Appendix X** for a description of the classification system used to discuss 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. 15 - 25 hours per week over a substantial period 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 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).
Funding provided under the HCWA EI provider program for early intervention is not sufficient to purchase 15 hours per week of early intervention for any significant period of time. The intent of the FaHCSIA early intervention funding is to supplement intervention funded from other sources.

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

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Review Part 1.

1.1. Introduction/Background

What are Autism Spectrum Disorders?

Autism spectrum disorders (ASD) are characterised by qualitative impairment 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, it is not 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 International Classification of Diseases (ICD-10) (WHO 1993).

ASD is generally considered to include autism, defined in Diagnostic and Statistical Manual of Mental Disorders, third edition (DSM-III) (APA 1980) as Infantile Autism, ~~and~~ 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 syndrome or Asperger disorder and
- atypical autism.

It is expected that with the release of DSM-V in 2013 the term ASD will become the official diagnostic term (dsmv.com) and all other diagnostic labels listed above will no longer be part of that classification system.

Individual variation

What all those working with children with autism know, is that children diagnosed with autism are as different from each other as they are similar. 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, ~~and~~ weaknesses and function that is thought so 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 remain the mainstay of diagnosis. However, diagnostic ~~they~~ classifications are of great relevance to those organisations funding intervention services for

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children with ASD and other disabilities, as they impact both the numbers of children identified and the type and duration of interventions that need to be available (Szatmari P., 2011).

Diagnosis and ~~A~~assessment.

Though ~~D~~diagnosis is clearly important ~~however~~ it is not the primary focus of ~~this element~~Early Intervention component of the HCWA ~~P~~package. Children need to be identified as having an autism spectrum disorder in order to access EI funding under the HCWA ~~P~~package. Diagnosis needs to be done by suitably qualified professionals working collaboratively with families 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 done for each child as part of a tailored, individualised approach to intervention. This is not the same as a diagnostic assessment, although one may inform the other. Individual assessment for programming purposes may be done by means of checklists and a number of/many/some??? established interventions for children with autism have checklists for assessment. Good practice dictates that an individualised approach is central to intervention for autism and that each child's strengths and needs must be assessed, goals for intervention developed and prioritised, and programs implemented reviewed and revised as required. A useful tool for this purpose, a planning matrix, is described in Appendix X.

Incidence and Prevalence

Estimates of the prevalence of autism using the DSM-III, DSM-IIIR DSM-IV or ICD-10 diagnostic classification systems, from published literature up to April 2004, vary between 1 and 40/10,000 and for any ASD between 3 and 82/10,000 (Williams JG, Higgins JPT, Brayne CEG., 2006). Publications from 2006 have estimated the prevalence of any ASD between 22 and 116/10,000 (Baird G, Simonoff E, Pickles A, Chandler S, Loucas T, Meldrum D, Charman T. 2006; E. Fombonne, R. Zakarian, A. Bennett, L. Meng, and D. McLean-Heywood. 2006; PascaleGuillem, Christine Cans, Vincent Guinchat, Marc Ratel, Pierre-Simon Jouk. 2006; Gillberg C, Cederlund M, Lamberg K, and Zeijlon L. 2006; Williams K, Macdermott S, Ridley G, Glasson EJ, Wray JA. 2008), however lower rates have also been reported (H. O. Atladottir, E. T. Parner, D. Schendel, S. Dalsgaard, P. H. Thomsen, and P. Thorsen. 2007; C.-Y. Chen, C.-Y. Liu, W.-C. Su, S.-L. Huang, and K.-M. Lin. 2007). Males are affected about four times more frequently than females.

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Collaborative Multidisciplinary Practice

Autism spectrum disorders are multifaceted conditions encompassing a range of core features (communication impairment, social interaction difficulties and repetitive behaviour and restricted interests), as well as a number of associated features (intellectual disability in some children, sensory processing differences, anxiety and challenging behaviours). A single discipline or approach is unlikely to address all the intervention needs of the child and their family in an 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 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, 2001). This is particularly the case in complex difficulties such as autism, as described by Jordan (2001): *'Autism...is a condition that straddles so many difference 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, utilising a transdisciplinary 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. Families are also integral members of multidisciplinary teams.

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Working with Ffamilies

Working with families and ensuring they are part of the goal setting, planning, intervention and evaluation of any program or intervention is crucial. To do this, parents require emotional support, advice, and training in working with their children. Families are the only 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 meaningful social contexts (Keen, 2007, Beatson, 2006). The following points require consideration:

- **Stress and grief:** It is recognised that families of children with autism 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 both which services to access and 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 ~~a~~is central to the decision making process (Keen, 2007). It is clear, however, that making decisions about ~~choosing~~ 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 decision making and seeking intervention but will continue to require support to engage with service providers and develop effective partnerships. Effective service delivery must accommodate the different 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, Baladin & Rossi, 2005); Vigil & Hwa-Froelich, 2004). The needs of families from culturally and linguistically diverse backgrounds must also be considered when providing intervention programm~~m~~es 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).
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Program Fidelity and Outcomes:

Challenges Inherent in Measuring Outcomes

The~~is~~ gap between program claims and empirically validated outcomes arises in part because the criteria for good science are based on rigorous experimental methods such as random assignment to treated and untreated groups and tight control of any variables which may affect outcomes, other than the specific intervention being assessed. In order to provide compelling evidence for the effectiveness of a particular intervention, a range of scientific criteria must be met.

However, intervention programs cannot always meet such criteria. Random assignment of participants to a treated, or an untreated comparison group, for example, may not be feasible or even legal, and complex variables such as the nature of the relationship between the person delivering the treatment (e.g. teacher) and the child cannot be easily controlled for. However without research to evaluate interventions, claims of successful results cannot be substantiated. It is possible, if

difficult, to design scientifically rigorous research studies in order to evaluate outcomes of intervention.

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 in a "flagrant perversion or disregard for evidence" (Schopler, Yirmiya, Shulman, & Marcus, 2001, p13).
Significant issues for any researcher looking at intervention outcomes include the variability or lack of precision in terms of the description of the nature of the autism spectrum disorder of participants, and variability in the outcome measures which make comparison of studies of different treatment evaluations difficult. There is also the issue of clinical versus statistical significance and the number of outcome measures, i.e. only one outcome measure of several may show significant results.

Fidelity refers to the confidence with which we can say that the program delivered was the one that was described. Firstly, a description of the program needs to be available, sufficient to replicate the intervention. This is usually 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.
The challenges ~~addressed~~ 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.

Heterogeneity of Aautism.

Autism is a spectrum disorder encompassing a range of individuals with characteristics which ~~a~~ range in severity across domains of communication and social development and restricted interests/repetitive behaviour. The range of autism increased significantly with the addition of Asperger's Disorder in the 1990s and now includes a majority of cognitively able individuals. Several well established interventions for autism, e.g. 'The Me Program' (Lovass,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 and, in addition to variation across domains there is variation depending on age, ~~and~~ maturity, ~~and variation of~~ family background and cultural expectations. The challenge for an 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 environmental factors.

Issue of Ttiming of iintervention

Recent growth in research and knowledge about intervention practice and progress reinforces the importance of intervention in early 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 co-morbid mental health problems ~~such as~~ like anxiety. As a result of this evidence the focus/target group? of the early intervention funding provided by FaHCSIA through the HCWA Package is ~~young~~ children ~~of preschool age~~under 7 years old.

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1.2 Making decisions about eligibility for ~~funding as an~~membership of the HCWA EI ~~autism p~~Provider Panel Or Purpose of Review

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 provider status is highly variable which poses significant challenges for those responsible for making decisions about eligibility for ~~funding~~membership on the HCWA EI Provider Panel.

This review summarises new developments in autism treatment, and ~~by~~ ratesing the efficacy of interventions reported and published, in terms of scientific merit and adherence to the principles of good practice in autism early intervention. Our goal is to bring confidence and validity to decisions on what works and what merits HCWA funding.

The process for evaluation of applications for provider status involves consideration of the following:

- Scientific Merit, 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 autism which informs us about how likely it is that the intervention will be effective based on our knowledge of the condition; and .
- Principles of good practice for early intervention generally and for autism intervention more specifically. These are characteristics of interventions reported in the research literature thate contribute to successful outcomes for children with autism/ASD? and their families.

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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 ~~published~~ treatments published ~~(~~between 2005 and ~~-~~2011,~~)~~ from a scientific point of view to identify and assess evidence for 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 efficacy from the results.

Methodology for Scientific Merit ~~R~~rating Scale (SMRS)

In this review we have used the Scientific Merit Rating Scale (SMRS) developed by the United States' National Autism Center for the National Standards ~~R~~report (2006). 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 SMR score are:

- Research design;
- Measurement of the dependent variable;
- Measurement of the independent variable or procedural fidelity;
- Participant ascertainment; and
- Generalisation.

For detail about the SMRS and process followed for this review please see appendix X

Limitations

There are two key limitations to the SMRS process used in this review:

Amount of evidence

There is some reliable evidence for a small number of interventions (see summary of systematic reviews and our own SMRS tables – appendix X) however the clear majority of interventions we have been asked to rate do not have an evidence base. As a result, Type 2 evidence (e.g. does the proposed intervention make sense in light of what we know about autism?) needs to be considered and we also need to consider 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 our recommendations concerns the information that should be provided in applications for eligibility to enable evaluation of the application.

Intensity

The second limitation concerns the intensity of the interventions assessed to be 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 possible with HCWA funding alone.

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1.2.2 Principles of Good Practice

In addition we refer to previous 2006 review (Roberts and Prior 2006) and the decision to work with guidelines (reference) established on the basis of that review to underpin eligibility, as far as is possible.

These guidelines will remain as core criteria for judgement of the suitability of interventions regardless of modifications stemming from this review:

Key elements of effective interventions

- Curriculum content
- Supporting the need for highly supportive teaching environments and generalisation strategies
- Supporting the need for predictability and routine
- A functional approach to challenging behaviours
- Transition Support
- Family involvement

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PLUS

- Use of Visual Supports
- Sufficient Intensity
- Multidisciplinary collaborative approach
- Inclusion of neurotypical (?)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 X**

1.3 Outcomes of Review for Children with ASD and their Families

The objectives are that families should get the best possible interventions for their children, and FaHCSIA should deploy their funding to achieve the best effects for ASD children and their families.

1.3.1 What is in and what is out and why as the basis of the review?

We focus on behavioural and learning based interventions including behavioural, developmental, family based, eclectic, in the updated review and recommendations, because these encompass what are known to be the overall most helpful and effective ways of treating ASD (see Roberts & Prior 2006)

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Katrina could you select key refs here please, don't think we need all of them!

2. Review of Early Intervention Therapies

The Review examined two different areas:

- Research into early interventions for ASD that had been carried out since the Roberts and Prior (2006); and
- Interventions proposed by members of the HCWA Early Intervention Provider Panel that were not easily identified as eligible according to existing criteria

Review of each area involved consideration of both scientific merit (using the Scientific Merit Rating Scale (SMRS) and taking into account both Type 1 and 2 research evidence) and principles of good practice in autism intervention as detailed in section 1.2.

2.1 Autism Research Literature Search

Explanation and summary – with Table attached as appendix

Part 2. Research literature search, rating of research using SMRS, discussion of extent to which intervention is base on research into characteristics of autism and principles of good practice in autism intervention.

Interventions based on learning

Combination of SMRS if available Methodology for searches and SMRS (see appendix X)
Consideration of scientific merit
Summary of information from key reviews (final column yet to be completed)

Type	Article	Current study	NAC, Effectiveness review and R&P
Behavioural Interventions Applied Behaviour Analysis (ABA) (Early) Intensive Behavioural	Zachor 2010	High quality study SMRS 3.88 comparing EIBI and eclectic interventions.	

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Interventions (EIBI/IBI) Contemporary ABA e.g. NLP	Virues-Outega (meta-analysis)	**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.	
	Peters-Scheffer 2011 (meta-analysis)	**Overall outcome:** EIBI group out performed control group on all dependent variables. 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 methodological (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).	
	Makrygianni 2010 (meta-analysis)	**Overall outcomes:** 1. Behavioural EIPs can improve their 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 are much more effective than the eclectic (control) programs in improving the intellectual,	

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		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. 4. 25hrs/week: ES >0.7 (High) for all outcomes; >25hrs/week no further effect	
	Eldevik 2010 (meta-analysis)	GR	
	Mancil 2009	GR	
	Lydon 2011	PRT vs. video modeling, good quality study (3.675) *(check paper and outcomes)*	
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	Smith 2010	Good quality study with unknown treatment effects (*check paper and outcomes).*	
	Zachor 2010	High quality study SMRS 3.88	
	Magiati 2011 (systematic review)	**Overall outcome:** Study is 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	

Alternative Program for Preschoolers and Parents)		not shed any light on efficacy of particular interventions.	
	Odom 2010 (systematic review)	Have – check details with Greta	
	Eikeseth 2009 (systematic)	**Overall outcome:** Twenty studies evaluated behavioural treatment, 3 studies evaluated TEACCH and 2 studies evaluated the Colorado Health Sciences Project. ABA treatment is demonstrated to be effective in/at? 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)	
	Peters-Scheffer 2010	Good quality study (3.54) of combined intervention (group program using TEACCH principles, individual using Lovaas), compared with no treatment (normal preschool program). Significant outcomes for developmental age and adaptive skills. No difference for ASD severity or behavior.	
Family Based Interventions *(and parent training)* The Hanen Program The Early Bird Program	Pillay 2011	Parent training course, low quality study (2.263). All data parent self-report. No comparison group. Reported improvements in parent knowledge and child behavior but interpret with caution.	
	Whittingham 2009	Stepping Stones Triple P, RCT. Good quality (3.95) with significant reductions in child behavior, improvement in parenting styles, greater parental efficacy at follow up.	
	McConachie 2007 (systematic review)	To add	

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	Carter et al 2011	Hanen MTW, good quality study (4.15). No main effect for child outcomes but higher outcomes for children with lower initial object (?) level.	
	Oosterling 2010	Good quality study (3.76) No difference found between parent training group and care as usual (though 'care as usual' was very comprehensive)	
	Keen 2010	Good quality study (3.72) comparing parent supported intervention (workshops & visits) with self-directed video based activities. Greater social communication reduced parenting stress levels.	
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	Gulsrud et al 2007	Good quality study (3.675) comparing two interventions, no control *(check article and outcomes)*	
	Stephenson 2009 (review article)	Weighted vest - GR	
	Kokina 2010 (meta-analysis)		
	Van der Meer 2010 (systematic review of SGD)	**Overall outcome:** Only 4 /23 studies had "conclusive " single-subject study designs comprising a total of 13 children. Two small studies had positive effects though these were small, non-RCT studies.	

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Communication (FC) Functional Communication Training (FCT) **Social skills interventions** **Sensory/Motor Interventions** Sensory Integration Auditory Integration Training Doman-Delacato method			
	Karkhaneh 2010 (systematic review)	**Overall outcome:** Majority of children in this review are >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 & Carter 2009 (systematic review) PECS	**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	
	Kagorah (2007) (systematic review)	**Overall outcome:** Video modelling. 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	
	Wong & Kwan 2010	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 size, reporting of data.	
	Kalyva 2005	Circle of friends program. Very small RCT, low quality (2.68), 5 participants (n=3 treatment). Improved communication initiation and response but interpret with caution.	
	McConkey 2010	Lower quality study (2.61), some beneficial outcomes reported. TEACCH, + PECS + Hanen ('Keyhole') – need to read article	

	Landa 2009	High quality study (4.57) with outcomes for both groups *(need to look at paper and outcome info)*	
	Whalen (teachtown)	Reasonable quality study (3.09) with beneficial treatment effects compared with controls)	
	Yoder 2010	High quality study (4.67) comparing PECS with 'Responsive education, pre-linguistic milieu' teaching. *Check paper and outcomes*	
Other Interventions Higashi/Daily Life Therapy The Option Method Music Intervention Therapy Spell The Camphill Movement Miller Method	Lim 2010	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 (sig differences, large effect size); low functioning participants showed greater improvement with music training than speech training	
Interventions for co-morbid conditions associated with autism such as anxiety, challenging behaviour CBT PBS			

Concluding summary to be completed

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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.

Move these Principles of Good Practice to Appendix??

Principles of good practice

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

Good Practice Principles

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 d~~-D~~evelopment of revised and if required new goals.

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as appropriate, and in collaboration with the family and other key people in the child's life.

Additional good practice principles includes the adoption of the following

- **Family centred practice** as described above
- **Collaboration with other professionals** as described above

Key elements of effective interventions for children with autism:

Curriculum 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 & Wolery (2001) suggested that effective programs utilise the following intervention strategies based on the learning characteristics of children with autism:

- ~~c~~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; and
- using strengths and interests to help with weak areas of development.

Services on the provider panel 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
- anxiety
- intellectual disability/learning difficulties and related problems

~~Supporting the need for h~~Highly Ssupportive Tteaching Eenvironments and Ggeneralisation Sstrategies

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

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~~Supporting the Need for~~P~~p~~redictability 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

A Ffunctional Aapproach to Cchallenging Bbehaviours

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.

Transition SSupport

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.

Family Iinvolvement

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 (Dawson & Osterling, 1997) up to date ref? e.g. tonge & Brereton, others from lit review. 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.

Use of Vvisual sSupports

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.

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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 transdisciplinary (assessments and programs are holistic, developed by a team of professionals but delivered by a single provider working across disciplines). Collaborative multidisciplinary and transdisciplinary approaches ensure that all areas of need seen in children with autism can be adequately addressed.

In addition a high level of intensity is recommended (see pg x)
Interventions reflecting good practice are also characterised by
Inclusion of typical peers,
Promotion of independent functioning and
Incorporation of obsessions and rituals.

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-Application of standards to FAHCSIA'S current provider list which we were asked to review i.e. combination of SMRS if any and consideration of how well guidelines for good practice are met .

Or

2.2 Review of Interventions Proposed by Members of FaHCSIA's Provider Panel

Summary of review and ratings of treatments -grouped according to classification system (SMRS done by team if not already completed):

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Table of eligible and non eligible interventions based on research evidence re program outcomes (Type 1 evidence), research analysis in relation to characteristics of autism (Type 2 evidence) and degree to which intervention meets principles of good practice based on information available about the intervention.
Interventions for which there is insufficient evidence to make an assessment are also shown.

Interventions for review

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Interventions	Type I evidence (current review, NAC, R&P)	Type II evidence &/or rationale	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 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.
D.I.R/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 training to allow for	• Limited direct evidence, addresses core features of autism utilising a developmental approach.

Interventions	Type I evidence (current review, NAC, R&P)	Type II evidence &/or rationale	comment
		high intensity program in the natural setting.	
The P.L.A.Y. 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. 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 (SCERTS)	No specific evidence of effectiveness.	Program focuses on key areas of autism – social communication, emotional regulation and providing transactional supports (including visual supports and other communication aides). Very strong basis in research for all components of the model.	SCERTS is a model of service provision, rather than a specific program. No research regarding the effectiveness as a whole but 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) (Tsang, 2007). Significant improvements in motor and cognitive, control group also made gains.	Components of program strongly based in established understanding of autism, utilising: • autism specific curriculum • structured teaching • routines and organisation • communication support • use of visual supports • strengths based content & 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.

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Interventions	Type I evidence (current review, NAC, R&P)	Type II evidence &/or rationale	comment
Triple P – Stepping Stones adaptation	Good quality (3.95) with significant reductions in child behavior, 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 • 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.
CATS (Northcott)	Assessment and provision of high tech communication devices (speech generating devices, SGD). No large scale RCT 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	From Roberts & Prior (2006) – • *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*	From Roberts & Prior (2006): • 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"	http://millermethod.org/ Very limited research evidence (type 1) Limited type 2 evidence Limited evidence for 'elevated platform' rationale Unknown best practice elements, including predictability and routine, autism specific curriculum, intensity

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Interventions	Type I evidence (current review, NAC, R&P)	Type II evidence &/or rationale		comment
	must be considered pre-experimental in nature	• strategies employed include narrating the children's actions while they are a metre above the ground on an 'Elevated Square' From website: • focus on sign AAC while narrating elevated activities • philosophy mentions social interaction, communication and behaviour but it is unclear how these are addressed		and transition support
		ASD specific curriculum content	?	
		supportive teaching environment	☑	
		generalisation strategies	☑	
		predictability and routine	?	
		functional approach to CBs	☒	
		transition support	?	
		family involvement	☑	
		visual supports	☒	
		intensity	?	
		multidisciplinary collaborative	☒	
Multi-sensory Environment (Snoezelen room) Also known as Snoezelen rooms, provides sensory stimuli across the range of sensory modalities within a specially built room. Initially designed for institutionalised patients. Also used with elderly population with dementia	• total 6 studies (autism + snoezelen, autism + multisensory environment) • 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 autism	Limited evidence for rationale		Limited Type 1 evidence Limited evidence for rationale Does not meet best practice criteria as a stand-alone intervention
		ASD specific curriculum content	☒	
		supportive teaching environment	☒	
		generalisation strategies	☒	
		predictability and routine	☒	
		functional approach to CBs	☒	
		transition support	☒	
		family involvement	☒	
		visual supports	☒	
		intensity	☒	
		multidisciplinary collaborative	☒	

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Interventions	Type I evidence (current review, NAC, R&P)	Type II evidence &/or rationale	comment
Sensory Integration Therapy Sensory Diet	Roberts & Prior (2006) found no supporting evidence for SIT Comparative Effectiveness Review (2011) indicated that studies of SI were of poor quality. Rodger et al (2010) describe *'no robust evidence supporting its efficacy in achieving functional outcomes by correcting underlying sensory integrative dysfunction'* (p.2).	Sensory processing differences are widely reported in autism but no quality evidence that SI changes sensory responses.	Children with autism may have marked responses to sensory information; however there is currently no evidence that SIT can correct underlying problems.
Auditory Integration Therapy	Limited evidence of effectiveness (see Roberts & Prior, 2006 for review). Comparative Effectiveness Review (2011) described two fair quality studies with no effect of treatment.	Sound sensitivities often reported but limited evidence of physiological differences (Stiegler & Davis, 2010). No evidence that AIT changes physiological level or behavioural response.	Also known as 'Tomtatis therapy', listening therapy and therapeutic listening. No research evidence of effectiveness. Not currently listed by FaHCSIA as an eligible therapy.
Alert Program for self-regulation	Program evaluated for students with 'emotional disturbances' in mainstream schools and a modified program for school aged children with foetal alcohol spectrum disorder No other empirical research found	Based on theories of self-regulation and SI, see above.	Aims to teach children (and/or their parents) to identify their sensory state (high, low, alert) and to use appropriate sensory diet strategies to self-regulate. Based
Cognitive Behaviour Therapy (Sydney Paediatrics, Kids First Children's therapy NSW)	Some direct evidence of effectiveness for school aged children with high-functioning autism or Asperger syndrome (ages 7+). No apparent evidence for early intervention population.	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.
Service based treatments specific to autism – referred to FaHCSIA to find out more about services.	This section to be referred to but removed		

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Interventions	Type I evidence (current review, NAC, R&P)	Type II evidence &/or rationale		comment
Learn & Grow Group (Grafton Community programs)	No direct evaluation of program, service based	Service based small group program, list appropriate structures, including assessments, reports, IEP, home visits, preschool visits, multidisciplinary, parents training, longer term commitment (1 term) Unclear whether there are autism specific components in group		Name of group - need to check individual components of: • ASD specific curriculum • Supportive teaching environment (including ratio, group size) • Predictability and routine • Approach to behaviour • Use of visual supports • Intensity
		ASD specific curriculum content	?	
		supportive teaching environment	?	
		generalisation strategies	☑	
		predictability and routine	?	
		functional approach to CBs	?	
		transition support	☑	
		family involvement	☑	
		visual supports	?	
		intensity	?	
		multidisciplinary collaborative	☑	
HAPP Approach	No direct evaluation of program, service based	Describes an autism specific program including: family centred approach, appropriate communication strategies (PECS, visual supports), interest based		Name of group at Horizon EI – describes an autism specific program including family centred approach, appropriate communication strategies, interest based.
		ASD specific curriculum content	☑	
		supportive teaching environment	☑	• Check PBS approach, generalisation, transition and routines • Check for further information about how the program works in practice
		generalisation strategies	?	
		predictability and routine	?	
		functional approach to CBs	☑	
		transition support	?	
		family involvement	☑	

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Interventions	Type I evidence (current review, NAC, R&P)	Type II evidence &/or rationale		comment
		visual supports	☑	
		intensity	☒	
		multidisciplinary collaborative	☑	
SERVAM • Sensory considerations • Environmental management • Routines and planned change • Visual supports • Autism friendly communication • Motivation	No direct evaluation of program, service based	• Program principles match current understanding of autism and best practice • elements of program drawn from research • unclear how principles are operationalised		Service based, developed by SP and OT. Also involves music therapy. • Publication, parent training + therapy services • intensive school readiness groups • unclear what other services are offered
		ASD specific curriculum content	☑	
		supportive teaching environment	?	
		generalisation strategies	☑	
		predictability and routine	☑	
		functional approach to CBs	☑	
		transition support	☑	
		family involvement	☑	
		visual supports	☑	
		intensity	?	
		multidisciplinary collaborative	?	
Play Links (Koorana)	No direct evaluation of program, service based	Autism specific preschool program 2 days per week IFSP Multidisciplinary Home visits		Name of preschool program, indications that it meets many best practice guidelines.
		ASD specific curriculum content	☑	
		supportive teaching environment	☑	
		generalisation strategies	☑	
		predictability and routine	?	
		functional approach to CBs	?	
		transition support	☑	

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Interventions	Type I evidence (current review, NAC, R&P)	Type II evidence &/or rationale	comment
		family involvement ☑ **visual supports** ? **intensity** ☑ **multidisciplinary collaborative** ☑	
Long Day Care at The Infants' Home. Supported placement in inclusive long-day care setting. Regular IEPs, IFSPs, regular therapy sessions and consultations	No direct evaluation of program, service based	Long day care, inclusion Multidisciplinary IEPs Therapy incorporated into setting **ASD specific curriculum content** ? **supportive teaching environment** ? **generalisation strategies** ☑ **predictability and routine** ? **functional approach to CBs** ? **transition support** ? **family involvement** ? **visual supports** ? **intensity** ☑ **multidisciplinary collaborative** ☑	Need more information about: • ASD content of the program • Supportive environment • Routines • Approach to behaviour • Family involvement • Visual supports Model sounds reasonable, possibly similar to ASELCC model with therapy and skills appropriately built in to regular program
Discover and Learn (St Anthony's)	No direct evaluation of program, service based	Insufficient information to provide details. Referred to FaHCSIA to contact service for more information.	
Single element components addressing one aspect of ASDs			
PALS Social Skills Program (Playing and Learning to Socialise) www.palsprogram.com.au	• One RCT found, good quality study (2.85) though not specific to autism	Based on rationale that children with an ASD have difficulties learning and using social skills. Program targets following skills: • greeting others • taking turns: talking and listening • taking turns at play • sharing • asking for help • identifying feelings	Well established program for typically developing, some use in autism, though no empirical research. ~~Rationale, teaching methods and program elements suggest~~ appropriate for some children. *Single element addressing one aspect*

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Interventions	Type I evidence (current review, NAC, R&P)	Type II evidence &/or rationale	comment
		• empathy • overcoming fear and anxiety • managing frustration • calming down and speaking up Uses video modelling, puppets, role play, songs to teach skills.	*of ASDs. For use combined with other ASD specific elements.*
Sleepwise©: Positive Sleeping Practices for Young Children with Developmental Delay	• One empirical study found (O'Connell & Vannan, 2008), 23 families, mixed diagnoses, all developmental disability ages 1;7 – 7years. • Treatments varied according to child characteristics and parental preferences • General gains, though outcomes and level of success were determined according to individual goals	• Increased prevalence of sleep disturbance in children with developmental delay that requires professional intervention (cited in O'Connell & Vannan, 2008) • High rates of sleep problems reported in children with autism (Richdale, 1999) • 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 • Techniques include social stories, visual supports, positive behaviour supports, sensory supports, appropriate for children with an ASD • Family based, working with parents	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 address a particular issue. *Single element addressing one aspect of ASDs. For use combined with other ASD specific elements.*
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.	http://www.shfpact.org.au/index.php?option=com_content&view=article&id=141:sosafe-user-training&catid=25:for-disability-workers&Itemid=128 Sexuality program for adults – check about use with children (02) 6247 3077
Toilet Time©: Toilet Training for Young Children with	One small study on the effects of traditional toilet training (operant conditioning) plus video modelling. Some impact of training plus video	• Evidence that toilet training can be delayed in children with an ASD • Limits opportunities for integration (e.g.	Addresses an issue for children with autism documented in the research, likely difficulties attributable to

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Interventions	Type I evidence (current review, NAC, R&P)	Type II evidence &/or rationale	comment
Developmental Delay	modelling compared with training alone. Carers reported that support was important (Keen et al., 2007)	preschool) • Parent training and support, use of visual supports, use of video modelling, behaviour analysis techniques are consistent with needs of children with autism	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 young children. • Current format would suggest that it is unsuitable.
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 principle s are met.	Service based; no direct evidence but matches particular area of need for some children with autism. *Single element addressing one aspect of ASDs. For use combined with other ASD specific elements.*
Music therapy	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	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

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Interventions	Type I evidence (current review, NAC, R&P)	Type II evidence &/or rationale	comment
	controls (sig differences, large effect size); low functioning participants showed greater improvement with music training than speech training. 2 low quality studies identified in Comparative Effectiveness Review (2011) describing outcomes for joint attention and communication skills.		need to meet best practice guidelines.
Service based and/or not specific to autism			
"Super-nanny" -whole family support provided by a mental health nurse in the family home using a DSP approach	No direct evidence of '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 & 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.
'Travelling teacher' – intensive live in (5 days)	No research evidence for intensive live-in services.	Unclear whether any core features of autism are addressed. Not multi-disciplinary, appears to be delivered by a single teacher rather than a multidisciplinary team	Limited information about components. No information about how good practice principles or key effective elements are addressed. Not multidisciplinary.
Phonological Awareness Group	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.
Leap into learning – literacy group	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.	Early literacy group, run by a therapy aide. Limited relevant rationale. FaHCSIA would need to be satisfied that any groups should be run by a therapy aide (unqualified) rather than a speech pathologist, teacher, OT or

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Interventions	Type I evidence (current review, NAC, R&P)	Type II evidence &/or rationale	comment
			psychologist.
Aquatic OT 10 Week Program	• One small survey regarding clinicians' perceptions of the benefits of aquatic therapy, though within a SI framework (Vonder Hulls et al, 2006). • 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 • children made gains in goals, parents were able to identify many areas of benefit for both their children and themselves • very limited study	Limited evidence that general aquatic interventions are relevant to the core features of autism 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. Potential to meet some good practice/effective elements guidelines, would need to be part of a more comprehensive service. **ASD specific curriculum content** ☑ **supportive teaching environment** ? **transition support** ? **family involvement** ☑ **visual supports** ☑ **intensity** ☒ **multidisciplinary collaborative** ☒ **generalisation strategies** ☒ **predictability and routine** ☑ **functional approach to CBs** ?	www.icms.com.au/apc2005/abstract/36.htm 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.
Aquatic OT School Holiday Intensive Program	As above	As above	As above
Fast ForWord Program • Computer based,	• Strong et al (2011) meta-analysis, PRISMA protocol. Included only RCT, had to include standardised measures of language, oral or	**Autism specific curriculum** ☒ **predictability and routine** ☒ **functional approach to CBs** ☒	• The best available meta-analysis of randomised controlled trials suggests there is no evidence that

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Interventions	Type I evidence (current review, NAC, R&P)	Type II evidence &/or rationale		comment
intensive • Designed to improve oral language and literacy From www.fastforword.com.au Fast ForWord helps many children on the autistic spectrum. It improves their language skills and attention. Parents and carers often report recognisable gains in the childrens' language functions. Autistic children find the Fast ForWord programs very engaging because of the visual appeal of the exercises and the frequently repeated tasks. Children diagnosed with Pervasive Developmental Disorders (PDD) can make significant gains in their oral language skills after doing Fast ForWord programs.	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.* • 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. • SMRS score 1.51 (*SMRS scores of 0 or 1 indicate that insufficient scientific rigor has 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)*	**transition support** **family involvement** **visual supports** **intensity** **multidisciplinary collaborative** **intensity** **multidisciplinary collaborative**	☒ ☒ ☒ ☒ ? ☑ ☒	Fast ForWord is an effective treatment for typically developing children with language or literacy difficulties • The only study found of ASD and FFW is of poor quality with no measures of functioning • There is no Type II evidence or rationale that would suggest that FFW would match the learning strengths/deficits of children with ASD • FFW does not match the best practice guidelines set out in Roberts & Prior (2006)
PROMPT PROMPTs for Restructuring Oral Muscular Phonetic Targets	One study of PROMPT with children with autism (Rogers et al 2006). Study design single subject design (5 participants), good scientific rigor (SMRS rating 3.6) but limited meaningful results, no control comparison, scattered results (1 child showed improvement). No calculation of sig differences on standardised tool. No generalisation measures.	• 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). • Limited evidence of efficacy with children with motor speech disorders • Limited evidence that childhood apraxia of speech is prevalent within the autism population (Shriberg et al 2011)		Limited evidence for rationale for use.

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Interventions	Type I evidence (current review, NAC, R&P)	Type II evidence &/or rationale	comment
SERVICES THAT HAVE BEEN IDENTIFIED AS REQUIRING MORE SPECIFIC INFORMATION – DETAILS GIVEN TO FaHCSIA			
Narrative therapy (Kids First NSW)	• One study found – adolescents with AS and narrative therapy • No studies found for narrative therapy in paediatrics		
Circles of support (inclusion program encourage other children to help the child participate in activities)			
Next Step program (Autism Action, Vic)			
Sensory and perceptual motor therapy (5energies, QLD)			
Jump Start (Autism Action)			
'I can do it' (Biala Peninsula VIC)			
Busy Hands group (Kalparrin ECI, VIC)			
Solution focussed brief therapy			
Narrative therapy			
AUSPsych (recovery station NSW)			
'Communication Sensation' (Bankstown Community Resource team)			
5 energies, QLD			

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Interventions	Type I evidence (current review, NAC, R&P)	Type II evidence &/or rationale	comment
Parent and family support			
Early Bird Advanced training Individual Parent Counselling Family Camp ABA Parent Training Individual Family Psychological Therapy Northcott Intensive Family Support - Family Therapists Parent/Family Workshops and Sibling Workshops	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: From the Comparative Effectiveness Review (2011) *Less intensive interventions focusing on providing parent training for bolstering social communication skills and managing challenging behaviors have been associated in individual studies with short-term gains in social communication and language use. The current evidence base for such treatment remains insufficient, with current research lacking consistency in interventions and outcomes assessed (p.ES-7)* Any training provided for parents under 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: • Autism specific curriculum, addressing the core features of ASDs and/or associated features • Functional approach to challenging behaviours • Predictability and routine • Visual supports • Multidisciplinary team involvement wherever appropriate		
Teacher/centre support			
Parent/teacher training Advanced Behaviour Management teacher training Coaching for preschool/child care staff EDUCATIONAL SERVICES. Training for teachers	Teacher training is not an approved service under the current guidelines. 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.		

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Interventions	Type I evidence (current review, NAC, R&P)	Type II evidence &/or rationale	comment
Let's Link: Mainstream child care setting support for staff			
Other			
Physiotherapy / motor skills			
EQUIPMENT PURCHASE			

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~~Part 2. Stakeholder Survey~~

~~2.1 Background and Methodology~~

~~Brief description of survey development and administration~~

~~2.2 Summary of findings for Advisors and AAB~~
~~2.3 Peak professional bodies~~
~~2.4 RCN~~

2.5 Synthesis of overall messages/outcomes from the surveys and amalgamation/integration of feedback received, leading to implications for the future

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Part 2. STAKEHOLDER SURVEYS

3. Stakeholder Surveys

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~~2~~3.1 Background and Methodology

After discussions with FaHCSIA, the project team undertook two surveys and one consultation with staff at the Parenting Research Centre (PRC) who have developed the Raising Children's Network website. In regard to the two surveys were undertaken, the first was with key autism peak bodies and professional groups whose constituents are service providers with the Helping Children with Autism Package (HCWA) and the second with Autism Advisors across the country. These will each be described.

~~3~~2.1.1 Peak Bodies Survey.

Background

Peak Bodies who represent members/professionals who are ~~registered~~ members of the HCWA Early Intervention Provider Panel ~~as Autism Panel Providers~~ (professionals ~~accredited~~ assessed by FaHCSIA to provide ~~renumerated~~ interventions to eligible children and families) ~~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 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 1).

Survey Instrument and Procedure

The project team, in consultation with FaHCSIA, developed a list of open ended questions of relevance to these peak bodies in relation to the HCWA package to obtain views about:

- the administration of the package,

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- the adequacy of current service provision under the package,
- concerns about the currently funded interventions,
- ~~views on~~ interventions that should be funded that currently are not,
- interventions that currently are funded that may be of concern,
- issues parents have in accessing funded early intervention services,
- improvements in implementation of the package,
- parents' satisfaction with the interventions funded,
- utilisation of the operational guidelines and
- suggestions for improvement. (See Appendix 1 for list of questions).

These questions were sent to three ~~autism~~ EI ~~p~~Panel P~~p~~roviders, one each from occupational therapy, speech pathology and psychology by way of piloting the questions. Minor modifications to the questions were made in response to feedback from these P~~p~~anel ~~p~~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 these 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 ~~f~~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 practitioner. The latter was sent to the appropriate peak body for inclusion in their response. Unsolicited submissions have not specifically been included in the summary of findings for this report.

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 also consensually developed and is presented.

Results

Views on the Administration of the HCWA Package in relation to Approval of Panel Providers

Australian Advisory Board

- ~~The initial clear guidelines have eased and weakened, especially with the approval of sole providers. This weakens the requirement for a multi-disciplinary approach to EI.~~

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- The initial clear guidelines have eased and weakened, especially with the approval of sole providers. This weakens the requirement for a multi-disciplinary approach to EI
- Current approval process has allowed the entry of service providers with limited experience and expertise in Autism.
- Idea of encouraging consortiums to develop has not worked in practice – often only liaise with each other for purpose of tendering for services, not for ongoing service delivery.

Speech Pathology, Australia (SPA)

- Some provider panel members do not have the necessary qualifications and experience
- SPA supports idea of consortiums but need to have processes in place to reduce time taken to set up.
- Concerns expressed regarding the level of experience and expertise of some panel providers.

Australian Psychological Society (APS)

- Need for a process to ensure better communication between service providers to ensure best outcomes for children. Suggest funding for teleconferencing between service providers.
- Difficulties forming consortiums and becoming panel members – application time too long and process too onerous. Suggest a review of procedures regarding requirement of panel providers.

Occupational Therapy Australia (OTAL)

- No major concerns but suggestions the process is too bureaucratic and time consuming

Royal Australasian College of Physicians (RACP)

- Intervention must be evidence-based
- Quality of services is highly varied – some lack of experience and expertise in autism
- Lack of case coordination and multi-disciplinary focus in some approved services

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Summary of issues:

- **Need for multi-disciplinary approach to intervention**
- **Consortiums should be monitored and guidelines in place**
- **Lack of experience and expertise in autism among service providers should be addressed**
- **Services to have a commitment to evidence-based interventions**

Views on the Administration of the HCWA Package in Relation to Approval of Specific Types of Intervention

Australian Advisory Board

- Definite need to develop an assessment tool for evaluation of service providers seeking panel membership.
- Need for ongoing monitoring of funded services to ensure they continue to meet quality of service provision requirements. Develop set of standards.
- Need to employ independent consultants with autism expertise, who can assist FaHCSIA in future applications from service providers.
- Focus should be on choosing services with focus on evidence-based practices.
- Need for more thorough application process – not just based on written applications.

Speech Pathology Australia

~~Concerns include:~~

~~Inconsistencies in approval of eligible programs,~~

- Inconsistencies in approval of eligible programs
- Consortiums using non-qualified staff/volunteers to implement programs,
-
- Approval of currently non-evidence based programs,
-
- ~~p~~Parents completing home programs without adequate supervision,
-
- ~~c~~Consortiums employing non-qualified staff

Occupational Therapy Australia

- Interventions should be goal oriented, evidence based and the outcome of collaborative planning and goal setting by family and multi-disciplinary team

Royal Australasian College of Physicians

- Quality of advice to families varies greatly – confusing for families and not always accurate
- Approval of panel providers not right – no expertise

Summary of issues:

- **Need to improve current procedures for the assessment and ongoing evaluation of panel providers. Recommend independent consultants with expertise and experience in autism work with FaHCSIA**

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- **Develop a set of standards to ensure the quality and consistency of service providers**
- **Approval for evidence-based interventions only**
- **Focus on services providing collaborative planning between families and multi-disciplinary teams**

Views on the Administration of the HCWA Package in relation to Panel providers' interaction with FaHCSIA

Australian Advisory Board

- Look at processes around payment of fees – higher rate for HCWA services
- Access and availability of FaHCSIA staff to assist service providers with any questions.
- FaHCSIA need to develop quality assurance framework (promised in 2010)

Speech Pathology Australia

- General interactions have been helpful with FaHCSIA staff professional and responsive
- Difficulties with direct contact with FaHCSIA staff can lead to frustration and time wasting.
- Lack of reporting of changes and new requirements not always carried out by FaHCSIA in timely manner
- Current fee schedule template is difficult to work with and problematic.

Occupational Therapy Australia

- No concerns

Royal Australasian College of Physicians

- Difficulties for some families to navigate the application for funding process – require assistance to understand processes
- Need to link primary diagnostician with the service providers for each child

Summary of Issues

- **Inconsistencies around current fee structure need to be addressed – inconsistencies in fees and the fee schedule template difficult to work with.**
- **Access to and availability of FaHCSIA staff often limited**
- **Changes to Guidelines not always well disseminated**
- **Quality assurance framework still not completed**

Adequacy of Service Provision of HCWA Funded Services in terms of Amount Allocated per Family

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Autism Advisory Board

- Interface between HCWA, State govt funding and geographical location has resulted in an inconsistent service experience for families.
- Cost of services is increasing annually leading to an erosion of purchasing power for families – funding needs to be appropriately indexed annually.

Speech Pathology Australia

- Amount is considered inadequate for intensive services for children with autism

Australian Psychological Society

- Families may require guidance in best way to utilise funding. Funding amount inadequate for more intensive programs (eg ABA). Suggest a means tested safety net for families unable to supplement govt funding

Occupational Therapy Australia

- Some concern that funding is not adequate as families unable to access similar services in public system

Royal Australasian College of Physicians

- Current allocation of funds not enough to meet needs. Not enough publicly funded services

Summary of Issues

- **Inconsistent service experiences across the different geographical areas**
- **Increase in cost of most services means that the funding should be indexed annually to reflect these increases**
- **Current funding levels inadequate for intensive services**
- **Need for some guidance for families to assist them to best utilise their funding allocations**

Adequacy of Service Provision of HCWA Funded Services in terms of Breadth of intervention provided

Autism Advisory Board

- No incentives for service providers to establish programs in thinly populated areas with low demand – disadvantages regional families
- Introduction of sole providers has negatively impacted on multi-disciplinary intervention focus
- Breadth of interventions may be driven by service availability rather than need – families take what they can get rather than what they need.

- Gap in services specifically targeted to indigenous families. – HCWA package should be extended for indigenous families for an additional 2 years (often diagnosed later).

Speech Pathology Australia

- Concern that not all interventions are widely available across all areas, especially to rural and remote families. Formatted: Bullets and Numbering
- Long waiting lists for certain interventions

Australian Psychological Society

- Problems with current model. Some advisors also service providers – conflict of interest and advisors unable to provide unbiased information, support and advice. Need to review current process. Formatted: Bullets and Numbering

Occupational therapy Australia

- No concerns expressed Formatted: Bullets and Numbering

Royal Australasian College of Physicians

- Introduce use of interpreters for non-English speaking families. Formatted: Bullets and Numbering
- Need to address the level of funding requirements vary from family to family depending on degree or disability

Summary of Issues

- **Insufficient appropriate services in rural and remote areas – forces families to accept what is available rather than what they really need**
- **Acceptance of sole providers has negatively impacted on multi-disciplinary intervention focus**
- **Delays in availability of some interventions**
- **Where advisors are also service providers- conflict of interest and unable to provide unbiased information**
- **Some families disadvantaged – non-English speaking, indigenous families**

Adequacy of Service Provision of HCWA Funded Services in terms of Quality of Advice to Parents from Autism Advisors

Autism Advisory Board

- Role of AAP to provide information about approved service providers – not case management support. Need for more flexible approach would benefit families. Formatted: Bullets and Numbering

- Role of advisors should be expanded to provide increased advice and brokerage support for families. This should then increase the knowledge base in each state of most effective services.
- Too narrow focus in the role – limited or inconsistent flexibility allowed leading to some families not accessing full range of services due to lack of information about services.

Speech Pathology Australia

- Concerns included: ← **Formatted:** Bullets and Numbering
- Intake inconsistent ← **Formatted:** Bullets and Numbering
- Advisors sometimes lack knowledge
- Variation in levels of expertise and experience
- Possible conflict of interest (advisors also service providers)

Australian Psychological Society

- No concerns expressed ← **Formatted:** Bullets and Numbering

Occupational Therapy Australia

- Some confusion about source of funding, based on their interaction with autism advisors – variability in roles of advisors across States ← **Formatted:** Bullets and Numbering

Royal Australasian College of Physicians

- Quality of advice to families varies greatly – confusing for families and not always accurate ← **Formatted:** Bullets and Numbering

Summary of Issues

- **Role of autism advisors should be expanded to include brokerage advice and support for families**
- **Advisors must have experience and expertise to ensure consistency of information to families**
- **Conflict of interest issues arise when advisors are also service providers**

Adequacy of Service Provision of HCWA Funded Services in terms of Time frame for Service Provision

Autism Advisory Board

- Extension of EI to 7 years blurs line between EI and early education- should be dealt with separately. Otherwise will dilute available resources for EI ← **Formatted:** Bullets and Numbering
- Suggestion that EI should be based on date of diagnosis rather than date of birth as some children may not be diagnosed until after age 7 but still need access to funding for services.

Speech Pathology Australia

- Problems for children given late diagnosis – miss out on funding ← **Formatted:** Bullets and Numbering

Australian Psychological Society

- Later diagnosis for higher functioning children – disadvantaged. Need to extend funding for 2 years post-diagnosis for children over age 7.

Occupational Therapy Australia

- Age limits imposed under the program restrict older children and adolescents who would benefit from the program but were diagnosed too late.
- Lack of awareness of the funding package

Royal Australasian College of Physicians

- Delays in accessing services

Summary of Issues

- **Cut-off date for EI funding disadvantages children not diagnosed until later.**
- **Funding should be based on age of diagnosis –provided for 2 years after diagnosis**
- **Lack of awareness of the funding package – needs to be more widely publicised**

Specific Concerns about Currently Funded Interventions

Autism Advisory Board

- Small number of panel providers misinforming families and suggesting "recovery from autism".
- Lack of supervision of providers, no monitoring of qualifications, no emphasis on ongoing training, refusing service to some families and locking families to specific service.
- Not always providing services as originally promised – no ongoing monitoring of intervention sessions
- Lack of autism expertise and experience among some providers

Speech Pathology Australia

Australian Psychological society

- Need to fund family work where parents are coached to work with their child without child being present
- FaHCSIA need to ensure that all funded interventions are evidence-based.

Occupational therapy Australia

- Need to ensure evidence-based practice for funded services.

- Need for transparency and accountability in selection and delivery of treatment services.
- Information about efficacy of various interventions available to families to help them make informed decisions about choosing services
- Greater consistency in fee structures across providers –process to be transparent

Royal Australasian College of Physicians

- Increase in fees by some panel providers exorbitant and some families unable to access multi-disciplinary therapies because of high fees.
- Some panel providers charge for ancillary/administration costs – resources to be purchased should be defined.

Summary of Issues

- **Lack of supervision and ongoing monitoring and evaluation of service providers**
- **Need for all services to be accountable and transparent in the selection and delivery of services**
- **Lack of autism expertise and experience among some service providers**
- **All funded services should be evidence-based**
- **Needs to be consistency in fee structures across services – transparent process**

Interventions that you Consider should be Funded that Currently are Not

Autism Advisory Board

- Physiotherapy as part of multi-disciplinary approach
- Music therapy as part of multi-disciplinary approach
- Geographically disadvantaged families require increased funding to access services

Speech Pathology Australia

- Dieticians,
- Music therapy
- Counselling and family therapy

Australian Psychological society

- Family coaching by trained therapists

Occupational therapy Australia

- Any additional services to be based on available evidence

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- Services that deliver interagency, intersectorial and effective collaboration should be funded

Summary of Issues

- **Services that are funded should be evidence-based**
- **Suggestions for physiotherapy, music therapy if part of a multi-disciplinary approach**
- **Need to increase funding allocation for geographically disadvantaged families**

Currently Funded Interventions that Should No longer be Funded.

Autism Advisory Board

- Provider able to manipulate current requirements – should have individual audit and establish best practice guidelines. Guidelines should have process to remove non-conforming providers, process to assist eligibility and confirm continued eligibility.

Speech Pathology Australia

- Specific intervention programs should be adequately evidence-based to ensure efficacy

Australian Psychological society

- Any interventions that are not evidence-based should not be funded

Occupational therapy Australia

- Advocates funding only for interventions that are evidence-based, goal-directed and lead to enhanced occupational performance and engagement.
- Need for services that are collaborative with families and not too narrow in focus or lacking evidence of efficacy

Royal Australasian College of Physicians

- Non evidence-based services should not be funded

Summary of Issues

- **Funding only for services that are evidence-based, goal-directed and collaborative with families**
- **Concern that providers able to manipulate current requirements – need to establish best practice guidelines and audit services**
- **Need for process to remove non-conforming services**

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Parents' Issues in Accessing HCWA Funded Early Intervention Services

Autism Advisory Board

- Lack of consistent national approach to diagnosis –leads to difficulties accessing services
- Long waiting lists and lack of appropriate services in some regions
- Cost of therapy
- Lack of experienced, knowledgeable providers to deliver best practice EI

Speech Pathology Australia

- Lack of services in rural areas or limited services requiring families to travel long distances
- Limited providers in some metropolitan areas
- Long waiting lists for some services
- Limited support for ESL families

Australian Psychological society

- The limited number of therapists because of the difficulty in obtaining panel membership – leads to lack of choice available to parents
- Lack of choice leads to higher fees to families and causes parents to travel further for services.
- Access to services and travel costs are major problems

Occupational Therapy Australia

- Problems with long waiting lists
- Lack of awareness of FaHCSIA package may lead to delays in accessing services early enough

Royal Australasian College of Physicians

- Parents like having access to the money under the program.
- Need to be more flexibility within families with more than one disabled child in how money is allocated

Summary of Issues

- **Access to appropriate services and travel costs to access service**
- **Long waiting lists and limited services in rural and remote regions – leads to lack of choice and higher fees**
- **Cost of therapy**
- **Need for more flexibility in how money is allocated**
- **Lack of experienced, knowledgeable service providers**

Suggestions for Improvements in Implementation of the HCWA package

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Autism Advisory Board

- Improved channels of communication and better sharing of information between all involved (FaHCSIA, lead agencies and consortium members)
- Complaints process in place
- Improved funding/payment guidelines and better accountability

Speech Pathology Australia

- Pre-pay for services
- Incentive payments in rural areas for service providers
- Better reporting of changes to processes
- Update website regularly and initiate IT process to keep central records accessible to service providers and families
- Co-ordination of services to avoid duplication of services
- Extra time for children with late diagnosis to use funding
- Restrict services from signing-up families for long term
- Ongoing evaluation process for families on program

Australian Psychological Society

- Improve communications between FaHCSIA, Autism Advisors, service providers and peak bodies – around changes to guidelines
- Widen funding base to include children of all disabilities not just autism

Occupational Therapy Australia

- Current package more suited to Metropolitan, provincial and larger regions with better access to multi-disciplinary services. Disadvantages for rural and remote families with limited access
- Process to prescribe therapeutic equipment extremely time-consuming and complicated.

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- Program should be extended to broader inter-sectorial integration around EI
- Paediatricians unable to refer families for HCWA – leads to delay and duplication.

Summary of Issues

- **Improved communications between FaHCSIA, advisors, service providers and families – especially around changes to guidelines**
- **Complaints process in place and better accountability for service providers**
- **Better funding guidelines – some changes in funding process recommended, and extension of funding to late diagnosed children and other disabilities**
- **Update website and keep central records for better access for families and service providers**
- **More accountability of service providers**

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Parents' Satisfaction with the Current Eligible Interventions Available through the HCWA Early Intervention Services

Autism Advisory Board

- Rural families would benefit from different rules around purchasing resources. Extra funding for rural service providers
- Support should be assessed and implemented in fair and evidence-based manner by trained professionals

Speech Pathology Australia

- No comment on parent satisfaction
- Main issues include – need for local services and information about the different services for their child in help make informed choices
- Access to family counselling

Australian Psychological society

- Parents want more consultation regarding new technologies – revise funding for equipment

Occupational therapy Australia

- Generally happy with package.
- More providers needed to meet demand, especially rural and remote areas
- Need to engage families in collaborative planning and goal setting for service provision options, especially in relation to available evidence and best practice.

Royal Australasian College of Physicians

- Some parents have concerns about having to disclose information about income – though services not means tested

Summary of Issues

- **Changes to guidelines for rural and remote families – extra funding and change rules for purchasing resources**
- **Ensure families and advisors are informed about range of services to assist them to make informed choices**
- **Increase services in rural and remote areas to meet demand for services**

Suggested Improvements to the Early Intervention Operational Guidelines

Autism Advisory Board

- Guidelines clear but no monitoring of implementation or practice
- Need to expand role of advisors to include greater brokering and support to assist families maximise services

Speech Pathology Australia

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- Use guidelines but need to update document and information regularly, improve clarity of service plans and provide guidance around purchase of resources

Australian Psychological society

- Provide updates on FaHCSIA website for dissemination of information

Occupational therapy Australia

- Valuable resource.
- Lack of understanding about how collected statistics are utilised in a value-adding way

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- Significant concerns about this type of funding model for children with complex disabilities.
- No capacity for comprehensive diagnostic framework
- Model is dependent on early diagnosis of a life long condition
- Inequities in funding and access to services between metropolitan and rural/remote families Should be equity of funding for other disabilities
- Funded interventions should have acceptable level of evidence base
- Need to look at alternative models for provision of EI for children with complex developmental disabilities.

Summary of Issues

- **Guidelines clear but need to update document and information regularly**
- **Need to provide clarity around development of service plans and guidelines around purchase of resources**
- **Alternative models for EI services**
- **Expand role of advisors to provide brokering support to maximise family services**
- **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 to meet the eligibility criteria. These requirements included:

- provision of a multi-disciplinary approach to service provision, with a focus on collaboration with families
- agreement to a system of ongoing monitoring and evaluation of services,
- a commitment to providing evidence-based intervention,

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- a commitment to employing staff members with experience and expertise in autism, and providing ongoing training in these areas to staff members.

Another key issue raised by all Peak Bodies was the need to improve 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.

Another concern among Peak Bodies was the inconsistency of service provision available to families across different geographical areas, especially a lack of appropriate early intervention services in certain rural and remote areas. With families having to travel long distances to access services, there is also no provision in the funding to compensate these families for the additional travel costs. In fact the issue of the current fee structure was widely discussed as problematic, with inconsistencies in fees and inadequacies in funding packages to provide intensive intervention. The current cut-off age for funding at age 7, was considered to disadvantage children, who may for any number of reasons, not be 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 to best utilise funding allocations and to offer family support. There was also concern that some autism advisors were also service providers, presenting a conflict in interest and therefore unable 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 and monitored.

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

Discussions were held with Mr Derek McCormack, Manager, Science Communication Content Manager, Raising Children Network re: *The role and function of the PRC Raising Children Network (Autism) Internet based services for families of children with ASD.* The RCN provides a suite of programs 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 156,000 visits to the website in total since launching in 2009, with an average of 200 visits per day. The two programs of particular relevance for the current review are: a) Reviews of treatment and interventions; these hich are posted on the Guide to Therapies Site,
http://raisingchildren.net.au/parents_guide_to_therapies/parents_guide_to_therapies.html
and, b) The online Parent Discussion Forum
http://raisingchildren.net.au/forum/Forum133-1.aspxThese are regarded as the two most popular sites in the RCN suite.

RCN's **Reviews of Treatment and Interventions**

The RCN is now in its third year of operation. It is the component of the HCWA package which is focused on internet delivery of information to families and provides sites as noted above which includes a guide to therapies and interventions for autism. This component sets out the features of each of a wide range of interventions and incorporates a rating scale of the status of each one, which is based on the scientific evidence for its value 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 on this site to identify and review current evidence and to translate and present the findings into 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 well together in making treatment decisions. For the selection of interventions to be researched and reported on the site, the RCN rely 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 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.

Further Comments:
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. For example,

> *In future it will be important to explore and review technological developments which could enhance learning and social networking for children with autism, although this area will probably address an older age group than that covered by the Early Intervention package. (MP comment)*

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 lead the team to expand it, and to break it into a few 'sub-forums' -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 their 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 in response to my request for his impressions of the HCWA provisions revealed that there is a need for more clarity around what the HCWA package offers. Choices are difficult if consumers do not know what is available. For many families the paperwork and personal research required to make use of the resources and funding package is very burdensome. It is likely that some families give up trying to access the support available because they cannot cope with the bureaucratic nature of the pathways. 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 well informed about resources and availability.

2.1.3 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 purposed 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 new 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, 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 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 satisfaction with panel providers, parents' informational needs and concerns. Both closed and open ended questions were utilised. See Appendix 2 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 list of Autism Advisors across all states/territories in Australia that was available to the project team 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 was 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

There were 29 responses to the survey from Advisors across all 8 States and Territories, with the majority of responses from NSW (25%) and Victoria (25%), with 14% each from South Australia and Western Australia, and 7% each from Queensland and ACT.

Demographics

The Autism Advisors provided information that alleviates some of the concerns expressed in the Peak Bodies Survey, about the professional backgrounds of staff members who are currently employed to provide early intervention services to children with autism. According to the Autism Advisors Survey, Advisors come from a variety of backgrounds including teaching and psychology, occupational therapy

and early childhood. Other professional backgrounds represented 46% that were not listed included counseling, social science, disability studies, speech pathology, human geography and community development, family support, communications, art therapy, information management and a parent. See Table 1.

Table 1: Professional Backgrounds of Autism Advisors survey respondants

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%

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 is 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 indicates 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. With only 4% of Advisors affiliated with a sole provider, the remainder (96%) were employed by Autism Associations. The majority of Advisors felt very well prepared (64%) or prepared (36%) for their role as Autism Advisors.

Service Provision

According to the survey results, 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 not to be adequately met. They reported that for these families there is a lack of services, limited choices for service and long waiting lists. Additional funding was reported by advisors as needing 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". It was suggested that FaHCSIA set more rigorous standards for eligibility of panel providers, especially in term of staff qualifications and experience, and monitor 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 4% of advisors felt that current services reflected these guidelines very well. Perhaps more effort needs to be made to address this issue. See Table 2.

Table 2: How well do most eligible interventions reflect current best evidence on effective 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 that it is the responsibility of service providers to advise parents on this matter.

Over 50% of Advisors indicated specific concerns over some of the currently eligible services, especially over 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 demonstrate evidence behind their practices. This is in line with a request from Peak Bodies.

Advisors were invited to suggest additional interventions that should be funded by FaHCSIA. 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. There were a number of issues that affected service delivery, especially in rural and remote areas. 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, the difficulty parents have in navigating services through FaHCSIA, lack of appropriate case management, social issues and poor time management also impacted on how parents are able to access appropriate services. See Table 3.

Table 3: 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%

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. They should 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. Services should also have an ASD specific content and focus. 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 surveyed, 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 govt services. In addition, some families wanted access to resources, information on financial support, preschools, respite and information about how to access grief counselling. See Table 4.

Table 4: 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%

Advisors reported that parents' information needs reflected need for information about services in their locality (93%), which intervention is right for their child (89%), 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 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 FaHCSIA clients.

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 of costs of FaHCSIA funded services
- clarification of relationship between providers and consortium members.

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 ongoing monitoring or auditing of all panel providers to ensure quality service provision according to the guidelines.

Part 4: Conclusions & Recommendations

In this section:
- Summary and recommendations in relation to issues raised by stakeholder and issues raised by FaHCSIA
- Recommendations re process and operationalisation of principles of good practice (2006 review)
- Recommendations about the application and assessment process

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Recommendations re applications of revised process for future based on the dot points and deliverables (*see beginning of this document for restatement of these) and stakeholder feedback.*

Issues highlighted in stakeholder feedback:

Comment [cw1]: Perhaps break this list into issues directly related to the quality of the Early Intervention Services provided and issues more operational or affecting structure of the EI component of HCWA – case management, additional funding etc

- Need for evidence based intervention
- Need for multidisciplinary teams
- Need for evaluation and monitoring
- Need for experienced qualified staff, & ongoing staff development.
- Assessment and ongoing monitoring of panel providers
- Remote rural & regional

Issues raised by FaHCSIA

Dot points

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Issue 1. A commitment to providing evidence-based intervention

Comment [cw2]: Suggest numbering of Issues and recommendations to enable easier reading and identification.

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- *Approval and funding for evidence-based interventions only*
- *Funding only for services that are evidence-based, goal-directed and collaborative with families.*

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Relevant criteria ~~for~~that interventions are~~to be~~ evidence based and meet good practice guidelines need to be tightened up and made specific in the application process. (See operationalisation of good practice guidelines pg x).

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(Note that p~~P~~arents and providers may choose non-recommended and non-evidence based intervention programs for their children but will have to fund these themselves).

The~~se~~ following recommendations are designed to facilitate a process for keeping up to date with the considerable literature on treatment/intervention which will

continue to emerge overtime, and which will necessitate regular updating of the list of evidence based treatments.

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Recommendation 1 ~~Methods to keep up to date with the emerging literature on early intervention for ASD, and recommendations for a process to achieve this aim.~~

~~a)~~ . Engage a consultant (person ~~,~~ or panel) to check the autism intervention research literature (post the 2011 review) and report every 6 months on any new studies of interventions with acceptable methods, which should be considered for approval for, or removal from list of funded programs.
This can be done by setting up automatic links to data bases to trigger notification of new/current autism intervention related publications e.g. ? PsychInfo etc.

If a University based panel is employed the links should be automatic. Failing that ~~FACS~~ FaHCSIA will need to finance this process.
Hand searches are also possible
While this will be a cost to ~~HCWA~~ FaHCSIA (probably small) it is likely to save wastage of funding on useless or harmful treatments in the longer term, and to reduce stress for FaHCSIA~~ACS~~ staff having to make decisions on questionable applications.

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Note that data from the last 10 years shows increases in publications on autism; for example in pubmed publications increased from 3000 to 11000, underlining the need to keep abreast with emerging literature.

FaHCSIA needs to be clear with applicants that intervention must have valid scientific evidence (Type 1 and or type 2) and principles of good practice indicating that this treatment will make a difference to autism in cognitive, adaptive, social behavioural, communicative development etc. as listed in modified current sections on this in FAHCSIA application document.

Issue 2 - **Provision of a multi-disciplinary approach to service provision, with a focus on collaboration with families**

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- *Focus on services providing collaborative planning between families and multi-disciplinary teams*

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- *Acceptance of sole providers has negatively impacted on multi-disciplinary intervention focus*

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- ~~s~~ *Suggestions for physiotherapy, music therapy if part of a multi-disciplinary approach*

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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 had a negative impact on multi-disciplinary practice~~not been helpful and recommends a multi disciplinary approach.~~.

~~Therefore we recommend~~Recommendation 2 - T~~t~~hat the requirement for providers to be multidisciplinary be reinstated with exceptions made for isolated families. Family involvement is a recommendation for good practice (see pg x) and should be specifically addressed in applications.

Issue 3 - **Agreement to a system of ongoing monitoring and evaluation of services,**

- *Develop a set of standards to ensure the quality and consistency of service providers*
- *More accountability of service providers; all services to be accountable and transparent in the selection and delivery of services*
- *Consortiums should be monitored and guidelines in place*
- *Quality assurance framework still not completed*
- *Complaints process in place and better accountability for service providers*

Concern about~~re~~ lack of supervision and ongoing monitoring and evaluation of service providers is a recurrent theme in the feedback from stake holders.

Recommendation 3 - ~~suggesting strongly that~~ t~~T~~here needs to be monitoring and evaluation of providers to ensure that services are being delivered as originally proposed.

Issue 4 - **Employment of service provider staff members with experience and expertise in autism, and provision of ongoing training.**

- *Lack of experience and expertise in autism among service providers should be addressed*
- *Advisors must have experience and expertise to ensure consistency and accuracy of information to families*

The lack of experience and expertise among service providers including autism advisors is a recurrent theme in stakeholder feedback. ~~In line with principles of good practice~~

Recommendation 4- All staff delivering the early intervention services and programs need to have experience and expertise plus ongoing training and support.

Issue 5 - **The need to improve the current procedures for the assessment and ongoing evaluation of eligible panel providers.**

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1-2 dot points from stakeholders – using some of sentences below?

~~*Need to improve current procedures for the assessment and ongoing evaluation of panel providers.*~~
~~*Recommend independent consultants with expertise and experience in autism work with FaHCSIA*~~
Stakeholders expressed great concern about the lack of ongoing monitoring and accountability. 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.
We conclude with suggestions regarding 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.~~..~~
~~Recommendations regarding monitoring and follow up of funded interventions~~

Many respondents to the survey have noted that once treatment has been funded, there is no 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.

Recommendation 5 ~~-We recommend~~ O~~o~~ngoing monitoring and reporting from providers covering the above noted principles, and submission of regular reports to F~~AC~~saHCSIA. This could be monitoring in vivo by a person on the ground, or a questionnaire, or parent survey.~~??~~ ~~above principles in the domains specified for on the ground, or a questionnaire, or parent survey?~~

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Issue 6 - **Rural/R~~r~~emote**

- *Long waiting lists and limited services in rural and remote regions – leads to lack of choice and higher fees*
- *Changes to guidelines for rural and remote families – extra funding and change rules for purchasing resources*
- *Access to appropriate services and travel costs to access service*

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Stakeholder feedback highlights inconsistent service experiences across the different geographical areas, especially a lack of appropriate early intervention services, which forces families to accept what is available rather than what they really need.

Recommendation 6 - Consider the advantage and feasibility of telehealth.

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Issue 7 - **Case management by~~for~~ autism advisors**

- *Need for case management*

- *Need for some guidance for families to assist them to best utilise their funding allocations*

- *Role of autism advisors should be expanded to include brokerage advice and support for families.*

There was discussion from stakeholders 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 to best utilise funding allocations and to offer family support.

Recommendation 7 - ??? if AARC has no specific recommendation here and for other issues perhaps a special category of issues – noting their importance for stakeholders but suggesting more investigation

Operational issues raised by stakeholders

Issue 8 - **Communication**

- *It was felt among the Peak Bodies that the current Guidelines were clear but should be regularly updated.*
- *FaHCSIA website should be regularly updated*
- *Need to provide clarity around development of individual service plans and guidelines around purchase of resources*
- *Ensure families and advisors are informed about range of services to assist them to make informed choices*
- *Update website and keep central records for better access for families and service providers*
- *Access to and availability of FaHCSIA staff often limited*
- *Changes to Guidelines not always well disseminated*
- *Lack of awareness of the funding package – needs to be more widely publicised*
- *Improved communications between FaHCSIA, advisors, service providers and families – especially around changes to guidelines*

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~~It is~~ recommendation 8.1 - ~~ed~~ that FAHCSIA circulates a list of approved interventions meeting criteria, and also post this on the internet in the interests of clearer and more universal communication to all stakeholders.

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Recommendation 8.2 - 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. Fa~~A~~HCSIA can refer callers to these sites, to help applicants to follow the rationale for decisions on acceptable interventions and this outline can underpin FAHCSIA staff responses to callers.

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Rules and guidelines for FACS staff to underpin decision making on program approval.

- Must conform to published guidelines in FACS docs. And must clearly demonstrate how conformity to guidelines will be shown throughout the intervention and how this will be monitored.
- When in doubt refer to consultant.
- Full details of all providers re. status, professional experience, and competence in the autism field required *(need to keep in mind that both the intervention 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.

Issue 9 - **Fees & funding process**

Dot points?

~~t~~The issue of the current fee structure was widely discussed as problematic, with inconsistencies in fees and inadequacies in funding packages to provide intensive intervention. The current cut-off age for funding at age 7, was considered to disadvantage children, who may for any number of reasons, not be diagnosed early enough to access the early intervention funding packages.

Recommendation 9 - ??

Issue 10 - **Current funding levels inadequate for intensive services**

Recommendation 10 -~~Recommend~~ FaHCSIA clarify restate/promote~~ication re~~ the intention of HCWA Early Intervention ~~for~~ funding ~~to be Intended~~ to be contribution (see pg x)

Issue 11 - **Conflict of interest**

-

Where advisors are also service providers- conflict of interest and unable to provide unbiased information

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Conflict of interest issues arise when advisors are also service providers.

There was also concern that some ~~a~~Autism ~~a~~advisors were also service providers, presenting a conflict in interest and therefore unable to offer unbiased advice or information to families.

Recommendation 11 - ??? FaHCSIA to promote and clarify existence of conflict of interest policies that Autism Advisors are required to have???

Delays in availability of some interventions

Some families disadvantaged – non-English speaking, indigenous families

Need for process to remove non-conforming services

Issues raised by FaHCSIA

Use of funds for diagnosis

Diagnostic assessment is not the same as assessment for program development and should therefore not be funded as part of this package (see pg x)

1:1 versus group intervention

small group intervention may be acceptable 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. A range of costs should be provided as acceptable for funding. It would be a good idea for FAHCSIA to put info re fees and charges on website, then services can be compared to each other.

Group fees should be less than 1:1.

Individual plans, assessment, goal setting, evaluation and review

Individual plans are fundamental to effective intervention. See appendix X for a resource that may be useful for planning (Planning Matrix)

Interventions targeting one domain only versus comprehensive interventions

It should be made clear to families whether an intervention is specific to one domain of functioning or comprehensive. As the total funding package is not adequate for the provision of comprehensive intervention, comprehensive or domain specific are both appropriate provided the family is making an informed choice.

Generic early intervention versus autism specific

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 a generic intervention is effective for autism it should not be funded under this package. 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

As above. It is important to note that training in speech pathology, psychology or

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occupational therapy per se does not qualify therapists to work with children with autism. In addition these services are more appropriately funded through medicare.

Recommendations re Process

Operationalisation: Key elements of effective programs

Key element	Yes, no or unknown?
ASD specific curriculum content	
supportive teaching environment	
generalisation strategies	
predictability and routine	
functional approach to CBs	
transition support	
family involvement	
visual supports	
intensity	
multidisciplinary collaborative	

From Roberts & Prior (2006) *with additional comments regarding operationalization*

Curriculum Content

FaHCSIA should be satisfied that the service addresses 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?*

Supporting the need for highly supportive teaching environments and generalisation strategies

FaHCSIA should be satisfied that the interventions provided include an appropriate staff to child ratio (ideally 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?*

Supporting the Need for Predictability and Routine

FaHCSIA should be satisfied that service providers are addressing 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

FaHCSIA should be satisfied that all service providers 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, 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

FaHCSIA should be satisfied that service providers 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

FaHCSIA should be satisfied that all service providers involve families to the extent that the family wishes and that families are involved in and supported to make decisions about their children's goals. 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.

Questions to ask include:

- *How does the service involve families in setting goals for their children?*
- *How does the service involve families in evaluating their children's progress?*
- *How are families supported to continue intervention strategies at home and in the community?*
- *What steps are taken to ensure that families can support their children's communication, social interaction and behaviour (as appropriate) at home and the community?*

Use of Visual Supports

FaHCSIA should be satisfied that services are using 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

FaHCSIA should be satisfied that children receiving the HCWA Early Intervention assistance funding are able to access 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

transdisciplinary (programs are holistic, developed by a team of professionals but delivered by a single provider working across disciplines). Collaborative multidisciplinary and transdisciplinary 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?*

Recommendations for the application process.

Current practice for assessing eligibility for provider panel membership:
A very wide range of treatment proposals, many of which have no documentation of an evidence base, have been received.

Applicants for provider status complete a form which involves the documentation of their current experience and qualifications and the components and methods of provision of proposed interventions. These must comply with the sets of criteria provided by FAaHCSIA and which are based on the guidelines for best practice as published in 2006 and summarized in the application form. These proposals are then screened by FAaHCSIA staff to assess whether they fulfil criteria and are suitable to be classed as eligible for funding.

There is great variation in the content, detail, attention to criteria and comprehensiveness of the submissions, making it difficult for FAaHCSIA staff to judge whether the interventions will provide effective early intervention which will improve outcomes for children with autism, including reducing dysfunctional behaviours characteristic of autism and which are therefore suitable for funding. We are therefore recommending specific changes in this process to underpin a more effective process of application and assessment, encompassing a smoother, more detailed and systematic adjudication.

APPLICATION PROCESS:
Suggested changes to the current form as supplied by Fascia, in particular;
PART 5, ESSENTIAL CRITERIA:

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Criterion 1.
What is listed here are not services but domains of development. This needs to be rewritten in more specific terms? (See below in reference to Criterion 2)

Criterion 2.
This is too loose and vague in dot point 2. Need to define what counts as 'overall well-being'.
This could be replaced with a set of core measures which cover: "documented gains in development in social, communicative, cognitive, adaptive, play, self care areas, and in improvement in problem behaviour areas" .
Applicants should incorporate information on what measures will be used to demonstrate change within and across those key areas, and how improvement will be operationalised and quantified for individual children (e.g. signs of language development, turn taking in play, decrease in repetitive behaviours etc.).

Criterion 3
List of measurable outcomes also needed also in Criterion 3.

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Emphasis should also be given to the requirement for multidisciplinary inputs

A current problem is that treatment is not being monitored. So the intent to monitor should be clear and at least random sample audits should be done (like the tax office). (see below for final recommendations)

Criterion 4.
Re: registration of allied health practitioners
Note that registration for psychologists has now become national rather then state based so Criterion 4 needs updating to reflect this. Also note that OTs are going national by 2012 (and Paeds KW?) *not sure about SpPaths.*

Requirements should include that all professional staff in services are deemed eligible to be providing interventions, not just the applicant providers.
More documentation of how students in training in any program will be involved and supervised, as well as fees/charges for student input is needed.

Second sentence in this Criterion and appended points should read:
Please submit a list of the skills, qualifications, and type and length of ASD experience for all personnel providing early intervention, including certification and licensing, and professional affiliations.
The multidisciplinary nature of interventions should be specified, with detailed information provided on how this will be achieved

Recommendations re FaAHSCIA operations in assessing provider applications in the future.

b). A recommended script for FaHCSIA staff to refer to, in drawing attention to the methods and rational leading to approval standards for stakeholders who contact the department.
In problematic or unclear cases, the submission could be referred to the panel as described above, for advice on treatment validity and funding suitability

Examples: *Questions for callers asking about the status of a particular intervention*
1. Have you consulted the FAHCSIA web site regarding our approved standards for funded interventions? If not, please do so before proceeding further so that you can understand the criteria for decisions about treatment proposals. Your proposal needs to address these standards specifically and in detail

2. Is your proposed intervention listed in the FACS site containing list of funded interventions?
If not, can you provide scientific evidence for the effectiveness of your proposed intervention (anecdotes and testimonials, newspaper reports etc. are not acceptable, single case study reports must be multiple and conform to evidence standards);
(refer to outline of review methods and standards noted above when documenting evidence).

If the answers to these questions are No and you wish to make a submission on the basis of evidence you have available, your submission should be consistent with the standards set out in the outline of review methods, and should include a copy of the report of the published evaluation of the intervention if available.

Submitted Evidence to be vetted by FAHCS IA (*or preferably by consultant noted above) before making decision.

Notes

Margot? Also note ~~FACS~~ FaHCSIA regulations from their introductory information for potential providers which we looked at on Tuesday and resolved to convert into a checklist