

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

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(this changed in 2011 to,
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REVIEW OF EARLY INTERVENTION THERAPIES FOR AUTISM SPECTRUM DISORDERS

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

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EXECUTIVE SUMMARY

Background

The Review was commissioned by the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) to provide up to date information about the evidence for efficacy of interventions for young children with Autism Spectrum Disorder (ASD) up to the age of 7 years. Ratings of the scientific merit of the intervention research, according to internationally established scientific criteria for evidence of treatment efficacy, were obtained. An update of the current understanding of what constitutes good practice in autism intervention was requested taking into account new research published since 2005/6 when the first review and guidelines were published by the Department of Health and Aging.

Recommendations from this report were designed to inform the processes used by FaHCSIA to assess the eligibility of interventions, and the suitability and capacity of potential providers to deliver effective autism early interventions under FaHCSIA's Helping Children with Autism (HCWA) Package.

Part 1 outlines the current issues around diagnosis, prevalence, and heterogeneity of ASD; and the importance of multidisciplinary practice and of working with families. Key elements of effective interventions are listed in this introduction. The recommended approach to assessing eligibility for membership of the HCWA Early Intervention Provider Panel (the Panel) is based on evidence of interventions with good scientific and clinical merit which are likely to contribute to improved outcomes for children with ASD and their families.

Part 2 describes the processes the authors implemented to assess the research for evidence of treatment efficacy of autism interventions. It includes a summary of the published research searches and rating methodology, and a review and summary of the literature evaluating outcomes of early intervention for autism. The Scientific Merit Rating Scale (SMRS) described in the 2009 National Autism Center (NAC) review (see www.nationalautismcenter.org/nsp) formed the basis of ratings of efficacy of interventions. A table summarising available information about interventions that have published trials available, including direct and indirect evidence, and best practice assessment was derived from the findings of this review. The table lists interventions and their standing, according to whether the evidence for efficacy was established, emerging, negative, or not available. Interventions of clinical usefulness when used with other treatments were also documented.

Part 3 Surveys of particular Stakeholder groups nominated by FaHCSIA were undertaken to provide feedback on current Early Intervention services and funding. The questionnaires and consultation methods used for this purpose and results of the surveys of Stakeholders are outlined. The surveys were sent to: (1) key autism peak bodies and professional groups whose constituents are service providers for the HCWA Package; and (2) Autism Advisors. The consultation was with the Parenting Research Centre (PRC) who developed the Raising Children's Network website. Summary findings from a specific set of questions covering administration of the HCWA package, incorporating views on: adequacy of service provision, particular concerns about currently funded Early Interventions, and limitations in access to services along with suggestions for improvement survey are presented.

A number of recommendations to ensure quality and consistency of service provision were common among the organisations, especially concerning the need for all potential panel providers to meet certain standards in order to meet the eligibility criteria, a multi-disciplinary approach to service provision, collaboration with families, ongoing monitoring and evaluation of service providers and services, a commitment to evidence-based interventions, and employing staff with at least 2 years experience and expertise in autism.

Part 4 includes responses to a list of particular issues raised by FaHCSIA for consideration during the development of the review including: use of funds for diagnosis; one to one versus group interventions and their funding; Individual plans, assessment, goal setting, evaluation and review; interventions targeting one domain only, versus comprehensive intervention; and generic early intervention versus autism specific intervention.

Part 5 reports the key findings and recommendations based on all of the information gathered by the AARC team. (Note that the AARC has now been converted into the Australasian Society for Autism Research, ASfAR).

Key Findings and Recommendations

Eligible and Ineligible Therapies

A key deliverable of the Review is a table that summarises the review of research evaluating early intervention therapies. Table 6 indicates if and how nominated therapies are deemed to be eligible according to their assessment against available evidence and/or best practice using categories ranging from established evidence for efficacy, through to no evidence for efficacy or no evidence available.

Improved communication and information sharing

The Review identified the need for improved communication and information sharing regarding the HCWA Package generally and the Early Intervention funding in particular. Specific areas included:

- Updating of the Early Intervention Operational Guidelines and the FaHCSIA website
- Improved clarity around the development of individual service plans, purchasing of resources and other operational issues
- Improved communication between all HCWA stakeholders
- Ongoing dissemination of information about the Package, including access to information and services to assist decision making
- Limitations in access and availability of services, especially in rural and remote communities and for families from different cultures and with languages other than English.

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

Due to the growth rate of research literature on ASD and the need to keep up-to-date with emerging data on Early Intervention the authors suggested a number of options:

- Set up automatic links to databases to trigger notification of new/current autism intervention related publications
- Engage a research officer to review and rate research studies as they are identified, on a regular basis and/or
- Engage a panel of experts to review the intervention literature and any needed updating of Table 6.

Reinvigoration of operationalisation of principles of good practice

The Review suggests a stronger emphasis on the need for service providers to meet good practice standards, particularly in the areas of multi-disciplinary practice and family involvement.

Stakeholder feedback also included concerns about lack of experience and expertise among service providers. The review team recommended stronger requirement for personnel to demonstrate substantial autism experience and expertise, for FaHCSIA to be informed of any changes to the staff skill and experience profile, ongoing scrutiny of training qualifications, and engagement of providers in relevant professional development.

Evaluating and managing service provider applications

The reviewers recommended a review and tightening of current procedures for assessing service provider applications with a focus on additional details on personnel, proposed interventions and how they will deliver best practice. Changes to the application form are suggested that will enable improved collection of information to assist with this assessment.

They also provided a 'script' for FaHCSIA staff when responding to enquiries from potential providers which draws attention to the rationale, key elements, and current status of effective interventions for children with ASD.

Role of Autism Advisors

It was recommended that the role of Autism Advisors be expanded to include brokerage advice and support for families.

Ongoing monitoring and evaluation of services

The Review identified stakeholder concerns about a lack of monitoring of service providers once they are on the Panel. Recommendations include:

- Ongoing monitoring by FaHCSIA
- Regular reporting to FaHCSIA encompassing reports of progress of children towards the stated goals of their intervention
- Accountability of funding through on-site visits, questionnaires or parents surveys
- Monitoring and follow-up of provider programs to ensure fidelity of treatment
- Clarify and promulgate clear and consistent fee schedules.

Innovation or changes to address identified problems

Consideration of tele-health methods is strongly recommended due to the inconsistent experience of services as a result of geographical challenges and distances.

Other issues raised by stakeholders included

- Inconsistencies in service provider fees
- 7 year old age cut-off for funding
- Inadequate funding levels
- Perceived conflict of interest for Autism Advisors who may also be involved in treatment provision
- Delays in availability of some interventions
- Disadvantage experienced by Indigenous, culturally and linguistically diverse (CALD) , and socio-economically and educationally poorer families
- Need for a process to monitor and if necessary, removal of non-conforming services which do not meet good practice standards.

Conclusion

The 2011 Review has provided a number of recommendations for the future based on both the research informing evidence of good practice for intervention services for children with ASDs, and on the views of key stakeholders involved with the implementation of the HCWA package with particular reference to therapeutic interventions for children up to the age of 7 years.

NOTE:

FaHCSIA is implementing a number of the recommendations from the 2011 Review. The following information will be progressively made available on the Helping Children with Autism (HCWA) pages on the FaHCSIA website - www.fahcsia.gov.au :

- Updated Operational Guidelines for the HCWA Early Intervention Services
- A Table of Interventions eligible for funding under the HCWA Package
- Updated Application Form and Guide for Applicants to the HCWA Early Intervention Service Provider Panel
- An easy English summary of the 2011 Review
- An Occasional Paper based on the 2011 Review – this will be instead of publishing the Review Report.
- An Updated Best Practice Guidelines booklet
- A HCWA Quality Monitoring Framework

For more information contact the ASD Support Helpdesk on 1800 778 581 or ASD.Support@fahcsia.gov.au .