



**Family &
Community Services**
Ageing, Disability & Home Care

Evaluation of four autism early childhood intervention programs Final Evaluation Report – Executive Summary



Document approval

Evaluation of four autism early childhood intervention programs Final Evaluation Report – Executive Summary has been endorsed and approved by:

Linda Mallett

Deputy Chief Executive

Peter De Natris

Executive Director, Community Access

Approved: 2 April 2013

Approved: 2 April 2013

Document version control

Distribution: ADHC Intranet and Website

Document name: Evaluation of four autism early childhood intervention programs Final Evaluation Report – Executive Summary

Version: Version 1.0

Document status: Current

File name: CORPORATE GOVERNANCE – Evaluation – ARTD Evaluation of four autism programs

Authoring unit: Community Access

Date: April 2013

ARTD evaluation team

Emily Verstege, Liesbeth Geerligs, Fiona Christian, Ofir Thaler, Kerry Hart, Miriam Motha and Chris Milne

Acknowledgements

This work was completed with the assistance of Rachel Kerslake and Lizzie Baxter from Autism Spectrum Australia (Aspect) and Micaela Rafferty and Jill Hellemans from Autism Behavioural Intervention (ABI) NSW.

We would also like to thank the many families who participated in the evaluation. We thank them for their time and insights and trust that their views are adequately represented in this report.

Disclaimer

This independent evaluation was undertaken with assistance from Ageing, Disability and Home Care (ADHC) in the Department of Family and Community Services. However, the information and views contained in this report are not intended as a statement of ADHC policy and do not necessarily, or at all, reflect the views held by ADHC, the NSW Government or the Minister for Ageing, Minister for Disability Services.

Table of contents

1	Executive summary.....	5
1.1	The evaluation.....	5
1.2	Key findings.....	7
1.3	Detailed findings.....	7
1.4	Implications for future service delivery	11

1 Executive summary

This report presents the findings on an independent evaluation by ARTD Consultants of Ageing, Disability and Home Care (ADHC), Family and Community Services four Autism Early Childhood Intervention programs delivered in four ADHC regions between 1 July 2008 and 30 June 2012.

The four programs—Footprints (Autism Behavioural Intervention (ABI) NSW), Building Blocks, More Than Words and Autism Pro (Autism Spectrum Australia (Aspect) NSW)—were funded through Stronger Together: A new direction for disability services in New South Wales, 2006–2016, under which an additional \$2bn of disability services funding was provided. These autism early childhood intervention programs provide specialist intervention services for children with autism aged 0 to 5 years, and were designed according to best practice principles. The programs vary in terms of their philosophical orientation, delivery (mode, intensity, duration) and the intervention focus (child or parent).

- Footprints (ABI) uses positive behaviour support processes to assess and treat challenging behaviour, in the family home as well as in other nominated settings, according to the principles of applied behavioural analysis.
- Building Blocks (Aspect) provides specialist home-based and centre-based early intervention services that take a comprehensive approach to supporting children.
- Autism Pro (Aspect) is an online service designed to support families—particularly those in regional and remote areas or those waiting for other services—and to complement other treatments and interventions.
- More Than Words (Aspect) is a training program for parents developed by the Hanen Centre for families with young children with autism, focusing on engagement and communication.

1.1 The evaluation

The purpose of the evaluation was to inform ADHC's decisions about the future direction of programs to support children with autism and their families.

ADHC developed a program logic model for the four programs, which provided the basic structure for the evaluation and guided our choice of performance measures and data collection methods. The program logic model identified outcomes at different levels and showed the causal links between them. The evaluation design used mixed methods and drew on existing client data sources collected by program staff and new data collected through interviews and surveys.

We interviewed 18 staff members from ADHC, ABI and Aspect by telephone or in person using a semi-structured interview guide. We analysed interview data against a coding framework to develop themes.

A survey of parents went to all 408 families of children who enrolled in the four programs between 1 July 2008 and 30 June 2011. We received 121 responses, a response rate of 33%. The survey collected demographic information about the child and family, the child's use of services, supports and therapies, and responses to a 27-item self-report measure, the Parent Perception Questionnaire (PPQ). The PPQ assessed parents' ability to cope. It also included seven retrospective post-test items to measure change in parents' self-reported knowledge of autism, understanding and ability to cope. We ran frequency analyses of all variables, and calculated the mean change (and associated effect size and significance) for the seven retrospective post-test items. We compared parents' perceptions of the mean changes across organisations and the number of programs children had done, and tested which group of parents were reporting the biggest changes.

We drew a stratified random sample of 25 families (each with at least one child in a program) who returned a survey and invited them to participate in case study interviews. For both the survey and case studies, we analysed qualitative data against a coding framework based on the principles of effective autism early childhood interventions. We used quantitative attributes (diagnosis, background, services used) to explore qualitative responses. All families who were approached agreed to be interviewed.

Existing outcomes data collected by service providers was also a key data source for the evaluation. We did frequency analysis of demographic variables for all children (N=467; ABI n=237 and Aspect n=230) who took part in the four programs between 1 July 2008 and 31 December 2011. For children who took part in Footprints or Building Blocks, program data also included an assessment of their skills and abilities across key developmental domains: social or social/ cognitive; communication; academic or pre-academic; play and leisure; personal and home management or activities of daily living; community; and motor skills. We calculated the average skill level at baseline and exit; the difference between the two was the child's 'level of progress'. We then developed a binary variable ('mastery') to determine for which children the program worked best. In ABI, children who achieved mastery were those rated by their parents as 'skilful' in at least 75% of their goals across all key developmental domains. In Aspect, children who achieved mastery were those rated by their therapists as 'yes' or 'generalised' in at least 75% of items across all key developmental domains. These definitions were reached in discussion with service providers for both Aspect and ABI. We then built multivariate logistic regression models for children in Footprints and Building Blocks to determine which child, family or program factors predicted mastery.

Confidence in the findings

Overall, the findings from the different methods were largely consistent and we are confident they provide evidence for a sound assessment that informs further discussion and investigation. Although the evaluation methods were implemented as planned, there were some methodological limitations. In

particular, the parent survey response rate was lower than expected (33%), the outcomes data was only available for children in Footprints or Building Blocks, and a substantial amount of outcomes data was missing. The findings reflect the population of children and families included in the study, but their outcomes cannot be generalised to the broader population of children with autism and their families.

1.2 Key findings

Families of children with autism commonly use multiple supports, services and therapies, even though many face economic and other challenges accessing services, especially if they live in rural areas. These patterns were evident in this evaluation, where many children used more than one of the four programs, in conjunction with other supports, services and therapies. We found that almost all families were also accessing Helping Children with Autism (HCWA) Package funds, and using these to pay for additional support from ABI or Aspect, or to access other types of therapy or support.

It is difficult to tease out the impact of these four intervention programs on service system capacity because of the concurrent changes to the service system due to HCWA, and because families use a range of services, supports and therapies. We cannot measure how much each program contributed to outcomes for children.

But, the evaluation shows that the four autism early childhood intervention programs successfully included children in the target age and diagnosis ranges. Parents chose programs that were consistent with their own idea of what skills, abilities and behaviours were important for their child to develop. The programs were regarded as valuable by parents.

The evaluation also shows that children who took part in one or more of the four programs—within the context of receiving other services, supports and therapies—demonstrated improved skills, abilities and behaviours. Their parents' knowledge, understanding and ability to cope increased. Parents' knowledge and understanding of autism significantly improved, and was greater for parents whose children did two or more of the four programs.

1.3 Detailed findings

Implementation challenges

The programs were a mix of new and existing programs and, as is common, all four programs faced some challenges in getting established or expanding to meet the demands of a higher client base. Two programs, Building Blocks and Footprints, were expanded under the current funding allocation. Both service providers found the initial six months of implementation difficult, particularly as they recruited and trained new staff to deliver the programs.

The most serious implementation challenge was that families either did not engage with Autism Pro or experienced technical problems accessing this

web-based service. As a consequence, Autism Pro was discontinued after 12 months and the remaining funds used to establish the More Than Words program in the Hunter region. After some early difficulties (which were resolved) More Than Words is now operating successfully in the region.

Limited evidence about the influence of the programs on regional waiting lists or service system capacity

This evaluation shows that almost all families who used one or more of the four programs were also accessing HCWA funds. In this environment, it is not possible to discern the effects the four programs had on regional waiting lists. In areas where there were previously few autism-specific services, especially the Hunter and Nepean regions (Metropolitan North), the programs are likely to have contributed to service system capacity. Elsewhere, it seems that the four programs are complementing the available services, supports and therapies available for children with autism and their families.

As established service providers, both ABI and Aspect had good working relationships with other providers in the ADHC regions before the programs were introduced or expanded. We have no evidence that the relationships were weakened or strengthened by these four new programs, but it seems that the links between agencies and providers were maintained.

Children in the target age and diagnostic ranges participated in the autism early childhood interventions

Service data shows that as at 31 December 2011, 467 children had accessed the four autism early intervention programs. Of these, 237 children used Footprints. A further 237 children participated in one or more of the Aspect programs with 56% of children using Building Blocks, 23% using More Than Words and 23% using Autism Pro. The program data is specific to the individual service providers and we cannot quantify how many children also accessed services from the other provider, although our parent survey and case studies indicate many children participate in programs at both ABI and Aspect.

Most (85%) of the children who used an ABI or Aspect program had a diagnosis of autism and were first enrolled when they were three (43%) or four years (34%) old, with no differences across programs in terms of enrolment age.

Children from Indigenous backgrounds are under-represented in the cohort of children who used the programs

The four programs reached some children and families from culturally and linguistically diverse (CALD) backgrounds but only a very small number of children (n=9) from Aboriginal backgrounds. Other research shows that it is often difficult for human services programs to reach children from Aboriginal backgrounds, for reasons that might include the requirement to have a formal diagnosis, or a preference to care for children within the extended family and

local community. Because there are so few Aboriginal children in the programs we cannot draw conclusions about the suitability of these four programs for children with autism from Aboriginal backgrounds.

Some families are geographically or socially isolated from services

It is likely that some children from families that are isolated—either due to location, lack of childcare, transport or within-family issues—are unable to access the programs. One in five children in the programs has a sibling with a disability; a further 10% have a family member with mental health problems. With the exception of Autism Pro, the programs only serviced families from highly accessible, metropolitan locations within the Metropolitan North, Metropolitan South, Southern and Hunter ADHC regions. Low or no income might also prevent some families from accessing the programs.

Children with autism use a wide range of services, supports and therapies

Multiple service use is common for children with autism, and was evident in this evaluation. Half of the parents surveyed said their child used two or more of the four autism early childhood intervention programs. Many children also used other supports, services and therapies, particularly speech therapy (65%) or occupational therapy (52%), mainstream preschool (33%) or childcare (31%). Almost all of the children (96%) were accessing support with the assistance of the Helping Children with Autism package.

Taking up an ADHC-funded place gave families the option to try a program they may not otherwise have been able to afford

Although our survey sample is biased towards families from higher socioeconomic backgrounds, many families said they could only afford the supports, services and therapies their child uses because they receive government funding. The ADHC-funded places seem to contribute to families' ability to choose a range of services, supports and therapies for their child: more than half (55%) the survey respondents chose to use their HCWA funds to buy services from providers other than ABI and Aspect.

Where there is outcomes data available, it shows that children made progress in key developmental domains

Pre- and post- outcomes data was only available for children in Footprints or Building Blocks, and there were some problems with the completeness of the data collected. But, where there was data available it showed that almost all children made some progress and very few children made no progress or showed a negative change. Children who took part in Building Blocks made the biggest gains in the key developmental domains of social skills, play skills and communication. By contrast, children in Footprints made the most progress towards their goals in the academic, social-cognitive and community domains. Children in Footprints showed a reduction in challenging behaviours: the average frequency of tantrums for all children fell from 3.8 per

hour to 0.87 per hour. Individually, many children were recorded as not having any tantrums in their exit assessment from the program.

There was moderate alignment between the program data and the changes parents who took part in the survey and case studies noticed in their children.

Improved skills and abilities are likely to improve children's transition to school

The parent survey shows that at the time of enrolling in an early intervention program, preparing their child for transition to school was less important than developing their child's specific skills and abilities. Only two-thirds of parents rated preparation or support with transition as 'very important', compared to 93% of parents who rated their child learning new skills or reducing challenging behaviours as 'very important'. Even so, almost two-thirds (60%) of parents believe that their child was better prepared to transition to school after doing one or more of the early intervention programs. It is likely that the importance parents place on transition increases with time; most children enrolled in these programs when they were a few years off the usual age to start school (three or four years old).

Isolating factors that predict what program 'works' for children is not straightforward

We explored what individual family and program factors are associated with 'mastery' through multivariate logistic regression modelling, although this analysis was limited by the outcomes data and also difficult because many children took part in more than one of the four programs. For children who took part in Footprints, family factors explained a statistically significant amount of the variance in mastery ($p=0.034$). In particular, children who took part in Footprints were significantly less likely to achieve mastery if there was a household member with health issues ($p=0.038$) or other issues ($p=0.031$), or if the family was from a low socioeconomic background ($p=0.05$). The model only explained between 8% and 12% of the variance in mastery scores, which suggests other factors not captured by the current service data impact on the results children achieve by participating in Footprints.

Family level data was not available for children who participated in Building Blocks, but for these children we found that children's baseline level of capacity was a strong and significant predictor of mastery ($p=0.003$). This model explained between 48% and 67% of the variance in mastery scores.

Parents' knowledge, understanding and awareness of autism increased and they felt better able to manage their anxiety

As a group, parents who responded to the survey reported better knowledge and understanding of autism and improved coping skills after their child took part in one or more of the four autism early childhood programs. Parents' self-reported knowledge and understanding of autism increased in line with the number of programs their child had done; in particular, parents whose child

participated in three programs had significantly better general knowledge about autism ($p=0.004$) and a better understanding of how children with autism process information and learn ($p=0.002$).

Parents who responded to the survey reported statistically significant improvements in their ability to manage their stress and anxiety about having a child with autism ($p=0.001$), and improvement in the level of support they have access to ($p=0.001$). Even though parents reported feeling more confident that they can now manage their child's challenging behaviours, this difference was not statistically significant. Unlike knowledge and understanding, improvements in parents' self-reported confidence and coping was not related to the number of programs accessed.

1.4 Implications for future service delivery

The findings highlight that no single autism early childhood intervention program will meet the needs of all children and families, and that families of children with autism will access a range of supports, services and therapies. Continuing to deliver a range of evidence-based early childhood intervention programs, services and supports means that families will continue to have the flexibility to choose a program that best meets their child and family's needs. Being able to access autism-specific programs, particularly those offered in places their child receives care, is important to families.

We found that it is important to parents that the available supports, services and therapies help them develop practical strategies to support their child with autism. Future early childhood programs could be strengthened by including a parent-training component, either as a standalone program for parents, or as part of a comprehensive wraparound program for children.

The results show it is difficult for some children and families to access early intervention, particularly if they live in rural areas, do not have access to transport, have low personal or financial capacity or lack of access to childcare. Children and families from Aboriginal backgrounds may not be able to access the programs. Remote service delivery was discontinued under this funding allocation, but given that this delivery mode may be the only way some geographically or socially isolated families can access intervention, it is important to consider it for the future.

This evaluation also demonstrates the importance of developing and implementing monitoring systems that allow high quality demographic, service and outcomes data to be captured in a way that is meaningful to individual service providers, but consistent across funded programs.