



Final Evaluation of the Helping Children with Autism Package (FaHCSIA components)

Summary report

FaHCSIA

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ARTD consultancy team

Jade Maloney, Wendy Hodge, Chris Milne, Emily Verstege, Janet Kidson, Florent Gomez-Bonnet, Fiona Christian, Kerry Hart, Marita Merlene, Ofir Thaler

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Executive summary

Helping Children with Autism Package

In 2008, the Australian Government committed \$190 million over four years to deliver the Helping Children with Autism (HCWA) Package. The Package aims to improve access to best practice early intervention, education and support for families of children diagnosed with autism. State and territory governments remain the primary providers of early intervention services for children with a disability; the Package is intended to complement these services.

The Package is delivered jointly through the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), the Department of Education, Employment and Workplace Relations (DEEWR) and the Department of Health and Ageing (DoHA). The DoHA component provides Medicare rebates for diagnosis and intervention. The DEEWR component provides workshops for parents/ carers of school-aged children and professional development for school staff.

The FaHCSIA component of the Package is centred on a new market-based and individualised approach to funding early intervention services. Eligible children receive an allocation of up to \$12,000 that can be used to purchase services from providers that deliver eligible services and are members of the Early Intervention Service Provider Panel (the Panel). Families are made aware of autism and available services through a range of education and support services (Autism Advisor Services, Early Days workshops, the Children with Autism pages of the Raising Children Network (RCN) website, PlayConnect playgroups).

Final evaluation

ARTD Consultants evaluated the FaHCSIA components of the Package in three phases (initial, mid-term and final evaluation) over two-and-a-half years (July 2009–December 2011). The main purpose of the final evaluation was to assess the Package's impact on access to services and to inform decisions about future directions. This report presents the findings from the final phase and uses data collected across the three phases to draw conclusions.

Key findings

Beginning as a new initiative in 2008, the FaHCSIA component of the Package has been successfully developed over three-and-a-half years, and has now reached a mature stage of implementation. It has been largely effective in reaching the target population, increasing access to approved early intervention services and producing positive outcomes for children and families, but there remains uncertainty about the extent to

which services are in line with some best practice principles for children with autism. The Package introduced a major change to the system and many refinements to the model were suggested to improve pathways to services for families.

The Package has achieved good reach into the population of children with autism. Between July 2008 and November 2011 almost 17,000 children have registered for the Package; of which 12,702 are currently eligible. This is equivalent to 0.7% of Australian children 0–6 years—a figure roughly in line with estimated prevalence rates for autism in children. But children from outer regional and remote areas¹ and those from culturally and linguistically diverse (CALD) backgrounds remain under-represented among registered clients, assuming autism prevalence rates are the same across different locations and family types. Indigenous registrations have increased steadily over the three-and-a-half years to date, but stakeholders remain concerned about the barriers these families can face in registering their children.

Most children registered (90%) have been able to make a claim(s) for services, and the average number of claims per child has increased over the years of operation as families have had more time to access services and as the number of providers on the Panel has grown. Evidence suggests at least some of these families would not have been able to access services without the early intervention funding, and others would not have been able to access services as frequently. But a lower proportion of registered children from regional and remote areas (including the Northern Territory) and those from Indigenous families have accessed services. This suggests a need to explore different service models to meet the needs of some of these families.

While the Panel is a means to ensuring children receive quality services and stakeholders generally believe most providers offer quality services, they did raise concerns about some providers' practice, indicating a quality monitoring process is needed. The Panel model is also intended to ensure children receive a multidisciplinary service, which is best practice for children with autism, but evidence suggests the current model is insufficient to ensure this occurs and new mechanisms should be explored to facilitate multidisciplinary practice.

The education and support components have played an important role in supporting families to understand autism and intervention types and to make decisions about which services to access for their child. Many of the families surveyed who had used these components reported positive outcomes associated with them. But some enhancements would ensure families receive the support they need to make effective decisions about services.

¹ Client data uses the Accessibility/Remoteness Index of Australia+ (ARIA+) to define location. Classifications are major cities, inner regional, outer regional, remote and very remote.

The Package model recognises that families of children with autism have different needs at various stages' of their journey, providing a combination of intervention and support components as well as education to assist in meeting these needs. But there could be greater synergies between Package components and with the existing service system to ensure effective pathways for families.

Overall, the available evidence is that the Package has had a positive impact on children and families, with families reporting children have improved social and communication skills and behaviour, and are better prepared for the transition to school. But, reflecting the differences in their ability to access Package services, there are some differences between reported outcomes by family type. Families from regional and remote areas (including the Northern Territory), Indigenous families and families from CALD backgrounds who have lower English proficiency were less likely to report positive outcomes for their children.

1. Final evaluation of the Helping Children with Autism Package (FaHCSIA components)

1.1 Helping Children with Autism Package

In 2008 the Australian Government committed \$190 million over four years to deliver the Helping Children with Autism (HCWA) Package. The Package aims to improve access to best practice early intervention, education and support for families of children diagnosed with autism. It is intended to complement existing state and territory government services and should be recognised as contributing to an existing and continuing system of support.

The Package is delivered jointly through the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), the Department of Education, Employment and Workplace Relations (DEEWR) and the Department of Health and Ageing (DoHA). FaHCSIA is responsible for the major share of the Package (\$127 million) focusing on access to services for children aged 0–7 years, intended to help parents in the crucial post-diagnosis period. The DoHA component covers Medicare rebates for diagnosis and treatment planning for children aged under 13 years and Medicare rebates for 20 sessions of intervention for children aged under 15 years. The DEEWR component focuses on the needs of school-aged children with workshops for parents/ carers and professional development for school staff.

The FaHCSIA component introduced a new approach to funding early intervention services to address the limited service access for children with autism in an area where the Commonwealth was not previously directly involved. Eligible children receive an allocation of up to \$12,000 that can be used to make claims for services until their seventh birthday. Families are able to select services from an Early Intervention Service Provider Panel (the Panel) of allied health professionals. The Package's market-based and individualised approach was a significant innovation in funding for early intervention services and involved setting up a new delivery system—the Panel and eight Autism Advisor Services based in state and territory autism associations² to register children and inform families about service options.

The FaHCSIA component also include three other education and support services—the Early Days workshops, the Children with Autism pages on the Raising Children Network (RCN) website and the PlayConnect playgroups—as well as six Autism Specific Early Learning and Care Centres (ASELCCs).

² The Northern Territory Advisor Service is under the auspice of the Autism SA.

1.2 Final evaluation

ARTD Consultants evaluated the FaHCSIA components of the Package in three phases over two-and-a-half years (July 2009–December 2011). The evaluation did not cover the ASELCCs, which are being evaluated separately. The DEEWR component of the Package has also been separately evaluated.³

The main purpose of the final evaluation was to assess the Package's impact on access to services and to inform future directions. This is the summary report, which is supported by a comprehensive technical report for internal use. It presents the findings from the final phase and uses data collected across the three phases to draw conclusions.

The methods for the final evaluation included surveys and interviews covering all major stakeholder groups (families, Panel providers, Autism Advisors, Playgroup Australia and Early Days workshops, representatives of the professional associations/ colleges, diagnosticians, state-based services, representatives from state government departments and Package managers), an analysis of administrative data collected by FaHCSIA (FaHCSIA Online Funding Management System [FOFMS] client data and Advisor Service, Early Days and RCN reports) and a scan of relevant research and evaluation reports. Detailed methods are provided in Appendix 1.

The evaluation methods were implemented largely as planned and provided comprehensive data for the evaluation. There were some limitations to the individual methods. In particular, while 4,437 families responded to the family survey, this is only 34% of all registered families. This means that although the findings highlight significant patterns, some caution should be taken in extrapolating the findings to all registered families. The methods were triangulated, in that they addressed the same questions from different stakeholders' perspectives, and the findings from the different methods were largely consistent. As a result, we are confident that the findings provide the evidence for a sound assessment. At the same time, the final evaluation uncovered some emerging issues about which there are competing claims and which would require further assessment to draw conclusions.

³ Allen Consulting Group, 2010, Evaluation of Positive Partnerships — the DEEWR component of the Helping Children with Autism Package, report to the Department of Education, Employment and Workplace Relations, November 2010 <http://www.deewr.gov.au/Schooling/Programs/Documents/PositivePartnerships.pdf>

2. Outcomes for children and families

2.1 Outcomes for children

The Package aims to improve access to best practice early intervention, education and support, with the assumption that this will contribute to improved outcomes for children with autism before they begin school. While the evaluation has focused on access rather than outcomes for children and families, the available evidence—from both families and Panel providers—indicates that the Package is also contributing to improved outcomes.

Throughout the evaluation, most families surveyed agreed that since accessing the Package their children have improved communication, social skills and behaviour and they are more prepared for the transition to school (Table 2.1). The generally positive family self-reports are supported by Panel providers—most surveyed (>83% for each outcome item) report all or most of the children they have seen have shown improvements in these core areas.

The HCWA funding has allowed us to access speech therapy, occupational therapy and psychology appointments. We could not afford these vital services if we did not have access to the HCWA funding. Our son is responding well to these therapies and in only a couple of months (we) have noticed an improvement in speech and behaviour. [Family survey respondent]

Fantastic opportunity for children to be prepared for and therefore successfully commence school with best outcome for child, family and school. Visionary. [Panel provider survey respondent]

Table 2.1: Child outcomes reported by families (2009–2011)

Since accessing the Package	% agree*		
	2009	2010	2011
...my child/ children have improved their communication skills.	83%	86%	89%
...my child/ children have improved their social skills.	80%	80%	84%
...my child/ children have improved behaviour.	–	78%	80%
...my child/ children is/ was better prepared to transition to school.	–	76%	78%

Source: Family survey 2009, 2010, 2011

*% agree refers to total 'agree' and 'tend to agree' responses

Of course, the outcomes achieved are not attributable to the Package alone because children often access other private and state-based services in addition to those paid for with the early intervention funding, but parents/ carers often associated their children’s outcomes with services accessed through the Package.

An emerging concern among a very small proportion of stakeholders in the final evaluation was sustainability of outcomes—while 25% of the children registered since

July 1 2008 have now transitioned, some have only done so recently so it is too early to make an assessment of sustainability of the outcomes achieved.

2.1.1 Outcomes for children by family type⁴

Reflecting the differences in access to the Package services by family type, the 2011 survey shows some differences between reported outcomes for children. A lower proportion of families from the Northern Territory and Indigenous families and a slightly lower proportion of those from regional and remote areas reported improvements for their child (for three to four of the core outcomes areas assessed).

A lower proportion of families with low gross weekly incomes (<\$600)⁵ reported improvements for their children, possibly because these families are less able to top up the intervention their child receives through services they pay for privately.

While stakeholders have concerns about access to the Package for families from CALD backgrounds, the families were, on the whole as positive about improvements for their children as English-speaking families who were surveyed.⁶ But those with lower English proficiency were less likely to report improvements in children's social and communications skills, possibly because they face greater barriers in service access.

2.2 Outcomes for parents/ carers

The Package's education and support components are intended to help families better understand autism and link them to services and supports. The available evidence indicates the Package is generally meeting this aim. Throughout the evaluation, most families surveyed reported that since accessing the Package they better understand autism and service options and feel better equipped to support their child (Table 2.2).

The HCWA Package has made what could have been a very scary, daunting time in our lives, so much more of a smoother process. [Family survey respondent]

By having access to these professionals and helping my son, we are able to connect again, instead of him always being in his own world and on his own agenda. [Family survey respondent]

⁴ Family type' refers to demographic categories used in the survey or in the FOFMS data: location, Indigenous status, CALD status and income band.

⁵ In discussion of survey data, these families are referred to as 'low income' families.

⁶ To define CALD families the survey used a proxy measure: whether the language mainly spoken at home was a language other than English. The survey also asked how well the child/ren's primary care giver speaks English so we could differentiate between families with high and low English proficiency.

Table 2.2: Parent/ carer outcomes reported by families (2009–2011)

Since accessing the Package	% agree*		
	2009	2010	2011
...I am better informed about autism and how I can get help for my child/ children.	79%	73%	78%
...I feel better equipped to support my child/ children with autism.	–	82%	84%
...I am undertaking more activities/ therapy in the home as part of my child's/ children's treatment/ service plan	–	76%	–

Source: Family survey 2009, 2010, 2011

*% agree refers to total 'agree' and 'tend to agree' responses

Despite positive outcomes overall, some families are reportedly stressed by making decisions about services or by their inability to access services and support locally.

2.2.1 Parent/ carer outcomes by family type

As for children, there were some differences in reported outcomes for parents/ carers by family type in the 2011 survey, some of which may relate to differences in service access and some of which may relate to differing starting levels of awareness of autism.

A lower proportion of family survey respondents from regional and remote areas reported improvements in outcomes for parents/ carers; and a slightly lower proportion of those from the Northern Territory reported being better informed about autism and how they can get help for their child. These differences are likely associated with having fewer local providers. A lower proportion of those from the Australian Capital Territory (ACT) reported feeling better equipped to support their child; possibly these families had a higher level of understanding of autism prior to accessing the Package.

A slightly lower proportion of low income family survey respondents reported they felt better equipped to support their child; possibly related to claims some stakeholders made that these families need additional supports to navigate the service system.

While stakeholders have concerns about access for Indigenous families, Indigenous families surveyed were about as likely to report improvements for parents/ carers as non-Indigenous families. But reflecting stakeholder concerns, some of the Indigenous families we spoke to reported needing more support than the Package provides.

While stakeholders are also concerned about access for families from CALD backgrounds, these families were more likely than English-speaking families to report improved understanding of autism and how to get help for their child. This may be because they had lower levels of understanding of autism before accessing the Package.

3. Awareness and registration

3.1 Pathways into the Package

Families can enter the system at many points; they might see a paediatrician or general practitioner, seek services from a private practitioner for a specific issue, or begin with a state-based early intervention service (sometimes for other issues). This means a range of stakeholders must be informed about the Package or able to access information as they need it to ensure effective referrals are possible. Families also need to be able to find information directly because some turn to the Internet when they first notice something might be different about their child.

Continued high rates of registration for the Package suggest that reasonably effective information and referral pathways are established, but diagnosticians—in particular diagnosing psychiatrists—could be better informed.

3.1.1 Promotional activities

Information about the Package is available through the FaHCSIA, DoHA and DEEWR websites and the Children with Autism pages of the RCN website. But to ensure stakeholders can obtain the information they need, the DEEWR and DoHA sites should provide links to components delivered through each of the other departments, and the Children with Autism pages should display a one-page diagram that covers all Package components and references the state service system.

Advisor Services are doing appropriate promotional activities targeting the range of stakeholder groups. National teleconferences could be used as an opportunity to share resources and learnings, particularly about working with CALD and Indigenous communities, and reduce duplication of effort.

3.1.2 Referrers' understanding of the Package

Diagnosticians have a key role in ensuring families of children with autism are connected with the Package. But many diagnosticians surveyed, particularly diagnosing psychiatrists, didn't feel well informed about Package components. While caution should be taken in extrapolating these findings to the broader population because the sample of diagnosticians that responded to the survey is not representative, it is consistent with feedback from other stakeholders implying diagnosticians could be better informed. This suggests a need for more systematic and regular communications with diagnosticians at the Package level through the Royal Australian College of Physicians, Division of Paediatric and Child Health and the Royal Australian and New Zealand College of Psychiatrists, Faculty of Child and Adolescent Psychiatry.

Data also suggests general practitioners could have more information about autism and the Package, which could be distributed through the Royal Australian College of General Practitioners.

State-based services that are also Panel providers are generally well-informed about the Package. But there were some differences in understanding between the state-based services that we spoke to that are not also providing Package services. This could be addressed through stronger links with state and territory government departments at the Package level.

3.1.3 Referrals

Despite not feeling well informed about the Package, over three-quarters (78%) of diagnosticians surveyed agreed they regularly inform families about Advisor Services and two-thirds (67%) agreed they regularly refer children to local Panel providers. But psychiatrists surveyed were far less likely than paediatricians to make these linkages, and the feedback from some stakeholders suggests more systematic communications with diagnosticians would help ensure smoother pathways to registration.

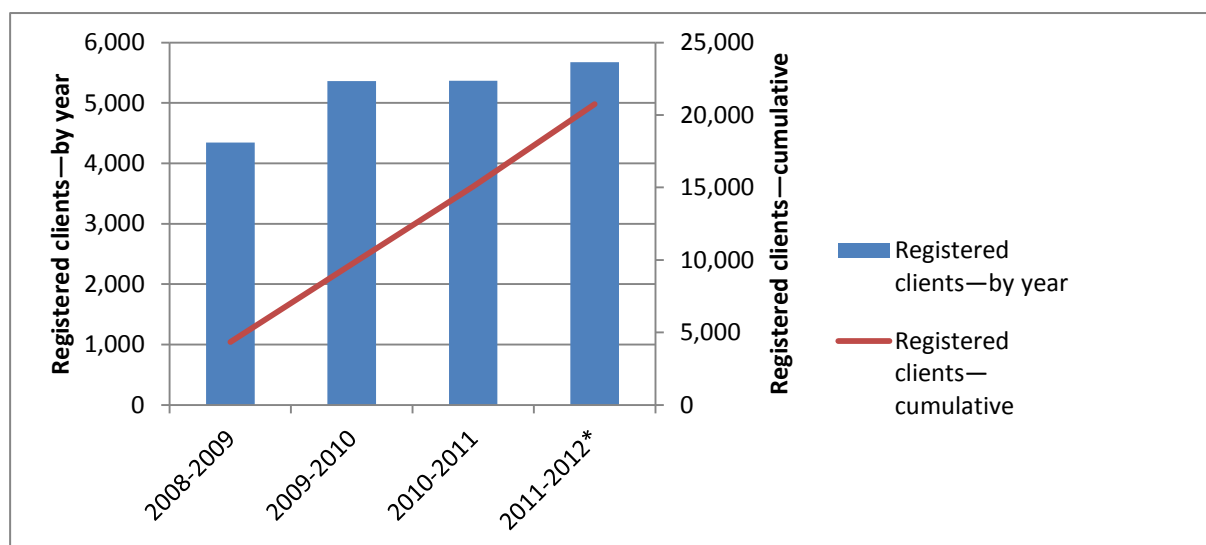
3.2 Registration

The Package aims to ensure all children with autism and their families from around Australia can benefit from increased access to support and services. To access early intervention services children must have a formal diagnosis of autism and register for the Package before their sixth birthday; funding can be claimed until the child's seventh birthday.

Client data indicates the Package has achieved good reach into the population of children with autism. Between July 1 2008 and November 3 2011, a total of 16,967 children were registered for the Package. Registrations grew between 2008–2009 and 2009–2010 when the eligibility age criteria changed⁷ and the Package became more established, but have since stabilised (Figure 3.1). Despite concerns about over-diagnosis, client numbers are roughly in line with estimated prevalence rates for children with autism.⁸

⁷ When the Package was first introduced, only children aged 0–6 years were eligible to use funding.

⁸ 12,702 clients are still under seven years old—equivalent to 0.7% of Australian children aged 0–6 years (calculated based on 2006 Census population data of 0–6 year olds). The Medical Research Council of the United Kingdom (2001) found that autism spectrum disorders affect approximately 60 per 10,000 children under eight years old and recent international research suggests an average prevalence of 1 in every 175 children (Insel, 2006) (cited in Prior, J. and Roberts, M., 2006, A Review of the Research to Identify the Most Effective Models of Practice in Early Intervention for Children with Autism Spectrum Disorders, report for DoHA, July 2006). The prevalence rate of 1 in 100 cited was cited as the 'best estimate' of prevalence studies referred to in the context of developing an autism strategy for Scotland (Mental health of children and young people in Great Britain, 2004 (Green *et al*, 2005) Office of National Statistics cited in Scottish Government, 2010, Towards an Autism Strategy for Scotland, <http://www.scotland.gov.uk/Publications/2010/09/07141141/2>)

Figure 3.1: Client registrations July 1 2008–November 3 2011

Registered clients by year from July 1 2008 to November 3 2011 are:

2008-2009: 4,346
 2009-2010: 5,360
 2010-2011: 5,369
 2011-2012*: 5,676

Cumulative registered clients from July 1 2008 to November 3 2011 are:

2008-2009: 4,346
 2009-2010: 9,706
 2010-2011: 15,075
 2011-2012*: 20,751

Source: FOFMS data July 1 2008–November 3 2011

*To estimate the number of registered clients for 2011–2012 we extrapolated based on the data available for the first four months.

Because eligibility is based on a formal diagnosis of autism, there is a need to consider how the Diagnostic and Statistical Manual of Mental Disorders V (DSM V), when introduced will affect autism diagnoses and eligibility for the Package.

3.2.1 Barriers to registration

Capacity of the diagnostic sector has been a concern throughout the evaluation, and less than one-third (32%) of diagnosticians surveyed agreed there is currently a sufficient diagnostic workforce. While the Medicare items have allowed some families to avoid public sector waiting lists, there are anecdotal indications that some private sector waiting lists are also long and some families may find it difficult to pay the gap fee to access private services. Diagnosticians suggested a need to boost the capacity of the workforce and a need for more training in diagnosing autism.

Other barriers to obtaining a diagnosis include a families' lack of awareness of autism or understanding of the signs and lack of willingness to seek a diagnosis. Anecdotal evidence suggests children with Asperger's Syndrome may be diagnosed later because the signs might only become apparent when they have greater interactions with other children at school.

3.2.2 Registration by family type

Advisor Services have developed strategies for working with families from regional and remote areas and those from CALD and Indigenous backgrounds who may face barriers to registering. While there have been improvements in rates of registration for some children, some family types remain under-represented.

Families from different states and territories

On the whole, the spread of registered clients broadly reflects the population data for children 0–6 years in each state and territory (Table 3.1). But children from Victoria remain over-represented and those from Western Australia and the ACT under-represented, assuming similar prevalence rates in all states and territories.

Table 3.1: Registered clients by state compared with 0–6 years population

State	2008–09*	2009–10	2010–11	2011–12**	Population 0–6 yrs
	N=4,346	N=5,360	N=5,369	N=1,892	N=1,779,010
	%	%	%	%	%
ACT	1%	1%	1%	1%	2%
NSW	32%	37%	32%	32%	33%
NT	1%	1%	1%	1%	1%
Qld	15%	16%	20%	20%	20%
SA	9%	7%	7%	7%	7%
Tas	2%	2%	2%	2%	2%
Vic	30%	31%	31%	32%	24%
WA	11%	6%	7%	6%	10%
No data/ other classification					N=1535

Source: FOFMS July 1 2008–November 3 2011. ABS Census 2006.

*When the Package was first introduced only children aged 0–6 yrs were eligible to use funding.

**Only four months of data is available for the 2011–12 financial year.

Families from regional and remote areas

When the Package was first introduced, families from regional and remote areas were under-represented, assuming similar prevalence rates across all areas. While there has been an increase in access for children from inner regional areas, children from outer regional, remote and very remote areas appear to be slightly under-represented (Table 3.2).

For remote and some regional families, the main issue is the lack of local diagnostic services and the difficulties associated with travel to centres where there are diagnosticians available. Recent changes to the Medicare items to allow multiple claims on one day are positive for families travelling to access a diagnosis. But as yet, it is unclear whether this will be enough to facilitate higher levels of registration.

Table 3.2: Registered clients by location (ARIA+) compared with 0–6 years population

Location	2008–09*	2009–10	2010–11	2011–12**	Population 0–6 years
	N=4,342	N=5,356	N=5,364	N=1,892	N=1,778,175
	%	%	%	%	%
Major city	77%	69%	70%	70%	68%
Inner regional	15%	22%	21%	20%	20%
Outer regional	7%	8%	8%	8%	10%
Remote	1%	1%	1%	1%	2%

Very remote	0%	0%	0%	0%	1%
No data/ other classification	N=4	N=4	N=5	N=0	N=2,366

Source: FOFMS July 1 2008–November 3 2011. ABS Census 2006.

Table notes: location classifications based on Accessibility/Remoteness Index of Australia+ (ARIA+).

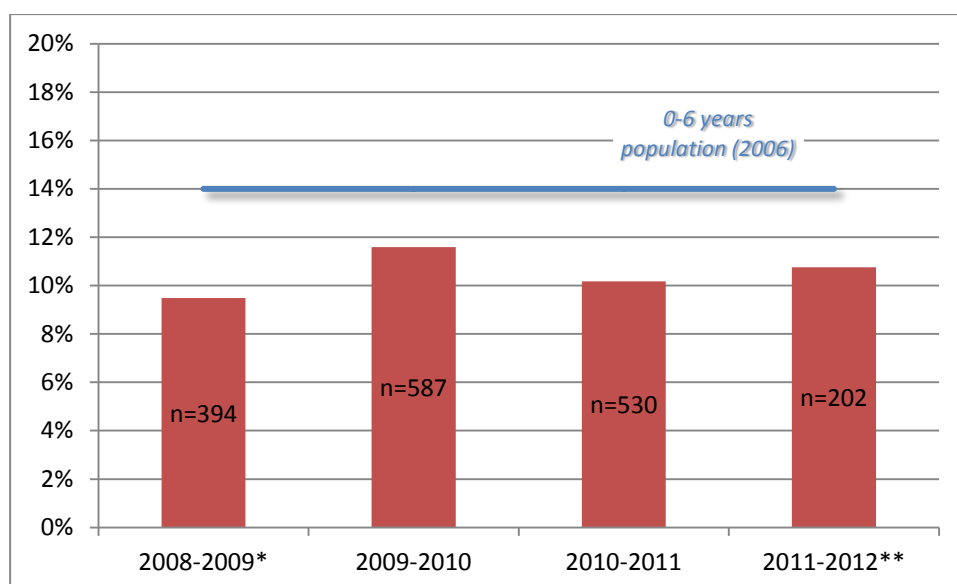
*When the Package was first introduced only children aged 0–6 yrs were eligible to use funding.

**Only four months of data is available for the 2011–12 financial year.

Families from CALD backgrounds

Children from CALD backgrounds (using language other than English mainly spoken at home as a proxy measure) remain somewhat under-represented among Package clients compared to the 0–6 years population. Rates have fluctuated between a low of 9% of registered clients in 2008–2009 and a high of 12% in 2009–2010, but children from CALD backgrounds make up 14% of the 0–6 years population (Figure 3.2).

Figure 3.2: Registered clients that speak a language other than English at home compared with 0–6 years population



Percentage of clients that speak a language other than English at home compared with 0–6 years population are:

2008-2009

Other language: 9% (n=394)

Other language – 2006 population data: 14%

2009-2010:

Other language: 12% (n=587)

Other language – 2006 population data: 14%

2010-2011

Other language: 10% (n=530)

Other language – 2006 population data: 14%

2011-2012:

Other language: 11% (n=202)

Other language – 2006 population data: 14%

Source: FOFMS July 1 2008–November 3 2011. ABS Census 2006.

Notes: Languages other than English include Australian Indigenous languages. Proportions calculated exclude 662 clients where language spoken at home was not stated.

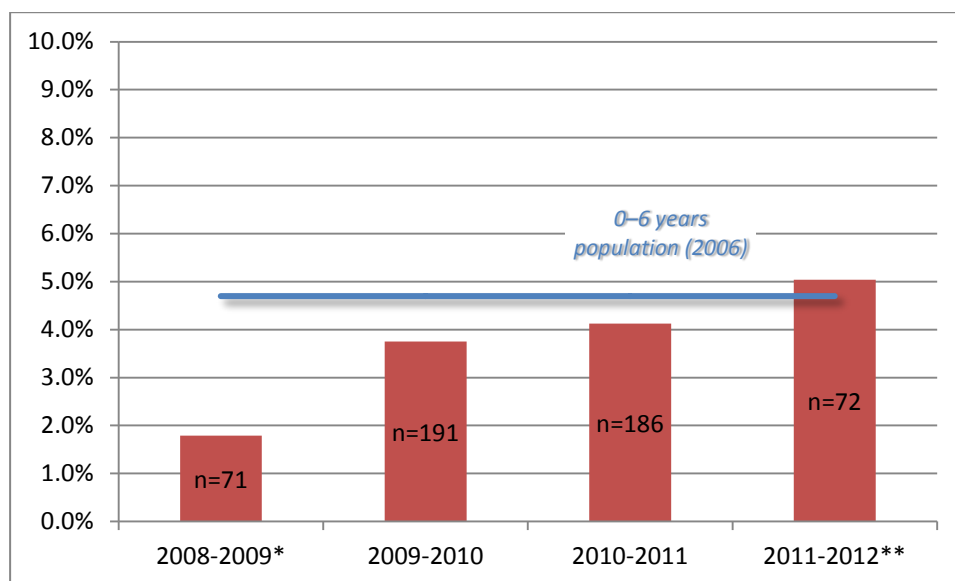
*When the Package was first introduced only children aged 0–6 yrs were eligible to use funding.

**Only four months of data is available for the 2011–12 financial year.

There are some indications that there may be lower levels of awareness of autism in some CALD communities, but the main barrier for families from CALD backgrounds identified throughout the evaluation has been the lack of translated information materials. Developing these materials at the Package level is the most logical first step to improving registrations for these families. Resources could be distributed through mainstream avenues, as well as through CALD organisations and Multicultural Resource Centres. Because of the importance of relationships in building effective referral pathways, particularly given the stigma that may be associated with disability in some cultures, Advisors should be supported to continue to develop links with CALD organisations.

Indigenous families

The proportion of registered clients that identify as Indigenous has increased steadily over the years of operation (Figure 3.3). The data for the first four months of 2011–2012 suggests registrations have reached expected levels, but this figure should be interpreted with caution because it is associated with a spike in Indigenous registrations in August and September 2011, followed by a decline in October 2011. Caution is also needed in interpreting the data overall because there are 1,977 clients for whom Indigenous status was not stated or that declined to answer. Also, qualitative data indicates stakeholders remain concerned about the barriers for these families.

Figure 3.3: Registered clients that Identify as Indigenous compared with 0–6 years population

Percentage of registered clients that identify as Indigenous, compared with 0-6 years population are:

2008-2009

Indigenous status: 1.8% (n=71)

Indigenous status – 2006 population data: 4.7%

2009-2010

Indigenous status: 3.8% (n=191)

Indigenous status – 2006 population data: 4.7%

2010-2011

Indigenous status: 4.1% (n=186)

Indigenous status – 2006 population data: 4.7%

2011-2012

Indigenous status: 5% (n=72)

Indigenous status – 2006 population data: 4.7%

Source: FOFMS July 1 2008–November 3 2011. ABS Census 2006

Notes: Proportions calculated exclude 1882 clients for whom Indigenous status was not stated and 95 that did not wish to answer.

*When the Package was first introduced only children aged 0–6 yrs were eligible to use funding.

**Only four months of data is available for the 2011–12 financial years.

Qualitative data from a various stakeholders indicates that Indigenous families may face a range of barriers to registering their children, including lower levels of awareness of autism and lack of culturally appropriate information resources, other significant health issues, barriers accessing mainstream services (and possibly Indigenous services staffed

by people they know), issues associated with required paperwork and potentially, reluctance to seek a 'label'.

The data suggests a need for plain English and culturally appropriate information resources at the Package level. Such resources could be distributed through mainstream avenues or Indigenous organisations, including Aboriginal Medical Services and preschools. But information is not enough; it is important that Advisors continue to be supported to develop strengths-based relationships with Indigenous organisations and communities. There is also some evidence of a need for strategies at the Package level to ensure effective pathways for Indigenous families to access the Package.

Low income families

There is no client data available on family income to objectively assess competing claims about how income influences access by families. Some stakeholders suggested low income families may face barriers to registering their children, including the cost of obtaining a diagnosis and difficulties in navigating the system; others suggest that the Package is increasing access for families from low socioeconomic areas. Advisor Services should record family income bands for registered clients—provided that they consent—so that access by low income families can be assessed.

3.3 Recommendations

Information and referral pathways

1. Establish more systematic and regular communications with diagnosticians and general practitioners through the professional colleges.

Registrations

2. Consider options to facilitate access for families in remote and particular regional areas that lack local diagnostic services.
3. Develop translated, culturally appropriate and plain English information resources at a Package level to facilitate access for CALD and Indigenous families. These could be made available through Autism Advisor Services and on the RCN and FaHCSIA websites.
4. Continue to support Advisor Services to develop relationships with CALD and Indigenous community organisations to facilitate access; lessons and strategies should be shared at a national level.
5. Develop options to ensure culturally appropriate service delivery and build trusting relationships between the Package and Indigenous communities, for example, establishing a national Indigenous Advisor position with the capacity to support and guide Advisor Services on work with Indigenous communities.

6. If families agree, Advisor Services should record family income for registered clients, so FaHCSIA can monitor the degree of access for low income families.

4. Early intervention

4.1 Service access

The early intervention funding component (up to \$12,000 per registered child) is intended to ensure all children with autism from around Australia are able to benefit from increased access to intensive early intervention.

Overall, the data suggests most children registered have been able to make at least one claim for service (or will be able to do so before they turn seven years of age)—90% of those registered between July 1 2008 and November 3 2011 have now made at least one claim for services. Indications are that at least some of the families accessing services with Package funding would have been unable afford to pay for services without it.

Evidence from stakeholders suggests the Package has generally enabled registered children to access services more frequently—most of the families (>80%), Panel providers (>90%) and diagnosticians (80%) surveyed agreed.

4.1.1 Panel growth

The Panel has continued to grow since it was established in 2008, enabling more children to access services. The introduction of sole providers (in late 2009) made a small but important contribution to increasing the capacity of the Panel. Despite the positive developments, there are indications that the capacity of the allied health workforce is limiting Panel growth and that broader workforce strategies, which are outside the direct control of the program, are needed—particularly as the Better Start Package (which commenced in July 2011) draws on some of the same providers. FaHCSIA could liaise with Health Workforce Australia about options for developing allied health workforce capacity.

Anecdotal evidence indicates the Panel application process may deter some providers from joining, and there were some suggestions to streamline the process. But there is also a need to consider concerns about provider quality and to maintain a rigorous assessment process.

4.1.2 Barriers to access

While families' satisfaction with service availability and timeliness of access has increased as the Panel has grown, not everyone has access to the services their child needs or to what they consider an adequate choice of local providers. The median wait time to access a service has decreased over the years of operation, but timeliness of access remains a concern for 42% of the families surveyed.

Some families find it difficult to decide which services are appropriate for their child, and would like or need additional support or information. Providing individualised advice is not within the scope of the Advisor role because it requires different qualifications and more time than they have available. But the role of the education components in providing guidance on effective decision making could be strengthened, and available information on evidence-based therapies could be better promoted.

Service lists also need to be up to date to ensure families don't miss out on a service in their local area.

4.1.3 Service access by family type

Families from different states and territories

Reflecting the low number of local Panel providers, and the fact that some of these have only recently joined, the Northern Territory has the lowest proportion of registered clients that have made at least one claim for services (Table 4.1).

Tasmania has the second lowest proportion of registered clients that have made a claim/s; this is likely related to the lack of service options in some areas, particularly the north west of the state, and/or difficulties with transport.

Table 4.1: Registered clients that have made at least one claim for services by state (July 2008–November 2011)

State	Made claim/s		No claims	
	n	%	n	%
NSW	5200	92%	456	8%
Vic	4719	91%	488	9%
Qld	2539	86%	409	14%
WA	1120	92%	104	8%
SA	1093	87%	164	13%
Tas	297	84%	58	16%
ACT	180	90%	19	10%
NT	90	74%	31	26%
TOTAL	15,238	90%	1,729	10%

Source: FOFMS July 1 2008–November 3 2011.

Notes: We have used cumulative claims data because it is not possible to calculate the percentage of eligible clients making claims by financial year (because the eligibility criteria changed and because children that are technically still eligible for funding may no longer be able to make claims because they have used their full allowance). For each year we have calculated the proportion of clients registered before that date who have ever made a claim. Thus the data may over-represent current inequities to some extent.

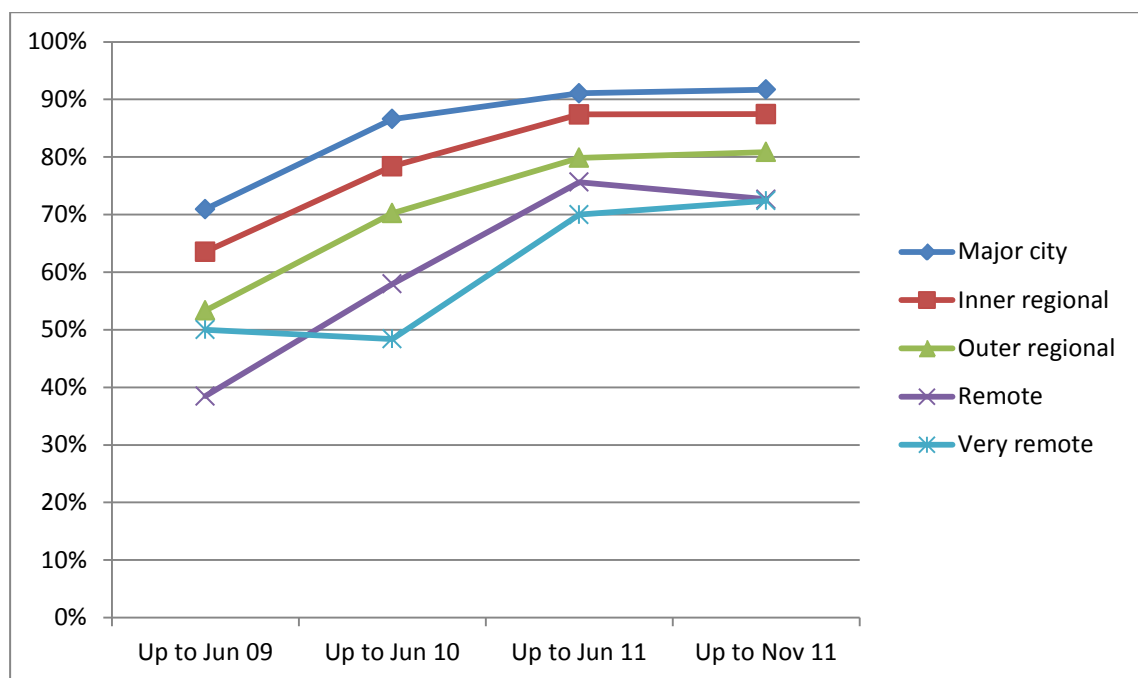
On average, families from the Northern Territory have also paid more per claim, reflecting the cost of travel and the use of outreach providers. While the average cost per claim is an indicative figure only because different claims cover different session lengths and types, it suggests that families in the Northern Territory will be able to claim fewer

services for their children under the current model. Given these issues, which reflect those for families in regional and remote areas more broadly, different service models should be explored to boost access.

Families from regional and remote areas

While the proportion of clients in regional and remote areas making claims has increased over the years of operation to date, the gap between these clients and those in major cities remains (Figure 4.1).

Figure 4.1: Registered clients who have made at least one claim for services by location (ARIA+), cumulative by year



Percentage of registered clients who have made at least one claim for services by location, cumulative year are:

Up to June 2009
 Major city; 71%
 Inner regional: 64%
 Outer regional: 53%
 Remote: 38%
 Very remote: 50%

Up to June 2010
 Major city: 87%
 Inner regional: 78%
 Outer regional: 70%

Remote: 58%
Very remote: 48%

Up to June 2011
Major city: 91%
Inner regional: 87%
Outer regional: 80%
Remote: 76%
Very remote: 70%

Up to November 2011
Major city: 92%
Inner regional: 87%
Outer regional: 81%
Remote: 73%
Very remote: 72%

Source: FOFMS July 1 2008–November 3 2011.

Notes: Location classifications are based on ARIA+. We have used cumulative claims data because it is not possible to calculate the percentage of eligible clients making claims by financial year (because the eligibility criteria changed and because children that are technically still be eligible for funding may no longer be able to make claims because they have used their full allowance). For each year we have calculated the proportion of clients registered before that date who have ever made a claim. Thus the data may over-represent current inequities to some extent.

On average, families in outer regional and remote areas have also paid more per claim (1.3 to 1.8 times as much as those in major cities), made far fewer claims than those in major cities (the average number of claims per client in remote and very remote areas is less than half the number per client in major cities), and spent less of their funding allowance.

In some areas there are too few clients to make a service sustainable, and Panel providers have difficulties servicing regional and remote areas under the current model because of the costs associated with travel and time lost while travelling. To a lesser extent some clients identified issues with lack of knowledge of demand and the extent of the demand in particular areas, which would allow pooled visits that cost less.

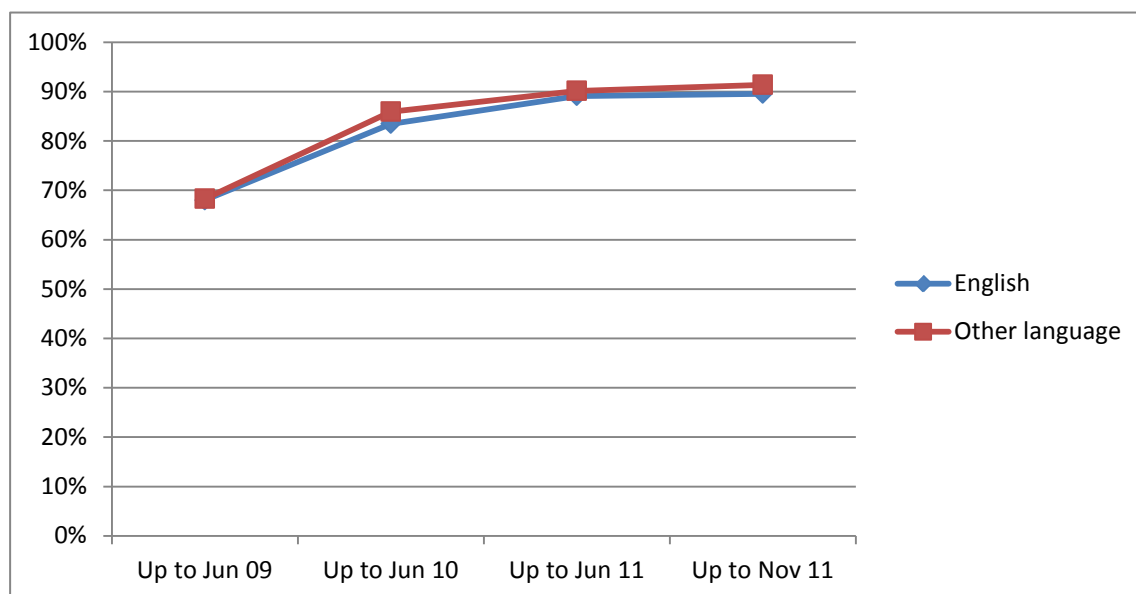
The evidence suggests alternative delivery models are needed for remote areas and particular regional areas that lack services. Options include exploration of tele-health approaches, funding providers for outreach, funding visiting services, up-skilling local services, providing incentives, and supporting trans-disciplinary approaches.

Families from CALD backgrounds

While stakeholders are concerned about access for children from CALD backgrounds, the proportion of CALD children registered who have made at least one claim for services is similar to that for English-speaking families (Figure 4.2).

While the finding is positive, qualitative data suggests those families with lower English proficiency may face greater barriers in accessing services. If the CALD clients that have registered are mostly those with higher levels of English proficiency, the findings may in part be a reflection of CALD clients' under-representation among registered clients.

Figure 4.2: Registered clients who have at least one claim for services by CALD status, cumulative by year



Percentage of registered clients who have at least one claim for services by CALD status are:

Up to June 2009

English: 68%

Other language: 68%

Up to June 2010

English: 83%

Other language: 86%

Up to June 2011

English: 89%

Other language: 90%

Up to November 2011

English: 90%

Other language: 91%

Source: FOFMS July 1 2008–November 3 2011.

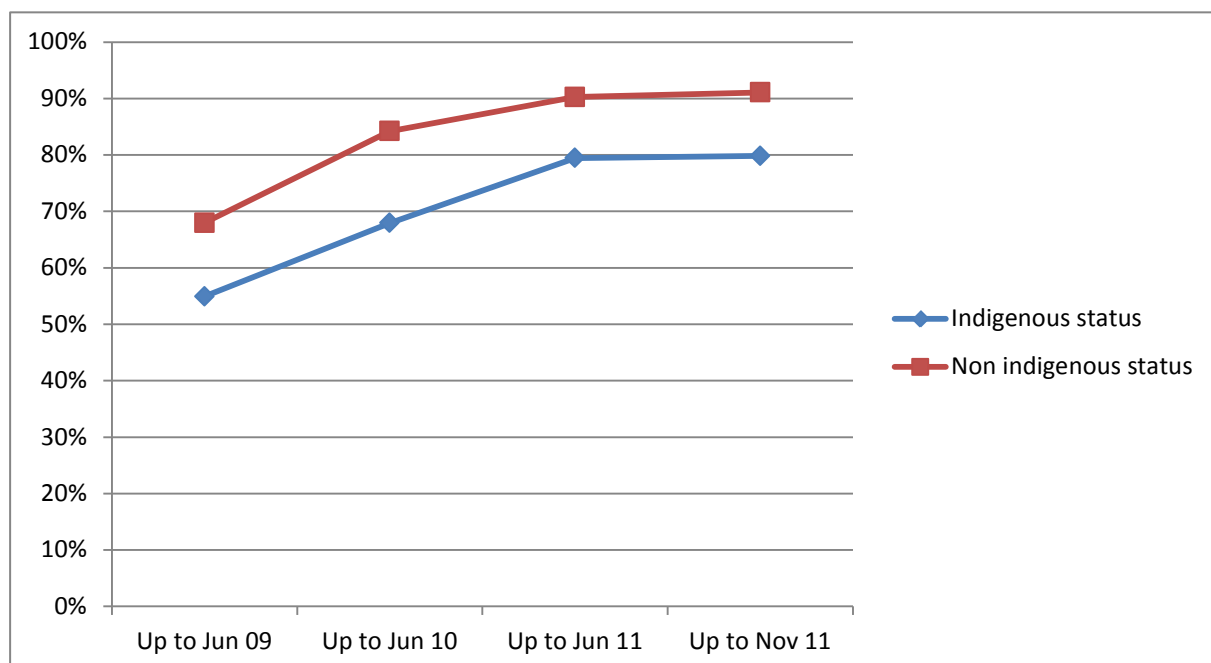
Note: We have used cumulative claims data because it is not possible to calculate the percentage of eligible clients making claims by financial year (because the eligibility criteria changed and because children that are technically still be eligible for funding may no longer be able to make claims because they have used their full allowance). For each year we have calculated the proportion of clients registered before that date who have ever made a claim. Thus the data may over-represent current inequities to some extent.

While stakeholders noted barriers for CALD families, their level of access to services suggests a range of factors might have facilitated their access, including the additional support Advisors said they provided some families from CALD backgrounds. Anecdotally, some families may also have found Panel providers able to deliver services in their language, helping to overcome the barriers they would otherwise face (but not all will be able to do this).

Indigenous families

While there have been some improvements in access over time, Indigenous children remain less likely to access services. Only 80% of those registered have made at least one claim for services, compared with 91% of non-Indigenous clients (Figure 4.3).

Figure 4.3: Registered clients who have made at least one claim for services by Indigenous status, cumulative by year



Percentage of clients claiming by Indigenous / non-Indigenous status

Up to June 2009

Indigenous status: 55%

Non-Indigenous status: 68%

Up to June 2010

Indigenous status: 68%

Non-Indigenous status: 84%

Up to June 2011

Indigenous status: 79%

Non-Indigenous status: 90%

Up to November 2011

Indigenous status: 80%

Non-Indigenous status: 91%

Source: FOFMS July 1 2008–November 3 2011.

Note: We have used cumulative claims data because it is not possible to calculate the percentage of eligible clients making claims by financial year (because the eligibility criteria changed and because children that are technically still be eligible for funding may no longer be able to make claims because they have used their full allowance). For each year we have calculated the proportion of clients registered before that date who have ever made a claim. Thus the data may over-represent current inequities to some extent.

Indigenous clients, on average, have also made fewer claims for services and used less of their funding allowance.

Interviews with Indigenous families and representatives as well as other stakeholders indicate these families may face a range of barriers in accessing services. Some may need more support to navigate the service system. More broadly, there is a need to consider options for ensuring culturally appropriate and accessible services, for example, through increasing the capacity of Indigenous organisations or supporting partnerships between Panel providers and Indigenous organisations. But because we interviewed only a small number of families and stakeholders, the extent to which the issues and suggestions apply across the broader population are unclear, and Indigenous stakeholders should be consulted about future strategies.

Low income families

There is no data on family income to assess claims about access for these families. But throughout the evaluation some stakeholders have raised concerns about service access for low income families, while others have said the Package has enabled families from low socioeconomic areas to access services they would not otherwise have been able to. As suggested previously, Advisors should collect data on income bands so FaHCSIA can monitor these families' claims and adjust strategies if needed.

4.2 The payment model

The early intervention funding component (up to \$12,000 per registered child) is intended to increase families' access to early intervention and to enable them to purchase resources important to their child's therapy. Families in outer regional and remote areas (as defined by the Accessibility/Remoteness Index of Australia+) and those that can prove significant difficulties accessing services can also receive the Access Support Payment (\$2000). It is intended to complement existing state and territory government services, and should be recognised as contributing to an existing and continuing system of support.

4.2.1 Sufficiency of the funding

Throughout the evaluation, most families surveyed agreed the Package had made services more affordable for them. There is evidence that the Package has enabled some families to access services they could not have otherwise afforded, and has reduced financial stress for others.

Less worry about where finances to pay for therapy are to come from has relieved a lot of stress in our family. [Family survey respondent]

But a common suggestion from families for improving the Package was to increase the funding. Emerging evidence from the final evaluation suggests this concern may grow as children are diagnosed and register earlier.

It is not enough money—we are spending \$5,000 a month, so the \$12,000 over two years is a tiny drop in the ocean [Family survey respondent]

While most families have not yet claimed the full \$12,000 of funding, this may be because of difficulties accessing Panel providers or because they are trying to spread the funding out over time. With the available evidence it is not possible to make a clear recommendation on the need to increase the funding, particularly as it is intended only as a contribution to an existing service system. There is, however, a need to consider indexing the \$12,000 over time to ensure the funding continues to buy a commensurate amount of services.

4.2.2 Fees and administrative charges

Throughout the evaluation a range of stakeholders have raised concerns about some providers' fees generally or about administrative fees (charged to cover processing payments and other administration requirements) in particular. Based on the available data it is not possible to compare fees charged under the Package with those of services more broadly, and monitoring the average cost per claim over time is ineffective because of the differences between claims made and between services, even within service types.

But the level of concern about administrative fees and the fact that 36% of providers surveyed said they charge families more for Package services (generally 5–20% more) suggests a need for some measures to address this issue. While FaHCSIA is unable to set the fees of private providers as some stakeholders suggested, reducing a providers' administrative burden may help reduce fees. It might also be possible to regulate administrative fees or require providers to display these (and the differences between their fees for Package and non-Package clients) on the Panel provider list.

4.2.3 Scope of the funding

Some families—particularly those lacking local providers and those with insufficient time to spend funds before their child turns seven years old—would like more flexibility in how they can spend their funding. While there is argument for greater flexibility, previous experience shows changes that introduce 'grey areas' to what is allowed can create confusion and inconsistent practice. Also, there is a need to consider the risk of funding being used for non-evidence based interventions—though only a low proportion of families surveyed suggested they should be able to spend funding this way, 28% indicated using biomedical or alternative therapies for their child.

4.2.4 Sustainability of the payment model

Panel providers surveyed had mixed views—across provider types—on whether the payment model is sustainable. Some were uncertain or suggested changes are needed; others had already made changes to ensure the true costs of service delivery are covered, mostly by raising fees to cover administrative costs. While the concerns about sustainability are widespread, there is little indication they have yet led to providers' ceasing to provide Panel services.

Challenges to sustainability include:

- unfunded time to support clients including coordination, planning and review
- high administration requirements, which are passed on to families as admin fees
- lack of predictable and consistent income, making it difficult to hire and retain the right number of staff
- inability to charge for cancellations (which is consistent with Medicare and private health funds' practice); some claim Package clients are more likely to cancel sessions and that when charged privately for cancellations some cannot pay.

Other (less common) concerns were not being able to charge in advance for multi-session programs, which makes them difficult to sustain unless fees are increased to cover dropouts. Some are unable to recoup fees when families accessing multiple services access more than they can afford with available funding—the requirement to process invoices within one month (introduced in late 2010) may help to address this.

4.2.5 The resources policy

While most families (91%) and Panel providers (92%) surveyed agreed resources purchased using Package funding have been important to children's outcomes, over the course of the evaluation, they have identified issues with the resources policy.

- While they understand a list of approved resources would not be appropriate because children's needs differ, providers think there could be greater clarity about the scope of resources that can be approved.
- Some providers claim families have pressured them to approve resources, suggesting families could also have more information about the resources policy and the need for resources to be an integral part of their child's therapy.
- Providers claim that processing resources claims takes a significant amount of time, which they are not able to recoup unless they can charge administrative fees. But if families were to buy their own resources to avoid this charge, it could disadvantage low income families who could not afford the upfront cost.

Access to resources for families in regional and remote areas

Given the lack of local providers in remote and some regional areas, families in these areas may be at a disadvantage in claiming resources. Access could be improved if other qualified professionals were allowed to approve resources for families without a Panel provider.

4.2.6 The Outer Regional and Remote and Access Support Payment

While most families surveyed (2010 data) that received the Outer Regional and Remote and Access Support Payment agreed it helped them access services, there are some indications the Payment is not sufficient to overcome obstacles to service access in some areas and for some families.

4.3 Ensuring quality and best practice

Having a Panel of approved providers is intended to ensure children receive only best practice early intervention services with their funding. The original requirement for providers to be multidisciplinary organisations or to form consortia aimed to ensure children receive a coordinated and multidisciplinary service. While sole providers are now allowed to join, they are also expected to coordinate with other providers.

4.3.1 Panel provider quality and experience

Families and Advisors surveyed generally agreed (>80% agreed) most Panel providers offer quality services. But throughout the evaluation representatives from a range of stakeholder groups (including families and Advisors) raised concerns about the quality of services delivered under the Panel. While these concerns were mostly general, a few

stakeholders had complaints about the practices of a small number of specific providers (that FaHCSIA has since investigated), and some raised concerns about particular intervention types allegedly being delivered by Panel providers. Quality is assessed as part of a provider's Panel application, but there is not currently a quality monitoring process to review practice, besides the investigation of particular complaints raised with FaHCSIA. The level of concern among stakeholders suggests a need for a quality monitoring process to be developed; random and targeted audits could be considered, as occurs for Medicare practitioners.

While families and Advisors generally agreed most providers have adequate expertise in autism, some stakeholders raised concerns suggesting that providers be required to have two years experience working with children with autism prior to joining the Panel. But not all agreed this is necessary, particularly if staff are adequately supported. There are also some indications this might limit Panel capacity. In considering this option, the extent of concerns about experience would need to be balanced with concerns about meeting demand.

4.3.2 Evidence-based interventions for autism

The Panel model is designed to ensure funding is used only for interventions with an evidence base for children with autism. While a small proportion of stakeholders suggested a need for other service types to be available under the Panel, assessing the merit of various intervention types was not a focus of the evaluation. FaHCSIA should be guided by the recent Prior and Roberts review⁹ in any consideration to expand interventions available under the Panel.

4.3.3 Best practice principles

Services planned to meet the individual needs of children with autism

The available evidence (from Panel providers) suggests individualised planning, programming and review, which are among the basic good practice principles Prior and Roberts cite as fundamental to working with young children and their families,¹⁰ are generally part of Panel providers' practice. Most also use strategies to promote the generalisation of new skills and that address children's need for predictability and routine, important aspects of effective early intervention for children with autism.¹¹

⁹ Prior and Roberts et al, 2011, A Review Of The Research To Identify The Most Effective Models Of Practice In Early Intervention For Children With Autism Spectrum Disorders

¹⁰ Prior and Roberts et al, 2011, Ibid

¹¹ Prior and Roberts et al, 2011, Ibid

Family-centred practice

Family-centred practice is one the basic principles of good practice that Prior and Roberts cite as fundamental to working with young children and their families and an important aspect of intervention for children with autism.¹² While data from Panel providers surveyed and interviewed suggests involving parents in planning their child's intervention and advising parents on continuing therapy in the home is part of most providers' practice, some state-based services (some of whom also provide Package services) and some state representatives were concerned that some Package services (particularly those of private practitioners) are not family-centred. Some of these stakeholders are concerned the Package favours a one-on-one medical model rather than capacity building with families. The differing views may to some extent be due to differing concepts of what constitutes family-centred practice.

Given the conflicting claims and the inability to balance these against families' experience (because we did not specifically ask families about family-centred practice), it is difficult to make an objective assessment whether services have actually been family-centred. This suggests Operational Guidelines should be reviewed to ensure they adequately cover family-centred practice and that family-centred practice should be assessed as part of a quality monitoring process.

Multidisciplinary practice

Multidisciplinary practice is one the basic principles of good practice Prior and Roberts cite as fundamental to working with young children and their families and an important aspect of intervention for children with autism.¹³ While having consortia and multidisciplinary organisations is intended to ensure coordinated practice, the evaluation findings suggest neither is sufficient to ensure this occurs. The model is based on the assumption that families will choose one consortium/ multidisciplinary organisation from which to access all their services, but this does not always occur. In practice families can choose providers that work for them or access providers with the first available appointment, and they are unlikely to access consortium members in different towns.

When clients are shared, those shared within a multidisciplinary organisation are more likely to receive a coordinated service. Coordinated practice within consortia appears to work best when providers are co-located because this allows for informal information sharing opportunities. The main barrier to coordination within consortia and multidisciplinary organisations is the lack of time and funding for coordination.

¹² Prior and Roberts et al, 2011, Ibid

¹³ Prior and Roberts et al, 2011, Ibid

When providers share clients with other Panel providers, coordinated practice is less likely to occur. Again, time (which is not funded) appears to be the main barrier, but conflicting approaches and some providers' apparent unwillingness to collaborate are also factors.

Evidence also suggests that collaborative practice does not always occur with state-based organisations with whom providers share clients. This suggests a need for more systematic linkages with these services, possible through strengthened communications between Package managers and relevant state and territory government departments.

While some stakeholders are concerned sole providers limit multidisciplinary practice under the Panel, survey and interview data suggest there is no need for concern about this group of providers more than any other. Moreover, removing sole providers from the Panel would have a detrimental impact on a families' ability to access services.

These are clear indications that other avenues for facilitating collaboration are needed, but there was little agreement among stakeholders about options for facilitating coordination and the amount of time required. The most common suggestions related to funding: either providing it or enabling providers to charge for coordination, which some already do. This suggests a need for greater consistency in practices of charging for coordination across Panel providers or at least making coordination charges transparent to clients.

Other suggestions for facilitating collaboration included having an online system in which providers working with the same child can share information (including the goals they are working on, progress and review), requiring collaborative meetings between providers at regular intervals, or using local networks. In considering options, the Package should draw on lessons from the practices in other multidisciplinary initiatives, for example, the Chronic Disease Management Medicare items and Better Access to Psychiatrists, Psychologists and General Practitioners through the Medical Benefits Schedule Initiative. More broadly, the education components could be used to inform parents of the benefits of multidisciplinary practice.

4.4 Recommendations

Service access

7. Monitor Package claims data, including wait times, as Better Start service delivery increases.
8. Liaise with Health Workforce Australia about options for developing allied health workforce capacity.
9. Consider how the education and support components can be strengthened to help parents develop effective decision-making processes.
10. Consider alternative delivery models in regional and remote areas. These may include tele-health approaches, funding providers for outreach, up-skilling local

- providers, enabling clients to group together to get services to travel to their region by providing data on demand.
11. Allow relevant non-Panel professionals to approve resources for families in remote and regional areas that lack a local Panel provider. Professionals might include state services, those registered with relevant professional bodies, and education support staff.
 12. Consider options to support Indigenous service access including consulting with Indigenous organisations about potential models, including delivery through Indigenous organisations, and supporting partnerships between existing providers and Indigenous organisations.

The payment model

13. Explore options to reduce administrative requirements for Panel providers and options to regulate administration fees or make providers display administrative charges on the Panel provider list on the FaHCSIA website.
14. Provide more information about the resources policy for Panel providers.
15. Better inform families about the requirements for approval of resources through various Package information sources (e.g. Advisor Services and the Raising Children Network website).
16. Consider indexation of the funding over time to ensure it can buy a commensurate amount of services.

Ensuring quality and best practice

17. Establish a quality monitoring process. The first step should be to advertise the current complaints mechanism to ensure families are aware of how they can make complaints. This should include examples of practices requiring investigation.
18. Review the Operational Guidelines to ensure they adequately cover family-centred practice and include assessment of family-centred practice as part of the quality monitoring process.
19. Establish a consistent policy on how coordination can be charged to families and have providers display these charges on the FaHCSIA website.
20. Explore alternative mechanisms for facilitating collaborative, multidisciplinary and trans-disciplinary practice. Options include developing information sharing systems, requiring case meetings, or facilitating networking. In considering options, the Package should draw on lessons from the practices in other multidisciplinary programs, for example, Chronic Disease Management, Better Access to Mental Health.
21. Educate families about the benefits of multidisciplinary practice through existing education and support mechanisms.

5. Education and support

5.1 Autism Advisor Services

Eight Advisor Services were established in state and territory autism associations¹⁴ to register children for the Package and to inform families about available services and supports and how they can access them. Given the complexity of the service system, Advisors are an important Package component as a first point of contact for families and as a mechanism to link families to Package components and other available services.

Advisor Services have evolved over time—establishing and streamlining processes, developing various information resources and refining their support models. Service models differ to some extent because family to Advisor ratios vary considerably between the larger and smaller states (Table 5.1) and because the state service systems and association services that families can draw on also vary between states.

Table 5.1: Advisor Services

State	Auspice organisation	FTE* Advisors	Children registered
NSW	Autism Spectrum Australia (Aspect)	8	5656
Vic	Autism Victoria	8.8	5207
Qld	Autism Queensland	6	2948
SA	Autism SA	4	1257
WA	Autism Association of WA	4	1224
Tas	Autism Tasmania	2	355
ACT	Autism Asperger ACT	1.3	199
NT	Autism SA—with staff in the NT	1.4	121

Source: Autism Advisor reports and FOFMS data July 1 2008–November 3 2011.

*Full Time Equivalent.

Client registration data suggest Advisor Services have had good reach to the population of children with autism, but families from outer regional and remote areas and those from CALD backgrounds remain under-represented. While registrations of Indigenous children have steadily grown, some stakeholders remain concerned about access for these children as well as for children from low income families.

Services have developed resources and refined their models to better support families over time, and overall most families have been satisfied with the support Advisors provided. But many families and some stakeholders think Advisors should provide

¹⁴ The Northern Territory Advisor Service is under the auspice of Autism SA.

additional supports. Advisors are not in a position to meet some of these identified needs, in particular individualised advice about services. But they could potentially provide a follow-up and exit appointment—something most families (>80%) surveyed would like. These are more aligned with Advisors' role and would help address issues identified during the evaluation. A follow-up appointment would help because some families find it difficult to take in all the information in the initial appointment, and survey data shows some are unaware of (or do not remember being informed about) particular components of the Package. An exit appointment to inform families about ongoing service options may help support families that feel anxious about the end of the funding period.

These additional roles would, however, have resource implications for Advisor Services. Some in smaller states have provided additional supports to families to meet system gaps, while others in larger states lacked the capacity to do so or have, in some cases, been able to refer families to other association services. If Advisors are to take on additional roles, the resource implications will need to be addressed. Advisors should also be consulted about appropriate timing and arrangements for the additional appointments.

Some representatives of the professional associations/ colleges and some Panel providers remain concerned about Advisors who are located within state and territory autism associations that also provide services, claiming this is a conflict of interest and may bias referrals. While the associations are among the ten providers that have processed the most claims for services, they were already large service deliverers before the Package was established, and there is no evidence of systematic bias in Advisors' referrals. Lack of timely updates to provider lists may be fuelling these concerns.

5.2 Early Days workshops

The Early Days workshops are an important component of the Package given a families' need for more information about autism and evidence-based therapies so they can make effective decisions about services for their children. The workshops were designed to offer parents/ carers the chance to

- learn about autism and what it means for their child and family
- learn practical strategies that can make a difference to their child's development
- learn how to choose between therapies and get the most out of services
- meet other parents and share ideas and experiences.

Throughout the evaluation most families surveyed who had attended Early Days workshops reported increased understanding and confidence (>80% agreed with outcomes items). But given other data suggesting families often find it difficult to make decisions about appropriate services for their children, the workshop content could be revisited to assess whether it could provide more guidance on decision making.

To date, the value of Early Days workshops has been restricted by their limited reach, a particular issue in regional areas. While the Early Days Consortium of Autism Specialist Providers (made up of state and territory autism associations) took over the delivery of the workshops in July 2011 with a focus on ensuring families get timely access to workshops through a streamlined registration process, it is too early to tell whether the new model is working because start-up was delayed while staff received training. Managers are, however, confident that it will prove effective.

The challenge going forward will be to design effective models for regional areas and further develop approaches suited to families from CALD backgrounds and Indigenous families. On these fronts, there is potential for shared lessons between Early Days and the DEEWR-funded Positive Partnerships component. In working with Indigenous families, there is also potential for both programs to learn from the recently established Talking up Autism project (run by Autism Spectrum Australia [Aspect] and funded by the DEEWR Parental and Community Engagement (PaCE) Program), which is raising awareness of autism in Indigenous communities. In working with regional families, there is also potential to learn from other organisations that have used virtual approaches to supporting clients (including the Western Australian Autism Association). The challenge will also be to increase reach and efficiency without limiting access for regional families or limiting the benefits families have gained through workshops that enabled them to connect with others in similar situations.

Even with new strategies, some families will still be unable to attend workshops because of other commitments, suggesting a need for information to be accessible in other formats, potentially online. This might also allow the program to develop more differentiated and detailed information, for example, by diagnosis and stage, to meet the needs identified by families.

5.3 Raising Children Network website: Children with Autism pages

Given a families need for information about autism and evidence-based therapies to make effective decisions about intervention for their child, the Children with Autism pages of the Raising Children Network website are a relatively small (in funding terms) but important component of the Package. The website is designed to provide information, online resources and interactive functions to support parents, carers and professionals. It also has information to help families understand the evidence base for therapies and a Services Pathfinder to help them locate local services.

While most families surveyed that had used the site agreed it helped them understand where to get help for their children and what services would be best for their child, survey data suggests a need to better promote this component (for example, through Advisor Service and FaHCSIA newsletters) to ensure families are able to benefit from it.

There are also some concerns about families who are less likely to have Internet access, for example, those from lower socioeconomic areas, and their ability to access information. While some Advisor Services reported handing out fact sheets from the Children with Autism pages to families, this could be part of standard practice for families without Internet access. To ensure access for Indigenous families and those from CALD backgrounds, translated and plain English information resources developed at a Package level could also be made available on the website.

It's positive that website content is updated to meet needs identified by families, but given the feedback that some families find it difficult to decide on services for their child, the content could also be revisited to ensure it provides adequate guidance about decision-making factors.

To ensure the website is useful, it's also important that the Services Pathfinder is updated and that it provides links to all relevant state government services—the evaluation found some broken links and some state-based services not included. Given the complexity of the service system, the website could also provide a one-page system pathways diagram, including all Package components and the state-based system.

5.4 PlayConnect playgroups¹⁵

PlayConnect playgroups, which don't require children to have a diagnosis and which allow siblings to attend, are an important Package component, providing a soft entry point to the system. They are a safe place for families to socialise and connect with others, a place they can attend when other commitments allow and a place where children's behaviour is understood and accepted.

Playgroup Australia has now reached the target of 150 PlayConnect playgroups around Australia. The playgroups usually have between three and six families attending, which is an appropriate size for this target group. Because the groups cannot reach everyone, Playgroup Australia (in consultation with Autism Victoria) has developed an information resource in the form of a USB flash drive that includes a range of information and ideas for play. The resource is easily transportable and doesn't require Internet access so will be suitable for a broad range of families.

Most families surveyed that attend regularly report gains for their children, including developing new skills and learning to play with others, and gains for parents/ carers including improved knowledge and connections. For families with little knowledge of autism and/or the service system, the groups can be a source of information. Importantly, given feedback about a families desire to connect with others in similar situations, playgroups are a source of informal support and a place to network. But they

¹⁵ This section is based on data from the 2010 evaluation of PlayConnect and interviews with Playgroup Australia and State and Territory Office (STO) managers in 2011.

have not suited all families; those that reported limited benefits described groups in which disruptive behaviour was not managed to their satisfaction or where their child's level of disability was too different from that of others attending, making it difficult for them to play with others.

Going forward, the main concern for the playgroups is sustainability. While the initial plan was for the groups to transition to self-management after a two-year funding period, for many groups this is unlikely to be feasible. Finding a parent to take responsibility for organising the groups can be difficult because of regular turnover as children move on to early intervention services or school and because of the intense demands already on many parents/ carers of children with autism. To date, Playgroup Australia has re-funded some groups to ensure their success. But further discussion is needed to develop a strategy to ensure the groups' sustainability.

5.5 Recommendations

Autism Advisors

22. In consultation with Autism Advisor Services, consider options to expand the Advisor role to provide additional appointments/ support, the appropriate timing for these appointments, and the resource implications of
 - a scheduled follow-up appointment/ contact
 - an exit interview/ support with transition (for example, information on other available services).

Early Days workshops

23. Establish a way to provide information to families not able to attend a workshop.
24. Have the Early Days Consortium of Autism Specialist Providers establish and maintain links with the DEEWR-funded Positive Partnerships providers to share strategies for working with Indigenous, CALD and regional communities and ensure the two programs do not duplicate information resources. The Consortium should also connect with other relevant projects, including the Talking Up Autism Project to draw on learning for working with Indigenous communities.
25. Monitor delivery under the new model to ensure strategies are working to achieve increased reach and efficiencies.

Raising Children Network: Children with Autism pages

26. Ensure the Children with Autism pages provide up-to-date service information, including links to all relevant state-based services for children with autism.
27. Have the Children with Autism pages include a one-page system diagram that includes all Package components and state-based services.

PlayConnect playgroups

28. Consult with Playgroup Australia to identify an appropriate and feasible model for ensuring the sustainability of individual playgroups.

6. The Package as a service model

6.1 Contribution to the service system

The FaHCSIA components introduced a new approach to funding early intervention services to address the limited service access for children with autism, in an area where the Commonwealth was not previously directly involved.

Available evidence indicates that the Package has helped most children registered (90%) to access services, and that at least some of these children would not have been able to access services without the early intervention funding or would not have been able to access services as frequently.

As the Panel has grown in the years of operation to date, more children have been able to access services. But, from the available data, we are unable to assess whether the Package is encouraging new providers to support children with autism or whether it is drawing existing providers away from other services.

The Package is intended to contribute to the existing service system, so outcomes are not attributable to it alone (Chapter 2). But in their comments on outcomes, families surveyed often associated their children's outcomes with services accessed through the Package, as did some families we spoke with.

Without this funding we wouldn't have been able to do such intensive therapies and achieved amazing results. [Family survey respondent]

Our son has come so far since having therapy and I would hate to think how far behind he would have been without the funding. He is further behind in school work than a typical child but he would have been much worse without funding for therapy. [Family survey respondent]

Many of the Panel providers interviewed that described positive outcomes for children associated these with the increased level of service the funding allowed them to provide to children.

...being able to actually have consistent sessions with kids because parents aren't concerned about payments. That's enabled better outcomes. [Panel provider interviewee]

I think we've really seen improvements for children and that's because of the regularity and quality of services that they can access with the additional money. [Panel provider interviewee]

But, reflecting that the Package is only intended to contribute to the service system, some families surveyed and some we spoke to say their child's outcomes could not be attributed directly or only to the early intervention funding. For some families that have been unable to access services, the Package did not contribute to outcomes.

...the HCWA therapists (intervention funding) have been fantastic help but in no way, if that was all we did, would our son have progressed so far. [Family survey respondent]

6.2 Linking the components

The Package recognises that families of children with autism have a range of needs at varying stages of their journey, and provides education and support as well as intervention services to assist with these needs. Not all families are accessing all Package components but most families surveyed that had accessed each component reported positive outcomes associated with it. This suggests each component is making an important contribution to the overall positive outcomes.

Autism Advisors are a key mechanism for linking families to service options and ensuring effective pathways for families, and most have developed linkages with other components. But evidence suggests there could be greater synergies between all components to ensure effective pathways for families through what can be a complex service system and to prevent duplication of effort between Package components.

As a new and emergent model there have been several changes to the Package, which were designed to enhance access to it. But Advisor Services and Panel providers have raised some concerns about the way changes have been managed and communicated. In some cases, changes have created confusion. Some stakeholders have also had difficulties obtaining timely responses to queries from FaHCSIA. FaHCSIA is currently developing a communications strategy and has already begun distributing newsletters to stakeholder groups—actions that should help address these concerns. The newsletters could also facilitate some cross-Package communication if stakeholders from different components are able to contribute to them.

6.3 The model's fit with best practice and emerging policy trends

6.3.1 Individualised funding

The Package is in line with broader trends towards individualised funding for service delivery in the disability sector. In practice, there are differences between individualised funding models that impact on how much flexibility and control funding provides people with disabilities and their families. In their review of individualised funding, Fischer et al found 'packages that are managed by the person with a disability, their family or a facilitator and that can be spent in the open market, can generally be tailored more easily towards the consumer's preferences than more restrictive packages or those that

must be spent through a single service provider.’¹⁶ The Package model provides this flexibility and control.

Some providers, who are used to block funding, noted concerns about the sustainability of the fee-for-service model, but a small number saw it as part of the broader trend in disability services funding and a way of trialling this delivery.

6.3.2 Service based on diagnosis

While the introduction of Better Start (July 2011) has enabled children of five other disability types to access services, some stakeholders remain concerned about inequity for children with other disabilities. There were also some suggestions to make access to intervention based on need rather than diagnosis, and indications some families may be less able, willing or ready to access a diagnosis. Some state representatives described the diagnosis-driven approach to delivery as out of sync with trends in education and early intervention. But a few believe because autism has historically been under-recognised there is an argument for singling it out until the service system has the capacity to meet these children’s needs. Some states and territories have or are developing autism plans, suggesting that autism-specific initiatives remain on the broader agenda.

6.3.3 Balancing family choice and need for support

Stakeholders had mixed views on the family choice model. While some saw it as empowering families to make choices about their intervention, others were concerned that some families need more support to make effective decisions than the Package model provides. In practice, decision-making support provided in other individualised funding Packages varies, and includes ‘information and guidelines, facilitators and coordinators, case managers, and use of peak bodies and advocacy organisations to work closely with people with disabilities.’¹⁷

Advisors, providers and diagnosticians all identified varying levels of need for case coordinators for Package clients. While about half of families surveyed said they have difficulties coordinating services, the real proportion may be higher because these families were at varying points along their journey and over time families become more accustomed to the system and need less help. Because not all families would need a coordinator, Advisors could identify need at point of entry, but without strict guidelines for assessing need this could cause confusion and over-referral.

There is also little agreement among stakeholders about who should provide coordination. If it sits with diagnosticians, this would involve an ongoing cost to families

¹⁶ Fischer K., et al, 2010, Effectiveness of individual funding approaches for disability support, Occasional Paper No. 29

¹⁷ Fischer K., et al, 2010, Ibid, p31

(having to pay the Medicare gap fee) that some may not be able to afford; if it sits with Panel providers there is potential for bias toward particular approaches; and if it sits with Autism Advisors this will entail questions regarding workload and the qualifications required. Also, some state-based services provide coordinators but because of waiting lists it's likely that families will choose a Panel provider before accessing a state-based service. Any plans to provide coordination would require further discussion with stakeholder groups, including state and territory government departments, about the appropriate location of the coordinator role and the resource implications.

6.3.4 Fit with best practice principles

As well as ensuring only evidence-based services are delivered, the Panel model is designed to ensure providers deliver services consistent with best practice principles for children with autism. Evidence (from Panel providers) suggests their practices largely incorporate individualised planning, programming and review, as well as strategies to promote the generalisation of skills and to address children's needs for predictability and routine, consistent with best practice for children with autism.

But some stakeholders remain concerned about the extent to which services are family-centred. A small proportion also suggested the need for more holistic services; similarly, a small proportion of family survey respondents raised the need for broader supports including support for parents, siblings or for respite. While these services may be needed, the Package cannot fulfil all needs within the available funding and should make the most of opportunities to effectively connect parents to services available through other initiatives (for example, the Better Access to Mental Health initiative, the Chronic Disease Management Medicare items and funded respite services) through Advisor Services.

Given the concerns about multidisciplinary practice and the evidence from Panel providers, there is a particular need for new strategies to ensure adherence to this best practice principle.

6.3.5 Age limits and services for children over seven years

Because children with autism are likely to have ongoing needs and services for children aged over seven years are generally limited or because their child was diagnosed late and unable to access the full amount of Package funding, a common suggestion among families was the need to extend the funding age limit. Some concerns related specifically to services for school-aged children and gaps in work with teachers and childcare staff. But, in considering any expansion to school-aged services, there is a need to consider potential for overlaps with state and territory government services and other federal initiatives.

6.4 Fit with the existing service system

The combination of education and support components the Package provides are all intended to complement existing services—they should be recognised as contributing to an existing and continuing system of support.

6.4.1 Impact on the diagnostic sector

Throughout the evaluation some stakeholders have raised concerns about the Package's impact on autism diagnoses. Among stakeholders consulted in 2011, some concerns remain about over-diagnosis or misdiagnosis; and about three-quarters of diagnosticians surveyed indicated feeling pressure from parents to provide an early diagnosis of autism so that they can access funding for early intervention services.

At this stage registrations remain roughly in line with estimated prevalence rates for autism in children. But given the concern among stakeholders, registration figures should continue to be monitored against prevalence estimates. The Package's impact on actual diagnostic rates, however, cannot accurately be scoped because diagnostic rates had already been increasing before the Package was introduced, meaning any increase may simply be a continuation of that trend.

6.4.2 Fit with state-based services

Linkages between state-based and Package services

The Package sits alongside existing state-based early intervention and education services for children with disabilities. Advisors inform families about state-based services as well as Package components and the state-based services we spoke to inform families about the Package if they haven't already heard about it. While these cross-referrals seem to be occurring, some stakeholders are concerned the Package has introduced another layer of complexity to the service system, causing confusion for families, particularly where eligibility criteria differ between state-based services and the Package. Only a minority of stakeholders, however, suggested the existing system should have been funded instead of the Package.

Impact on access to state-based early intervention

While it is not state government policy to deny children eligible for Package early intervention funding access to state-based services or give them lower priority for these, there are indications that this may be occurring in some cases. This seems to be because state-based services with limited capacity must make choices about prioritisation of children on waiting lists. Throughout the evaluation, a range of stakeholders raised concerns that the Package has impacted on children's access to state-based services. Of the families surveyed in 2011, less than one-third (28%) reported accessing early

intervention through state-based services. Some of those not accessing state-based services may be on waiting lists or too old for early intervention. Given that one of the arguments for establishing the Package was the need to increase service access for children with autism, some children may not have had access to a service regardless of whether the Package was introduced. But family survey data, combined with stakeholder feedback, suggest some cause for concern.

Interaction with education services

While the Package is intended to ensure children receive early and intensive services, some families (because of their child's age at diagnosis, or because they consider it important to access services to support their child during transition) are using the funding to support their children with the transition to school or support them once they begin school. State-based early intervention services also provide transition support and the extent to which the Package overlaps with this is unclear. State-based services generally end before children begin school and in-school services are often stretched, so using Package services to support children in their first term of school can help fill a system gap.

Anecdotally, some Panel providers and state representatives had heard of some schools preventing Panel providers, or certain providers, from working in their school, in some cases because of previous negative experiences. While some education stakeholders suggested a need for training of both school staff and allied health professionals about each other's approaches to ensure effective working relationships; the most efficient way of providing this information may be through fact sheets. To ensure coordination, providers working in schools could also be required to link with student support services (or equivalent) in schools. Some education representatives were also concerned the Package has increased family expectations of the education system, for example, expectations of ongoing autism-specific supports.

Opportunities for linkages with state government departments

The evidence suggests a need to establish communications processes between relevant state and territory government departments and FaHCSIA National Office to discuss achieving better coordination between the two systems and to identify gaps and overlaps. More connections could also be made at the local level between Autism Advisor Services and state and territory government departments.

6.4.3 Fit with other funding options

Since the establishment of the Better Start Package (July 2011), an emerging issue in the final evaluation was how the two Packages fit together. Children with a dual diagnosis are only able to access one Package, but there was some concern families that might need help deciding which services to access. Another concern was that because autism may be diagnosed later than other disabilities, children will not have access to autism-

specific services because they will have accessed Better Start first. Some Advisors were also concerned about any change that would see their role absorbed into Better Start.

Families of children with autism might also be able to access services through the Better Access to Mental Health initiative and Chronic Disease Management Medicare items. Some families consulted were well aware of the range of available funding options and how to make use of them but, if not doing so already, Advisors could inform families of these options. Given the amount of information families need to take in, these other options could also be noted on the RCN website's Service Pathfinder.

In future there will also be a need to consider how the Package (and Better Start Package) will fit with the National Disability Insurance Scheme (NDIS).

6.5 Recommendations

The Package as a service model

29. In considering changes to the Package model, consider first what is available in the existing service system, including the variations across states and territories.
30. Within funding constraints, and in consultation with relevant stakeholders, consider options for providing case coordination assistance for families that require it.
31. Establish a mechanism/s for cross-Package communication, sharing of resources and opportunities to form relationships. Communicate directly with all Panel provider organisations.
32. Establish communication links between FaHCSIA and relevant state and territory government departments at National Office level unless State Offices have existing connections with these departments in relation to autism. This should include a process for informing state and territory government departments about cases in which Package clients have been denied access to state-based services.
33. Monitor and report client data internally on an annual basis, and share trends and milestones with stakeholders through newsletters.
34. Monitor registration rates against estimated autism prevalence rates.

7. Complete list of recommendations

Awareness and registration

Information and referral pathways

1. Establish more systematic and regular communications with diagnosticians and general practitioners through the professional colleges.

Registrations

2. Consider options to facilitate access for families in remote and particular regional areas that lack local diagnostic services.
3. Develop translated, culturally appropriate and plain English information resources at a Package level to facilitate access for CALD and Indigenous families. These could be made available through Autism Advisor Services and on the RCN and FaHCSIA websites.
4. Continue to support Advisor Services to develop relationships with CALD and Indigenous community organisations to facilitate access; lessons and strategies should be shared at a national level.
5. Develop options to ensure culturally appropriate service delivery and build trusting relationships between the Package and Indigenous communities, for example, establishing a national Indigenous Advisor position with the capacity to support and guide Advisor Services on work with Indigenous communities.
6. If families agree, Advisor Services should record family income for registered clients, so FaHCSIA can monitor the degree of access for low income families.

Early intervention

Service access

7. Monitor Package claims data, including wait times, as Better Start service delivery increases.
8. Liaise with Health Workforce Australia about options for developing allied health workforce capacity.
9. Consider how the education and support components can be strengthened to help parents develop effective decision-making processes.
10. Consider alternative delivery models in regional and remote areas. These may include tele-health approaches, funding providers for outreach, up-skilling local providers, enabling clients to group together to get services to travel to their region by providing data on demand.

11. Allow relevant non-Panel professionals to approve resources for families in remote and regional areas that lack a local Panel provider. Professionals might include state services, those registered with relevant professional bodies, and education support staff.
12. Consider options to support Indigenous service access including consulting with Indigenous organisations about potential models, including delivery through Indigenous organisations, and supporting partnerships between existing providers and Indigenous organisations.

The payment model

13. Explore options to reduce administrative requirements for Panel providers and options to regulate administration fees or make providers display administrative charges on the Panel provider list on the FaHCSIA website.
14. Provide more information about the resources policy for Panel providers.
15. Better inform families about the requirements for approval of resources through various Package information sources (e.g. Advisor Services and the Raising Children Network website).
16. Consider indexation of the funding over time to ensure it can buy a commensurate amount of services.

Ensuring quality and best practice

17. Establish a quality monitoring process. The first step should be to advertise the current complaints mechanism to ensure families are aware of how they can make complaints. This should include examples of practices requiring investigation.
18. Review the Operational Guidelines to ensure they adequately cover family-centred practice and include assessment of family-centred practice as part of the quality monitoring process.
19. Establish a consistent policy on how coordination can be charged to families and have providers display these charges on the FaHCSIA website.
20. Explore alternative mechanisms for facilitating collaborative, multidisciplinary and trans-disciplinary practice. Options include developing information sharing systems, requiring case meetings, or facilitating networking. In considering options, the Package should draw on lessons from the practices in other multidisciplinary programs, for example, Chronic Disease Management, Better Access to Mental Health.
21. Educate families about the benefits of multidisciplinary practice through existing education and support mechanisms.

Education and support

Autism Advisors

22. In consultation with Autism Advisor Services, consider options to expand the Advisor role to provide additional appointments/ support, the appropriate timing for these appointments, and the resource implications of
 - a scheduled follow-up appointment/ contact
 - an exit interview/ support with transition (for example, information on other available services).

Early Days workshops

23. Establish a way to provide information to families not able to attend a workshop.
24. Have the Early Days Consortium of Autism Specialist Providers establish and maintain links with the DEEWR-funded Positive Partnerships providers to share strategies for working with Indigenous, CALD and regional communities and ensure the two programs do not duplicate information resources. The Consortium should also connect with other relevant projects, including the Talking up Autism Project to draw on learning for working with Indigenous communities.
25. Monitor delivery under the new model to ensure strategies are working to achieve increased reach and efficiencies.

Raising Children Network: Children with Autism pages

26. Ensure the Children with Autism pages provide up-to-date service information, including links to all relevant state-based services for children with autism.
27. Have the Children with Autism pages include a one-page system diagram that includes all Package components and state-based services.

PlayConnect playgroups

28. Consult with Playgroup Australia to identify an appropriate and feasible model for ensuring the sustainability of playgroups.

The Package as a service model

29. In considering changes to the Package model, consider first what is available in the existing service system, including the variations across states and territories.
30. Within funding constraints, and in consultation with relevant stakeholders, consider options for providing case coordination assistance for families that require it.
31. Establish a mechanism/s for cross-Package communication, sharing of resources and opportunities to form relationships. Communicate directly with all Panel provider organisations.

32. Establish communication links between FaHCSIA and relevant state and territory government departments at National Office level unless State Offices have existing connections with these departments in relation to autism. This should include a process for informing state and territory government departments about cases in which Package clients have been denied access to state-based services.
33. Monitor and report client data internally on an annual basis, and share trends and milestones with stakeholders through newsletters.
34. Monitor registration rates against estimated autism prevalence rates.

Appendix 1: Final evaluation methods

The final evaluation used a mixed-method approach, analysing existing administrative data and collecting new data. Methods were chosen to provide a high-level indication of development over the life of the Package (through survey data), to focus in depth on the issues identified in the initial and mid-term evaluations (through site visits and stakeholder interviews), and to assess the Package's impact (through administrative data, surveys and stakeholder interviews).

Table 1.1: Data collection methods and sources

Study population	Source/ method	Date	Sample	Comments
Registered clients	Analysis of unit record client data (FOFMS)	July 1 2008–November 3 2011	Population n=16,967	
Registered clients	<ul style="list-style-type: none"> ▪ Online survey ▪ Paper survey 	<ul style="list-style-type: none"> ▪ Online: 18/8/11–16/9/11 ▪ Paper: 25/8/2011–4/10/2011 	Population <ul style="list-style-type: none"> ▪ Online: 10,706 ▪ Paper: 2,503 	Response rate: <ul style="list-style-type: none"> ▪ Online: 35% (n=3,778, excludes 3 failed to send) ▪ Paper: 27% (n=659, excludes 19 failed to send) ▪ Combined: 34% (n=4,437). Follow up: <ul style="list-style-type: none"> ▪ Online: 2 reminders, survey period extended by 1 week ▪ Paper: reminders not possible, survey period extended by 1 week. Representation: <ul style="list-style-type: none"> ▪ Proportion of respondents from each state and territory is broadly in line with proportion of clients from each state and territory ▪ Families from regional and remote areas are slightly over-represented (42% of respondents vs 29% of Package clients, but some of the difference may be because the survey did not use ARIA+ categories) ▪ CALD families are under-represented (7% of respondents vs 11% of registered clients) ▪ Proportion of Indigenous respondents is in line with proportion of registered clients (3.2% respondents vs 3.5% registered clients).

Study population	Source/ method	Date	Sample	Comments
Follow-up registered clients	Semi-structured phone & face-to-face interviews	August–September 2011	Half of the original stratified random sample (from 2009) still relevant to contact n=13	Response rate: 2 families we intended to contact could not be contacted; we were able to interview 2 other families from the original sample instead. Representation: The sample includes families from all states and territories and from metropolitan, regional and remote areas.
CALD registered clients	Semi-structured phone & face-to-face interviews	August–September 2011	Opportunistic sample n=11	Approach: We asked NSW, ACT, WA & SA Advisors to approach clients that might be willing to participate. SA was unable to identify clients within the evaluation timeframe. ACT & WA Advisors approached clients for permission. Because of their high client load, NSW Advisors were unable to approach families directly; instead we sent a letter to families then called to ask if they were willing to participate. Representation: The sample is not representative but includes families from three states (WA n=1, ACT n=3, NSW n=7) and families from a range of nationalities: Assyrian, Bengali, Korean, Vietnamese, Thai, Pakistani, Sri Lankan, Ethiopian, Indonesian, Russian and Portuguese. Of the 11 families, 4 were born overseas.
Indigenous registered clients	Semi-structured phone & face-to-face interviews	September 2011	Opportunistic sample n=10	Approach: We asked NSW, ACT, WA & SA Advisors to approach clients that might be willing to participate. SA & WA were unable to identify clients within the evaluation timeframe. ACT has a very small number of Indigenous clients that would be easily identifiable so we did not approach these families. Because of their high client load, NSW Advisors were unable to approach families directly; instead we sent a letter to families then called to ask if they were willing to participate. Representation: The sample is not representative. All interviewees are from NSW—Sydney (n=6) and regional areas (n=4).
CALD and Indigenous stakeholders	Unstructured phone interviews	September 2011	Opportunistic sample n=4	Approach: We identified stakeholders opportunistically. Representation: The sample is not representative. Data from these stakeholders is intended to supplement information from client interviews. The data from Indigenous stakeholders supplements data from interviews with Indigenous organisations and organisations delivering services to Indigenous clients undertaken in 2010 (n=11).
Autism Advisor Service staff and managers	Online survey	<ul style="list-style-type: none"> ▪ Advisors: 27/7–26/8/2011 ▪ Team leaders & Association CEOs: 10/8–7/9/2011 	All Autism Advisor Service staff and managers n=57	Response rate: 61% (n=35). Low response rate is likely due to evaluation fatigue as Advisors were also surveyed for the Prior and Roberts review (2011). Because we were also able to draw on data from focus groups and Advisor Service reports, we are confident we were able to capture the views of these stakeholders. Follow up: 2 reminders sent (for both), survey period extended by 1 week
Autism Advisors	<ul style="list-style-type: none"> ▪ Focus groups ▪ Discussion at Advisor forum 	20/5/2011	All Advisors attending the forum n=32	Focus groups: Advisors were divided into 3 groups (Group 1: SA, NT, ACT, Tas, WA; Group 2: Qld, NSW; Group 3: Vic). Forum: The evaluation also draws on discussions held throughout the 2-day forum.

Study population	Source/ method	Date	Sample	Comments
Autism Advisor Services	Autism Advisor Service four-monthly reports	November 2010–June 2011	Last 2 reports for each Service	Representation: We obtained all reports except for the March 2011–June 2011 report from the Tasmanian Service.
Panel providers	Online survey	5/8/2011–2/9/2011	Population n=488	Response rate: 59% (n=252 + 24 drafts, excludes 20 failed email addresses and 2 who requested to be removed). Follow up: 2 reminders sent, survey period extended by 1 week. Representation: We are unable to assess the representativeness of the respondent sample because the contact list for Panel providers does not include all consortia members, but there were respondents from all states and territories, representing all provider types.
Early Intervention Service Providers	Semi-structured face-to-face & phone interviews	August–October 2011	Select sample n=65 organisations + group interview with representatives of 5 organisations	Representation: The interview sample chosen to cover all states and territories, metropolitan, regional and remote areas AND different provider models: 8 sole providers, 41 consortium leads and partners (from 15 consortia) and 16 multi-disciplinary organisations (13 of which also provide state-funded services).
Diagnosticians (paediatricians and psychiatrists)	Online survey	<ul style="list-style-type: none"> ▪ Royal Australian College of Physicians (RACP): 29/7/2011–19/8/2011 ▪ Autism Advisor Services (AAS) (NSW, NT, ACT) paediatrician contacts: 29/7/2011–19/8/11 ▪ Royal Australian and New Zealand College of Psychiatrists (RANZCP): 5/8/2011–26/8/2011 	Not representative	Response: n=99 (1 parent and 1 diagnostician who did not provide answers were excluded). Representation: <ul style="list-style-type: none"> ▪ It was not possible to obtain a representative sample of diagnosticians. The RACP distributed the survey to paediatricians through their weekly e-newsletter Pot-pourri. The RANZCP distributed the survey to members of the Faculty of Child and Adolescent Psychiatry. The final sample included 62 paediatricians and 37 psychiatrists. ▪ NSW, NT, ACT Advisor Services also distributed the survey to their contacts. Other Advisor Services were unable to distribute the survey because their paediatrician contact lists were fax or post only. Follow up <ul style="list-style-type: none"> ▪ RACP sent 2 reminders ▪ Advisor Services and RANZCP sent 1 reminder.
Professional colleges/ associations	Semi-structured phone interviews	July–September 2011	N=5 colleges/ associations	Representation: <ul style="list-style-type: none"> ▪ Speech Pathology Australia ▪ Occupational Therapy Australia ▪ Australian Psychological Society ▪ Royal Australian College of Physicians, Division of Paediatric and Child Health ▪ Royal Australian College of General Practitioners. The interview with Speech Therapy Australia involved more than one representative.
State government Human Services (Disability) and Education departments	Semi-structured phone interviews	July–October 2011	Representatives from relevant department/s in each state	Response: We interviewed representatives of Education and Human Services (Disability) services in all states where relevant, except for a Human Services (Disability) representative from Victoria (whom we were unable to contact). We interviewed representatives from 18 departments/ organisations; the sample includes 1 Health representative and 1 state diagnostic service representative.

Study population	Source/ method	Date	Sample	Comments
				About half the interviews were group interviews where the department thought it important to involve multiple representatives. Note: This component also included a search of state department websites to identify relevant services.
State-delivered & funded (state-based) early intervention services	Semi-structured face-to-face & phone interviews	August–October 2011	Select sample n=8 + 13 Panel providers that also deliver state-funded services	Approach: In states with multiple funded services, we asked department stakeholders to provide contact lists from which we could select providers. Representation: The sample is not representative but includes services from all states and territories. Interviews with the 13 services that provide both state-funded and Panel services covered both aspects.
DoHA & DEEWR managers	Semi-structured phone interviews	September 2011	2 departments	Representation: <ul style="list-style-type: none"> DoHA involved 3 representatives from relevant sections DEEWR involved 2 representatives.
FaHCSIA State and Territory Offices (STOs)	Semi-structured phone interviews	September 2011	Representative from each relevant STO n=6	Representation: We were able to interview a representative from each relevant STO. The NSW STO also manages the ACT Service and the SA STO also manages the NT Service; in these cases interviews covered both services managed.
Mental Health & Autism Branch Program Managers	Ongoing discussion	Throughout the evaluation period	Management team	
Early Days workshops and PlayConnect playgroups	Semi-structured phone interviews	September 2011	2 funded organisations	Representation: <ul style="list-style-type: none"> PlayConnect involved 3 staff Early Days National Coordinator.
Early Days workshops	Parenting Research Centre (PRC) & Early Days Consortium of Autism Specialist Providers data	<ul style="list-style-type: none"> PRC: July 2010–June 2011 Consortium: July 2011–September 2011 	N/A	Note: Since the delivery of Early Days changed hands in June 2011 and new staff were still being trained in the period to October 2011 it is too early to assess the new model.
RCN website, Children with Autism pages	RCN report	January-June 2011	N/A	Note: RCN report includes qualitative data as well as web statistics.
Other Package components and relevant research	Scan of other reports	Throughout the evaluation period	N/A	<ul style="list-style-type: none"> Positive Partnerships evaluation 2010 Prior and Roberts et al, 2011, <i>A Review Of The Research To Identify The Most Effective Models Of Practice In Early Intervention For Children With Autism Spectrum Disorders</i>, report to FaHCSIA Prior, J. and Roberts, M., 2006, <i>A Review of the Research to Identify the Most Effective Models of Practice in Early Intervention for Children with Autism Spectrum Disorders</i>, report for DoHA, July 2006 Asia Pacific Autism Conference (APAC) 2011 presentations

Study population	Source/ method	Date	Sample	Comments
Opportunistic (full range of stakeholders)	Semi-structured interviews & emails from relevant stakeholders that contacted the evaluation team	August–September 2011	N/A	<ul style="list-style-type: none"> ▪ Families: 9 via email; 3 through phone interviews ▪ Early childhood intervention representatives (state-based and state-funded services): focus group

Confidence in the findings

The evaluation methods were implemented largely as planned and provided comprehensive data for the evaluation. While there were limitations to some individual methods, the methods were triangulated in that they addressed the same questions from different stakeholders' perspectives, and the findings from the different methods were largely consistent. As a result we are confident that the findings provide the evidence for a sound assessment. At the same time, the final evaluation uncovered some emerging issues about which there are competing claims and which would require further assessment to draw conclusions.

The evaluation has also collected survey data on some questions across the three phases but, because of the differences in sampling strategies, comparisons between the 2009, 2010 and 2011 surveys should be considered as indicative only.

Interviews with CALD and Indigenous registered families and stakeholders

Given the small sample size and approach to identifying interviewees, data collected through interviews with CALD and Indigenous families and stakeholders is not representative of all CALD or Indigenous families' experiences. In particular, the CALD families we spoke to were fairly proficient in English—it's likely that families with lower English proficiency have had different experiences. Interview data is used to identify issues and support data collected through the family survey and from other stakeholders, as well as patterns identified in client data.

Family survey

Only 35% of families with children registered responded to the survey so the extent to which the findings can be extrapolated to the broader population is uncertain. Families of all types were represented among respondents, but CALD families were under-represented and regional families over-represented; the latter may in part relate to different location categorisations used by the survey and in client data.

The overall responses, however, are in line with findings from previous years, with higher levels of agreement for some items for which improvements would be expected over time. Also, the differences identified between family types in the survey were reflected in data collected through other sources.

Comparisons between families in regional and remote areas and those in major cities combine data from regional and remote families because of the small number of families in remote areas; but in some cases differences were larger between remote families and those in major cities.

Comparative data: The 2010 and 2011 surveys used a different sampling strategy to the 2009 survey. The 2010 and 2011 surveys included families of all registered clients

(though the 2010 survey could not be sent to all families that did not have a registered email address) while in 2009 we selected a stratified sample of 2,000 families to survey.

Panel provider survey

Of the Panel providers contacted, 59% responded to the survey, but the extent to which the sample can be considered representative and the findings extrapolated to the broader population is unclear because the contact list for the survey did not include all consortium partners.

The overall responses, however, are in line with findings from previous years, as are the differences in level or agreement between Panel provider types. Also, the differences between Panel provider types reflect those identified through other data sources.

Comparative data: The 2009, 2010 and 2011 surveys used different sampling strategies. The 2011 survey used the provider list which was missing contact details for some consortia partners; the 2010 survey was sent to all providers with an email address registered with FOFMS; in 2009 only lead agencies and multidisciplinary organisations were targeted.

Autism Advisor survey

Comparative data: The respondent sample for the questions on management of the Package differs between the 2009, 2010 and 2011 surveys. In 2010 and 2011 only managers and team leaders/ coordinators answered management questions, but in the 2009 survey all respondents answered these questions.

Diagnostician survey

Because there is no comprehensive list of diagnosticians available, we used an opt-in survey, meaning it was likely completed by those with a specific viewpoint or interest. As such, the results cannot be considered representative.

Comparative data: The 2009 and 2011 surveys are not directly comparable because the 2011 survey targeted psychiatrists and the 2009 survey did not.

Outcomes data

The evaluation did not include the direct measurement of children's social, behavioural and emotional outcomes. The evaluation relies on the perceptions of families about the changes they have seen in their child/ren and the perceptions of Panel providers about the changes they have seen in the children accessing their services Package funding.