Implementation of the NDIS in the early childhood intervention sector in NSW

Final Report

Prepared by the Social Policy Research Centre for

Early Childhood Intervention Australia NSW/ACT

May 2018

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The Social Policy Research Centre is based in Arts & Social Sciences at UNSW Sydney. This report is an output of the 'Implementation of the NDIS in the early childhood intervention sector in NSW' research project, funded by Early Childhood Intervention Australia NSW/ACT.

Suggested citation:

Christiane Purcal, Trish Hill, Ariella Meltzer, Nirosha Boden, Karen R Fisher (2018). *Implementation of the NDIS in the early childhood intervention sector in NSW – Final report* (SPRC Report 2/18). Sydney: Social Policy Research Centre, UNSW Sydney.
http://dx.doi.org/10.4225/53/5b2ae9c2563c5

Acknowledgements

Project Sponsor: Margie O'Tarpey, CEO, ECIA NSW/ACT

Project Manager: Libby Forsyth, Deputy CEO and Programs Manager, ECIA NSW/ACT

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Reference Committee: Alice Lans, Noah's Inclusion Services; Mary Hawkins and Karen Hargans, NDIA; Ann Rao, Kerry Dominish, Early Ed; Karen Tippet, Family Advocacy; Kerrie Turner, Family Representative; Rani Dibley, Hunter Prelude; Karen de Mar, FACS; Sylvana Mahmic and Susan Macgillycuddy, Executive Board members ECIA NSW/ACT.

Project funder: NSW Department of Aging Disability and Home Care.

Foreword

Early Childhood Intervention Australia NSW/ACT

The transition of the Early Childhood Intervention (ECI) sector to the full National Disability Insurance Scheme (NDIS) has been a transformational reform.

The NDIS enables families to make choices about which services best meet their children's needs. It also requires ECI service providers to begin to deliver services under the NDIS, using its core approaches of maximising choice and control and individualised service provision. The ECI registered service providers in NSW will be complemented by the Early Childhood Partners (ECP), who will now undertake the role of Early Childhood Early Intervention (ECEI). This will involve early engagement, assessment, planning and referral and the provision of short-term support services.

The management of the transition to the NDIS has important implications for children with developmental delay or disability, their families and ECI service providers.

The critical issue is ensuring families are aware of best practice to enable them to have informed choice and control. The challenge presented to the system and to the sector is to continue the promotion and implementation of best practice in Early Childhood Intervention. Best practice entails a family centred team around the child, a collaborative approach to intervention, preferably with the family in their natural environment such as the home.

With this transformational change to the ECI sector, ECIA NSW/ACT instigated an essential research project with UNSW to gather evidence of family and service provider experiences of the NDIS.

ECIA NSW/ACT, with the Social Policy Research Centre at UNSW, undertook this longitudinal research project in 2017, which involved families and early childhood intervention practitioners and service providers. Little research has been undertaken in this area to explore what happens as more children, families and ECI service providers move to the NDIS. The findings of the research show a wide range of experiences among both families and service providers regarding preparations for the NDIS and their early experiences while in the Scheme.

Many families continue to experience delays and communication issues in transitioning to the NDIS, especially disadvantaged families.

Service providers have advanced in their adaptation to NDIS processes, while systemic issues remain. The findings suggest implications for further transition to the NDIS and sustainability of good practice and ECI service types.

National Disability Insurance Agency (NDIA)

NDIA needs to consider modifications that lead to timely, consistent and equitable support for families including:

- providing families with independent information and preparatory support about the NDIS that is easily accessible and culturally appropriate
- additional support for families from Aboriginal and Torres Trait and culturally diverse backgrounds, and for families who are socio-economically disadvantaged or have complex needs; for example, provide funding for case managers, family workers and interpreters
- more formalised information and preparation resources for families and service providers across the state, including in all regional and rural areas
- resourcing for the new Early Childhood Partners to perform more family information and preparation functions
- offering respectful formats for NDIS planning meetings that consider families' needs regarding time, location, cultural and communication preferences
- informing families about the progress of their NDIS application in real time and maintaining ways for families to proactively seek updates rather than wait for NDIA contact
- working with families and service providers to manage gaps in funding while waiting for the NDIS, or finding alternative sources of support
- providing families with NDIA planners and staff with adequate and consistent expertise in early childhood development and disability, including family centred practice, inclusion, teamwork and evidence-based practice with an outcome-based approach
- giving families and service providers opportunities for feedback to NDIA if the transition process is inadequate
- providing timely and adequate access to early childhood intervention supports through the Early Childhood Early Intervention pathway
- monitoring supply and demand for NDIS ECI services and being responsive to gaps and issues.

NDIA could also recognise the additional challenges of change management for small providers and providers in non-metropolitan areas and offer ongoing opportunities for ECI and mainstream providers to give feedback and have input into NDIS design.

NDIA can inform mainstream services about the NDIS, including ECI good practice guidelines such as trans-disciplinary approaches and inclusion, or liaise with sector peak bodies such as ECIA to disseminate such information. NDIA could further support collaborative practice between the ECI sector and mainstream services.

Service providers

ECI service providers reported a variable experience with their transition to the NDIS. In general, large organisations appeared to cope better with adapting to the new NDIS environment than smaller organisations, due to differences in financial and organisational capacity. In transition, services have simultaneously accommodated mechanisms for managing increased referral numbers and adapting staff roles and work practices to NDIS requirements.

The transitional issues have included higher workloads due to NDIS plan writing and implementing operational changes (administration, record keeping, and software) without adequate compensation. Inconsistent and changeable information from NDIA has made operational change and business planning difficult.

It is recommended that service providers:

- continue to develop family-centred, peer-to-peer and family participatory models of practice in conjunction with ECIA as the peak body
- build family capacity to navigate the NDIS system, take over unfunded tasks (e.g. sourcing equipment) and choose appropriate, evidence-based support
- implement innovative travel solutions e.g. service brokerage, satellite offices or working from home and telehealth.
- adapt mechanisms for staff communication and collaborative practice e.g. core office days or online apps
- facilitate ongoing social connections for parents, e.g. through providing supported playgroup spaces
- bridge funding gaps by tapping into a diversity of services and funding sources
- build collaborative practice between ECI and mainstream providers, i.e. through ILC grants.

Systemic issues

There are systemic issues particularly within the pricing framework that are yet to be addressed. We need to:

- ensure that adequate funding mechanisms are in place to cover travel and cancellation costs
- review the pricing mechanisms to support collaborative multidisciplinary practice for families and children
- ensure that funding allows for services to work collaboratively in the community and with mainstream services
- ensure that there is sufficient resourcing for staff and students to undertake essential professional development and supervision
- review the administrative load, which is more problematic for small organisations than bigger ones due to reduced overall financial capacity
- address the shortage of therapists and early childhood intervention educators and retention of experienced early childhood intervention practitioners, especially outside metropolitan areas.

ECIA will continue to:

- promote and develop the ECI sector’s approach to and application of best practice in early childhood intervention
- support sector development around the transition to NDIS and to the EC Partners
- provide professional development for the wider sector, e.g. ECE and community services, around inclusive practice
- monitor outcomes and undertake ongoing research and evaluation
- advocate and represent the sector through effective policy frameworks
- monitor the potential gaps produced by the systemic change
- advocate for access to adequate and timely early childhood intervention supports for families and their children with complex issues and developmental delays.

Signed

Susan Macgillycuddy
President

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CEO

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Abbreviations

ADHC	NSW Government Family and Community Services – Ageing, Disability and Home Care
ASD	Autism Spectrum Disorder
COAG	Council of Australian Governments
ECEC	Early Childhood Education and Care
ECEI	Early Childhood Early Intervention
ECI	Early Childhood Intervention
ECIA	Early Childhood Intervention Australia
FACS	NSW Government Family and Community Services
HCWA	Helping Children with Autism
ILC	Information, Linkages and Capacity Building
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NSW/ACT	New South Wales/Australian Capital Territory

Executive summary

The transition of the early childhood intervention (ECI) sector to the full National Disability Insurance Scheme (NDIS, the Scheme) requires families to make new choices about which services best meet their children's needs. It also requires ECI service providers to begin to deliver services under the NDIS, using its core approaches of maximising choice and control and individualised service provision. The quality of the transition to the NDIS has important implications for children with developmental delay or disability, families and ECI service providers.

Little research has examined what happens as more children, families and ECI service providers move to the NDIS. Understanding what happens in the transition process will ensure that key issues can be identified and addressed as NDIS implementation progresses, to achieve good practice ECI for children and families, as well as innovation and sustainability for ECI service types.

Early Childhood Intervention Australia (ECIA) NSW/ACT commissioned the Social Policy Research Centre (SPRC) to conduct research during 2017 into the experiences of families of children aged 0-8 years, and of ECI service providers, in the transition to the NDIS in New South Wales (NSW). The study followed previous research into transition experiences in two early NDIS sites (Meltzer et al. 2016a). This report provides an analysis of the findings from the 2017 research and implications of the findings for the ongoing rollout of the NDIS.

The SPRC conducted a two time-point study with surveys, interviews and case studies. In addition, relevant data in NDIA quarterly reports was collated (Appendix C NDIA quarterly reports data).

The research found a wide range of experiences among both families and service providers regarding preparations for the NDIS and their first experiences while in the Scheme. There was modest change from Round 1 to Round 2 of data collection. Many families continued to experience delays and communication issues in transitioning to the NDIS, especially disadvantaged families. Service providers had advanced in their adaptation to NDIS processes, while systemic issues remained. The findings suggest implications for further transition to the NDIS and sustainability of good practice and ECI service types.

Family experiences

There were no consistent family experiences in any aspect of the transition.

- In general, families appeared to fare better when they had educational and social capital to navigate the support system, evaluate services to maximise choice and quality, financial resources to cover any funding gaps while waiting for the NDIS, effective support from an ECI provider, a knowledgeable and helpful National Disability Insurance Agency (NDIA) planner or a combination of the above.
- On the other hand, families who were disadvantaged in any way – be it socially, culturally or financially – or who had unhelpful interactions with services or the NDIA were at higher risk of experiencing funding and service gaps, delays, frustration and distress.
- There appeared to be common delays, communication issues and inequalities in NDIA planning, approval and review processes, which had not significantly improved by the second round of data collection. Any delays in funding allocation seemed particularly problematic in the

context of early childhood as it put the efficacy of potential early intervention in question, thereby risking higher support need in the long term. Families coped better where they had services that could provide interim ECI support, accessed peer networks or had financial resources. Once in the NDIS, access to support and range of choice of provider varied among regions.

The implications of the findings are that NDIA might consider modifications that lead to timely, consistent and equitable support for families during their transition process, including:

- provide families with independent information and preparatory support about the NDIS that is easily accessible and culturally appropriate
- consider especially the additional requirements of families from Aboriginal and diverse language backgrounds, and of families who are socio-economically disadvantaged or have complex needs – provide funding for, e.g., case managers, family workers and interpreters
- consider funding support for family members, e.g. counselling and respite for parents and siblings
- develop more formalised information and preparation resources for families and service providers across the state, including in all regional and rural areas, e.g. a knowledge pathway and funding for peer support
- always offer respectful formats for NDIS planning meetings that consider families' needs regarding time, location, cultural and communication preferences
- inform families about the progress of their NDIS application in real time and maintain ways for families to proactively seek updates rather than wait for NDIA contact
- work with families and service providers to manage gaps in funding while waiting for the NDIS, or to find alternative sources of support
- provide families with NDIA planners and staff who have adequate and consistent expertise in early childhood development and disability
- once in the NDIS, support families to exercise choice by providing more information about appropriate therapies and support for their child – this could come from well-informed planners or from health professionals
- address any delays in children accessing timely ECI supports – before, during and after their transition to the NDIS
- give families and service providers opportunities for feedback to NDIA if any aspect of the transition process is inadequate.

Service provider experiences

The transition experiences of service providers were widely variable as well. In general, large organisations appeared to cope better with adapting to the new NDIS environment than smaller organisations due to differences in financial and organisational capacity. Providers in regional and rural areas often mentioned additional difficulties in accessing information and training about the NDIS and incorporating travel times into their pricing structure. Interviewees were complimentary about ECEI Transition Advisors, whom they found approachable and supportive.

By the second round of data collection, transition processes had advanced and some providers had developed mechanisms for managing increased referral numbers and adapting staff roles and work practices to NDIS requirements.

The adaptation issues that providers mentioned fell into two categories: some were transitional issues, which occur as service providers move to the NDIS and which are likely to resolve once the NDIS is well established; others were systemic issues, which are embedded in the new NDIS environment and will likely remain unless they are addressed.

The transitional issues are:

- higher workloads due to NDIS plan writing and implementation of operational changes (administration, record keeping, software) without compensation
- insufficient, inconsistent and changeable information from NDIA, which makes operational change and business planning difficult.

The systemic issues are:

- ensuring adequate funding mechanisms to cover travel time – NDIS policy has since changed to address this issue, and the impact of these changes needs to be monitored
- supporting collaborative practice in the sector and with mainstream services
- improving support for inclusive mainstream services
- managing higher ongoing administrative load and cost, which is more problematic for small organisations than bigger ones due to less overall financial capacity
- ensuring sustainable and varied service types across the state, including in rural and remote areas
- supporting workforce availability and capacity, e.g. addressing a shortage of qualified, experienced therapists, especially outside metropolitan areas.

The research indicates that both types of issues could be addressed by NDIA. The Agency could provide infrastructure and investment to manage supply and demand of ECI services, monitor service quality and enhance workforce capacity to enable a smoother transition process for providers as well as a varied service network over time.

Implications

The research findings have implications for service providers and the NDIA, in particular:

Good practice for children and families

Service providers might attempt to:

- build family capacity – to navigate the NDIS system and take over unfunded tasks (e.g. sourcing equipment)
- implement innovative travel solutions – e.g. service brokerage, satellite offices or working from home

- adapt mechanisms for staff communication and collaborative practice – e.g. core office days or online apps
- facilitate ongoing social connections for parents, e.g. through providing supported playgroup spaces, parenting classes and parent support groups
- bridge funding gaps by tapping into a diversity of services and funding sources and lobbying NDIA
- lobby NDIA to fund collaborative practice between ECI and mainstream providers, e.g. through Information, Linkages and Capacity Building (ILC) grants.

Innovation and sustainability of ECI service types

Implications for NDIA:

- monitor whether families' access differs between Early Childhood Early Intervention (ECEI) and non-ECEI transition providers
- recognise the additional challenges of change management for small providers and providers in non-metropolitan areas; for example, offer more NDIS training in rural and remote communities or subsidise provider travel to information sessions in larger centres
- offer ongoing opportunities for ECI and mainstream providers to give feedback and have input into NDIS design.

Implications for service providers:

- ensure good organisational leadership, which helps with change management
- consider changes in staffing and internal administrative processes, staff training, marketing and diversifying the business
- establish or foster local provider networks
- talk with families about managing changes in funded service types, e.g. how travel can be accommodated within packages.

Effective interface with mainstream services

- NDIA can monitor and, if necessary, adjust referral pathways to ensure efficient and timely early intervention
- NDIA can inform mainstream services about the NDIS, including ECI good practice guidelines such as trans-disciplinary approaches and inclusion, or liaise with sector peak bodies to disseminate such information
- NDIA can support collaborative practice between the ECI sector and mainstream services
- ECI providers can proactively inform mainstream services about NDIS and the ECI sector.

In addition, ECIA can support the transition through its continued role in:

- promoting and developing the sector's approach to, and application of, good ECI practice

- facilitating sector development around transition to NDIS and the Early Childhood Partners model
- providing professional development for the wider sector, e.g. ECEC and community services, around inclusive practices
- monitoring outcomes and undertaking ongoing research and evaluation
- advocating and representing the sector in the policy process, such as through the ECIA recommendations regarding the NDIS Pricing Inquiry
- monitoring potential gaps produced by the systemic change
- advocating for access to adequate and timely early childhood intervention supports for families and their children with complex issues and developmental delays.

1. Research background and scope

1.1 Background

With the introduction of the National Disability Insurance Scheme (NDIS), the disability support system in Australia is extensively restructured. In the past, people with disability accessed most support through service provider organisations that received block funding from state and territory governments. Under the NDIS, access to government-funded services is through information and referral, short-term intervention supports, or an individualised funding package to a person with disability who can then make choices about which services best meet their needs. The individual package enables reasonable and necessary supports for early intervention and social and economic participation.

Early childhood intervention (ECI) is provided through the NDIS as part of the disability service system. In the ECI context, children with developmental delay and disability and their families receive support through information and referral, short-term intervention supports, or through individualised funding and personalised, trans-disciplinary, collaborative ‘team around the child’-services.

While under trial since July 2013, the NDIS began its full roll out in New South Wales (NSW) and across Australia on 1 July 2016. In February 2016, the National Disability Insurance Agency (NDIA) announced its Early Childhood Early Intervention (ECEI) approach. The NDIS ECEI approach intends to help children with developmental delay or disability and their families to achieve better long-term outcomes through support services in their local community, regardless of diagnosis.

In October 2016, the NDIA announced that it had worked collaboratively with the NSW Government and Early Childhood Intervention Australia (ECIA) NSW/ACT to determine a transitional approach to the implementation of the ECEI approach in NSW. This transitional approach meant that until June 2018, current NSW ECI providers who provided supports consistent with elements of the NDIA's ECEI approach were contracted as ECEI Transition Providers, to continue to deliver ECI, referral and information support to families through the NSW Government (ADHC). These providers also developed and recommended reasonable and necessary supports to be funded under the NDIS. This aimed to retain referral pathways, maintain capacity for short-term support and information provision, minimise disruption to children and families, and support the transition of ECI to the NDIS. In May 2017, the NDIA also appointed two organisations across NSW as NDIS Transition Advisors, to support ECEI transition providers with coaching and mentoring, reviewing the quality of plans, and providing advice on ECI support requirements.

Meanwhile, the number of children in NSW with NDIS individual packages increased from 1,807 in the second quarter of the 2016/17 financial year to 4,926 in the first quarter of 2017/18. The speed of this transition mirrored that in Australia overall, where during the same period the number of children with NDIS plans increased from 2,267 to 6,716 (Appendix C NDIA quarterly reports data). The numbers also show that NSW is home to more than 70% of Australian children with an NDIS package, and therefore developments in NSW have national significance.

From July 2018, contracted Early Childhood Partners deliver the ECEI approach. Their role is to build a profile of the child and their family's circumstances and needs, provide short-term interim supports, and support the child's family to access mainstream services and the community. The Early Childhood Partner is also responsible for completing a request to access the NDIS, developing the child's plan, supporting the family to implement the child's plan, and reviewing the plan when it lapses, usually after 12 months.

The ECI sector in NSW is therefore currently in transition to the full NDIS, with the arrangements for the ECEI approach forming a key part of the transition. The transition to the NDIS full scheme requires families to make new choices about which services best meet their child's needs. It also requires ECI service providers to begin to deliver services under the NDIS, using its core approaches of maximising choice and control and individualised service provision.

The quality of the transition to the NDIS has important implications for children, families and ECI service providers. Previous research in the Hunter region (an NDIS trial site) and the Nepean Blue Mountains (an early roll-out site) indicated key transitional issues as ECI service provision moves to the NDIS (Meltzer et al. 2016a), including managing service levels, trans-disciplinary collaboration, and working under a billable-hours system. In the Nepean Blue Mountains, where the NDIA's ECEI approach was first implemented before its national roll-out, ECI service providers found this approach useful for providing services to children who might not access NDIS individualised packages (Meltzer et al. 2016a).

In this context, there is a need to further understand what happens as more children, families and ECI service providers move to the NDIS, what transitional issues they experience, and how these issues can best be addressed. It is important to understand the benefits, challenges and unintended consequences that different groups of families and providers may be experiencing over time. While some study of these issues has taken place as the NDIS has been trialled and in the early roll-out phase, there is a need for more thorough research about the transition as the full roll out takes place (including the ECEI approach). This will ensure that a range of key transitional issues can be identified and addressed as the roll out occurs, to best achieve good practice ECI for children and families, and innovation and sustainability for ECI service types.

There is also a need for research into how different groups experience the transition. Families have different levels of experience of the NDIS and of ECI service provision, including those who have had experience of ECI services pre-NDIS, those who have had only NDIS ECI services, and those who have had no NDIS experience. Service providers also have different backgrounds, including those directly providing ECI services, and those who work closely with ECI, but come from education, health, allied health and other mainstream services. Each has a different experience of the transition, which needs to be understood and any issues to be addressed.

Therefore, ECIA NSW/ACT commissioned the Social Policy Research Centre (SPRC) to conduct research into the experiences of families and ECI service providers in the transition to the NDIS in NSW. The research was conducted in 2017, and findings from the first round of data collection were published in Purcal et al. (2017). This is the final report from the research. It is based on the first report and incorporates findings from the second round of data collection.

1.2 Policy update

Significant developments took place during and after the data collection period of this study, which was completed in the last quarter of 2017. These developments will change the policy landscape and need to be seen as the future context in which this report is historically situated. They are:

1. The NSW ECEI Transition model was completed by 30 June 2018, and the Early Childhood Partners model is rolled out from 1 July 2018. This means that the existing 52 Transition Providers and 4 Early Childhood Partners will cease their ECEI role, which will be transferred to the incoming Early Childhood Partners.

2. The NDIA has announced reforms based on consultation with NDIS participants and services providers. These include:

    a. new provider and participant pathways including a specific pathway for children with disability and developmental delay aged 0-6

    b. a tailored planning process to achieve outcomes

    c. an update to the MyPlace Portal including the Service Finder

    d. setting up of specific teams to address backlog in provider payments, unscheduled plan reviews and Assistive Technology requests.

3. A revised pricing model for therapy supports including early childhood intervention was introduced under the banner of the Independent Pricing Review report (McKinsey & Company 2018). The report made recommendations pertaining to therapy service provision, including dividing up therapy services into psychological and physical therapy groups with associated tiered pricing levels, greater use of allied health assistants, travel for therapy, cancellation policy for therapy and being able to charge for writing reports requested by the NDIA. These recommendations, with the exception of recommendations regarding tired pricing and a staged implementation for allied health assistants, will be adopted in the NDIS Price Guide for 2018-19.

4. The Joint Standing Committee on the NDIS’s Report on the Provision of services under the NDIS Early Childhood Early Intervention Approach (Joint Standing Committee 2017) addressed a number of key aspects of the Scheme including the role of ECEI Partners, supports for families, adequacy of funding of children's plans as well as assessment and plan building processes.

5. The Joint Standing Committee on the NDIS’s report on the Transitional arrangements for the NDIS (Joint Standing Committee 2018) dealt with issues including the interface between the NDIS and mainstream services, delivery of services, thin markets and emerging service gaps.

6. In April 2018, ECIA NSW/ACT completed and disseminated its Position Paper on Gaps in Provision of Services post June 2018 (ECIA NSW/ACT 2018), outlining the key interface points between NDIS and mainstream services for children aged 0-6 and their families, including groups that are at greatest risk of ‘falling through the gaps’ between systems.

1.3 Research objectives and questions

The research was conducted to identify issues in the transition to the NDIS and to inform ways to address these issues for the full NDIS implementation. The objectives of the research were to:

- add to the evidence base about the transition to the NDIS in the ECI sector
- understand the experience and implications of the transition to the national ECEI approach in NSW
- inform practice change
- improve outcomes for children and families (by providing the information necessary to address transitional issues as they arise).

The research questions were:

- What are the family, ECI service provider and mainstream provider experiences of the current transition to the NDIS in NSW?
- How can ECI service types be delivered, including under the ECEI approach, to best achieve:
    - good practice services for children and families?
    - innovation and sustainability of ECI service types?
    - an effective interface with other service types?

2. Methodology

2.1 Research approach

The research was a two time-point study with surveys, interviews and case studies. Data was collected in the first and second half of 2017, with capacity for participants to contribute once or twice based on preference. This design allowed information to be collected at the aggregate level, while also exploring longitudinal change. It also allowed focus on the perspectives of families and service providers who entered the NDIS in both Years 1 and 2 of the transition. The project had three phases, as outlined below. Further detail about the methodology can be found in Meltzer et al. (2016b).

2.1.1 Planning and project set-up

The project commenced in early 2017 with planning with ECIA NSW/ACT to confirm the research focus, questions and methodology. A Reference Group composed of ECIA staff and Board members, ECI service providers and sector experts informed the project. The literature review conducted for previous, similar research in the Hunter region and the Nepean Blue Mountains (Meltzer et al. 2016a) was updated to inform the project context (Appendix D).

2.1.2 Data collection Round 1 and preliminary analysis

In Round 1 of data collection in the second quarter of 2017, semi-structured telephone interviews and online surveys were conducted with family members and service providers to gain both in-depth and aggregate information about their experiences in the transition to the NDIS. Family members were asked about their experiences of using services, while service providers were asked about the changing experiences of their work and their perceptions of changes in the structure and system they worked in.

2.1.3 Data collection Round 2, final analysis and reporting

Interviews and surveys were repeated in the last quarter of 2017. Questions covered the same topics as in Round 1 but focused on change since the first round and examined how well any strategies to adapt to the NDIS had worked. Participants from Round 1 were invited to take part again, and some new participants were recruited, to assess both longitudinal and aggregate change since the first round. Appendix A contains the interview and survey questions. This phase of the research also included analysis data in the *National Disability Insurance Scheme Council of Australian Governments (COAG) Disability Reform Council Quarterly Reports* prepared by the NDIA. This data outlined the number of children with plans through ECEI and indicators for children and parents and family members by age groups of NDIS participants and compared data for all of Australia to NSW.

2.2 Sample and recruitment

Across both rounds of data collection, 38 semi-structured interviews were conducted: 16 with family members and 22 with service providers. Of those, five family members and five service providers took part in both rounds of interviews, providing longitudinal and case study data. Therefore, 11 distinct family members and 17 service providers participated in interviews. The anonymous online survey was completed by 344 people: 153 family members and 191 service providers. Of those, 28 family members and 34 service providers took part in both survey rounds, so the survey was completed by 282 distinct respondents: 125 family members and 157 service providers. (Table 2-1).

The total number of participants in data collection may include double-counting, as people may have completed the survey as well as taken part in an interview. In addition, individual families may have completed the survey multiple times if they had concerns about the development of more than one of their young children or had more than one child with a disability.

Table 2-1 Sample for data collection (N)

	Family members		**Service providers**		**Total[1]**
	Round 1	Round 2 (repeats[1])	Round 1	Round 2 (repeats[1])	
Interviews	10	6 (5)	14	8 (5)	**38 (10)**
Surveys	67	86 (28)	112	79 (34)	**344 (62)**
Total[2]	**77**	**92 (33)**	**126**	**87 (39)**	**382 (72)**

Notes: [1]Number of those in Round 2 who had also participated in Round 1 in brackets
[2]There may be double counting as research participants may have completed both the interview and the anonymous survey.

ECIA NSW/ACT assisted with marketing the survey and recruiting for interviews by distributing the online survey links to their membership, non-members and distribution lists, including asking key personnel, such as board members, to pass on the information. ECIA NSW/ACT also directly invited potential interview participants, by asking providers to (a) nominate a staff member to be interviewed and (b) extend the interview invitation to one or two family members to whom they provided services. The family member contact details were passed on to the researchers only with permission and once the family had agreed to participate. The service provider agencies that were contacted were spread across metropolitan and regional areas and types of agencies (e.g. ECI, ECEC, disability, education, health and mainstream services) to ensure that a variety of views were represented. Providers who were known to specifically service Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities were also included, with requests that they nominate family members from these communities for the interviews.

Recruitment of service providers was less successful in the second round of data collection than in the first. One likely reason is that the tender for the Early Childhood Partners was due at the time. Service providers who did participate in second-round interviews mentioned how labour intensive the tender process was, with regards to both writing a proposal and managing families' anxieties about future service provision.

2.3 Participant profile

The characteristics of the participant sample are summarised below. Detailed findings about the survey participants are in Appendix B.

2.3.1 Child and family characteristics and support

Both the family interview and the online survey for families included questions about the demographic characteristics of the child aged 0-8 years who received support or a child who a family member had concerns about and about the kind of support that the child and family received. The parents reported:

- most children were boys

- most were aged three to six years old; the overall age profile was older in the second survey round, with fewer children aged 0-3 and more aged 7 and 8
- the large majority spoke English at home; among the 11 interview participants, two were from a non-English speaking and two from an Aboriginal and Torres Strait Islander background
- about one-half lived in the Sydney metropolitan region, and the others lived in regional and rural areas
- most children had a disability or developmental delay, most commonly social, communication, sensory processing and/or cognitive disability; more than half of the children with disability in survey Round 1 had four or more types of disability, while in Round 2 children had fewer disabilities overall
- almost all families were receiving early intervention services; those in the first survey round most often received services from community or non-government organisations, and those in the second round, most often from the NDIS
- the most common types of support that children received were for communication and interaction with others, sensory processing and self-help; the least frequent, for service planning and coordination, community access, and sleep
- a large majority of children had used allied or specialist health services or a general practitioner in the last 12 months, while few children had used mental health services
- reflecting the age profile of the children across both survey rounds, Round 1 children were more likely to participate in some form of early childhood education, while those in Round 2 were more likely to be in primary school
- the majority of family members said that the child needed more support than they were receiving, with the types of support that were needed varying widely
- less than half the family members had received support for themselves and if they had, the support type was most likely parenting education, support groups or counselling.

2.3.2 Service provider characteristics

Service providers who completed the online survey and/or interview gave the following information about their role and their organisation and its services:

- similar numbers of survey respondents had a management or direct worker role, and about one-third had dual roles in their organisation, working both as managers and directly with children and families
- all but one of the interview participants had a management role exclusively (although several came from a practice background), and one was working directly with children and families
- the most common service types that the organisations provided were ECI and specialist disability support; in survey Round 1, there were also significant numbers of child care centres and preschools, while several hospitals and specialist health services participated in Round 2; the proportion of private practitioners was equal across both rounds, at 8 per cent
- about half of the interview participants were ECI providers

- service locations included all Health or FACS areas in NSW, but respondents were concentrated in the Greater Sydney and surrounding areas; the second survey round had a higher proportion than the first one from Southern and Western NSW, and fewer respondents from Northern NSW
- the majority of first-round survey respondents provided services in areas that were already in the NDIS, and by the second round, almost all respondents were in NDIS areas, consistent with the progressing rollout of the Scheme
- the proportion of survey respondents who were offering services under the NDIS rose from one-half to three-quarters between survey rounds; there were more providers in the second round who were new to the Scheme
- about one-half of the organisations in the Round 1 survey were ECEI transition providers/community partners, compared to two-thirds in Round 2; 13 of the 17 interview participants were ECEI transition providers
- 80% or more of the organisations in both survey rounds provided support with the child's communication, interaction with others, playing, participation in education settings, behaviour and transition, and self-help and sensory processing in the survey Round 2; the lowest help category in both survey rounds was medical needs
- many organisations also supported family members, most commonly through providing referrals, parenting education and information, and supporting the family to access ECI funding; fewer organised parent or sibling support groups, or mental health counselling.

3. Family experiences

Eleven family members – ten mothers and one father – took part in the semi-structured interviews in 2017. Their perspectives are reported in this section. In some places, the views of service providers talking about their perceptions of the experience of family members were also included. This is because service providers contributed perspectives on the experiences of families who did not participate in the research, including some families from disadvantaged backgrounds.

As explained in 2.1, both interview rounds covered the same topics, and Round 2 focused on change. Therefore, much of the information in this section is from the first round of interviews, which provided comprehensive data on all research questions. Modest change was observed between the two rounds, which is consistent with the relatively short timeframe between the rounds (about six months) and the smaller number of participants in Round 2 (Table 2-1). Relevant observed change – or no change – is indicated throughout the text.

Quantitative and qualitative findings from both survey rounds were incorporated into this section where appropriate alongside the interview data. The complete quantitative survey findings are in Appendix B. Most of the qualitative survey answers were provided as optional comments, and families were, in the majority, complimentary of specific service providers but critical of NDIA processes.

3.1 Experiences prior to entering the NDIS

Four families in the first interview round had not yet had their NDIS planning meeting. These families spoke about their expectations of the NDIS, the preparation they were involved in and their service and funding arrangements in the meantime. By the second round of interviews, one of these families had been approved an NDIS package, while the other three were still in the pre-planning stage. The seven families who were just entering or already in the NDIS at the time of their interview also spoke in hindsight about their experiences prior to entry into the NDIS.

3.1.1 Perceptions of upcoming entry into the NDIS

Family members expressed a variety of views about their perceptions and emotions regarding their upcoming entry into the NDIS. Some families were looking forward to their child's entry into the NDIS and were hopeful that the Scheme would enable more consistent funding and also more choice and control for the family, for example over which service provider organisations they used, which support workers came to their homes and which therapists they had access to.

Other families were worried about the upcoming entry of their child into the NDIS. They spoke about how the NDIS was a significant change, which felt overwhelming, and that they experienced inconsistent and confusing information provision:

> What worries me is how it's constantly changing all the time … it's one thing today and then tomorrow might be something different.

Several families made similar comments in the survey. One parent suggested the NDIA establish information centres for families as a starting-off point. Service providers echoed some difficult experiences, noting that many families they worked with were anxious about their child's upcoming entry into the Scheme.

Other common concerns among parents whose children were yet to enter the NDIS were whether their child would be eligible and, if so, how long the entry process would take. They were also concerned that they needed to make good decisions when it came to their child's planning:

> It's pretty hard having a child at the age of four to be able to predict what they may or may not need. A lot of the time, you cannot even be aware of it.

Some service providers also noted this difficulty, highlighting that an important part of their role was 'helping families plan further ahead'.

Those families who were already receiving ECI and/or disability services were also commonly concerned about whether they would continue to receive the same services, services at the same level or services from the same providers. Continuity and consistency were important to many families, as they wanted to retain the services they had worked hard to find prior to the NDIS. In the survey, more than one-half of the families indicated they themselves had found at least some of the services they were using.

By the time of the second interview, three families who had participated in the first round were still waiting for their NDIS planning meeting, without word from the NDIA in the interim. Two felt they benefitted from good support from their ECI service providers. One of these families had a responsive key worker and preschool. The mother said that because of their support, and because of the NDIS information she had received from these providers, she felt 'more confident' and not 'as anxious and overwhelmed' as at the time of the first interview. The other family had stable, ongoing early intervention and felt the child was not missing out at the moment, although they would prefer to have a timeline for entering the NDIS. The third family received limited services and found waiting for the NDIS, without any indication of a timeline, most challenging.

3.1.2 Preparation for the NDIS

Many family interview participants reported involvement in activities to prepare for the NDIS. The information in this section is from the first interview round, unless indicated otherwise. Most families and service providers who participated in the second round were either further along in the transition process or reported no change since the time of the first interview; except one family who, as mentioned above, had received pre-planning information from their providers since the first interview and now felt less anxious.

Several families in the interviews had been involved in preparation and opportunities to learn about the Scheme, including attending seminars, getting assistance from their service providers and filling in pre-planning resources. As a result, they had gained confidence about their child's upcoming entry to the NDIS. For example:

> I'd say that our physio and my key worker … have been excellent. Because I ... had no idea, and all the way along they kept saying 'Have this ready and think about this'.

Similarly, families in the survey added comments about how helpful their service provider had been in preparing them for the NDIS and guiding them through the application process.

Some families noted that planning experiences for previous services, including individualised funding packages, had helped them prepare. One service provider said her area had intentionally brought in an individualised funding program, which she called a ‘mini NDIS’, in the few years before their area transitioned to the Scheme to help up-skill families in planning for and using this type of funding.

Other families had found the preparatory process less effective. Some families had received inconsistent information, which meant that they did not feel well prepared for the upcoming change. For example, a parent wrote in the second survey:

> Every time I have called the NDIA and spoken to health professionals about it, I get a different story. No-one seems to know what is going on, and I keep getting palmed about and not receiving callbacks as promised by NDIA.

Some of these families had sought information from peer support networks, finding that some of the best information came from other parents, often through personal contacts. One parent recalled in the second interview:

> I had help from a friend who had already gone through the system … To be honest, most of my mentoring came from her. Without her I would have been lost.

Other parents commented on experiences with peer support via social media, with some finding online groups helpful and others saying such forums could be negative and the family did not wish to seek support there.

Not all families had equal access to preparatory support. Families and service providers reported that there was less support to prepare and become aware of the NDIS in some regional and rural areas. One provider suggested the NDIA put more formalised supports in place across the state, such as a knowledge pathway and peer support.

Several providers stated that families from culturally or linguistically diverse backgrounds had a particularly difficult time transitioning to the NDIS, as the information they needed to navigate was presented in too complex a manner. These and other service providers also felt that Aboriginal families had not received enough information or formalised preparatory support:

> My biggest concern is for Aboriginal children and families that we service, they just do not know about the NDIS. I work with one provider in town, he’s the Aboriginal Liaison and he doesn’t know about the NDIS either.

The provider noted that information and support for Aboriginal families needed to be driven by Aboriginal liaisons – ‘it can’t be a service like us going in and telling them what to do, it has to be driven by their own community’ –, which has implications for informing and funding the liaison positions.

Mixed experiences with information provision are also evident from the survey findings, where family responses varied from ‘always’ to ‘rarely/never’ regarding how easy it was to find information about support, how easy it was to understand and how helpful the information was. Most difficulty was reported with ease of finding information, with 22% in the first round and 31% in the second indicating that it was ‘rarely’ or ‘never’ easy, and around 40% saying it was ‘sometimes’ easy to find. Knowledge about the NDIS remained relatively steady between survey rounds. The proportion of respondents saying they knew ‘a lot’ increased from 22% to 27%, those knowing ‘not much’ reduced from 30% to 22%, while 48% and 51% respectively ticked they knew ‘some’.

A common concern during the preparation phase for the NDIS was long wait times after first contact with the NDIA had been made or the child had been put on a ‘define’ list. In the interviews, one mother said that she had to wait for six months to get the planning process started. During that time, she called the NDIA repeatedly to gauge how long the wait might take but was not given any indication: ‘They sort of would just say to me: No, you just have to wait for the call’. The three families who were still in preparation had no contact from the NDIA between the first and second interviews, indicating ongoing issues with wait periods and information provision. Several families in the survey echoed this experience.

The observation of long wait times was confirmed by several service providers. One mainstream provider added that, in their experience, wait times for the NDIS were significantly longer than they had been for previous funding streams such as Helping Children with Autism and Better Start.

In some cases, long wait times may have been a result of families being either new entrants to the NDIS or transitioning from Commonwealth programs such HCWA and Better Start. The transition process for those children was more lengthy and complex than for others as they needed to meet eligibility first.

3.1.3 Funding and service arrangements while waiting for the NDIS

Family participants also spoke about the funding and services they were receiving while waiting for their child to enter the NDIS. Some families had a range of ECI services and therapies, which were funded through existing Better Start, other disability or ECI funding, or through families’ own financial resources. All three families who were still waiting for their planning meeting by the second interview reported they had adequate services. Two were particularly complimentary of their service providers, who they characterised as ‘supportive’, ‘flexible’ and ‘partners’.

However, several families reported service gaps, extending up to 18 months from when their previous funding finished to the start of their NDIS funding. For example, one survey respondent commented in writing:

> We are devastated. Our son has had no funding or services since January 2016. We were approved for the NDIS in July 2016 and told our meeting will be in 2018. I had to approach Ombudsman and local MP [member of parliament] to get meeting. Just had meeting yesterday [April 2017]. Still need to fight for funding.

The families’ experience of long waiting lists and service gaps is echoed by service providers. It was one of the main issues they commented on in the second, most recent survey.

Some families, both in the interviews and survey, were self-funding all or part of their current services. Families varied in the extent to which this was financially sustainable. Even those who felt it was a viable solution were, for example, taking funds out of their mortgage payments to cover the costs of their child’s services. One provider had seen families take out a second mortgage or being stressed because they had to work a second job to cover expenses. For these families, the opportunity to potentially receive adequate, funded services through the NDIS was promising and something they looked forward to.

Some service providers talked about the implication for children's development of a funding gap. One health service provider noted that it was problematic where very young children did not receive therapy in a timely manner, as delays of as little as a few months could have significant implications for their development.

Other service providers, in both interview rounds, said they managed the funding gap by continuing to provide services to families at reduced or no cost, although this put, as they said, a 'huge financial strain' on the organisation. One provider said this arrangement extended to 85% of their client families.

3.1.4 Experiences at the point of entry to the NDIS

Three families took part in the first interview shortly after their planning meeting had occurred or when they had just been advised their child was eligible for an NDIS individual package. Other families already in the NDIS were also able to talk about experiences at their point of entry to the Scheme in hindsight.

Some people indicated that their contact with the NDIA and process of entry into the NDIS had proceeded as expected, and they appeared satisfied. Some who had been apprehensive about their child's entry into the NDIS found the process easier and quicker than they had anticipated. For example, one mother's positive comment on her child's planning meeting was:

> There was lots of room for me to outline what my concerns and what my hopes were for my son. And I found the person that conducted the meeting really supportive and helpful.

Other parents said that they had received mixed messages or confusing or inconsistent information in their contact with the NDIA, that the staff they spoke with did not have sufficient knowledge, or that the NDIA's technological systems did not work well enough to determine their child's eligibility. Some parents said these problems with the process undermined the confidence they had built during their preparation for the NDIS. Service providers confirmed that such experiences were common and that providers had to assist families to 'unravel what the real message is'.

One mother noted she felt that the NDIA planner did not take the time to listen to her closely and respond to her questions during the planning meeting. A service provider connected to this mother explained that her NDIS planning meeting had been conducted over the phone without the mother being aware that the planning meeting was taking place. They said that the mother did not seem to have received adequate support from the planner in the phone meeting to clearly articulate her child's needs and to frame what she wanted from their NDIS plan. The service provider said this process had happened in a similar fashion to many of the families they supported, and that many had subsequently appealed their NDIS plans.

A mother who had her planning meeting between the first and second interviews said she received incorrect information in the meeting. She said when she stated that she wanted to self-manage the package the planner replied, 'well, it's up to the NDIS to determine how your plan is managed'. The mother said she was taken aback but summoned her confidence and kept pushing, and she was now self-managing.

Another mother said the process of going to the planning meetings and having the required conversations with the NDIA had been time consuming on top of existing therapy appointments, and this was particularly difficult for her as she had more than one child receiving services under the Scheme.

Several families noted delays, insufficient information from the NDIA and communication issues during the transition process. Common observations were that phone calls and e-mails were not returned, and that the only available NDIA phone access number connected them to generic staff who did not know their case and could not answer questions about details of the application or timelines. The interviews with families and service providers indicate that this process continued between the two interview rounds. However, in that time one mother asked the NDIA staff on the phone for the 'activation code' for her application and received it, which enabled the mother to check online at any time whether the plan had been approved. The mother found this useful:

> It just meant I didn't have to ring up, I didn't have to sit on hold… I could just jump in and have a look when I had a spare five minutes.

Several parents, both in the interviews and surveys, suggested the NDIA assign applications to particular staff and give families that staff member's direct phone number so they could access information and support directly and without delay.

One service provider observed positive change in their region. Between the two interview rounds, the NDIA had assigned a person to liaise directly with families and their providers about the progress of individual families' planning and approval processes. The provider said this was 'a good thing'.

3.2 Experiences in the NDIS

Seven families who took part in an interview had a child who had already entered the NDIS. These families could talk about their experiences in the Scheme compared to their expectations of it and their experiences beforehand.

Some families expressed positive experiences in the Scheme. For example, one mother said in the second interview, after a few months' experience with self-managing her child's NDIS package:

> To have the power to be able to spend the funding the way you know is going to be best spent, it's been fabulous.

Another mother expressed her relief at not having to self-manage her child's funds. She found her experience better than expected:

> The [service provider] came and we had a meeting with them just to see if we wanted to spend the allocated money with them … then we just went through what [child] would need for the year … I was super nervous, but it was so easy.

Some families also said they had more choice under the NDIS; for example, they could emphasise therapy types as they felt appropriate. Service providers thought that families had always had choice between providers, but that the NDIS gave them the space and impetus to, as one provider put it, 'think about what their choices are and comparing different, distinctive features or benefits between different services'. One mother described how she used NDIS funding in an innovative way that increased her choices: she had hired a therapy assistant who came several times a week to do home therapy work, such as speech therapy and OT, and to help with implementing alternative therapies that, by themselves, were not covered under the Scheme. The mother said:

> It's been an absolute game changer for us … I do lots of alternative therapy with [child] that isn't funded at all, and that is what my therapy assistant helps with … To be able to access [alternative therapies] would be beneficial, because the same things don't work for all the kids.

The experience of having more choice was also reported to some degree in Round 1 of the survey data but not in Round 2. The number of survey families in the NDIS was small (n=17 in Round 1 and n=35 in Round 2), and thus the survey findings should be interpreted with caution. In survey Round 1, 64.7% of families in the NDIS said they 'often' or 'always' had a choice over the kind of support their child was getting compared to 34.0% of families not yet in the NDIS. Due to the small sample size, the estimates have relatively wide 95% confidence limits (38.3 to 85.8 for families in the NDIS and 21.2 to 48.8 for those not in the NDIS). While the difference is statistically significant,[1] this result must be interpreted with the small sample size in mind. In Round 2, the respective figures for those in the NDIS and not in the NDIS who said they 'often' or 'always' had a choice over the kind of support their child was getting were 51.4% compared with 45.1%.

In response to the question about whether families had more choice about who provides the support, in Round 1 of the survey 76.5% in the NDIS said they 'often' or 'always' had a choice compared to 34.0% of those not yet in the NDIS. Once again, while this difference is statistically significant (p=0.004, Fishers exact test), the confidence limits were also wide (50.1 to 93.2 for families in the NDIS and 21.2 to 48.8 for those not in the NDIS). This finding did once again not hold for Round 2 of the survey, where 60.0% of those in the NDIS and 56.9% of those not in the NDIS said they 'often' or 'always' had a choice about who provides the support and there were no statistically significant differences.

Some parents noted that they had learnt how to navigate the new system. For example, one mother said that because of going through the NDIS planning process for the first time, she had learnt more about how to frame what she asked for from NDIS services. She commented:

> I think I'm a bit more clued up about how to ask for what I want. How to communicate what their needs are, in a very specific way that meets the NDIS framework.

Service providers also described families learning to navigate the system, including learning more about planning, reviews, timing and budgeting. One provider, for example, described how 'families are becoming savvier around shopping around and really evaluating … both the dollar value as well as the quality value in services'.

The survey data provided some limited, mixed support for this finding, although the small samples sizes in both rounds mean that the findings should be interpreted with caution. In Round 1, 94.1% of families in the NDIS felt that the people supporting their child and family were 'often' or 'always'

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[1] p=0.045, Fishers exact test

building their knowledge and skills to help them support their child compared to 60.0% of families not yet in the NDIS (statistically significant difference p=0.013, Fishers exact test, 95% confidence limits: 71.3 to 99.9 for families in the NDIS and 45.2 to 73.6 for those not in the NDIS). However, in Round 2 of the survey, there were no statistically significant differences between the two groups, with 80% of those in the NDIS and 72.3 % of those not in the NDIS, reporting that the people supporting their child and family were ‘often’ or ‘always’ building their knowledge and skills to help them support their child.

Several families were pleased that not much had changed because of the transition to the NDIS. These families had chosen to keep the same service providers and service arrangements as before the NDIS and had received sufficient funding to do so. Others said that small changes to their services occurred after entry into the Scheme, but that these had been likely to happen anyway, as their child’s support needs changed over time.

Two families in the interviews said their children had received less funding under the NDIS than under their previous arrangements. One was disappointed because they felt the child did not speak well enough to keep up at school. The other family advocated for more support for their child by writing a detailed letter to their local Member of Parliament. The letter argued that the child would have received significantly more hours of intervention through previous programs including HCWA than he did now, under the NDIS.

Both families and service providers also commented on issues with the yearly review process. One service provider observed that many families struggled with the recurrent effort and because the outcomes focus of the NDIS required parents of young children to look far into the future, which could involve grief and fear. While this provider felt that overall the focus on outcomes was beneficial for children and families, she worried that parents were not receiving adequate emotional and practical support during the regular review processes.

Several survey respondents commented on disappointing review processes. Similarly, one mother in the interviews described hers as ‘inefficient and demoralising’. She said that supports agreed during the meeting were rejected, and the mother felt this was possibly due to the indirect process of an ECEI transition provider conducting the meeting rather than the NDIA planner who made the review decision; that overall funding was reduced despite the child receiving an additional diagnosis after the last plan; that the review process was delayed, resulting in a funding gap of several months; and that during this time the family did not receive updates on the review progress.

This parent and others expressed a wish for feedback from the NDIA about the reasoning behind plan approvals and review decisions. One mother found out by chance that her service provider had received a detailed letter from the planner outlining itemised funding decisions, and also recommending the parents provide more documentation about the child’s support needs in order to potentially increase the funding amount. The mother suggested the NDIA give this information to all parents directly, as well as service providers.

Another difficulty mentioned by several service providers was the process of families getting used to more actively managing their child’s funding and service choices – one service provider felt some families found having more choice and control was challenging and overwhelming. Other service providers made similar comments, saying that this shift required proper support and information, for example:

> Organisations like ours are going to have to get very good at communicating why it is that we do things the way we do, so that families can make an informed choice [...] If organisations that haven't had to explain that difference before, start getting better at explaining that difference, and if some families start to understand it, then perhaps there'll be some changes in community attitudes about what early intervention constitutes,

A few families in the interviews reported difficulty with accessing the NDIA portal and keeping track of their funds. One family who had difficulty accessing their portal account suggested:

> I'd keep ringing [the NDIA] yet was shoved around from this person to that person. … I think if everyone was assigned to someone, like a case manager … and you can ring them and they have the ability to help you directly.

Some families also had difficulties finding suitable therapists once in the NDIS. Two of the six families in the second interview round had this experience. One had not been able to find an occupational therapist since their package started a few months before, and the other family found a speech therapist only after a lengthy search. Several families in the second survey described locational difficulties in accessing support under the NDIS. In their non-metropolitan areas, few service choices were available, and the families had to travel long distances to access support.

Several families in the interviews, and a majority in each survey round, stated that family members needed support but were not receiving any or too little under the NDIS. Families said they needed counselling and respite for parents and siblings. A few families said their key worker or a preschool teacher provided mental health support, and one mentioned a sibling support group.

Service providers, both in the interviews and the survey, reported inequities and inconsistencies in plan assessments and allocations. Experiences varied overall, with some providers finding children with high needs were more likely to receive adequate support under the NDIS than those with low to medium needs, whereas others observed that children with low to medium needs were at an advantage. Several providers gave examples of families who had not received all that they felt was 'reasonable and necessary' for their children. Other providers had observed inconsistencies in plans, with widely differing package sizes for children of similar needs and ages. Differences in social capital seemed to accentuate such inequities, with larger packages typically going to highly educated, well-off parents, who were better able to articulate their needs. Mixed experiences were also evident in both rounds of interviews and surveys. One parent wrote in the second survey:

> My child is getting the supports he needs, BUT I fought for 11.5 months and all the way to the Commonwealth Ombudsman before his high support needs were taken seriously. I am anticipating having the same fight every year.

Research participants were also concerned about the amount and type of service provision that some families received. Several parents felt they missed out on important types of support that were covered before the NDIS. This included therapy for the child, such as paediatric physio and specialised swimming lessons, but also services that had social benefits for the parents as well, such as early intervention playgroups and parent groups. Several parents wrote in the second survey that they missed those groups and felt lonely. One mainstream provider observed that some children had had regular key worker attendance through the NDIS but minimal therapy, which the provider felt was responsible for delays in self-care and language development, leaving the children unfit for school. The provider suggested that professional assessments be conducted before NDIS planning so that appropriate early invention therapies could be included.

3.3 Summary of family experiences

There were no consistent experiences in any aspect of the transition. Families appeared to fare better when they had educational and social capital to navigate the support system, were able to evaluate services to maximise choice and quality, had financial resources to cover any funding gaps while waiting for the NDIS, received effective support from an ECI provider, including support for family members, had a knowledgeable and helpful NDIA planner or a combination of the above. On the other hand, families who were disadvantaged in any way – be it socially, culturally or financially – or who had unhelpful interactions with services or the NDIA, were at higher risk of experiencing funding and service gaps, delays, frustration and distress.

There appeared to be common delays, communication issues and inequalities in NDIA planning, approval and review processes, which had not significantly improved by the second round of data collection. Families coped better where they had access to interim ECI support, participated in peer networks or had financial resources. Once in the NDIS, access to support and range of choice of provider varied among regions.

4. Service provider experiences

This section is based on the views of 17 service providers who took part in the semi-structured interviews in 2017. Similar to the findings reported in section 3, both interview rounds covered the same topics, while Round 2 focused on change. Therefore, much of the information in this section is from the first round of interviews, which provided comprehensive information on all research questions. Modest change was observed between the two rounds, which is consistent with the relatively short timeframe between the rounds (about six months) and the smaller number of participants in Round 2 (Table 2-1). Relevant observed change – or no change – is indicated throughout the text. During the time of Round 2 interviews, service providers were preoccupied with the tender for NDIS Early Childhood Partners.

Survey results were added where appropriate. The complete quantitative survey findings are in Appendix B. Data collection tools, while qualitative answers are integrated into this section. Most of the qualitative survey answers were provided as optional comments, and they were largely critical of NDIS processes and outcomes so far.

4.1 Maintaining good practice

Service providers were conscious of the importance of maintaining good practice for children and families and spoke about how this could best be achieved under the NDIS. They positioned this goal in the context of the move from traditional, expert-driven models towards choice and control for families. Several providers referred to the ECIA Best Practice Guidelines (ECIA 2016) as their reference for good practice principles.

They also acknowledged how important it was to keep families informed about the NDIS process:

> The huge responsibility is on ECI … to have that thorough understanding and to be up to date and … efficiently disseminating to our families, because how can they be empowered and have choice and control … if they don't understand it.

Providers added that, to exercise choice, families needed more information about appropriate therapies and supports for their child. This information could come from well-informed planners or from health professionals. By the second interview round, some providers felt that information from NDIS directly to families had improved, through user-friendly brochures on the NDIA portal.

Providers said they had developed mechanisms for sharing with other providers their experiences regarding innovative, evidence-based practices. These mechanisms included e-mail lists and regular forums.

In the second interview round, service providers positioned good practice also in the context of collaboration between the NDIA and the ECI sector in order to ensure coordination and continuity of supports for children and families. Service providers suggested good practice be maintained through 'structured communication processes', 'open information pathways' and 'NDIS-supported collaborative activities'.

Three interviewees spoke about their experiences with Transition Advisors, and all were highly complementary of the organisations and people fulfilling that role: they were ‘fantastic’, ‘very supportive and helpful’ and ‘very contactable, very willing to share information’.

The Early Childhood Partners tender process in October and November 2017 dominated the interviewees’ work during the second interview round. They said proposal writing and the need to support families who were anxious about future service provision impacted on their ability to provide day-to-day services.

Within their discussion of maintaining good practice under the NDIS, service providers also raised some particular issues, detailed below.

4.1.1 Good practice and efficiency

Service providers discussed the tension between maintaining good practice for children and families and adjusting to the NDIS business model and efficiency focus. Providers said they held conversations with families to inform them of the change and to build their capacity to take over some of the tasks that were not covered under the new funding regime, such as sourcing equipment and attending specialist appointments.

By the second interview round, some providers were receiving significantly increased numbers of new referrals from mainstream services. Providers said they created innovative procedures to manage this increase in both an efficient and transparent manner. These included new triage systems for NDIS-related referrals separate to ECI referrals:

> The other families that we’ve been supporting have been, really not much has changed for them, and we just need to move forward putting them through the process or looking at referring them out, … I guess we’re just trying to manage the backlog of referrals so that people aren’t waiting too long.

Some service providers in the second interview round saw the NDIS efficiency requirements and implementation of the billable-hours model as having a positive impact on overall service provision, for instance staff working off-site and remotely:

> You can be cynical and go, the NDIS is all about saving money, and maybe some elements of it are for that, but where the services are required to actually step up their game and provide services in a transparent fashion and have to work to certain targets I think there’s nothing wrong with that, because it just introduces an efficiency to the sector that wasn’t there before.

For example, one provider said staff now completed the documentation of service provision as part of the actual session, together with the family, rather than afterwards in the office. The provider felt this more efficient practice also made service provision more transparent for the families.

Other service providers in the second interview round mentioned that efficiency requirements and the billable-hours model had created new administrative roles in their organisation:

> It's been good that we've been able to get to that critical point where we can actually engage with increased admin support instead of having existing staff trying to work it into their role.

Some survey respondents observed that the drive towards efficiency had led to employment of junior staff with little expertise, reduced support for existing staff and, as a result, less evidence-based practice. One service provider was concerned that families might sacrifice high-quality but costly service types or elements because they perceived them as too expensive. This may include therapy planning, highly specialised interventions or joint therapy sessions. However, this provider also noted that, while challenging, the drive towards efficiency in the NDIS might ensure that service providers considered the most essential elements of their practice.

4.1.2 Travel costs of diversified services

Service providers spoke about servicing children and families in natural environments such as homes, schools and playgrounds as a key element of good practice, as opposed to services being provided in centres. With individualised funding under the NDIS, this type of good practice was becoming increasingly possible and prioritised. However, the diversification of services and locations also came with associated travel costs, which service providers acknowledged were not always well covered in children's plans and therefore could be challenging for good practice.

This was particularly an issue for service providers in rural and regional areas, where the travel distances were larger. One provider in the Sydney metro area suggested this balanced out when both travel time and distance were considered, as city distances might be shorter but traffic flow could be slower. Another provider in the second round of data collection observed that NDIS families were increasingly choosing to have support in clinical settings, in order to save travel costs.

Service providers discussed some ways that they had been able to maintain good practice despite travel and distance barriers. This included brokerage, where a service provider in a small regional town organised another provider to send therapists out from a regional centre. Two larger services with staffing and resourcing capacity opened an additional office site to minimise travel costs. One of these providers also established online administrative processes so staff could work more from home. These changes had reduced overheads in the original office, making the additional work site more affordable. This good practice solution would not be available to all service provider organisations, particularly smaller ones.

Some providers pointed out that more travel also reduced face-to-face contact between staff, potentially reducing collaboration and knowledge sharing between team members. To manage this risk, one provider had maintained weekly staff meetings on a particular day when staff would organise to be in the office. Another had introduced an app for staff to connect with each other electronically.

Previous research found other solutions to travel costs, including joint visits, arranging several visits on one day, recruiting new staff close to children and technological solutions (Meltzer et al, 2016a). Comments in the second-round service provider survey indicate that many organisations were still struggling with travel costs.

4.1.3 Collaborative teams

Service providers who had worked under the key worker in a trans-disciplinary team model spoke about the importance of this way of working for good practice. These models had been an important part of the NDIS in trial and early roll-out sites (Meltzer et al, 2016a). In this project, some providers expressed concern that the models might be diminished under the NDIS, as families might choose to spend their funds on separate therapists whose approaches might not be coordinated:

> That concerns me that that team around the child will not be as effective [under the NDIS] as I think it is now… I think we miss out when everyone's not on the same page.

One provider suggested that families and referral sources such as paediatricians receive more information about the key worker in a trans-disciplinary team model so they understand it better.

On the other hand, one mainstream provider and her colleagues had the perception that the key worker model appeared to shift emphasis away from early intervention. They believe key workers were generally not qualified to undertake ongoing assessments or to put appropriate therapies in place. As a result, these providers had observed that some children under the NDIS were missing out on essential early intervention therapy:

> … we're seeing children again for assessment after 12 months of intervention and there's been no movement because they're not getting what they need. It's pretty devastating.

The providers believed this was because parents had not received enough information during their NDIS planning process about the role of the key worker in a trans-disciplinary approach. As a solution, providers felt more rigour was needed in the planning process. For example, if a child received an autism spectrum diagnosis, parents needed to be informed about what services to engage, how to prioritise interventions and what reasonable outcomes could be expected in which timeframe. The interviewees suggested health professionals perform this role; if NDIS planners were to, they would need more training.

In the service provider survey, responses to relevant questions shifted between Round 1 and Round 2, as ECI providers in NDIS areas observed increased and better-quality collaboration in the sector. During second-round interviews, service providers highlighted the need for the NDIA to fund collaborative practice between NDIS and ECI provider organisations. In the meantime, providers had developed mechanisms of their own, at their own expense and on unpaid time. These mechanisms included network meetings, regular forums and e-mail lists.

4.1.4 Providing services to all children who need them

Service providers saw the ECEI approach as an important way of maintaining good practice under the NDIS as it enabled them to continue to provide services to children who did not yet have a diagnosis, who were waiting for confirmation of their NDIS eligibility or who would not receive an NDIS package. By the second interview round, providers were concerned about how the new EC Partners chosen through the tender at the end of 2017 would service families appropriately, especially if they were not local providers.

Providers in both the interviews and surveys expressed frustration about lengthy wait times for families to get NDIS approval, without these families having sufficient access to interim funding. Organisations were reluctant to reject families who did not have funding. Instead they spent some unfunded time with those families and referred them to other services. A common provider statement was:

> We wouldn't just leave someone hanging, particularly if they are distressed.

One service provider in the second interview criticised this approach:

> Some services are providing work for free to fill the gap, and I think that’s a mistake. I think you have to expose the gap so that you can then say to the NDIS this is a problem, and it’s going to be a massive problem unless you implement something.

That provider said they had developed a system of prioritising families and working with an early linker to help families access other support while they were waiting for their plan. One provider mentioned that they believed the NDIA was considering an emergency fund plan for children with hearing loss, to enable essential early intervention until NDIS packages were approved. Others relied on existing partnerships with community organisations to fill gaps in service provision for children who were not eligible for an NDIS package.

Many of the providers were used to working with families from various backgrounds, including culturally and linguistically diverse, Aboriginal and Torres Strait Islander, and socio-economically disadvantaged families. Several providers in both interview rounds mentioned that transitioning to the NDIS added time in translating, interpreting and explaining the new processes to the families, especially since information material sent by the NDIS often appeared complex, contained jargon and was not always presented in culturally appropriate formats. One provider was concerned that the selection of Early Childhood Partners might result in families disengaging from the system if the organisation was not familiar to them or not specific enough to their culture and needs. Concern for families from different cultural backgrounds and with complex needs was a main topic of comments in the second-round service provider survey.

Providers managed additional needs of families by, for example, supporting them with making phone calls to the NDIA. Several said they provided ongoing advocacy for families with the NDIA. In the second round, one provider mentioned the need for interpreters, which were not covered by the NDIS:

> We’re still having difficulties getting NDIS to recognise that interpreters are really important. It does seem something that we’ve had to cover the cost of, and therefore we’ve cut back on it, and that’s very poor practice, really.

Another provider in the second interview round was concerned that families with complex needs were losing out under the NDIS, partly due to lack of funding for dedicated family workers who could provide specialist service coordination and support. As a consequence, families might miss therapy sessions, which disadvantaged the child further; and families might miss their NDIS planning meetings, putting future support at risk. At the time of the interview, the provider was covering the cost of family workers while lobbying the NDIA to step in.

The quantitative survey findings reinforce the impressions from the interviews. Overall, the responses suggest that it has become easier between Rounds 1 and 2 to provide support for children with an NDIS individualised package. However, the responses in Round 2 suggest that it has become harder than at the time of Round 1 to support children:

- accessing ECEI funding only
- not accessing NDIS but who will be eligible

- who are not eligible for the NDIS
- from culturally and linguistically diverse communities
- from Aboriginal and Torres Strait Islander backgrounds
- with complex needs
- in families at risk.

4.2 Ensuring innovation and sustainability

Almost all service providers in the interviews, whether they were already in the NDIS or not, reported that they had been involved in internal change and innovation processes for some time, and that they expected these processes to continue for years until the NDIS was well established. All service providers expressed concern about the sustainability of their organisation – some more than others – without any change in concern between the two interview rounds. The main issues providers mentioned and the solutions they proposed are summarised in this section. Relevant survey questions were answered by a small number of respondents (16 or 17 in Round 1 and 29 in Round 2), and the findings are reported in Appendix B.

Providers acknowledged that larger organisations were generally better placed than smaller ones to adapt to change because they had greater financial scope. Other differences in capacity to adapt might relate to the types of services offered: some providers felt those in niche markets, for example for particular disabilities, might do better than generalist providers; and some had experienced that ECEI transition providers might have an advantage over other providers because new families who were coming into the system built a relationship first with their ECEI transition provider and were then less likely to buy services from a competitor.

4.2.1 Innovation: Operational change management

Providers observed significant changes in tasks and workload since they started preparing for the NDIS. For example, they needed to set up new administrative and financial systems to process individual family payments and keep service records; they learnt to write NDIS plans for families; and they tried to keep up-to-date with the rapid development of the NDIS.

These activities were in addition to regular, ongoing service provision, leading to increases in the workload for many staff. In a few extreme cases, providers said ‘our workload has doubled’ or ‘we are all drop-dead exhausted’. These statements are mirrored in the survey findings, with observed increases in workload between Rounds 1 and 2: 44% of respondents in Round 1 and 64% in Round 2 reported that their workload had increased ‘a lot’, 33% and 28% respectively that it had increased ‘somewhat’, while 22% and 5% reported ‘no change’.

Several participants in both interview rounds found it difficult to prepare due to uncertainties about the NDIS. They expressed frustration with inconsistent, late or insufficient information from the NDIA. Some were not sure about how many staff members to retain or whether to employ more, because future income streams were uncertain. Generally, providers expressed change fatigue across their organisations after years of ongoing transition processes, and a need to support staff who had experienced distress, exhaustion or feelings of helplessness. Where change processes worked well, providers often said their organisation had good leadership:

> We have a very supportive management team… they have invested into helping with change management for the past two years… I believe that's helped staff to be able to change, to be a little bit more flexible.

Several service providers in the interviews had modified staff roles, upskilled their staff or recruited new staff, including managers, administrators, finance staff, therapists and other child support workers. Larger organisations were generally at an advantage compared to smaller ones due to their higher financial capacity. One person said they had difficulty attracting new staff because people were not changing jobs due to uncertainty in the sector. Several survey respondents, in both rounds, mentioned a general shortage of qualified, experienced therapists. An interview participant assumed this was because the NDIS had created employment opportunities across allied health services.

Those who were not expanding hoped that high workloads during the transition phase would reduce once the NDIS was in place. In the survey, 37% of respondents in Round 1, and 52% in Round 2, indicated an increase in staff numbers since the NDIS started in their area, but most of the others reported no change so far.

Providers usually said they had invested in extensive and ongoing staff training. Interviewees mentioned internal administration training for all staff, and managers sharing information from NDIA sessions. Some providers sent staff to external training and conferences. Providers from rural areas suggested, in both interview rounds, that the NDIA organise more training in smaller towns to make it easier for providers to attend or subsidise their travel to information sessions in larger centres.

Several providers had introduced new software for case, time and financial management, which they said was more efficient than previous systems and allowed staff to work more flexibly and from home.

Some said they had found that cooperating with similar organisations had helped them manage the transition. One partnership of five ECI providers had existed before but had been strengthened since preparation for the NDIS started. Another model involved six organisations in one geographical area who, in the lead up to the NDIS, had been funded by the local ADHC office to develop NDIS-style planning and administrative processes and thereby prepared both families and providers for the roll-out. The provider found this program extremely helpful and felt well prepared for the NDIS.

Of the few ECI providers who answered relevant survey questions, the majority of Round 1 respondents reported no change to the amount or quality of collaboration, whereas in Round 2, most respondents observed more or better-quality collaboration, or no change.

4.2.2 Sustainability: Adapting to the new business model

All providers in the interviews had some concern about their organisation’s sustainability under the NDIS. Smaller providers generally felt more vulnerable than larger ones. Some non-ECEI transition providers were worried about maintaining client numbers when they would not be the first point of contact for new families in the NDIS. Some observed increased competition in the sector. The challenge for everyone was to get a sufficient number of NDIS families to remain sustainable. Many struggled with ongoing funding uncertainty as the NDIS was progressively rolled out and permanent ECEI models were being established. However, all accepted that they needed to work under a new business model, and they reported using various strategies to adapt and remain financially viable, including:

- employing therapists for the first time, or employing more therapists, to gain a prospective income stream under the NDIS
- streamlining administrative systems and operations to reduce cost, e.g. using the client record management system for workforce and travel planning; or documenting therapy work together with the family as part of a session
- assigning particular staff to NDIS planning to build expertise and increase efficiency
- putting aside contingency funds for employing additional staff if and when needed
- adapting to the new service model by reducing staff numbers and service provision
- offering new types of programs that are evidence-based, e.g. a 'social skills group'
- introducing or enhancing marketing, e.g. providers were advertising in the local paper and distributing brochures in schools and doctors' surgeries; for some this was new, for example 'We've never had to address the marketing… because there's always been waiting lists'; another provider said their marketing had already been successful and increased their profile in their town
- increasing the number of weeks of service provision per year, in one case from 40 to 44 weeks; this not only improved financial viability but also made it easier for the provider to recruit new therapists and teachers
- diversifying the business, e.g. buying and selling real estate, and broadening the geographical area in which the provider operated
- applying for grants, or partnering with larger organisations on grants in order to provide the ECI component of a funded program
- providing services to families at reduced or no cost during the gap between previous funding and NDIS; one provider said they had been financially carrying 85% of the families to continue with the child's therapy until their NDIS package came through.

Many of these strategies involved substantial financial investment, which was an option only for larger providers. Most of those who used the strategies reported financial strain to their organisation.

Some providers made suggestions for how the NDIA could address sustainability issues. Small organisations and those in remote areas said they needed support with travel and overhead costs. Several interviewees and survey respondents felt the NDIA could work more in partnership with them to support a sustainable, diversified provider network, e.g. referring to smaller and bigger providers equitably, or agreeing on reference packages with fixed amounts for certain support needs rather than variable, itemised funding.

4.3 Interfacing with mainstream services

According to the providers, relationships between the ECI sector and mainstream services were unsettled and in a state of flux in transition to the NDIS. Providers spoke about changes in referrals from mainstream services, and in their contacts and collaboration with schools, ECEC settings, medical practitioners and child protection agencies.

4.3.1 Referrals from mainstream services

Referral experiences varied among the providers who participated in interviews, with some feeling that referral pathways were similar to before the transition to the NDIS started and some expressing confusion about the current processes. Others had observed changes: for one ECI provider in the first interview round, ADHC's impending departure meant an established referral pathway had broken down and their vacancies had increased, while a mainstream health provider said they now received more referrals for assessments and had longer waiting lists. In the survey, a mainstream provider expressed uncertainty about how to ensure their organisation made referrals equitably to a range of ECI service providers.

In the second interview round, some providers talked about an increase in referrals over the last few months, while another said referrals from traditional sources had practically dried up; this included direct phone calls from parents who were worried about their child and referrals from health providers, including hospitals, especially for babies and toddlers. The provider assumed the latter issue was because hospitals had set themselves up as NDIS partners and were referring to their own clinics.

Providers spoke about how they dealt with changes in referral patterns. Several had increased their marketing efforts. Another provider had used alternate funding sources by becoming a registered Medicare provider:

> Children that aren't being picked up by the NDIS or they might get picked up at some point but haven't had anything for at least 18 months, at least we can provide something to them under Medicare funding.

One organisation said they had created 'information and referral packages' for mainstream providers, with a handbook about the NDIS and the role that ECI services could play. In general, providing information to the community and to mainstream services was one of the roles of the ECEI transition providers.

The interviews indicated that referral issues may vary among different types of providers as the NDIS is established. For example, a provider of ECI services for children with hearing loss, who was also an ECEI transition provider, voiced concern that the ECEI approach might cause delays that could reduce the effectiveness of early intervention, such as a baby receiving a cochlear implant (if the parents wanted the operation) much later than medically advised. The provider said they had lobbied the NDIA to either retain existing referral pathways for hearing loss that went directly from diagnosis to treatment options, to create accelerated pathways, or to provide emergency funds for early surgery if the family wanted it:

> There are a number of different sorts of solutions, but they all involve the fact that the families get to us super quickly without being held up in bureaucracy.

Providers in the interviews had observed few changes in referrals back to mainstream services. A few talked about linking families with services in their local area while they were waiting for their

NDIS plan. In the survey, few respondents answered questions about referrals to other services since the NDIS started in their area. Most said referrals were ‘hard’ or ‘neither easy nor hard’.

4.3.2 Collaboration between ECI and mainstream services

Many providers in the interviews had observed changes in their collaborative relationships with mainstream services, especially those from the education, health and child protection sectors. Staff from the provider organisations said they had no funding to visit mainstream settings and to provide case management for families. They were worried that networking, collaboration and informal exchanges would suffer. On the other hand, the providers acknowledged the need to maintain communication with mainstream settings under the NDIS, to ensure effective service provision and community inclusion of children with disability.

Interviewees observed that many mainstream services were not well informed about the NDIS. Some responded to requests from schools, preschools or hospitals to give presentations about the NDIS to staff and parents, which was also part of the role of the ECEI transition providers. One provider said these requests had increased between the first and second interview rounds. Many providers had proactively prepared written information about the NDIS that they distributed in schools and doctors’ surgeries. ECEI transition providers felt that traditional medical models of early childhood intervention were still dominant among mainstream services, which created tension with the best-practice NDIS approach that they advocated, including the key worker in a trans-disciplinary team model (section 4.1.3).

In the Round 2 survey, ECI providers in NDIS areas observed increased and better-quality collaboration in the sector compared to the Round 1 survey. Providers considered their continued engagement with mainstream services important but said it put additional strain on their resources. One provider suggested that governments, or health or educational peak bodies, take responsibility for informing mainstream providers about the NDIS and the current good practice approaches in early childhood intervention.

Apart from informing mainstream services about the NDIS, the second collaboration issue that many ECI providers talked about was negotiating access of therapists to educational settings according to good practice guidelines. Several providers described how they talked with school principals or ECEC services to facilitate therapists or key workers to either provide inclusive support in the classroom or work with the child somewhere else on school grounds. By the second interview round, schools had received guidelines from the Department of Education that clearly identified what was required of external providers to deliver services on school grounds. Providers acknowledged this was work still in progress, as the needs of the school, the service provider, the children and their families all had to be reconciled:

> This is where choice and control [for families] is problematic because … the principal needs to be on board, it needs to be a reasonable time, we need to be able to get there.

More fundamentally, one provider felt that more advocacy for inclusion was needed:

> What I would like is for the federal government to start working with mainstream organisations and doing much more campaigning about inclusion and about society being welcoming for everybody.

4.4 Summary of service provider experiences

The transition experiences of service providers were also widely variable. In general, large organisations appeared to cope better with adapting to the new NDIS environment than smaller organisations, due to differences in financial and organisational capacity. Providers in regional and rural areas often mentioned additional difficulties in accessing information and training about the NDIS and incorporating travel times into their pricing structure. Interviewees were complimentary about Transition Advisors, whom they found approachable and supportive.

By the second round of data collection, transition processes had advanced, and some providers had developed mechanisms for managing increased referral numbers and adapting staff roles and work practices to NDIS requirements.

The adaptation issues that providers mentioned fell into two categories: some were transitional issues, which occur as service providers move over to the NDIS and which are likely to resolve once the NDIS is well established; others were systemic issues, which are embedded in the new NDIS environment and will likely remain unless they are addressed.

The transitional issues are:

- higher workloads due to NDIS plan writing and implementation of operational changes (administration, record keeping, software) without compensation
- insufficient, inconsistent and changeable information from NDIA makes operational change and business planning difficult.

The systemic issues are:

- establishing safeguards to ensure continuation and enhancement of good practice
- ensuring adequate funding mechanisms to cover travel time; NDIS policy has since changed to address this issue, and the impact of these changes needs to be monitored
- supporting collaborative practice in the sector and with mainstream services
- improving support for inclusive mainstream services
- managing higher ongoing administrative load and cost, which is more problematic for small organisations than bigger ones due to reduced overall financial capacity
- ensuring sustainable and varied service types across the state, including in rural and remote areas
- supporting workforce availability and capacity, e.g. addressing a shortage of qualified, experienced therapists, especially outside metropolitan areas.

This research indicates that both types of issues could be addressed by NDIA. The Agency could provide infrastructure and investment to manage supply and demand of ECI services, monitor service quality and enhance workforce capacity, to enable a smoother transition process for providers as well as a varied service network over time.

5. Implications for NDIS transition and ECI service provision

This project found a wide range of experiences among both families and service providers regarding preparations for the NDIS and their first experiences while in the Scheme. There was modest change from Round 1 to Round 2 of data collection. Many families continued to experience delays and communication issues in transitioning to the NDIS, especially disadvantaged families. Service providers had advanced in their adaptation to NDIS processes, while systemic issues remained. This section includes implications of the findings, structured according to the research questions. These implications are included in the Executive Summary.

It appears that NDIA processes were variable and might lead to inequitable Individual Funding Package funding and service provision among families. Any delay in funding allocation seemed particularly problematic in the context of early childhood as it put the efficacy of potential early intervention in question, thereby risking higher support need in the long term.

Transition for children and families

The implications are that NDIA might consider modifications that lead to timely, consistent and equitable support for families during their transition process, including:

- provide families with independent information and preparatory support about the NDIS that is easily accessible and culturally appropriate
- consider especially the additional requirements of families from Aboriginal and diverse language backgrounds, and of families who are socio-economically disadvantaged or have complex needs – provide funding for, e.g., case managers, family workers and interpreters
- consider funding support for family members, e.g. counselling and respite for parents and siblings
- develop more formalised information and preparation resources for families and service providers across the state, including in all regional and rural areas, e.g. a knowledge pathway and funding for peer support
- always offer respectful formats for NDIS planning meetings that consider families' needs regarding time, location, cultural and communication preferences
- inform families about the progress of their NDIS application in real time and maintain ways for families to proactively seek updates rather than wait for NDIA contact
- work with families and service providers to manage gaps in funding while waiting for the NDIS, or to find alternative sources of support
- provide families with NDIA planners and staff who have adequate and consistent expertise in early childhood development and disability
- once in the NDIS, support families to exercise choice by providing more information about appropriate therapies and supports for their child – this could come from well-informed planners or from health professionals

- address any delays in children accessing timely ECI supports – before, during and after their transition to the NDIS

- give families and service providers opportunities for feedback to NDIA if any aspect of the transition process is inadequate.

Good practice for children and families

The implications are that providers might attempt to:

- build family capacity – to navigate the NDIS system and take over unfunded tasks (e.g. sourcing equipment)
- implement innovative travel solutions – e.g. service brokerage, satellite offices or working from home
- adapt mechanisms for staff communication and collaborative practice – e.g. core office days or online apps
- facilitate ongoing social connections for parents, e.g. through providing supported playgroup spaces, parenting classes and parent support groups
- bridge funding gaps by tapping into a diversity of services and funding sources and lobbying NDIA
- lobby NDIA to fund collaborative practice between ECI and mainstream providers.

Innovation and sustainability of ECI service types

Implications for NDIA:

- monitor whether access to client families differs between ECEI and non-ECEI transition providers
- recognise the additional challenges of change management for small providers and providers in non-metropolitan areas; for example, offer more NDIS training in rural and remote communities or subsidise provider travel to information sessions in larger centres
- offer ongoing opportunities for ECI and mainstream providers to give feedback and have input into NDIS design.

Implications for service providers:

- ensure good organisational leadership, which helps with change management
- consider changes in staffing and internal administrative processes, staff training, marketing and diversifying the business
- establish or foster local provider networks
- talk with families about managing changes in funded service types, e.g. how travel can be accommodated within packages.

Effective interface with mainstream services

- NDIA can monitor and, if necessary, adjust referral pathways to ensure efficient and timely early intervention

- NDIA can inform mainstream services about the NDIS, including ECI good practice guidelines such as trans-disciplinary approaches and inclusion, or liaise with sector peak bodies to disseminate such information
- NDIA can support collaborative practice between the ECI sector and mainstream services
- ECI providers can proactively inform mainstream services about NDIS and the ECI sector.

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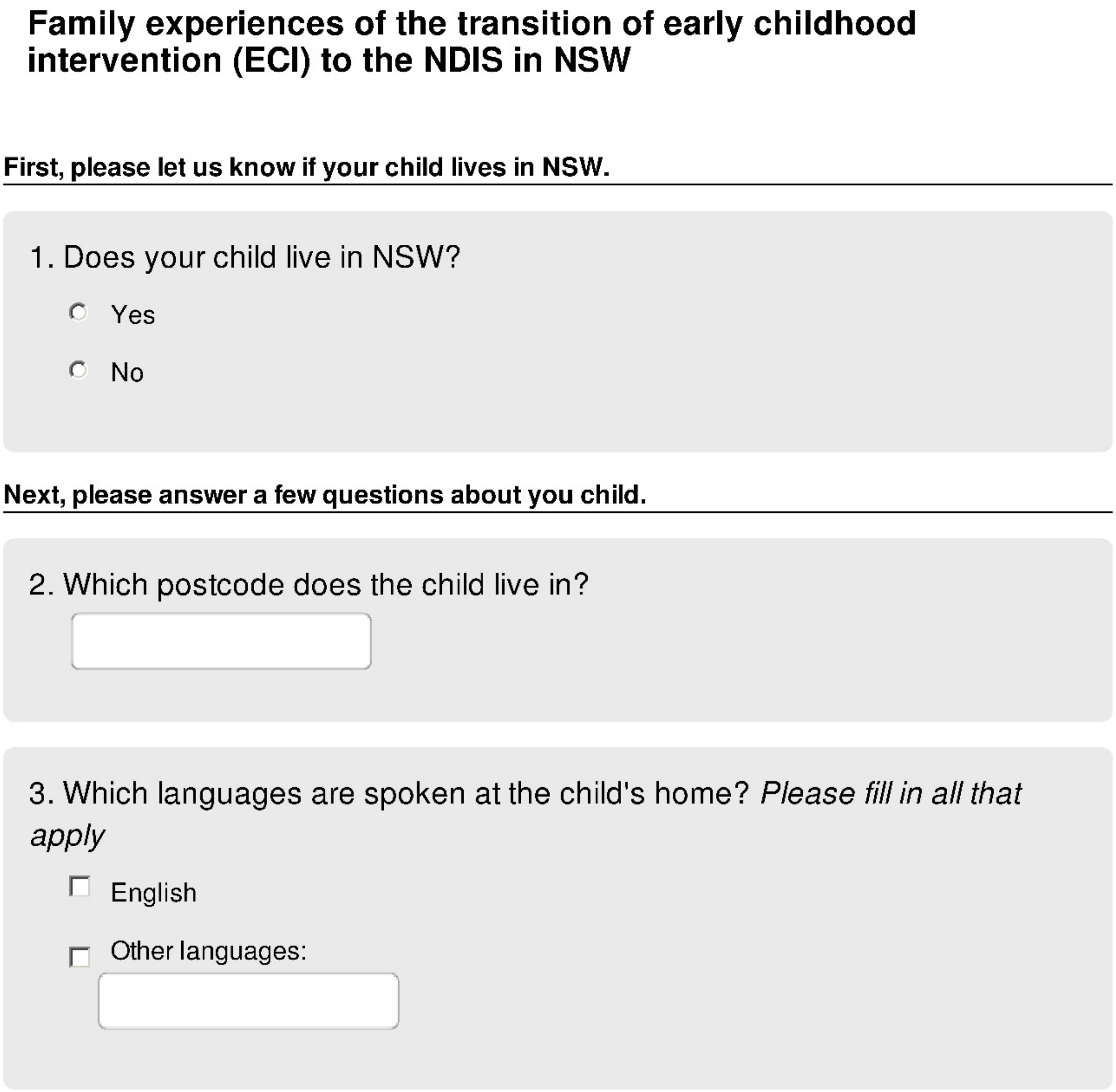
Appendix A Data collection tools

Surveys Round 1:



Family experiences of the transition of early childhood intervention (ECI) to the NDIS in NSW

First, please let us know if your child lives in NSW.

1. Does your child live in NSW?

○ Yes

○ No

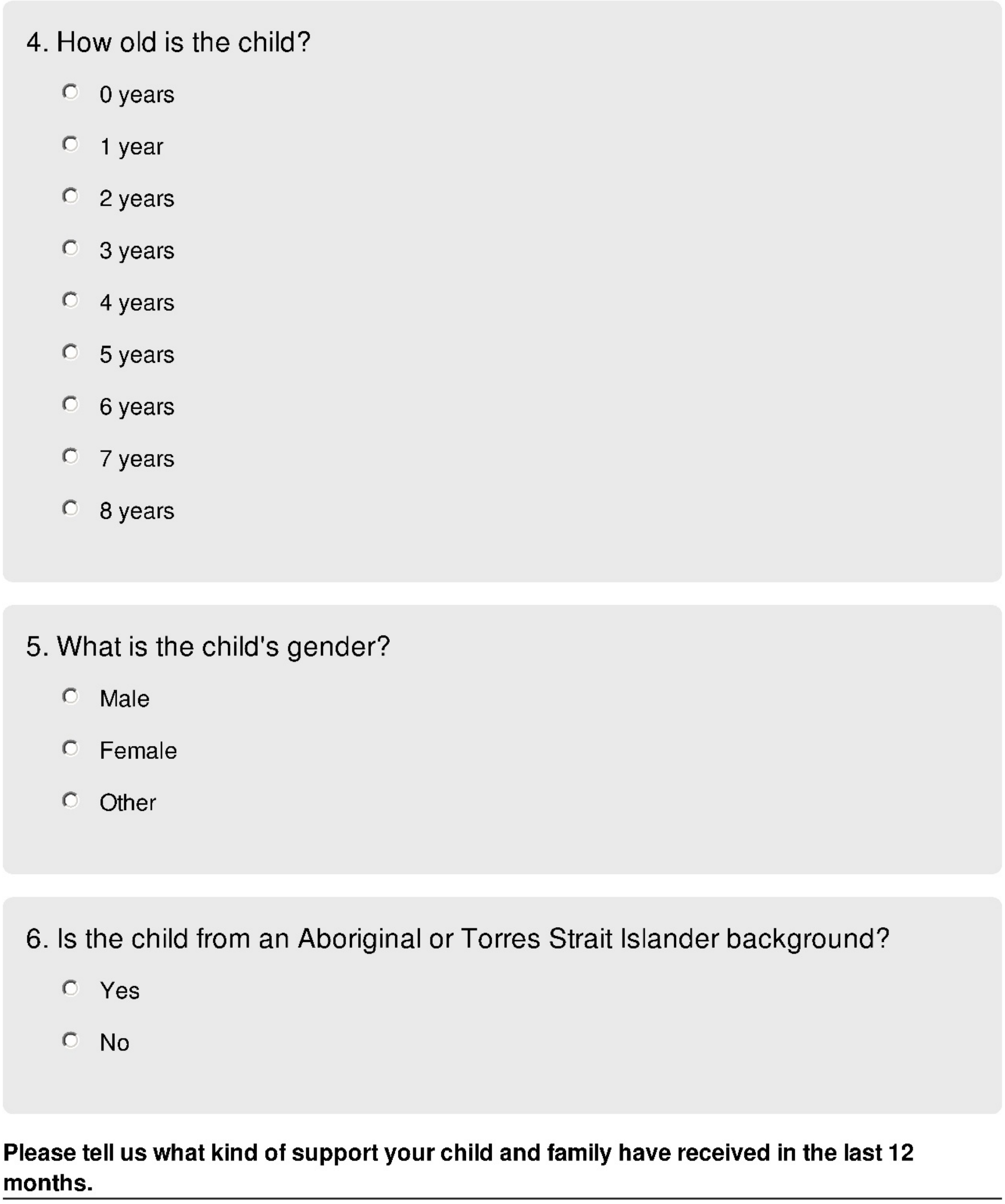
Next, please answer a few questions about you child.

2. Which postcode does the child live in?

3. Which languages are spoken at the child's home? *Please fill in all that apply*

☐ English

☐ Other languages:



4. How old is the child?

- ○ 0 years
- ○ 1 year
- ○ 2 years
- ○ 3 years
- ○ 4 years
- ○ 5 years
- ○ 6 years
- ○ 7 years
- ○ 8 years

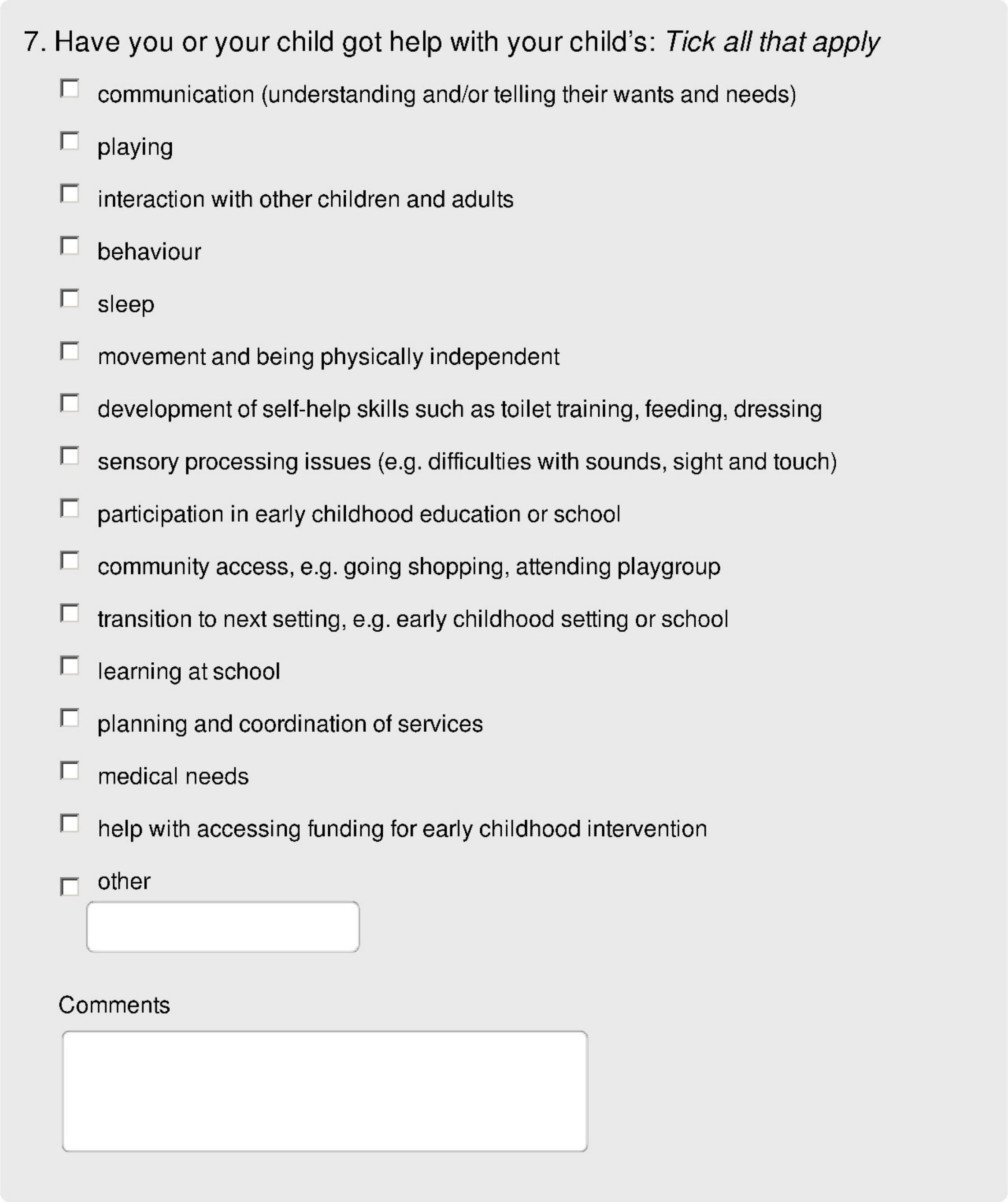
5. What is the child's gender?

- ○ Male
- ○ Female
- ○ Other

6. Is the child from an Aboriginal or Torres Strait Islander background?

- ○ Yes
- ○ No

Please tell us what kind of support your child and family have received in the last 12 months.



7. Have you or your child got help with your child's: *Tick all that apply*

☐ communication (understanding and/or telling their wants and needs)

☐ playing

☐ interaction with other children and adults

☐ behaviour

☐ sleep

☐ movement and being physically independent

☐ development of self-help skills such as toilet training, feeding, dressing

☐ sensory processing issues (e.g. difficulties with sounds, sight and touch)

☐ participation in early childhood education or school

☐ community access, e.g. going shopping, attending playgroup

☐ transition to next setting, e.g. early childhood setting or school

☐ learning at school

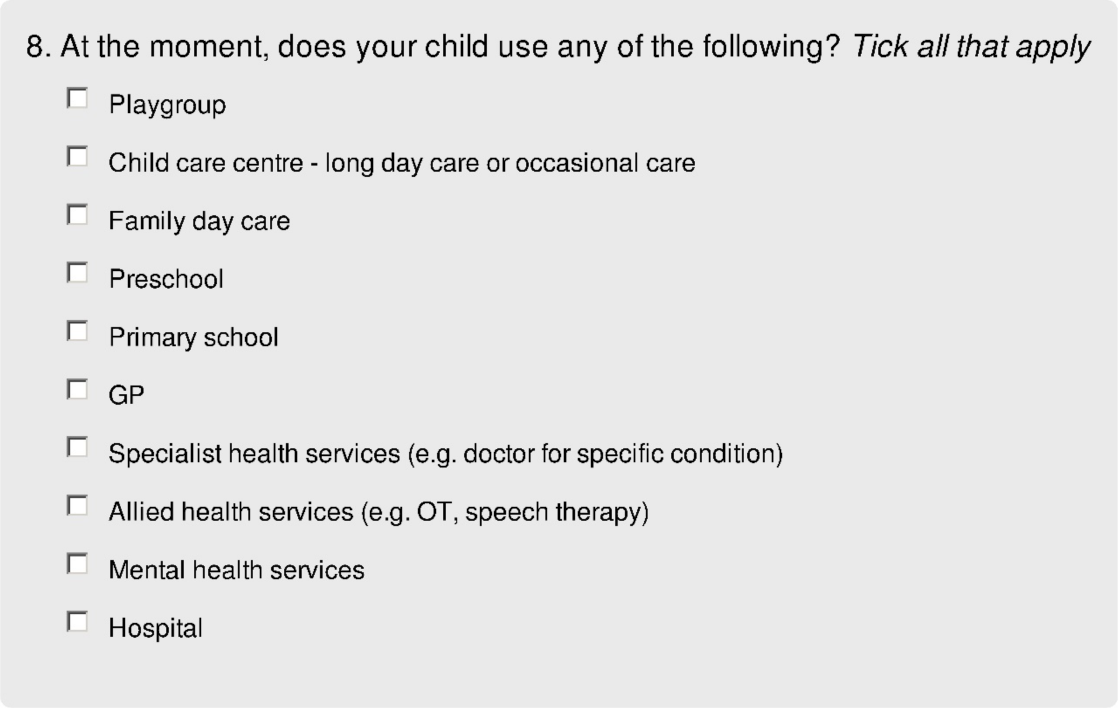
☐ planning and coordination of services

☐ medical needs

☐ help with accessing funding for early childhood intervention

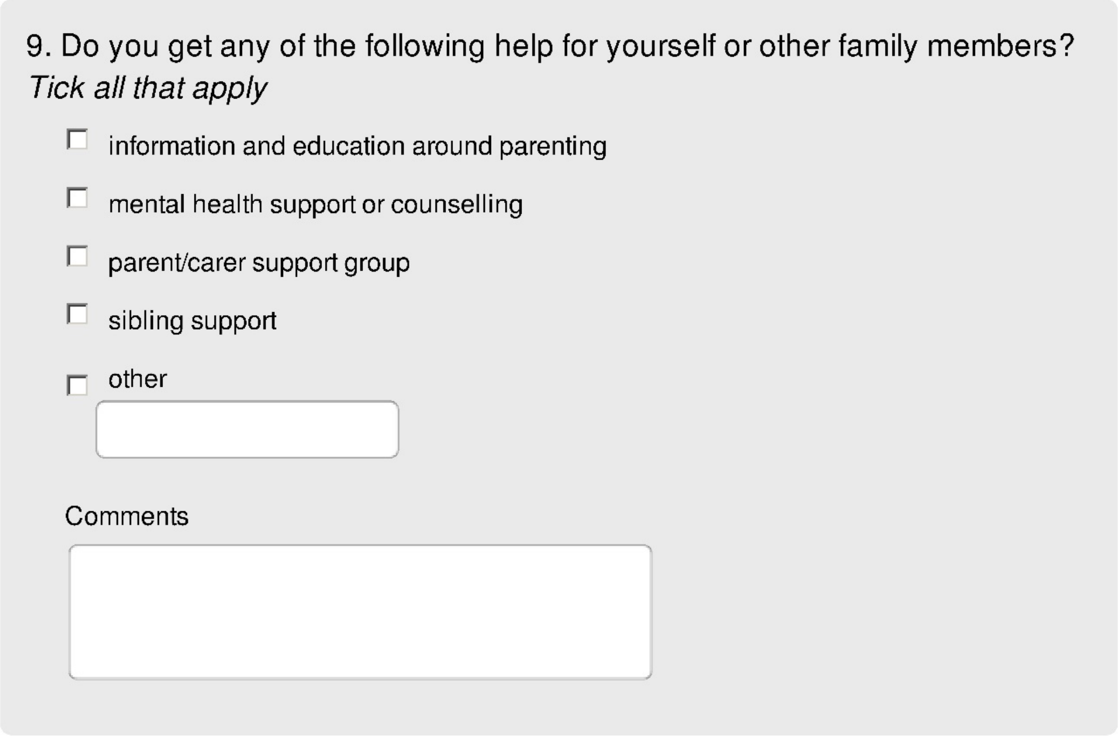
☐ other

Comments



8. At the moment, does your child use any of the following? *Tick all that apply*

- ☐ Playgroup
- ☐ Child care centre - long day care or occasional care
- ☐ Family day care
- ☐ Preschool
- ☐ Primary school
- ☐ GP
- ☐ Specialist health services (e.g. doctor for specific condition)
- ☐ Allied health services (e.g. OT, speech therapy)
- ☐ Mental health services
- ☐ Hospital



9. Do you get any of the following help for yourself or other family members? *Tick all that apply*

- ☐ information and education around parenting
- ☐ mental health support or counselling
- ☐ parent/carer support group
- ☐ sibling support
- ☐ other

Comments

10. Does your child need any support that he/she is not getting at the moment?

○ No

○ Yes - what support do you need?

Comments

The next questions are about any early intervention services you may use. Early intervention services are organisations or groups that help you with a young child's disability or with a concern about a young child's development.

---

11. Are you currently involved with early intervention services?

○ Yes

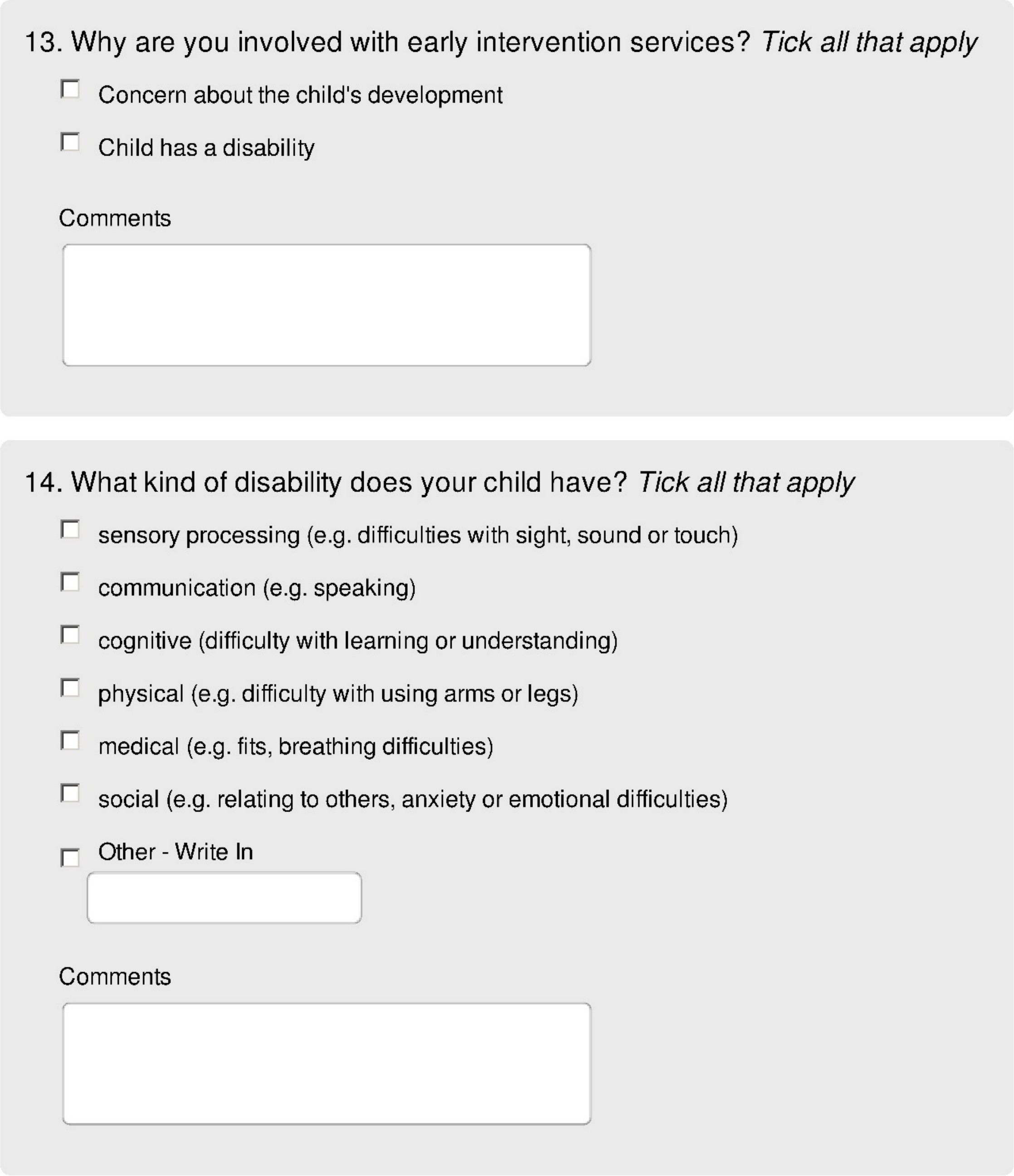
○ No

○ Not sure

12. How long have you been involved with early intervention services?

Months

Years



13. Why are you involved with early intervention services? *Tick all that apply*

☐ Concern about the child's development

☐ Child has a disability

Comments

14. What kind of disability does your child have? *Tick all that apply*

☐ sensory processing (e.g. difficulties with sight, sound or touch)

☐ communication (e.g. speaking)

☐ cognitive (difficulty with learning or understanding)

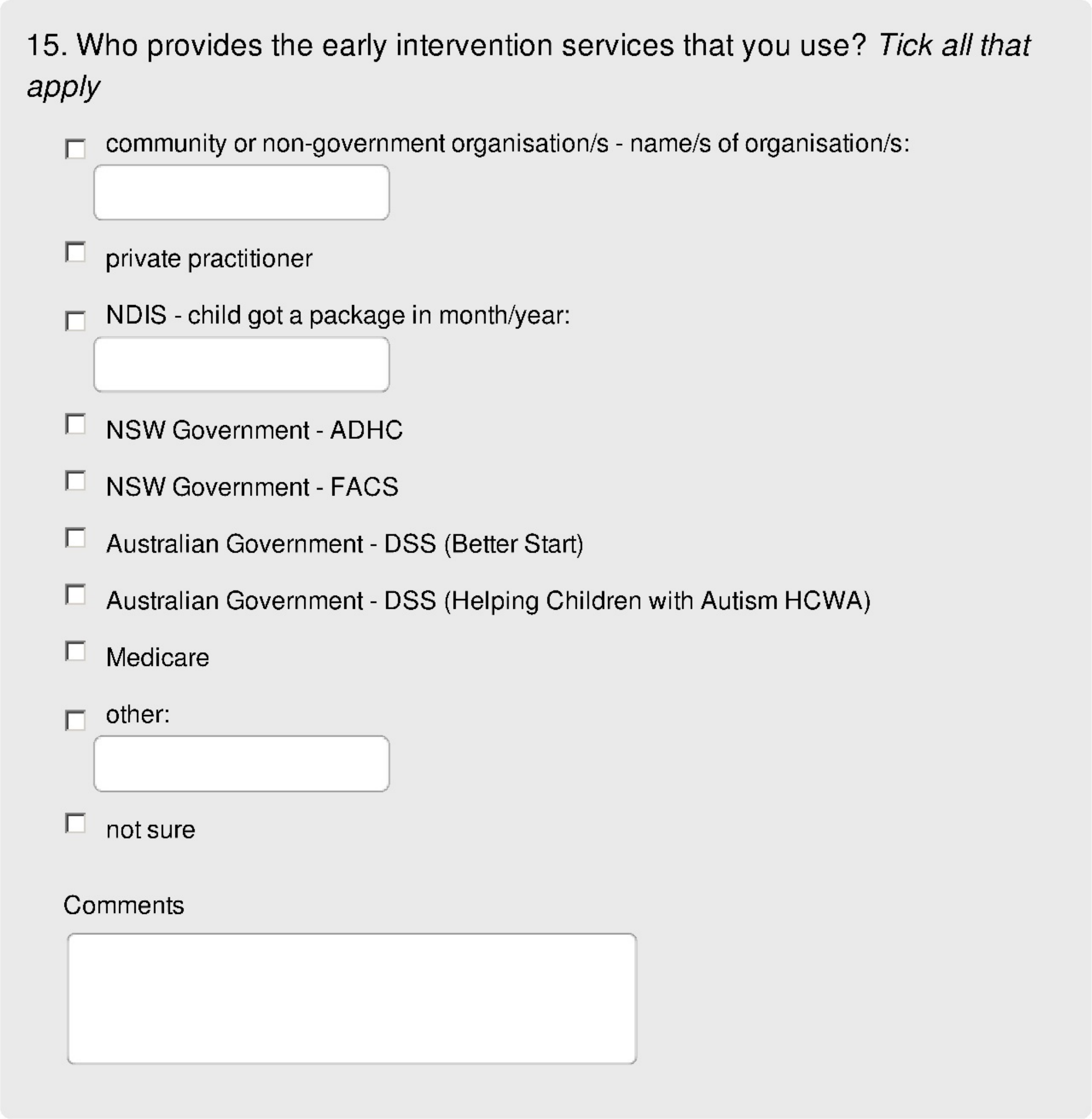
☐ physical (e.g. difficulty with using arms or legs)

☐ medical (e.g. fits, breathing difficulties)

☐ social (e.g. relating to others, anxiety or emotional difficulties)

☐ Other - Write In

Comments



15. Who provides the early intervention services that you use? *Tick all that apply*

- ☐ community or non-government organisation/s - name/s of organisation/s:
- ☐ private practitioner
- ☐ NDIS - child got a package in month/year:
- ☐ NSW Government - ADHC
- ☐ NSW Government - FACS
- ☐ Australian Government - DSS (Better Start)
- ☐ Australian Government - DSS (Helping Children with Autism HCWA)
- ☐ Medicare
- ☐ other:
- ☐ not sure

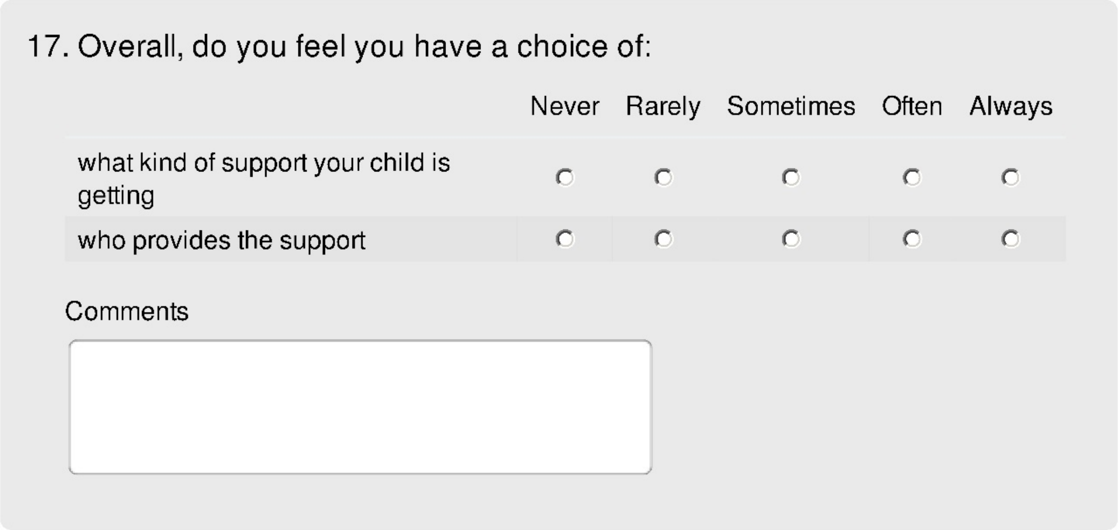
Comments

Please tell us about your experiences with the support you may be getting for your child and family.

16. Is information about support for your child's development:

	Never	Rarely	Sometimes	Often	Always
easy to find	○	○	○	○	○
easy to understand	○	○	○	○	○
helpful	○	○	○	○	○

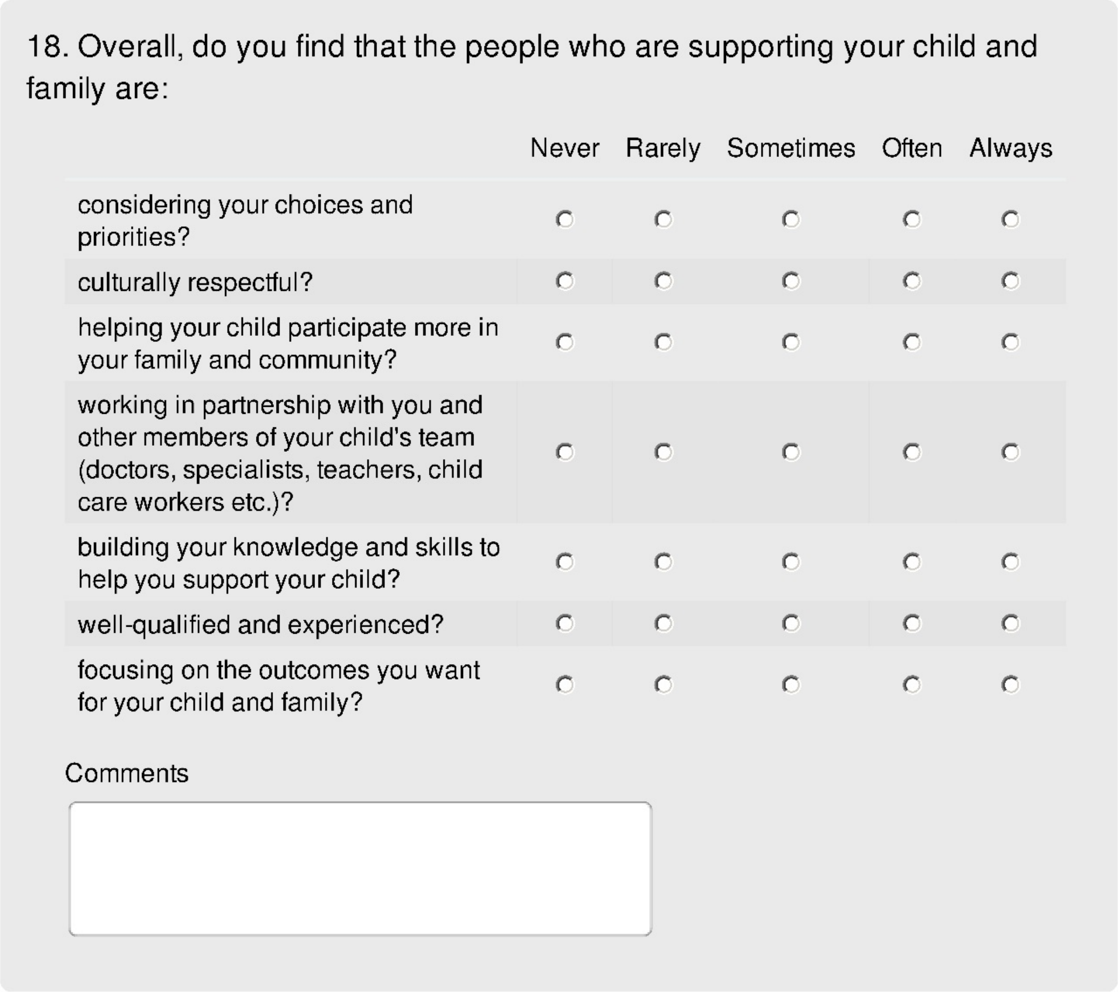
Comments



17. Overall, do you feel you have a choice of:

	Never	Rarely	Sometimes	Often	Always
what kind of support your child is getting	○	○	○	○	○
who provides the support	○	○	○	○	○

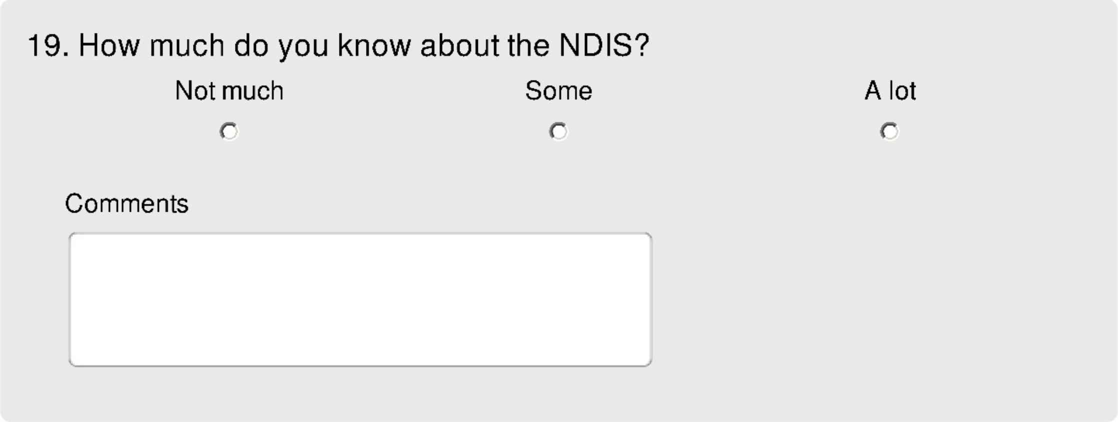
Comments



18. Overall, do you find that the people who are supporting your child and family are:

	Never	Rarely	Sometimes	Often	Always
considering your choices and priorities?	○	○	○	○	○
culturally respectful?	○	○	○	○	○
helping your child participate more in your family and community?	○	○	○	○	○
working in partnership with you and other members of your child's team (doctors, specialists, teachers, child care workers etc.)?	○	○	○	○	○
building your knowledge and skills to help you support your child?	○	○	○	○	○
well-qualified and experienced?	○	○	○	○	○
focusing on the outcomes you want for your child and family?	○	○	○	○	○

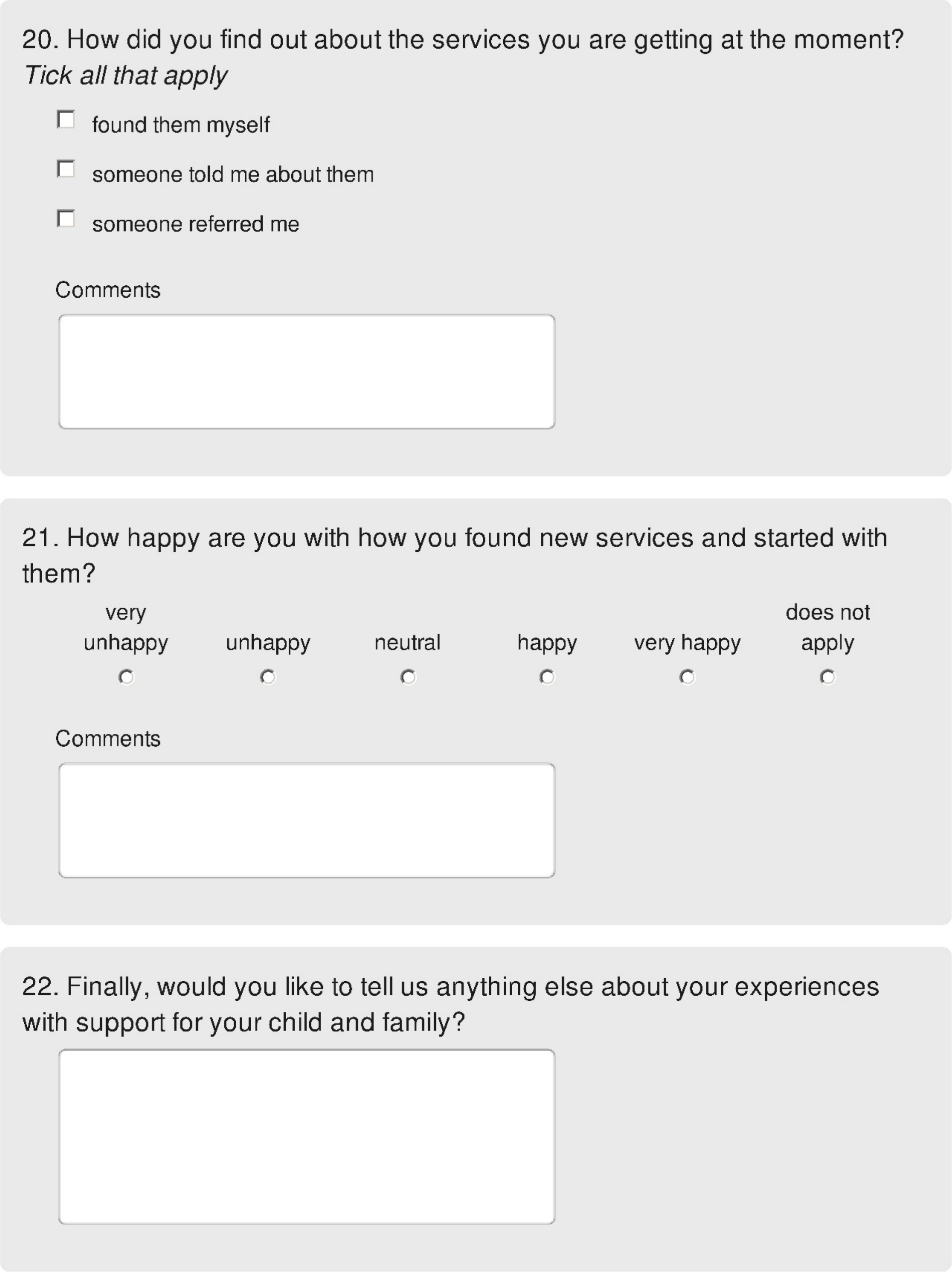
Comments



19. How much do you know about the NDIS?

Not much	Some	A lot
○	○	○

Comments



20. How did you find out about the services you are getting at the moment? *Tick all that apply*

- ☐ found them myself
- ☐ someone told me about them
- ☐ someone referred me

Comments

21. How happy are you with how you found new services and started with them?

very unhappy	unhappy	neutral	happy	very happy	does not apply
○	○	○	○	○	○

Comments

22. Finally, would you like to tell us anything else about your experiences with support for your child and family?

Service provider experiences of the transition of early childhood intervention (ECI) to the NDIS in NSW

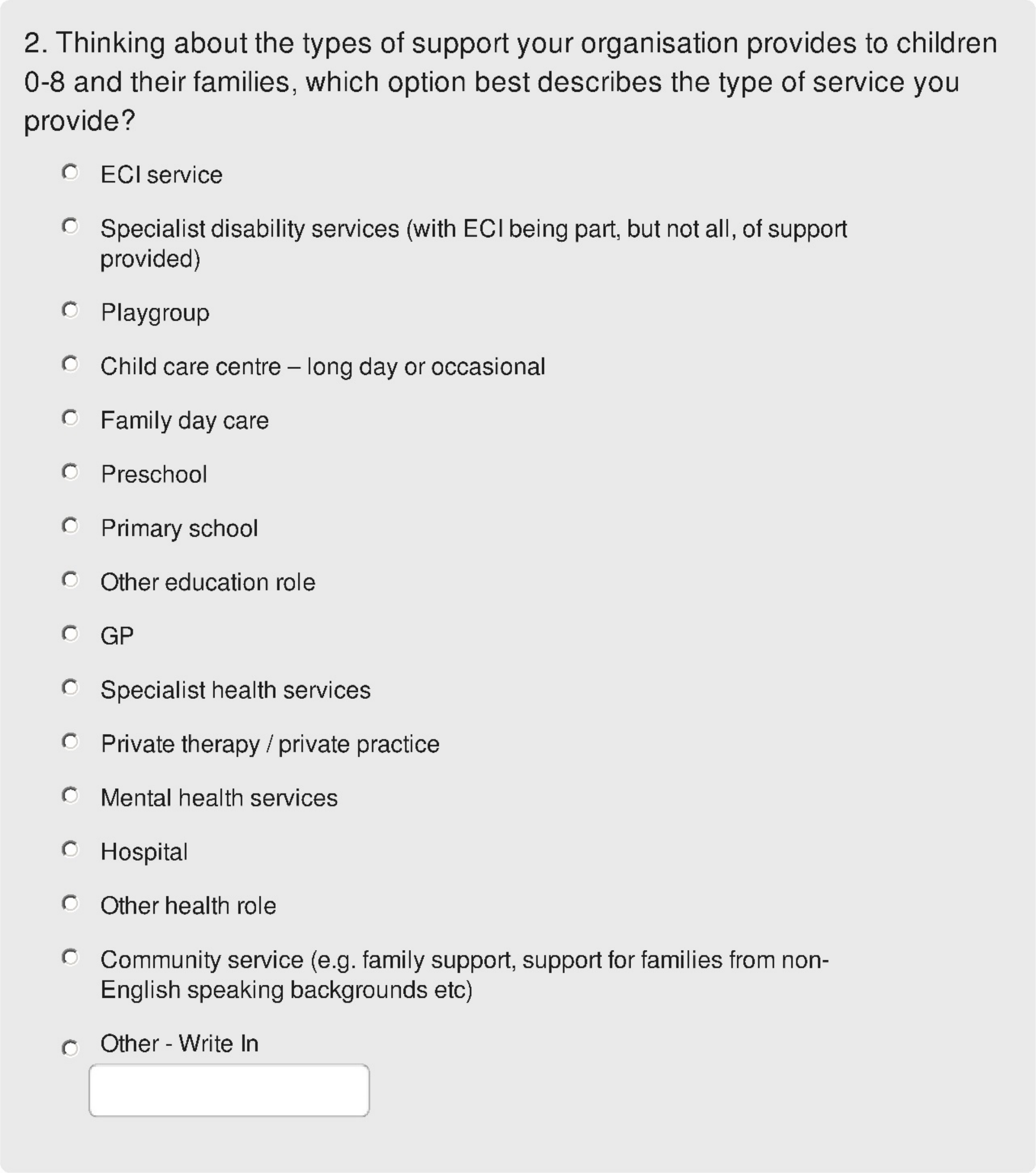
Location

1. Do you and your organisation you provide services to children and families in NSW?

○ Yes

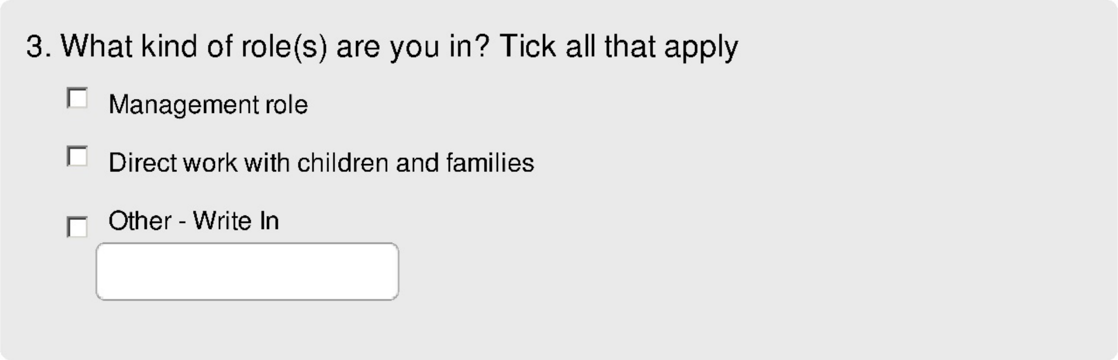
○ No

Questions about the organisation you work for



2. Thinking about the types of support your organisation provides to children 0-8 and their families, which option best describes the type of service you provide?

- ○ ECI service
- ○ Specialist disability services (with ECI being part, but not all, of support provided)
- ○ Playgroup
- ○ Child care centre – long day or occasional
- ○ Family day care
- ○ Preschool
- ○ Primary school
- ○ Other education role
- ○ GP
- ○ Specialist health services
- ○ Private therapy / private practice
- ○ Mental health services
- ○ Hospital
- ○ Other health role
- ○ Community service (e.g. family support, support for families from non-English speaking backgrounds etc)
- ○ Other - Write In

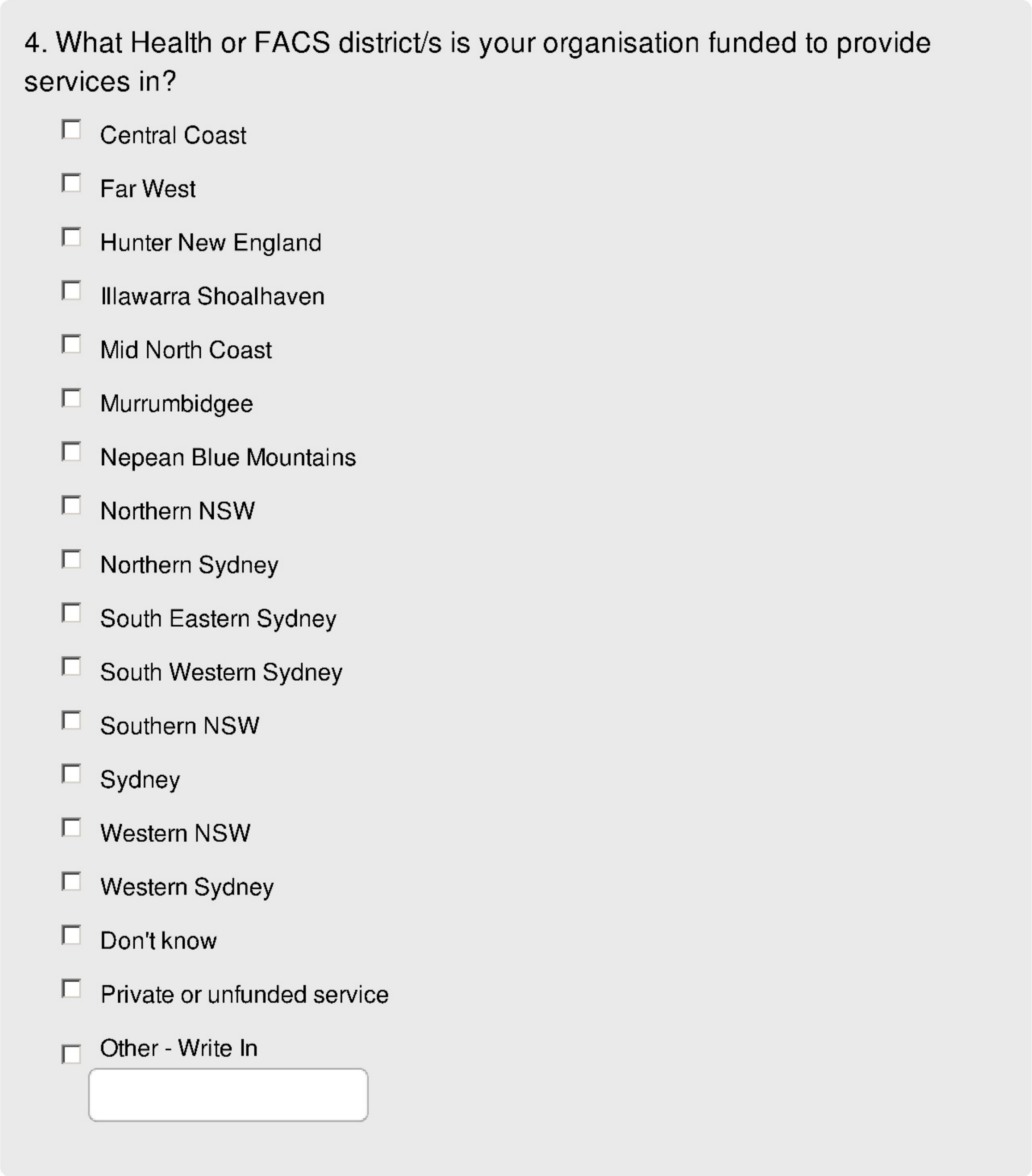


3. What kind of role(s) are you in? Tick all that apply

☐ Management role

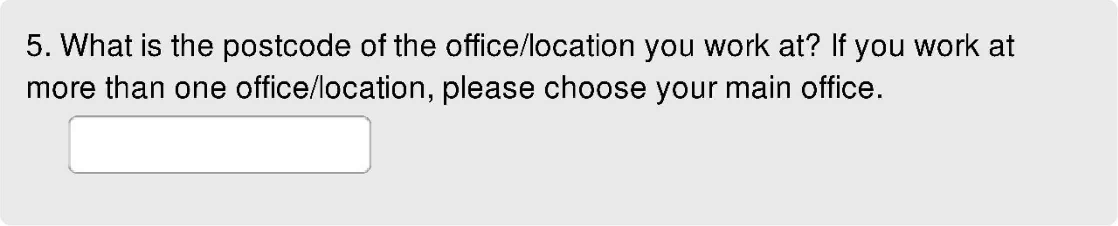
☐ Direct work with children and families

☐ Other - Write In



4. What Health or FACS district/s is your organisation funded to provide services in?

☐ Central Coast
☐ Far West
☐ Hunter New England
☐ Illawarra Shoalhaven
☐ Mid North Coast
☐ Murrumbidgee
☐ Nepean Blue Mountains
☐ Northern NSW
☐ Northern Sydney
☐ South Eastern Sydney
☐ South Western Sydney
☐ Southern NSW
☐ Sydney
☐ Western NSW
☐ Western Sydney
☐ Don't know
☐ Private or unfunded service
☐ Other - Write In



5. What is the postcode of the office/location you work at? If you work at more than one office/location, please choose your main office.

6. Are your Health/FACS area/s currently in the NDIS?

○ Yes - All areas we service

○ Yes - Some areas we service

○ Not yet

○ Not sure

7. Is your organisation currently providing services under the NDIS?

○ Yes

○ No

○ Not sure

8. When did your organisation start providing services under the NDIS?

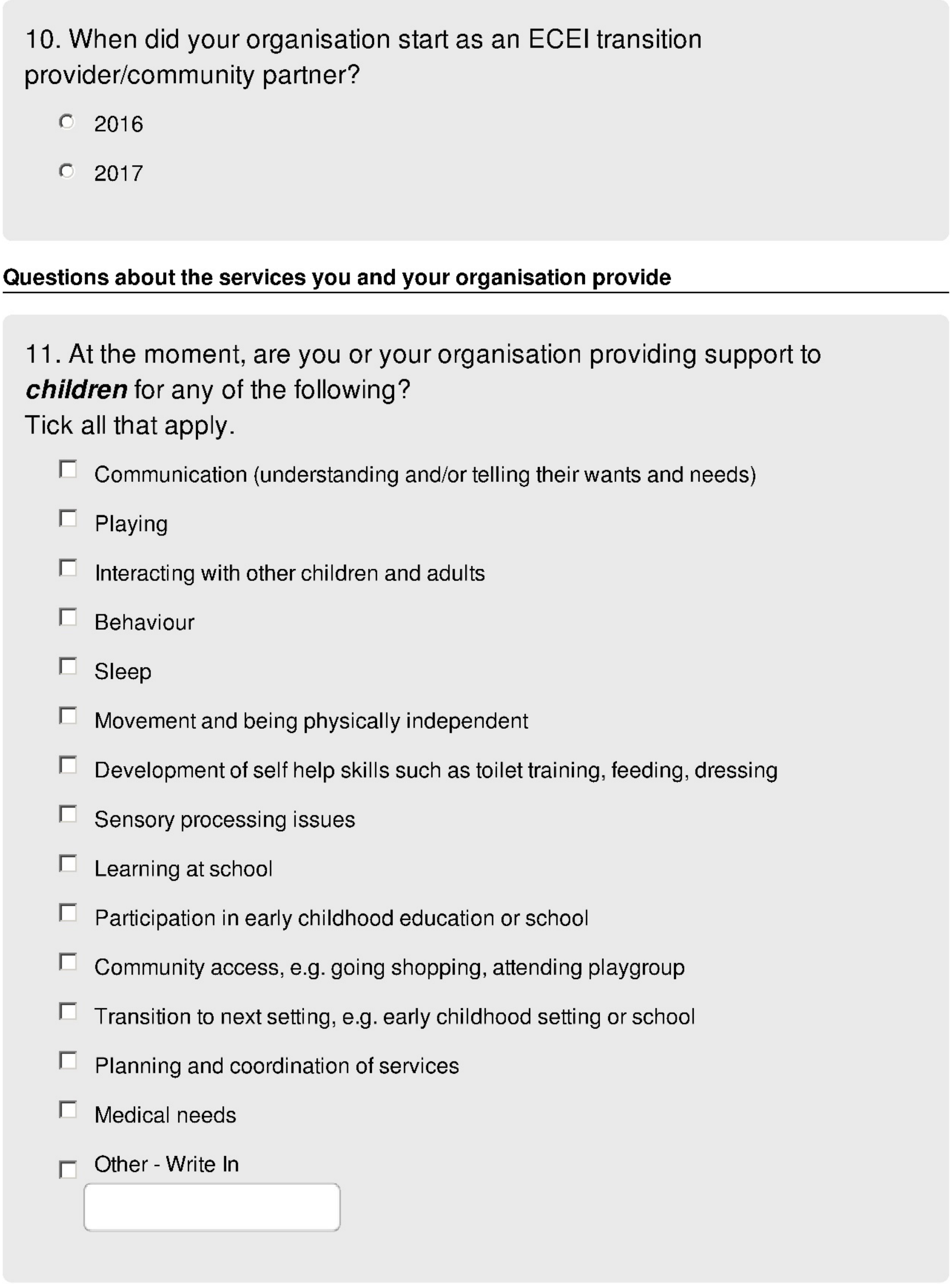
2015
2016
2017

9. Is your organisation an Early Childhood Early Intervention (ECEI) transition provider/community partner?

○ Yes

○ No

○ Not sure



10. When did your organisation start as an ECEI transition provider/community partner?

○ 2016

○ 2017

Questions about the services you and your organisation provide

11. At the moment, are you or your organisation providing support to ***children*** for any of the following?
Tick all that apply.

☐ Communication (understanding and/or telling their wants and needs)

☐ Playing

☐ Interacting with other children and adults

☐ Behaviour

☐ Sleep

☐ Movement and being physically independent

☐ Development of self help skills such as toilet training, feeding, dressing

☐ Sensory processing issues

☐ Learning at school

☐ Participation in early childhood education or school

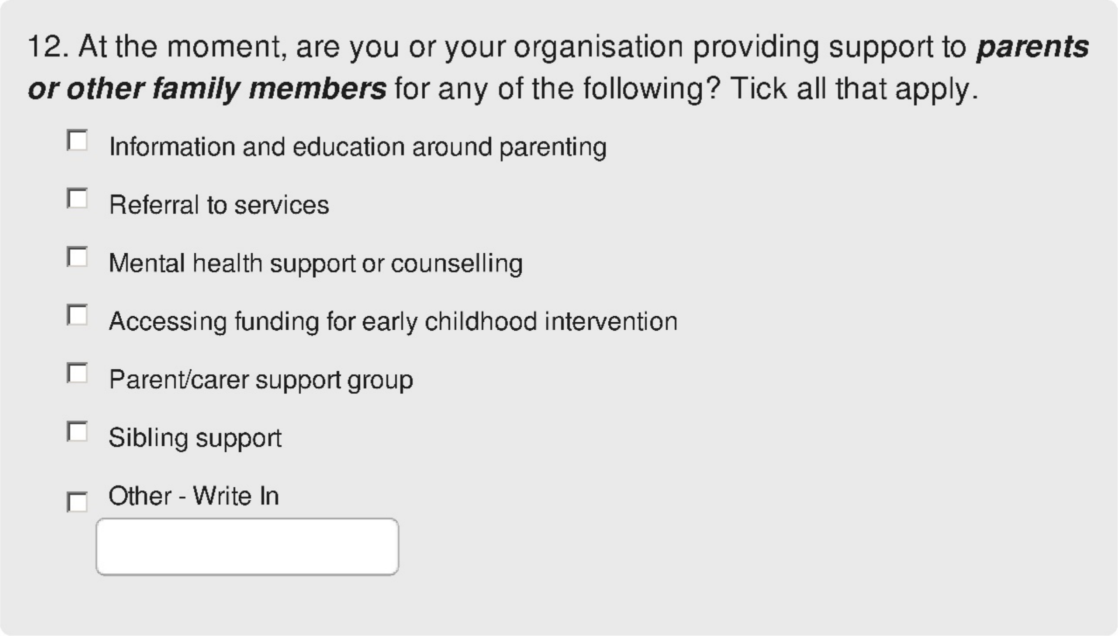
☐ Community access, e.g. going shopping, attending playgroup

☐ Transition to next setting, e.g. early childhood setting or school

☐ Planning and coordination of services

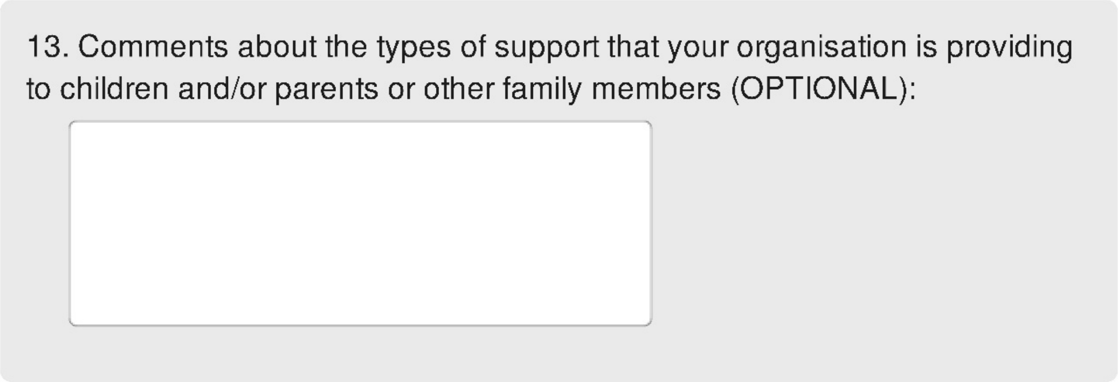
☐ Medical needs

☐ Other - Write In



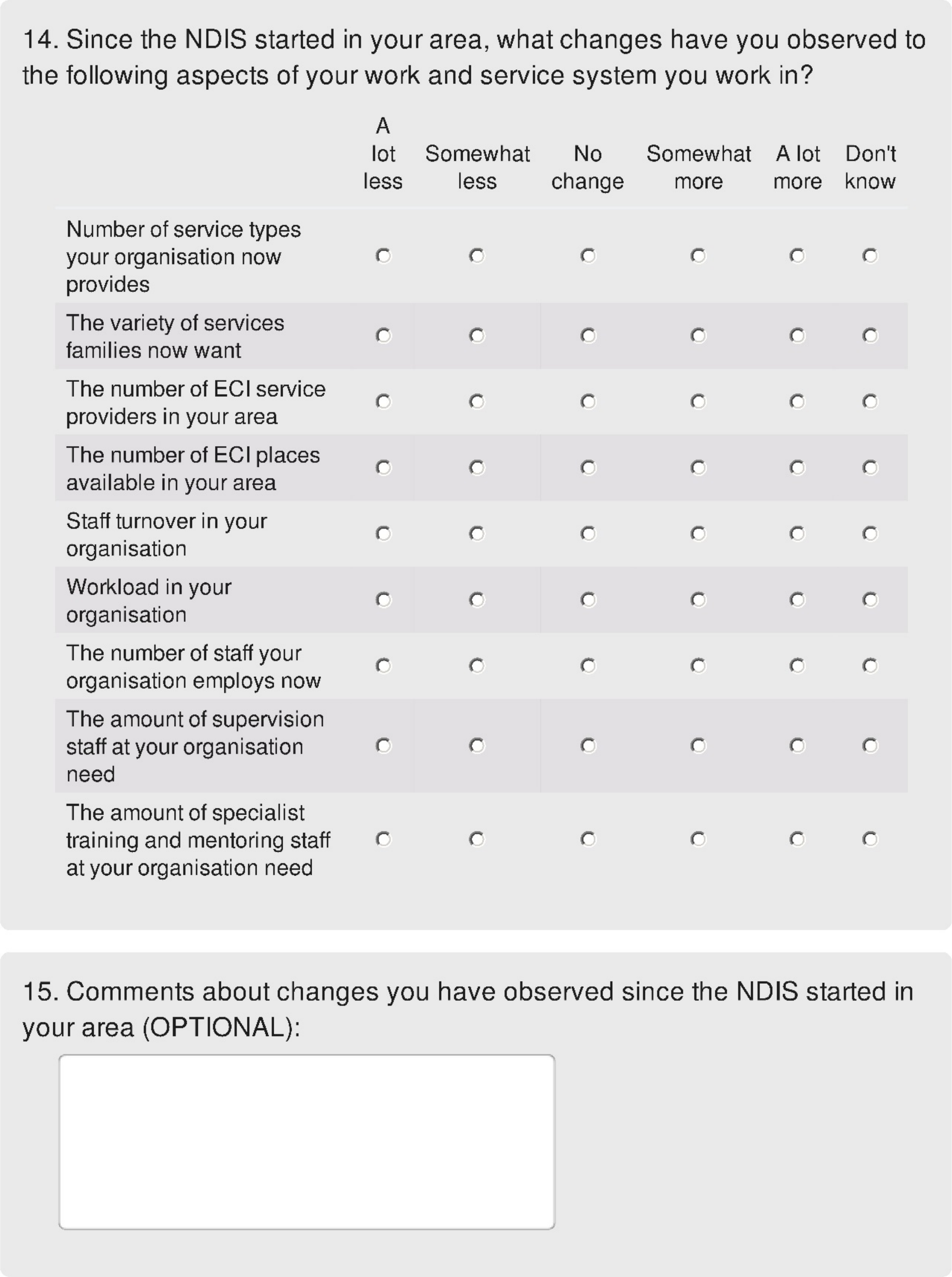
12. At the moment, are you or your organisation providing support to ***parents or other family members*** for any of the following? Tick all that apply.

☐ Information and education around parenting
☐ Referral to services
☐ Mental health support or counselling
☐ Accessing funding for early childhood intervention
☐ Parent/carer support group
☐ Sibling support
☐ Other - Write In



13. Comments about the types of support that your organisation is providing to children and/or parents or other family members (OPTIONAL):

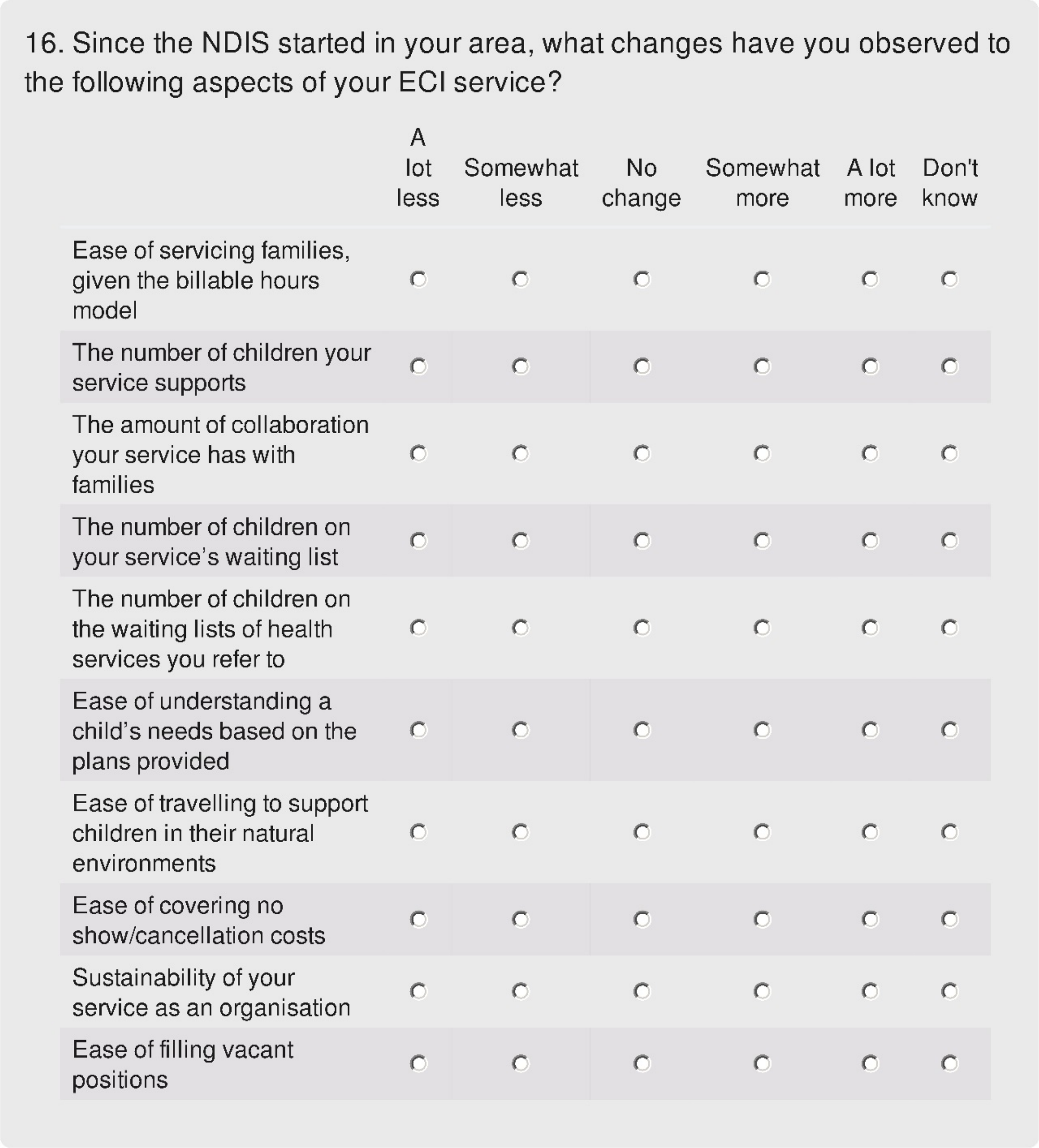
Questions about the transition to the NDIS



14. Since the NDIS started in your area, what changes have you observed to the following aspects of your work and service system you work in?

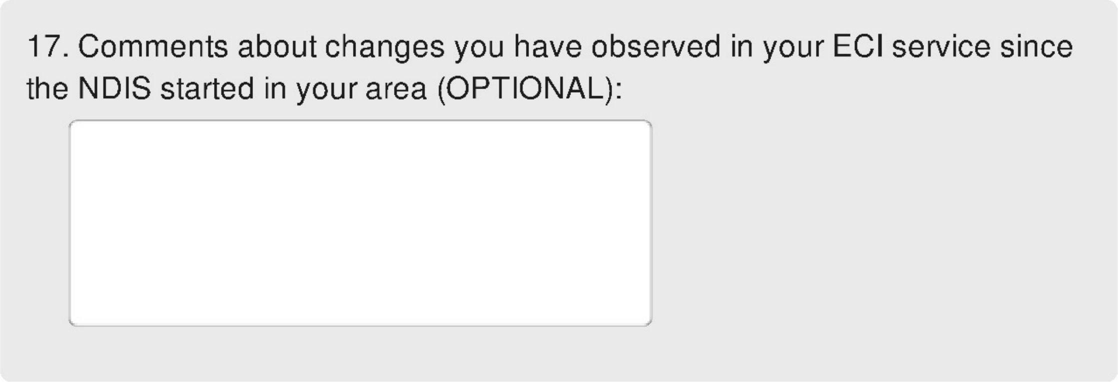
	A lot less	Somewhat less	No change	Somewhat more	A lot more	Don't know
Number of service types your organisation now provides	○	○	○	○	○	○
The variety of services families now want	○	○	○	○	○	○
The number of ECI service providers in your area	○	○	○	○	○	○
The number of ECI places available in your area	○	○	○	○	○	○
Staff turnover in your organisation	○	○	○	○	○	○
Workload in your organisation	○	○	○	○	○	○
The number of staff your organisation employs now	○	○	○	○	○	○
The amount of supervision staff at your organisation need	○	○	○	○	○	○
The amount of specialist training and mentoring staff at your organisation need	○	○	○	○	○	○

15. Comments about changes you have observed since the NDIS started in your area (OPTIONAL):

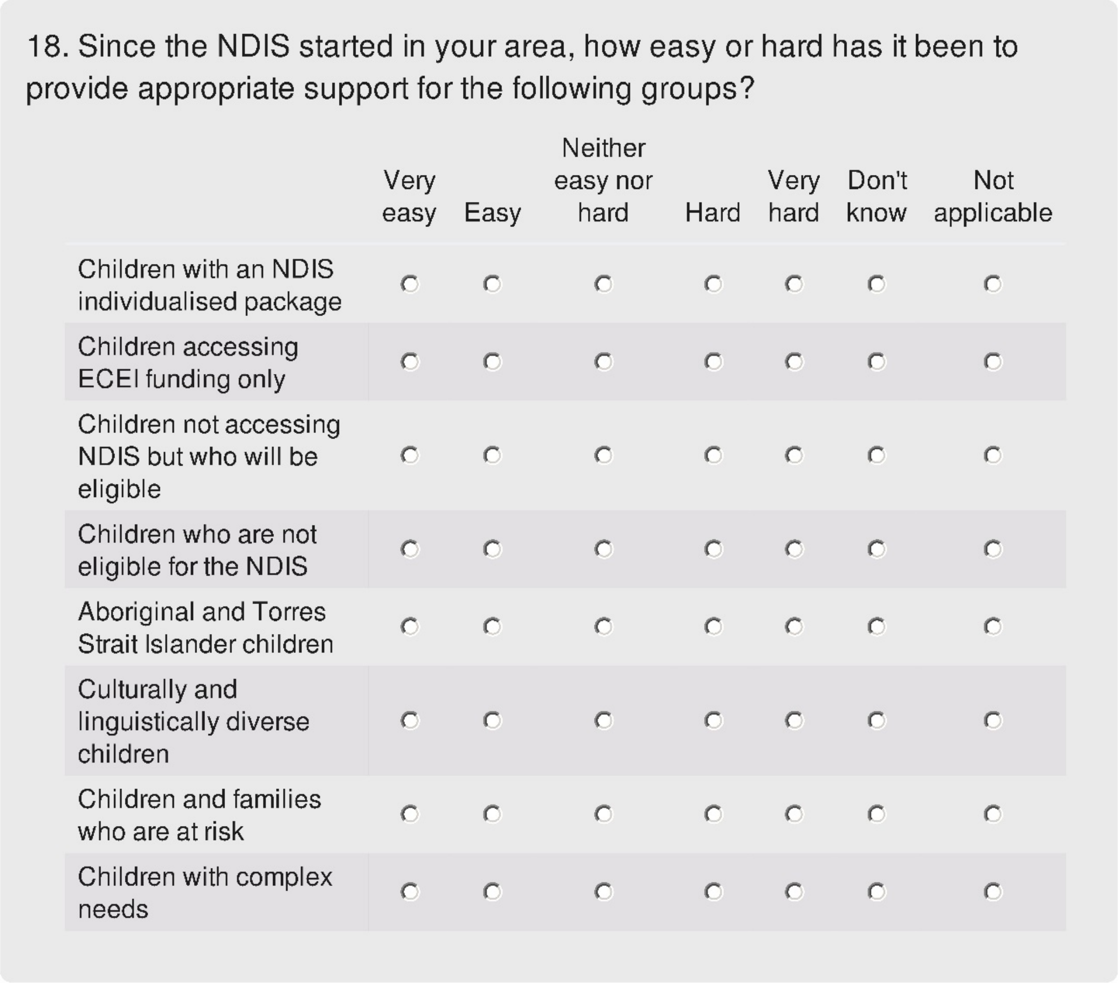


16. Since the NDIS started in your area, what changes have you observed to the following aspects of your ECI service?

	A lot less	Somewhat less	No change	Somewhat more	A lot more	Don't know
Ease of servicing families, given the billable hours model	○	○	○	○	○	○
The number of children your service supports	○	○	○	○	○	○
The amount of collaboration your service has with families	○	○	○	○	○	○
The number of children on your service's waiting list	○	○	○	○	○	○
The number of children on the waiting lists of health services you refer to	○	○	○	○	○	○
Ease of understanding a child's needs based on the plans provided	○	○	○	○	○	○
Ease of travelling to support children in their natural environments	○	○	○	○	○	○
Ease of covering no show/cancellation costs	○	○	○	○	○	○
Sustainability of your service as an organisation	○	○	○	○	○	○
Ease of filling vacant positions	○	○	○	○	○	○

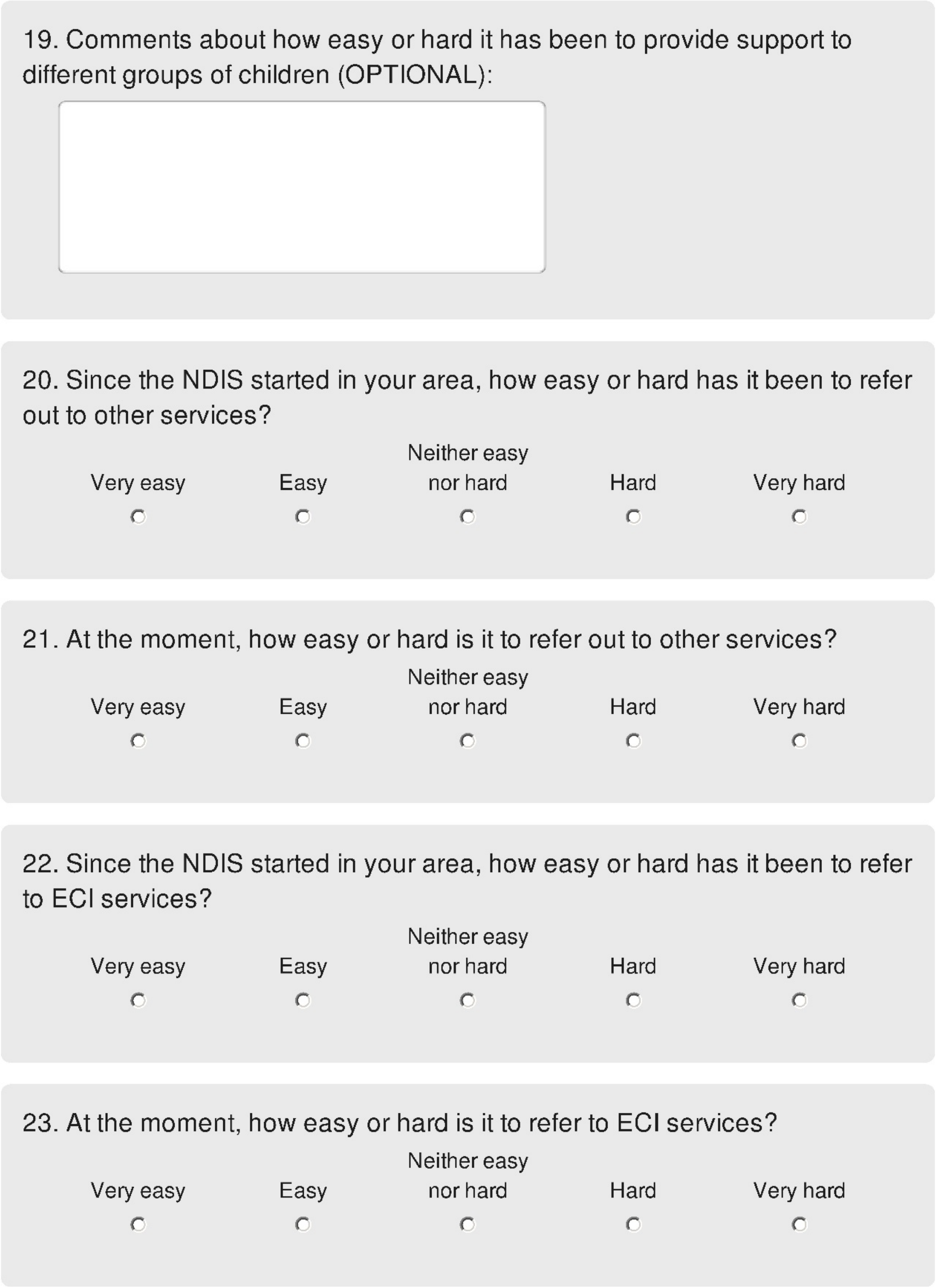


17. Comments about changes you have observed in your ECI service since the NDIS started in your area (OPTIONAL):



18. Since the NDIS started in your area, how easy or hard has it been to provide appropriate support for the following groups?

	Very easy	Easy	Neither easy nor hard	Hard	Very hard	Don't know	Not applicable
Children with an NDIS individualised package	○	○	○	○	○	○	○
Children accessing ECEI funding only	○	○	○	○	○	○	○
Children not accessing NDIS but who will be eligible	○	○	○	○	○	○	○
Children who are not eligible for the NDIS	○	○	○	○	○	○	○
Aboriginal and Torres Strait Islander children	○	○	○	○	○	○	○
Culturally and linguistically diverse children	○	○	○	○	○	○	○
Children and families who are at risk	○	○	○	○	○	○	○
Children with complex needs	○	○	○	○	○	○	○



19. Comments about how easy or hard it has been to provide support to different groups of children (OPTIONAL):

20. Since the NDIS started in your area, how easy or hard has it been to refer out to other services?

Very easy	Easy	Neither easy nor hard	Hard	Very hard
○	○	○	○	○

21. At the moment, how easy or hard is it to refer out to other services?

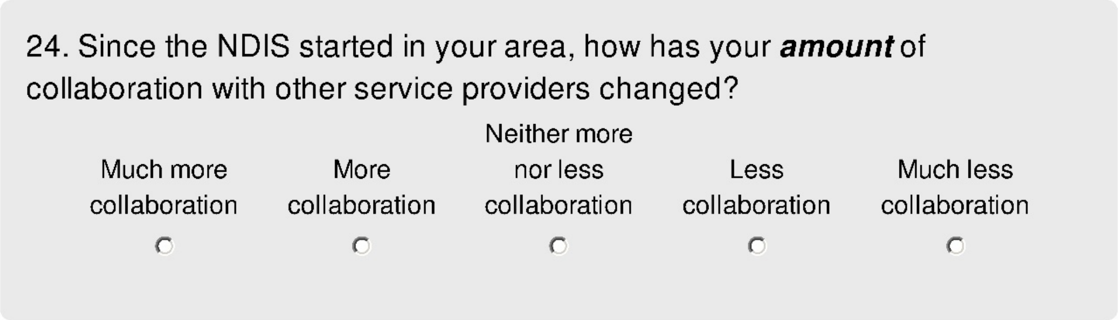
Very easy	Easy	Neither easy nor hard	Hard	Very hard
○	○	○	○	○

22. Since the NDIS started in your area, how easy or hard has it been to refer to ECI services?

Very easy	Easy	Neither easy nor hard	Hard	Very hard
○	○	○	○	○

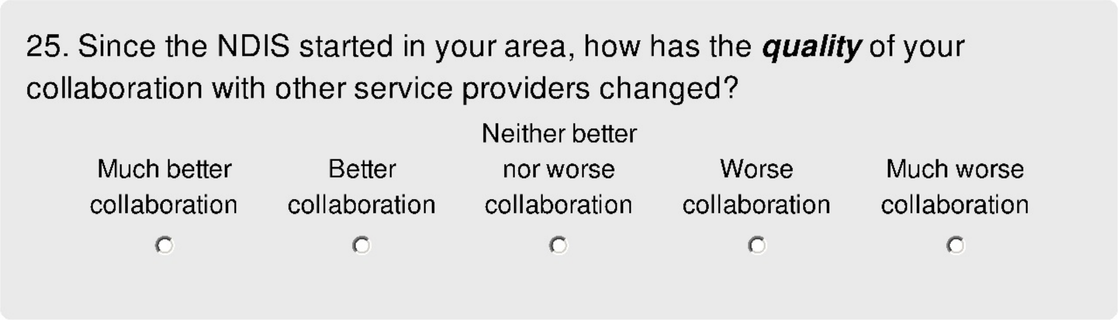
23. At the moment, how easy or hard is it to refer to ECI services?

Very easy	Easy	Neither easy nor hard	Hard	Very hard
○	○	○	○	○



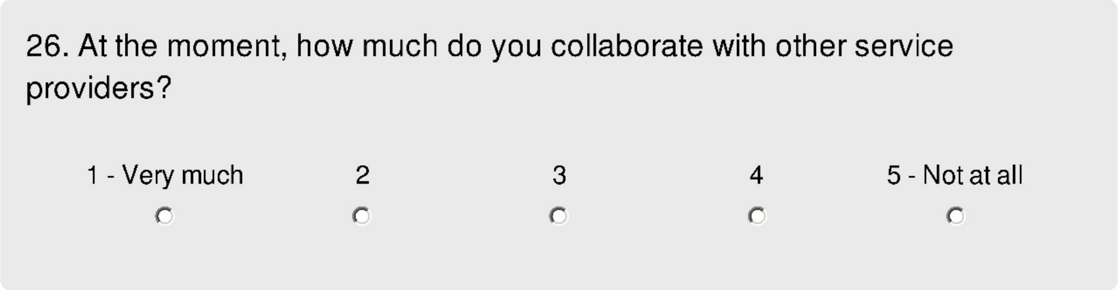
24. Since the NDIS started in your area, how has your ***amount*** of collaboration with other service providers changed?

Much more collaboration	More collaboration	Neither more nor less collaboration	Less collaboration	Much less collaboration
○	○	○	○	○



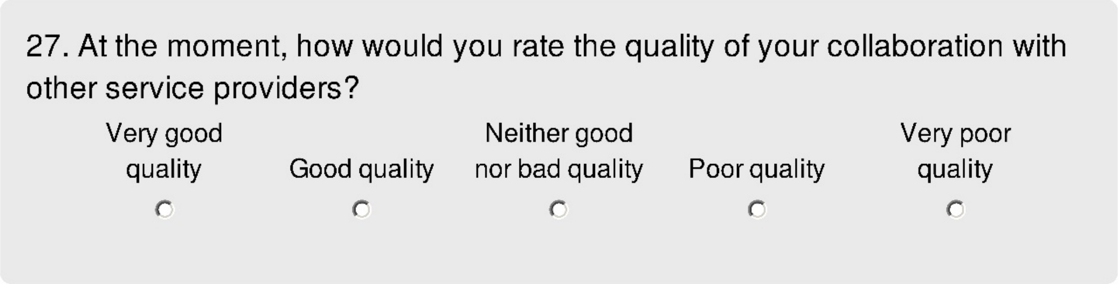
25. Since the NDIS started in your area, how has the ***quality*** of your collaboration with other service providers changed?

Much better collaboration	Better collaboration	Neither better nor worse collaboration	Worse collaboration	Much worse collaboration
○	○	○	○	○



26. At the moment, how much do you collaborate with other service providers?

1 - Very much	2	3	4	5 - Not at all
○	○	○	○	○



27. At the moment, how would you rate the quality of your collaboration with other service providers?

Very good quality	Good quality	Neither good nor bad quality	Poor quality	Very poor quality
○	○	○	○	○

28. Since the NDIS started in your area, how has your ***amount*** of collaboration with ECI providers changed?

Much more collaboration	More collaboration	Neither more nor less collaboration	Less collaboration	Much less collaboration
○	○	○	○	○

29. Since the NDIS started in your area, how has the ***quality*** of your collaboration with ECI providers changed?

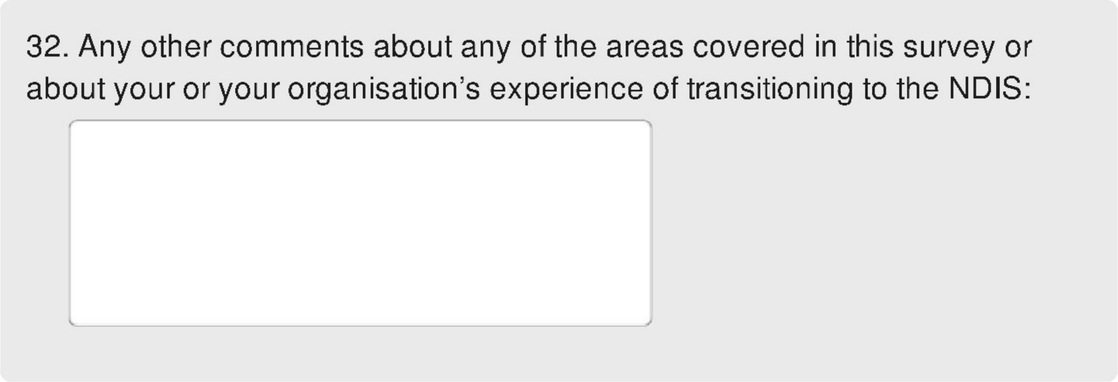
Much better collaboration	Better collaboration	Neither better nor worse collaboration	Worse collaboration	Much worse collaboration
○	○	○	○	○

30. At the moment, how much do you collaborate with ECI providers?

Much more collaboration	More collaboration	Neither more nor less collaboration	Less collaboration	Much less collaboration
○	○	○	○	○

31. At the moment, how would you rate the quality of your collaboration with ECI providers?

Very good quality	Good quality	Neither good nor poor quality	Poor quality	Very poor quality
○	○	○	○	○



32. Any other comments about any of the areas covered in this survey or about your or your organisation’s experience of transitioning to the NDIS:

Interview schedules Round 1:

Family member interview schedule

1. Ask briefly: Can you tell me a little about your child and your family?
   Prompts:
   - *Child's gender, age, support needs/concern re development;*
   - *Number of people in the family, location, background*

2. Is your child currently using any services?
   If yes: What services are they? / What do the services help your child with? / Are there any services your child still needs?
   If no: What services does your child need? Have there been any barriers to getting these services? How would you suggest addressing these barriers?
   Prompts:
   - *Early child intervention services / disability services*
   - *Health or allied health services*
   - *Education services*

3. Are you or other family members using any services?
   If yes: What services are they? / What do the services help you with? / Are there any services you or other family members still need?
   If no: What services do you and other family members need? Have there been any barriers to getting these services? How would you suggest addressing these barriers?
   Prompts:
   - *Referral or help to access funding/services*
   - *Parenting support, support group*
   - *Health and mental health*
   - *Sibling support*

Seek more in depth responses:

4. **If using services:** How did you find out about and get into these services for your child and/or yourself?
   Prompts:
   - *Easy or hard*
   - *Availability and suitability of information about service options*
   - *Extent of choice of services, including of mainstream and specialist disability options*

5. Is your child currently in the NDIS?
   If yes:
   - What has it been like since your area moved into the NDIS?
   - Has it been as you expected?
   - What has changed or remained the same about your child's services?
   - What has been good about it?
   - What has been challenging? How would you suggest addressing these challenges?
   - Did you get any support with the move of your area into the NDIS? How was that?

   If no:
   - What do you think about your area moving into the NDIS in the future?
   - What do you think will be good about it?
   - What are you worried about? What do you think will be challenging?
   - Have you had any support to get ready? How has that been?

6. What do you think makes a good quality service for your child and yourself?
   Prompts / follow up questions:
   - *What do you want to get out of the services for your child, yourself and your family?*
   - *What life events or transitions should a good quality service help with?*

   If in the NDIS:
   - What do you think has been the quality of your services so far since your child has been in the NDIS?

7. Is there anything else you wanted to say today?

Service provider interview schedule

Background

1. Please tell us a little about where you work:
   a. What organisation do you work for?
   b. What kind of services does your organisation provide to children and families?
   c. What is your role there?
2. What is your role and experience in relation to ECI?
3. Is your area currently in the NDIS? Is your organisation currently providing services under the NDIS? **If ECI under the NDIS:** Is your organisation an ECEI transition provider?

Transition to the NDIS

Changes for children and families

4. What do you think is changing for children and families as they move into the NDIS?
   Prompts:
   - *Service and support choices available*
   - *Referral pathways*
   - *Quality of services and supports*
   - *Outcomes achieved*

5. What do you think the move into the NDIS has been like for children and families so far? How do you think this will continue to change over time?
   Prompts:
   - *Benefits*
   - *Challenges*
   - *Concerns*

Changes in your work

6. What has changed about your work as your area / organisation [as relevant] has moved to providing services under the NDIS?
   Prompts – changes in:
   - *How you can support children and families*
   - *How you can support different groups (e.g. at-risk, Aboriginal and/or culturally diverse, children with different service entitlements)*

- *Your own role and workload*
- *Staffing in your organisation*
- *Training requirements in your organisation*
- *Partnerships and collaboration between your organisation and others*

7. Thinking about these changes in your work, what has been your experience of the move to the NDIS so far? How do you think it will continue to change over time?
   Prompts:
   - *Benefits*
   - *Challenges*
   - *Concerns*

<u>*Changes in the system you work in*</u>

8. What has changed about the system you're working in as your area / organisation [as relevant] has moved into the NDIS?
   Prompts – changes in:
   - *Children's service entitlements*
   - *Business and funding model, pricing*
   - *Referral processes, ECEI approach*
   - *Processes for innovation*
   - *Processes for efficiency*
   - *Processes for sustainability of services*
   - *Working towards outcomes*

9. Thinking about these system changes, what has working in the changed NDIS system been like so far? How do you think it will continue to change over time?
   Prompts:
   - *Benefits*
   - *Challenges*
   - *Concerns*

10. Given the system changes, what do you think are the best ways for ECI to achieve:
    a. Good practice and innovation for children and families?
    b. Sustainability of ECI service types?
    c. A good interface with other services (e.g. health and education)?

11. Is there anything else you wanted to say today?

Appendix B Survey results

This appendix outlines the results from both rounds of the family and service provider surveys. While the results provide a snapshot of the experiences of families and services providers at two points in time, care should be taken in interpreting these results for several reasons. First, the surveys had relatively few numbers in both rounds. Second, comparisons between Round 1 and Round 2 should be undertaken with caution, as the surveys had respondent profiles that differ on important factors (age of children and type of service providers). Finally, while we can identify the number of respondents who indicated that they participated in both surveys, we cannot identify these respondents in both surveys, so no longitudinal comparisons about experiences can be made for that group.

Family survey

The family survey had a total of 67 responses in Round 1 and 86 in Round 2 from families with children living in NSW. Of the 86 responses in Round 2, 28 respondents had completed the survey in Round 1. In both surveys, if families had concerns about the development of more than one of their young children or had more than one child with a disability, they were asked to answer the survey about the youngest child only. They were also given the option to complete the survey again for other children.

Demographics

The language profile of the family survey respondents in Round 2 was similar to that in Round 1, with almost all respondents (66 in Round 1, 84 in Round 2) speaking English at home. In Round 1 six respondents reported that they spoke other languages including Cantonese, Creole, Filipino, French and Hungarian, and in Round 2 seven respondents reported speaking other languages including French, Italian, Korean, Russian, Spanish, Marathi, Hindi and Vietnamese. In Round 1 seven respondents, and in Round 2 eleven respondents, indicated that the child was from an Aboriginal or Torres Strait Islander background.

Table B- 1 outlines the gender composition of the children in Rounds 1 and 2. The majority of children were male in both surveys, although Round 2 had proportionately fewer male children (64% in Round 2 compared to 78% in Round 1). The age groups of children are outlined in Table B- 2. In Round 2, a higher percentage of children were in the older age group (aged 7 and 8 years) than in Round 1 (33% compared to 14%).

Table B- 1 Gender of children

	Round 1		Round 2	
	Number	**Per cent**	**Number**	**Per cent**
Female	15	*22*	31	*36*
Male	52	*78*	55	*64*
Total	**67**	***100***	**86**	***100***

Table B- 2 Age of children

	Round 1		Round 2	
	Number	**Per cent**	**Number**	**Per cent**
0-2 year	8	*11*	7	*8*
3 years	12	*18*	5	*6*
4 years	15	*22*	19	*22*
5 years	11	*16*	15	*17*
6 years	11	*16*	12	*14*
7 years	3	*4*	13	*15*
8 years	7	*10*	15	*17*
Total	**67**	***97****	**86**	***99****

Note: *Percentages may not sum to 100 due to rounding.

Table B- 3 provides a breakdown of the geographical area of residence of children in the family survey by NSW Local Health Districts. In both rounds, nearly an equal number of respondents lived in metropolitan areas and rural and regional areas. The largest group lived in the Hunter New England region (26% in Round 1, 33% in Round 2).

Table B- 3 Geographical area of residence of children

	Round1		Round 2	
NSW Local Health Districts	**Number**	**Per cent**	**Number**	**Per cent**
Central Coast	4	*6*	4	*6*
Illawarra Shoalhaven	n/a	*n/a*	n/a	*n/a*
Nepean Blue Mountains	3	*5*	5	*8*
Northern Sydney	8	*12*	4	*6*
South Eastern Sydney	4	*6*	4	*6*
South Western Sydney	4	*6*	7	*11*
Sydney	3	*5*	4	*6*
Western Sydney	4	*6*	n/a	*n/a*
Total metropolitan*	**32**	***48***	**32**	***49***
Hunter New England	17	*26*	22	*33*
Mid North Coast	n/a	*n/a*	n/a	*n/a*
Murrumbidgee	7	*11*	7	*11*
Southern NSW	n/a	*n/a*	n/a	*n/a*
Northern NSW	n/a	*n/a*	n/a	*n/a*
Western NSW	8	*12*	n/a	*n/a*
Total rural and regional*	**34**	***52***	**34**	***52***
Total	**66**	***100***	**66**	***101***

Notes: Missing= 1. ‘n/a’ indicates fewer than 3 respondents. * Distinction between metro and rural/regional follows NSW Health groupings: http://www.health.nsw.gov.au/lhd/Pages/default.aspx. Totals may not add up to 100 due to rounding.

Support received

The survey asked families about the support they had received for their children in the last 12 months (Table B- 4). The most common types of support in both rounds were for the child’s communication (82% in Round 1 and 71% in Round 2). In Round 2 the next most common types of support were for sensory processing issues (55%) and development of self-help skills (55%). This differed to Round 1, where interaction with other children or adults (64%), playing (58%), behaviour (58%), sensory processing issues (57%) and participation in early childhood education (57%) were more common. In Round 1, the least frequent types of support accessed were planning and coordination of services (19%) and community access (27%). In Round 2, the lowest reported type of support was for help with the child's sleep (16%), and once again, relatively few respondents indicated they received support for planning and coordination of services (24%).

Table B- 4 Help received in the last 12 months

	Round 1		Round 2	
Have you or your child got help with your child's: (Tick all that apply)	**Number**	**Per cent**	**Number**	**Per cent**
Communication	55	*82*	61	*71*
Playing	39	*58*	37	*43*
Interaction with other children or adults	43	*64*	45	*52*
Behaviour	39	*58*	36	*42*
Sleep	22	*33*	14	*16*
Movement and being physically independent	21	*31*	39	*45*
Development of self-help skills	37	*55*	47	*55*
Sensory processing issues	38	*57*	47	*55*
Participation in early childhood education or school	38	*57*	43	*50*
Community access	18	*27*	23	*27*
Transition to next setting	22	*33*	26	*30*
Learning at school	24	*36*	27	*31*
Planning and coordination of services	13	*19*	21	*24*
Medical needs	26	*39*	26	*30*
Help with accessing funding for early childhood intervention	27	*40*	26	*30*

Note: Total number of respondents: Round 1=67, Round 2=86

Table B- 5 outlines the number of types of support used by children in both rounds of the survey. In Round 1, around one-third of respondents were in each category, with 33% using 1–4 types of support, 34% using 5–9, and 31% using 10–14 types of supports. By contrast, in Round 2 almost half (49%) indicated that they were receiving between 1 and 4 types of support, another 43% received between 5 and 9, and very few (3%) received more than 10 types of support.

Table B- 5 Total number of types of support used

	Round 1		Round 2	
Number of types of support	**Number**	**Per cent**	**Number**	**Per cent**
Zero	n/a	*n/a*	4	*5*
1–4	22	*33*	42	*49*
5–9	23	*34*	37	*43*
10–14	21	*31*	3	*3*
Total	**66**	***98****	**86**	***100***

Note: *Percentages may not sum to 100 due to exclusion of cells containing fewer than 3 respondents.

Other services that children used at the time of the survey are outlined in Table B- 6. The results are similar for Round 1 and Round 2 for several services. The majority of children used allied health services (85% in both rounds), a general practitioner (76% in Round 1, 72% in Round 2) or specialist health services (70% in both rounds). Relatively few children had been engaged with mental health services (13% in Round 1 and 7% in Round 2) or used hospitals (24% in Round 1 and 27% in Round 2). Around one-third of children in the survey in Round 1 had used playgroups (34%), but only 13% of children in the survey in Round 2 were identified as using playgroups. Slightly fewer children in the Round 2 survey used child care centres (31% in Round 1, 26 % in Round 2) and preschool (31% in Round 1 and 23 % in Round 2). However, slightly more children in the Round 2 survey attended primary school (37% in Round 1 and 47% in Round 2). This may reflect the age profile of the children in the Round 2 survey.

Table B- 6 Services children use

	Round 1		**Round 2**	
At the moment, does your child use any of the following? (Tick all that apply):	**Number**	**Per cent**	**Number**	**Per cent**
Playgroup	23	*34*	11	*13*
Child care centre - long day care or occasional care	21	*31*	22	*26*
Family day care	n/a	*n/a*	n/a	*n/a*
Preschool	21	*31*	20	*23*
Primary school	25	*37*	40	*47*
General practitioner	51	*76*	62	*72*
Specialist health services (e.g. doctor for specific condition)	47	*70*	60	*70*
Allied health services (e.g. occupational therapy, speech therapy)	57	*85*	73	*85*
Mental health services	9	*13*	6	*7*
Hospital	16	*24*	23	*27*

Notes: ‘n/a’ indicates fewer than 3 respondents

The survey also asked whether family members were receiving any help (Table B- 7). A similar profile of support was evident in both surveys, with the most common support received being information and education around parenting (40% in Round 1 and 26% in Round 2), and around one-quarter attending a parent/carer support group (28% in Round 1 and 24% in Round 2). One-quarter had received mental health support or counselling (25%) in Round 1; this reduced to 15% in Round 2. In both rounds, relatively few respondents had received sibling support.

Table B- 7 Help received by family members

	Round 1		Round 2	
Do you get any of the following help for yourself or other family members? (Tick all that apply)	**Number**	**Per cent**	**Number**	**Per cent**
Information and education around parenting	27	*40*	22	*26*
Mental health support or counselling	17	*25*	13	*15*
Parent/carer support group	19	*28*	21	*24*
Sibling support	6	*9*	7	*8*
Other (No help)	n/a	*n/a*	3	*3*

Notes: 'n/a' indicates fewer than 3 respondents. Total number of respondents: Round 1=67, Round 2=86

In Round 1, when asked whether their child needed any support that he/she was not getting now, 61% (40 respondents) indicated that they did need further support, while 39% (26 respondents) indicated that no more was needed. In Round 2, 56% indicated they needed further support, while 44% indicated that they did not. Responses to what support was needed in Round 1 included: speech therapy, behavioural therapy, physiotherapy, occupational therapy, psychology, hearing, food therapy, assistance with transition and integration at school, social skills and activities, sporting and extra-curricular activities, case management, counselling for parents, respite, transport and travel, NDIS funding, and more community services. In Round 2 similar issues were raised, with responses including: social support, assistive technology to participate in the community and equipment such as a safety sleeper, assisted travel funding for school, help to understand how to support child and siblings and how to cope, speech therapy, occupational therapy, physiotherapy, paediatric physiotherapy and orthotics, functional neurology, support at school and transition to school, behaviour management, food therapy/dietitian, water therapy, mental health services, peer interaction with other children with disabilities and inclusion in mainstream activities, family support and respite to spend time with the other children in the family, and funding for home modification and equipment. Parents in Round 2 also indicated issues with accessing NDIS support and funding, services having long waiting lists, and needing more help with NDIS coordination.

Early intervention services

The majority of respondents (85% in Round 1 and 70% in Round 2) indicated that they were currently involved in early intervention services. The length of time they had been involved is outlined in Table B- 8. A higher percentage of respondents in Round 2 had been involved in early interventions services for more than 3 years (54% compared with 33% In Round 1). Respondents were asked why they were involved with early intervention services and given two possible responses (Table B- 9): in Round 1, 18% indicated that they were concerned about the child's development, 32% indicated that the child had a disability, while 51% indicated that both these reasons were relevant. In Round 2, 50% indicated that the child had a disability, while just over a third (37%) indicated that it was for both reasons.

Table B- 8 Length of time involved in early intervention services

	Round 1		Round 2	
	Number	**Per cent**	**Number**	**Per cent**
Less than one year	14	*25*	12	*20*
1 to less than 2 years	13	*23*	6	*10*
2-3 years	11	*20*	7	*12*
3-4 years	5	*9*	14	*23*
4-5 years	6	*11*	7	*12*
5 years and over	7	*13*	14	*23*
Total	**56**	***101***	**60**	***100***

Notes: Round 1: One respondent missing data. Total per cent may not sum to 100 due to rounding.

Table B- 9 Reasons for involvement with early intervention services

	Round 1		Round 2	
Why are you involved with early intervention services?	**Number**	**Per cent**	**Number**	**Per cent**
Concern about the child's development	10	*18*	8	*13*
Child has a disability	18	*32*	30	*50*
Both reasons	29	*51*	22	*37*
Total	**57**	***101***	**60**	***100***

Notes: One respondent missing data. Total per cent may not sum to 100 due to rounding.

The types of disability children had differed slightly between the rounds: While communication and cognitive disability were predominant in both rounds, a lower percentage of children in Round 2 had sensory processing and social disability, and a higher percentage had a physical disability.

Table B- 10 Type of disability

	Round 1		Round 2	
What kind of disability does your child have? (Tick all that apply)	**Number**	**Per cent**	**Number**	**Per cent**
Sensory processing	39	*83*	32	*62*
Vision or hearing	0	*0*	na	*na*
Communication	40	*85*	41	*79*
Cognitive	32	*68*	38	*73*
Physical	8	*17*	26	*50*
Medical	6	*13*	6	*12*
Social	43	*91*	29	*56*

Notes: Percentage refers to number of respondents with disability as denominator: Round 1= 47, Round 2= 52.

The number of types of disability reported for the children in the family survey are outlined in Table B- 11. Twenty-one (31%) of the children had no reported disability. A small number (6%) had one or two disabilities, 13% had three, 33% had four, and 10% had five or six types of disabilities. Therefore, more than half of the children with disability had four or more types of disability. In Round 2, a higher percentage of the children (40%) had no reported disability and only 29% had four or more disabilities.

Table B- 11 Number of types of disabilities reported for children

	Round 1		Round 2	
	Number	**Per cent**	**Number**	**Per cent**
Zero	21	*31*	34	*40*
One	4	*6*	7	*8*
Two	4	*6*	8	*9*
Three	9	*13*	12	*14*
Four	22	*33*	14	*16*
Five or More	7	*10*	11	*13*
Total	**67**	***100***	**86**	***100***

The sources of early intervention services for the respondents indicating involvement with these services are outlined in Table B- 12. Respondents could provide more than one answer. The most common source of services in Round 1 was community or non-government organisations (51% of respondents), whereas in Round 2, it was the NDIS (58%). Services were also received in both rounds from private practitioners (around one-third of respondents) and Medicare (33% in Round 1 and 25% in Round 2).

Table B- 12 Early intervention service providers

	Round 1		Round 2	
Who provides the early intervention services that you use? (Tick all that apply)	**Number**	**Per cent**	**Number**	**Per cent**
Community or non-government organisation/s	29	*51*	24	*40*
Private practitioner	18	*32*	18	*30*
NDIS	17	*30*	35	*58*
NSW Government - ADHC	6	*11*	3	*5*
NSW Government - FACS	5	*9*	na	*na*
Australian Government - DSS (Better Start)	3	*5*	5	*8*
Australian Government - DSS (Helping Children with Autism)	12	*21*	3	*5*
Medicare	19	*33*	15	*25*
Other	8	*14*	3	*5*
Not sure	n/a	*n/a*	4	*7*

Notes: ‘n/a’ indicates fewer than 3 respondents. Number of respondents: Round 1= 57, Round 2 =60.

Experiences with support

Respondents were asked a range of questions about their experiences with support. The first question related to information about support. Table B- 13 and Figure B- 1 to Figure B- 3 report the percentage of respondents who found information about support for their child’s development easy to find, easy to understand and helpful. In both rounds, most difficulties were reported with ease of finding information, with 22% in Round 1 and 31% in Round 2 indicating that it was rarely or never easy. Sixteen percent of respondents in Round 1 and 21% of respondents in Round 2 indicated that information about support was rarely or never easy to understand. Fifty-five percent of the respondents in Round 1 and 43% of respondents in Round 2 found the information about support 'always' or 'often' helpful.

Table B- 13 Information about support (%)

Is information about support for your child's development:	Always	Often	Sometimes	Rarely/never
Round 1				
Easy to find?	5	29	45	22
Easy to understand?	12	32	41	16
Helpful?	15	40	33	12
Round 2				
Easy to find?	13	18	38	31
Easy to understand?	12	26	40	21
Helpful?	18	25	45	12

Figure B- 1 Information about support is easy to find

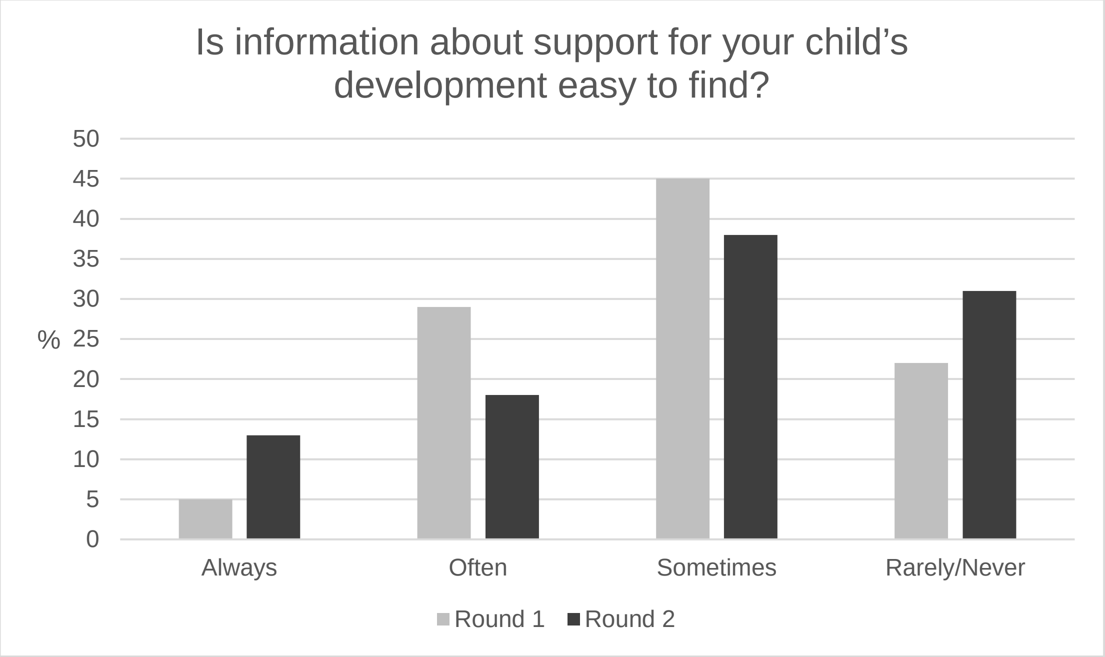


Figure B- 2 Information about support is easy to understand

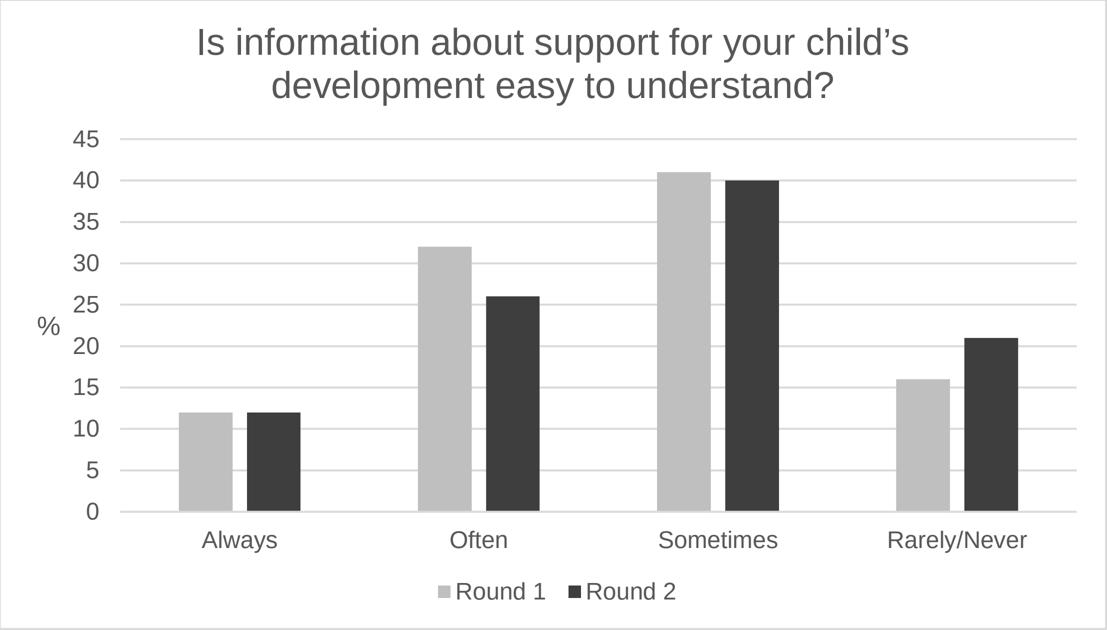
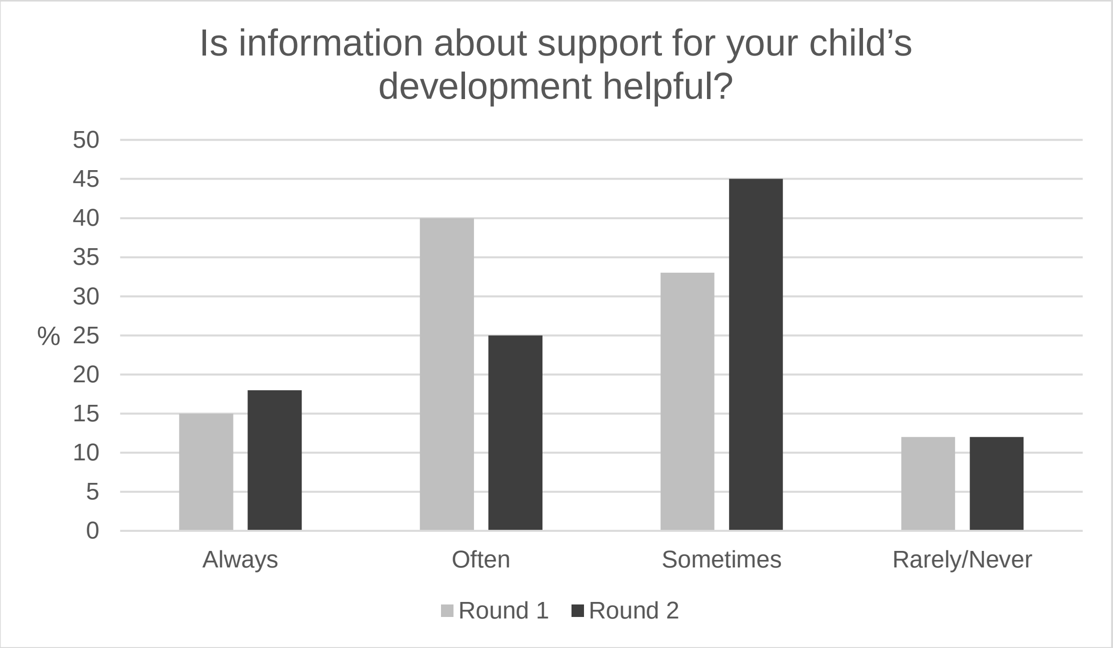


Figure B- 3 Information about support is helpful



Respondents were also asked about their perceptions of choice in relation to what kind of support their child received and who provided the support (Table B- 14 and Figure B- 4 and Figure B- 5). The most common response to the question about choices about 'what kind of support' your child is getting in both rounds of the survey was 'sometimes' (39% in Round 1 and 38% in Round 2). In Round 2, around 30% of respondents indicated that they always had a choice about what kind of support and who provides the support, compared to 19% in Round 1.

Table B- 14 Perception of choice (%)

Overall, do you feel you have a choice of:	Always	Often	Sometimes	Rarely/never	Number of respondents
Round 1					
What kind of support your child is getting?	*19*	*22*	*39*	*19*	67
Who provides the support?	*19*	*25*	*33*	*22*	67
Round 2					
What kind of support your child is getting?	*29*	*19*	*38*	*14**	86
Who provides the support?	*30*	*30*	*22*	*18*	83

Figure B- 4 Choice about what kind of support

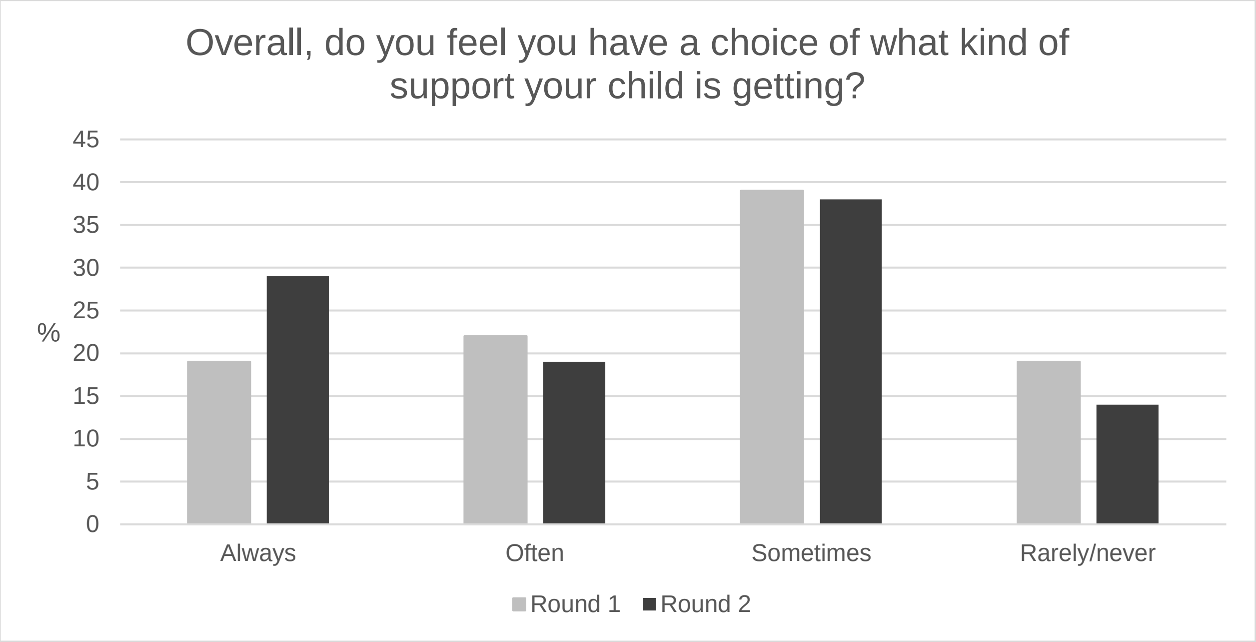
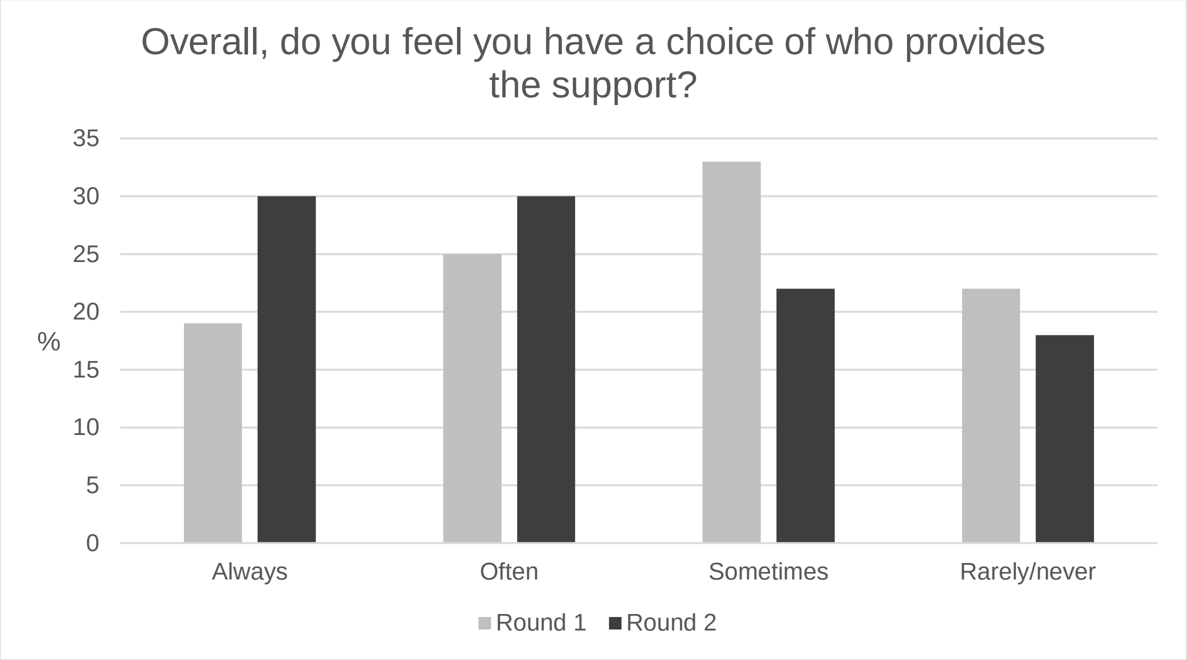


Figure B- 5 Choice about who provides the support



The analysis also examined whether the experience of support differed for those receiving support from the NDIS compared to those who did not receive support from the NDIS (Table B- 15). The small number of respondents in the NDIS in both rounds (17 in Round 1 and 35 in Round 2) means that the data should be interpreted with caution. While in Round 1 there were differences which were statistically significant ($p<0.05$ Fishers Exact test), there were no statistically significant differences between those in or not in the NDIS in Round 2. The relatively large confidence intervals for the estimates should also be noted.

Table B- 15 Perception of choice by whether in the NDIS (percentage and confidence limits)

		95% confidence limits for percentage	
Overall, do you feel you have a choice of:	**Percentage “often/always”**	**Lower**	**Upper**
What kind of support your child is getting?			
Round 1			
Not in NDIS	34.0	21.2	48.8
In NDIS	64.7	38.3	85.8
Round 2			
Not in NDIS	45.1	33.1	59.7
In NDIS	51.4	34.0	68.8
Who provides the support?			
Round 1			
Not in NDIS	34.0	21.2	48.8

In NDIS	76.5	50.1	93.2
Round 2			
Not in NDIS	56.9	42.3	70.7
In NDIS	60.0	42.0	76.1

Notes: Number of respondents: Round 1 = 67. Round 2=86.

Respondents were also asked about their perceptions in relation to several questions outlined in Table B- 16 and Table B- 16. Figure B- 6 and Figure B- 7 provide graphs showing the distribution of responses to each of these questions. The overall profile of responses is fairly similar in both survey rounds, with slightly more respondents indicating that people were ‘always’ providing those experiences of support for the child and family in Round 2.

Table B- 16 Experiences of support (percentages) Round 1

Overall, do you find that the people who are supporting your child and family are:	**Always**	**Often**	**Sometimes**	**Rarely**	**Never**
considering your choices and priorities?	*30*	*39*	*19*	*6*	*6*
are culturally respectful?	*59*	*29*	*6*	*6**	
helping your child participate more in your family and community?	*28*	*37*	*18*	*10*	*6*
working in partnership with you and other members of your child's team (doctors, specialists, teachers, child care workers etc.)?	*27*	*36*	*24*	*13**	
building your knowledge and skills to help you support your child?	*28*	*40*	*21*	*10**	
well-qualified and experienced?	*46*	*33*	*16*	*4**	
focusing on the outcomes you want for your child and family?	*39*	*30*	*24*	*7**	

Notes: Number of respondents = 67, except for culturally respectful question where the number of respondents = 66. * indicates that ‘Rarely’ and ‘Never’ categories have been combined due to small numbers in either category (3 or fewer).

Table B- 17 Experiences of support (percentages) Round 2

Overall, do you find that the people who are supporting your child and family are:	**Always**	**Often**	**Sometimes**	**Rarely**	**Never**
considering your choices and priorities?	*38*	*38*	*19*	*na*	*na*
are culturally respectful?	*69*	*24*	*6*	*na*	*na*
helping your child participate more in your family and community?	*34*	*25*	*25*	*8*	*8*
working in partnership with you and other members of your child's team (doctors, specialists, teachers, child care workers etc.)?	*36*	*25*	*25*	*12*	*na*
building your knowledge and skills to help you support your child?	*34*	*42*	*19*	*5*	*na*
well-qualified and experienced?	*45*	*38*	*15*	*na*	*na*
focusing on the outcomes you want for your child and family?	*42*	*34*	*20*	*na*	*na*

Notes: Number of respondents = 86. ‘n/a’ indicates fewer than 3 respondents

Figure B- 6 Experiences of support, Round 1

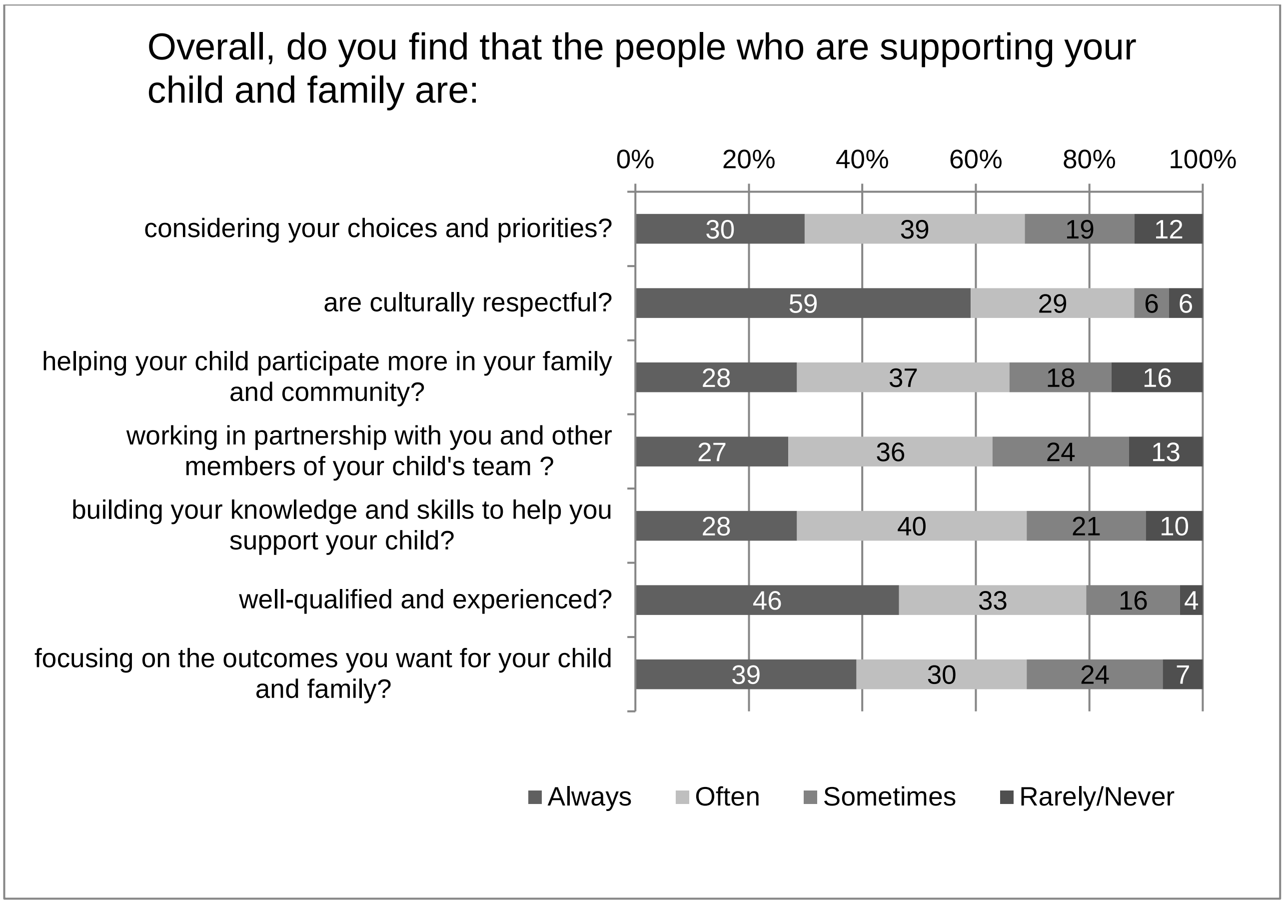
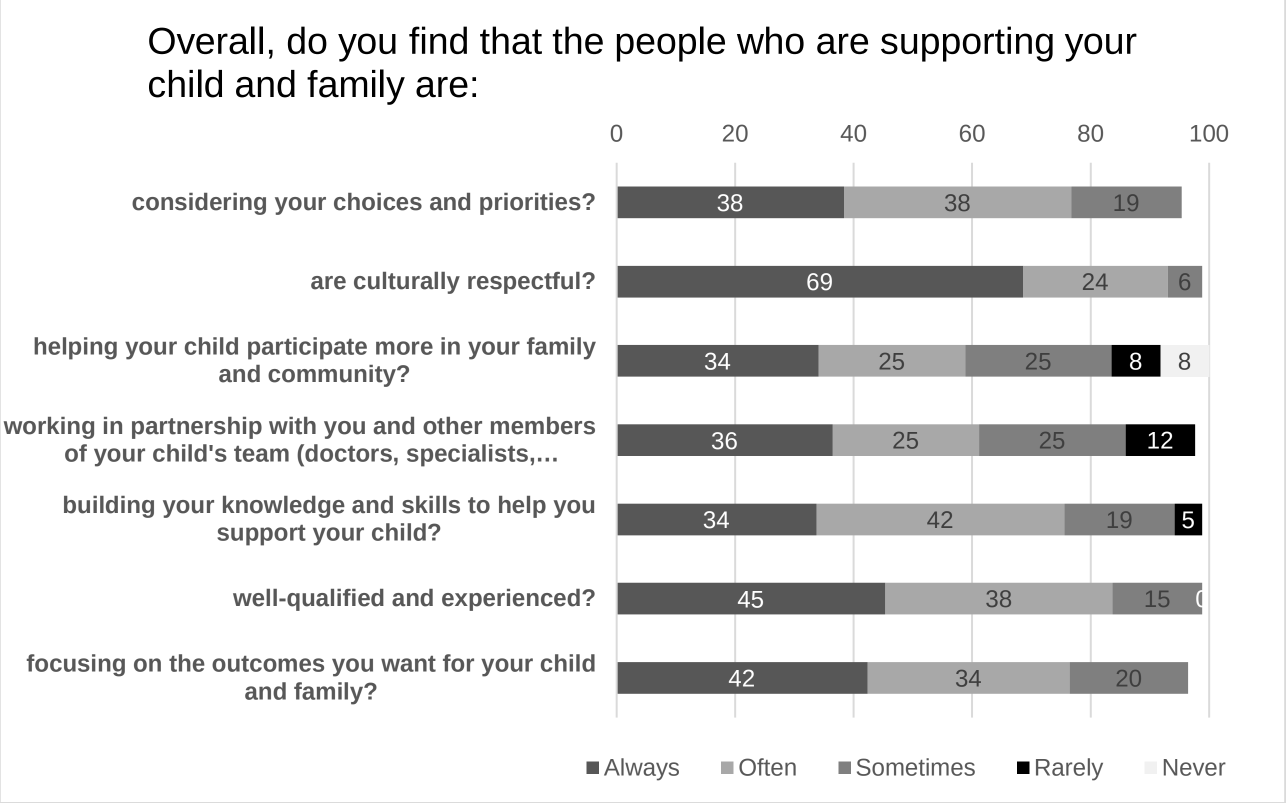


Figure B- 7 Experiences of support, Round 2



The analysis also considered whether there were any differences in the experience of support between the respondents who were in the NDIS or not in the NDIS. In Round 1 there were statistically significant differences between the groups on the question of whether “the people who are supporting your child and family are building your knowledge and skills to help you support your child, but this finding did not hold in Round 2 (Figure B- 17).

Table B- 18 Experiences of support by whether in the NDIS (percentage and confidence limits)

		95% confidence limits for percentage	
Overall, do you find that the people who are supporting your child and family are:	**Percentage “often/always”**	**Lower**	**Upper**
Building your knowledge and skills to help you support your child?			
Round 1			
Not in NDIS	60.0	45.2	73.6
In NDIS	94.1	71.3	99.9
Round 2			
Not in NDIS	72.3	58.3	84.1
In NDIS	80.0	63.1	91.6

Notes: Number of respondents: Round 1=67. Round 2=86.

Respondents were also asked about their knowledge of the NDIS (Table B- 19). Around one-quarter (22% in Round 1 and 27% in Round 2) indicated that they knew ‘a lot’, while around half

(48% in Round 1 and 51% in Round 2) knew ‘some’, and 30 % in Round 1 and 22% in Round 2 indicated that they did not know much.

Table B- 19 Knowledge of the NDIS

	Round 1		Round 2	
How much do you know about the NDIS?	**Number**	**Per cent**	**Number**	**Per cent**
A lot	15	*22*	23	*27*
Some	32	*48*	44	*51*
Not much	20	*30*	19	*22*
Total	**67**	***100***	**86**	***100***

Sources of information for the services people were getting are outlined in Table B- 20 and are similar in both surveys. Respondents could choose more than one answer: over half (60% in round 1 and 52% in Round 2) had found out about services themselves, around half of the respondents (51% in Round 1 and 48% in Round 2) had been referred by someone, and around one-third (31% in Round 1 and 34% in Round 2) had been told by someone else.

Table B- 20 Sources of information about services

	Round 1		Round 2	
How did you find out about the services you are getting at the moment? (Tick all that apply)	**Number**	**Per cent**	**Number**	**Per cent**
Found them myself	40	*60*	45	*52*
Someone told me about them	21	*31*	29	*34*
Someone referred me	34	*51*	41	*48*

Notes: Total respondents: Round 1 =67. Round 2=86

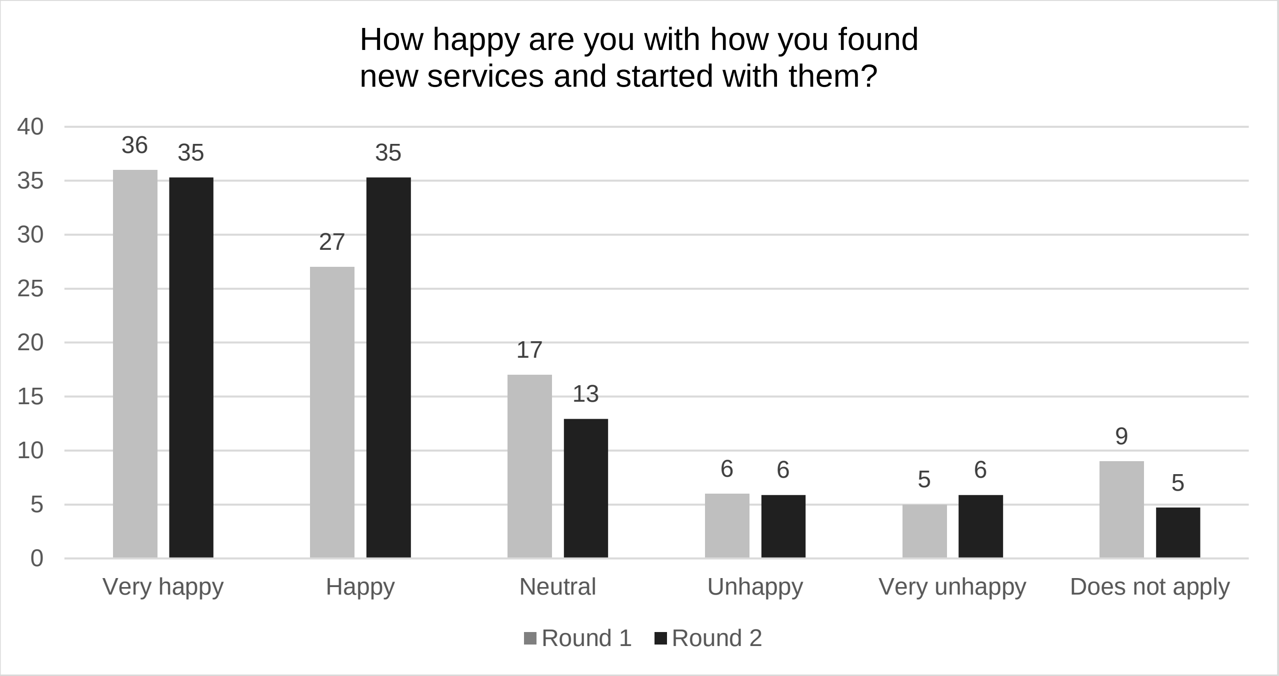
Respondents to the family survey were also asked how happy they were with how they found the new services and started with them (Table B- 21 and Figure B- 8). Around two-thirds of respondents indicated that were very happy or happy (total for these categories was 63% in Round 1 and 70% in Round 2).

Table B- 21 Satisfaction with finding new services

	Round 1		Round 2	
How happy are you with how you found new services and started with them?	**Number**	**Per cent**	**Number**	**Per cent**
Very happy	24	36	30	35
Happy	18	27	30	35
Neutral	11	17	11	13
Unhappy	4	6	5	6
Very unhappy	3	5	5	6
Does not apply	6	9	4	5
Total	**66**	**100**	**85**	**100**

Notes: Round 1: Missing=1. Round 2: Missing=1.

Figure B- 8 Satisfaction with finding new services



Service provider survey

The service provider survey had 112 submitted responses from organisations in NSW in Round 1 and 79 responses in Round 2.

Respondents were asked about the type of support their organisation provided. Table B- 22 gives an overview of the types of organisations. The largest category in both rounds of the survey was the ECI service group, with 23% of Round 1 and 39% of Round 2 respondents. The second largest group was specialist disability services (22% in Round 1 and 27% in Round 2). While child care centres and preschools each comprised about one-fifth of respondents in Round 1, there were few of these other types of services in Round 2. Eleven percent of service provider survey respondents were from hospitals in Round 2, and none of those had been identified in Round 1.

Table B- 22 Service types

	Round 1		**Round 2**	
Thinking about the types of support your organisation provides to children 0-8 and their families, which option best describes the type of service you provide?	**Number**	**Per cent**	**Number**	**Per cent**
ECI service	25	*23*	31	*39*
Specialist disability services (with ECI being part, but not all, of support provided)	24	*22*	21	*27*
Child care centre: long day or occasional	22	*20*	n/a	*n/a*
Community service (e.g. family support, support for families from non-English speaking backgrounds)	3	*3*	na	*na*
Family day care	n/a	*n/a*	n/a	*n/a*
Playgroup	n/a	*n/a*	n/a	*n/a*
Preschool	18	*16*	n/a	*n/a*
Other education role	n/a	*n/a*	n/a	*n/a*
Private therapy/private practice	9	*8*	6	*8*
General practitioner	n/a	*n/a*	n/a	*n/a*
Hospital	n/a	*n/a*	9	*11*
Specialist health services	n/a	*n/a*	3	*4*
Other - Write In	5	*5*	n/a	*n/a*
Total	**111**	***100***	**79**	***100***

Notes: Round 1: Missing = 1.. Round 2: missing=0.‘n/a’ indicates fewer than 3 respondents

A similar profile of respondent roles was evident in both surveys: between half and two-thirds of respondents were in management roles (64% in Round 1 and 57% in Round 2). In both surveys around two-thirds were involved with direct work with children (62% in Round 1 and 68% in Round 2), and around one-third indicated that they were engaged in both these roles (31% in Round 1 and 32% in Round 2). (Table B- 23). In Round 1, respondents mentioned other roles including educator, supervisor, NDIS planning, administration and owning a private practice. In Round 2, other roles included administration and finance, advocacy, ECEI transition planner and NDIS planning.

Table B- 23 Respondent roles

	Round 1		Round 2	
What kind of role(s) are you in? Tick all that apply	**Number**	**Per cent**	**Number**	**Per cent**
Management role	72	*64*	45	*57*
Direct work with children and families	69	*62*	54	*68*
Both management role and direct work with children and families	35	*31*	25	*32*
Other	8	*7*	5	*6*

Notes: Number of respondents: Round 1 = 112, Round 2 = 79

In both survey rounds, respondents provided services across a range of areas in NSW, with organisations also providing services in multiple areas (Table B- 24). The area with the highest proportion of service providers in these surveys was Hunter New England (22% in Round 1 and 16% in Round 2).

Table B- 24 Location of services (multiple responses possible)

	Round 1		Round 2	
What Health or FACS district/s is your organisation funded to provide services in?	**Number**	**Per cent**	**Number**	**Per cent**
Central Coast	7	*6*	6	*8*
Illawarra Shoalhaven	11	*10*	13	*16*
Nepean Blue Mountains	21	*19*	11	*14*
Northern Sydney	16	*14*	3	*4*
South Eastern Sydney	13	*12*	7	*9*
South Western Sydney	16	*14*	10	*13*
Sydney	15	*13*	6	*8*
Western Sydney	12	*11*	12	*15*
Hunter New England	25	*22*	13	*16*
Mid North Coast	8	*7*	5	*6*
Murrumbidgee	8	*7*	3	*4*
Southern NSW	7	*6*	10	*13*
Western NSW	8	*7*	10	*13*
Far West	6	*5*	4	*5*
Northern NSW	14	*13*	6	*8*
Don't know	5	*4*	na	*na*
Private or unfunded service	11	*10*	3	*4*
Other – all NSW	*	*	3	*4*
Total responses	**203**		**127**	

Notes: ‘n/a’ indicates fewer than 3 respondents. Round 1: respondents =112. Round 2: respondents =79. * indicates that this response was not provided in Round 1.

In Round 1, 40% of respondents provided services in areas that were all in the NDIS, and for 21%, the NDIS was in some of the areas they serviced. By contrast, in Round 2 the majority of service providers (84%) indicated that all areas that they serviced were in the NDIS, while most of the others indicated that some of the areas they serviced were in the NDIS (Table B- 25).

Table B- 25 Areas in the NDIS

	Round 1		Round 2	
Are your Health/FACS area/s currently in the NDIS?	**Number**	**Per cent**	**Number**	**Per cent**
Yes - All areas we service	45	*40*	66	*84*
Yes - Some areas we service	23	*21*	10	*13*
Not sure	19	*17*	na	*na*
Not yet	25	*22*	na	*na*
Total	**112**	***100***	**79**	***100***

Notes: 'n/a' indicates fewer than 3 respondents.

In Round 1, around half (51%) of the service providers were offering services under the NDIS, one-third (34%) were not, and 14% were unsure, while in Round 2, 76% were offering services under the NDIS and 20% were not (Table B- 26).

Table B- 26 NDIS services

	Round 1		Round 2	
Is your organisation currently providing services under the NDIS?	**Number**	**Per cent**	**Number**	**Per cent**
Yes	57	*51*	60	*76*
No	38	*34*	16	*20*
Not sure	16	*14*	3	*4*
Total	**111**	***99***	**79**	***100***

Notes: Round 1: Missing = 1. May not sum to 100% due to rounding

Among those organisations providing services under the NDIS in Round 1, just over half (54%) had provided services since 2015, and another one-third began in 2016, whereas in Round 2, 10% had commenced in 2013, around one quarter each in 2015 and 2016 and 38% in 2017 (Table B- 27).

Table B- 27 When commenced services under the NDIS

	Round 1		Round 2	
When did your organisation start providing services under the NDIS?	**Number**	**Per cent**	**Number**	**Per cent**
2013/14	*	*	7	*12*
2015	31	*54*	16	*27*
2016	20	*35*	14	*23*
2017	6	*11*	23	*38*
Total	**57**	***100***	**60**	***100***

Notes: Question only asked of respondents who indicated 'yes' in Table B- 26.* indicates response not available in Round 1.

Just under half (45%) of survey respondents, who indicated that they were providing services under the NDIS or not sure about whether they were in Round 1, were from organisations that were transition providers/community partners, compared to 67% in Round 2 (Table B- 28). In Round 1, the majority of these organisations (79% or 26 organisations) had commenced in 2016, with the rest in 2017 (21%, 7 organisations), while in Round 2 just over half (57%) had commenced in 2017 and 43% commenced in 2016.

Table B- 28 ECEI Transition providers/partners

	Round 1		Round 2	
Is your organisation an Early Childhood Early Intervention (ECEI) transition provider/community partner?	**Number**	**Per cent**	**Number**	**Per cent**
Yes	33	*45*	42	*67*
No	29	*40*	n/a	*n/a*
Not sure	11	*15*	n/a	*n/a*
Total	**73**	***100***	**63**	***100***

Notes: Respondents asked this question only if they answered 'yes' or 'not sure' in Table B- 26. n/a indicates data confidentialised due to small cell sizes.

Respondents were asked about the types of support provided to children (Table B- 29). The most common forms of support for 80% or more of providers in both rounds of the survey included communication, interacting with other children and adults, playing, behaviour, participation in early education or school, and transition to next setting. In Round 2 only, over 80% of providers also indicated that they provided support for the development of self-help skills such as toilet training, feeding, dressing and sensory processing issues. Overall, respondents in Round 2 were more likely to report that they provided support for a range of other activities, which may be a result of the different profile of the types of services the respondents were from in the two surveys.

Table B- 29 Types of support provided to children

	Round 1		Round 2	
At the moment, are you or your organisation providing support to children for any of the following? Tick all that apply.	**Number**	**Per cent**	**Number**	**Per cent**
Communication (understanding and/or telling their wants and needs)	97	*87*	67	*85*
Playing	93	*83*	65	*82*
Interacting with other children and adults	96	*86*	67	*85*
Behaviour	91	*81*	65	*82*
Sleep	45	*40*	42	*53*
Movement and being physically independent	64	*57*	57	*72*
Development of self-help skills such as toilet training, feeding, dressing	80	*71*	65	*82*
Sensory processing issues	83	*74*	64	*81*
Learning at school	64	*57*	59	*75*
Participation in early childhood education or school	93	*83*	69	*87*
Community access, e.g. going shopping, attending playgroup	45	*40*	50	*63*
Transition to next setting, e.g. early childhood setting or school	90	*80*	63	*80*
Planning and coordination of services	50	*45*	53	*67*
Medical needs	23	*21*	20	*25*
Other - Write In	11	*10*	5	*6*

Notes: Number of respondents: Round 1 = 112, Round 2=79.

The types of support provided to parents and family members was similar in both rounds of the survey (Table B- 30): most organisations were engaged in providing referrals (88% in Round 1, 89% in Round 2), information and education around parenting (78% in Round 1 and 77% in Round 2), and accessing funding for early childhood interventions (71% in Round 1 and 76% in Round 2). In addition, Round 1 respondents indicated that they provided advocacy and emotional support, support around trauma, domestic violence, homelessness and child protection, education around hearing loss, networking with other therapists, support to access ECEC and transition to school, and Certificate III in Disability Support Work. In Round 2, other types of support included diagnosis and assessment, nutrition, writing ECEI plans and orientation and mobility skills.

Table B- 30 Support provided to parents

	Round 1		Round 2	
At the moment, are you or your organisation providing support to parents or other family members for any of the following? Tick all that apply.	**Number**	**Per cent**	**Number**	**Per cent**
Information and education around parenting	87	*78*	61	*77*
Referral to services	98	*88*	70	*89*
Mental health support or counselling	31	*28*	29	*37*
Accessing funding for early childhood intervention	79	*71*	60	*76*
Parent/carer support group	49	*44*	42	*53*
Sibling support	24	*21*	27	*34*
Other - Write In	13	*12*	na	*na*

Notes: Total respondents: Round 1 = 112. Round 2 = 79

Transition to the NDIS

Respondents were asked questions about changes that they had observed since the NDIS started in their area. The findings from these questions for Rounds 1 and 2 are outlined in Table B- 31 and Table B- 32 and Figure B- 9 to Figure B- 17. The following figures compare the responses to these questions for Rounds 1 and 2. In interpreting the figures, the differing service provider organisation profiles should be borne in mind; that is, in Round 2 the service providers were predominantly providing ECI or disability specialist services.

Overall, the respondents in Round 2 compared to those in Round 1 of the survey indicated that there was ‘a lot more’ or ‘somewhat more’ with respect to:

- number of service types your organisation now provides (Figure B- 9)
- the variety of services families now want (Figure B- 10)
- workload in your organisation (Figure B- 14)
- the number of staff your organisation employs now (Figure B- 15)
- the amount of supervision staff at your organisation need. (Figure B- 16)

The main aspect where respondents indicated that there were ‘a lot less’ in Round 2 compared to Round 1 was in respect of ‘the number of ECI places available in your area’ (Figure B- 12)

Table B- 31 Changes since the NDIS (percentages) Round 1

Since the NDIS started in your area, what changes have you observed to the following aspects of your work and service system you work in.	A lot more	Some-what more	No change	Some-what less	A lot less	Don't know	Total %	n
Number of service types your organisation now provides	*16*	*22*	*42*	*6*	*6*	*8*	*100*	86
The variety of services families now want	*17*	*37*	*37*	*n/a*	*n/a*	*7*	*100*	87
The number of ECI service providers in your area	*15*	*29*	*22*	*10*	*n/a*	*23*	*100*	87
The number of ECI places available in your area	*6*	*17*	*25*	*14*	*7*	*31*	*100*	84
Staff turnover in your organisation	*9*	*19*	*65*	*n/a*	*n/a*	*3*	*100*	86
Workload in your organisation	*44*	*33*	*22*	*n/a*	*n/a*	*n/a*	*100*	85
The number of staff your organisation employs now	*16*	*21*	*53*	*7*	*n/a*	*n/a*	*100*	85
The amount of supervision that staff at your organisation need	*14*	*37*	*43*	*n/a*	*n/a*	*6*	*100*	86
The amount of specialist training and mentoring that staff at your organisation need	*21*	*43*	*31*	*n/a*	*n/a*	*5*	*100*	86

Notes: ‘n/a’ indicates fewer than 3 respondents, including zero. Questions asked only of respondents who indicated ‘yes in all areas we service’, ‘yes - in some areas we service’ or ‘not sure’ to the question about providing services in areas currently in the NDIS (Table B- 25).

Table B- 32 Changes since the NDIS (percentages) Round 2

Since the NDIS started in your area, what changes have you observed to the following aspects of your work and service system you work in.	A lot more	Some-what more	No change	Some-what less	A lot less	Don't know	Total %	Total n
Number of service types your organisation now provides	26	31	32	5	na	na	100	74
The variety of services families now want	23	43	24	5	na	6	101	75
The number of ECI service providers in your area	20	28	25	13	na	11	100	75
The number of ECI places available in your area	9	12	21	16	20	21	99	75
Staff turnover in your organisation	16	19	52	na	4	7	101	75
Workload in your organisation	64	28	5	na	na	na	100	75
The number of staff your organisation employs now	21	31	37	5	na	4	99	75
The amount of supervision that staff at your organisation need	28	36	28	na	na	4	98	74
The amount of specialist training and mentoring that staff at your organisation need	31	39	24	na	na	5	101	75

Notes: 'n/a' indicates fewer than 3 respondents, including zero. Questions asked only of respondents who indicated 'yes in all areas we service', 'yes - in some areas we service' or 'not sure' to the question about providing services in areas currently in the NDIS (Table B- 25). * percentages may not sum to 100 due to rounding.

Figure B- 9 Number of service types your organisation now provides

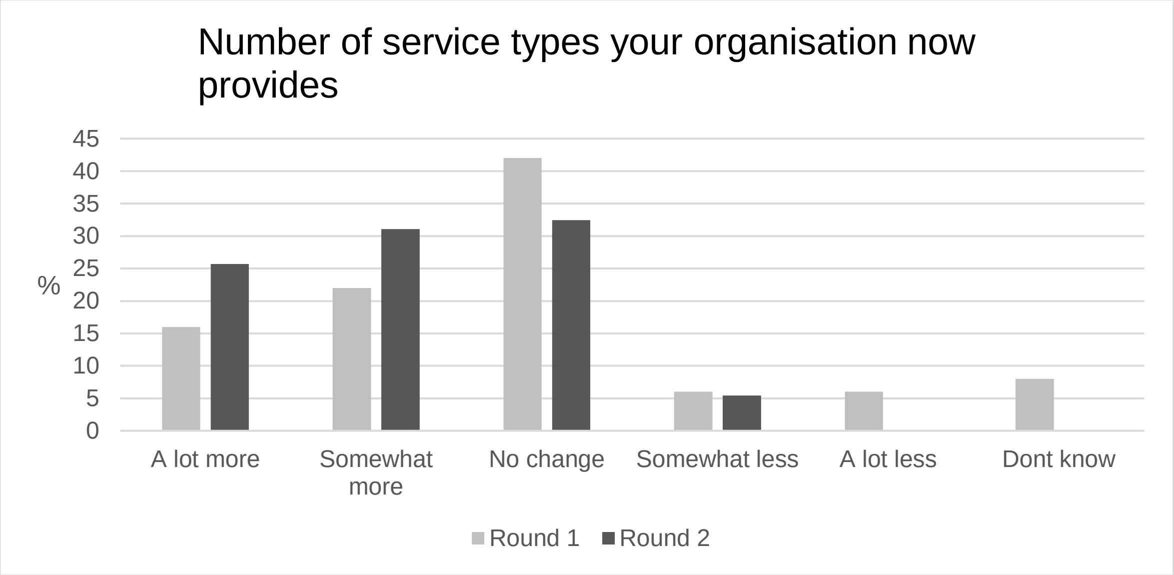


Figure B- 10 The variety of services families now want

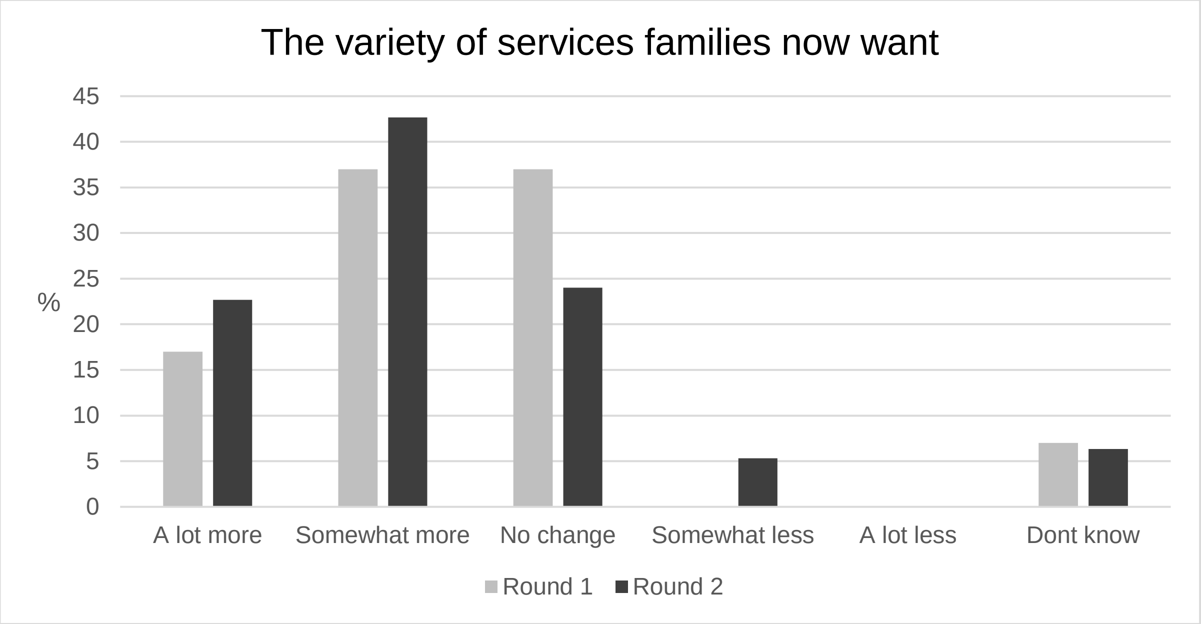


Figure B- 11 The number of ECI service providers in your area

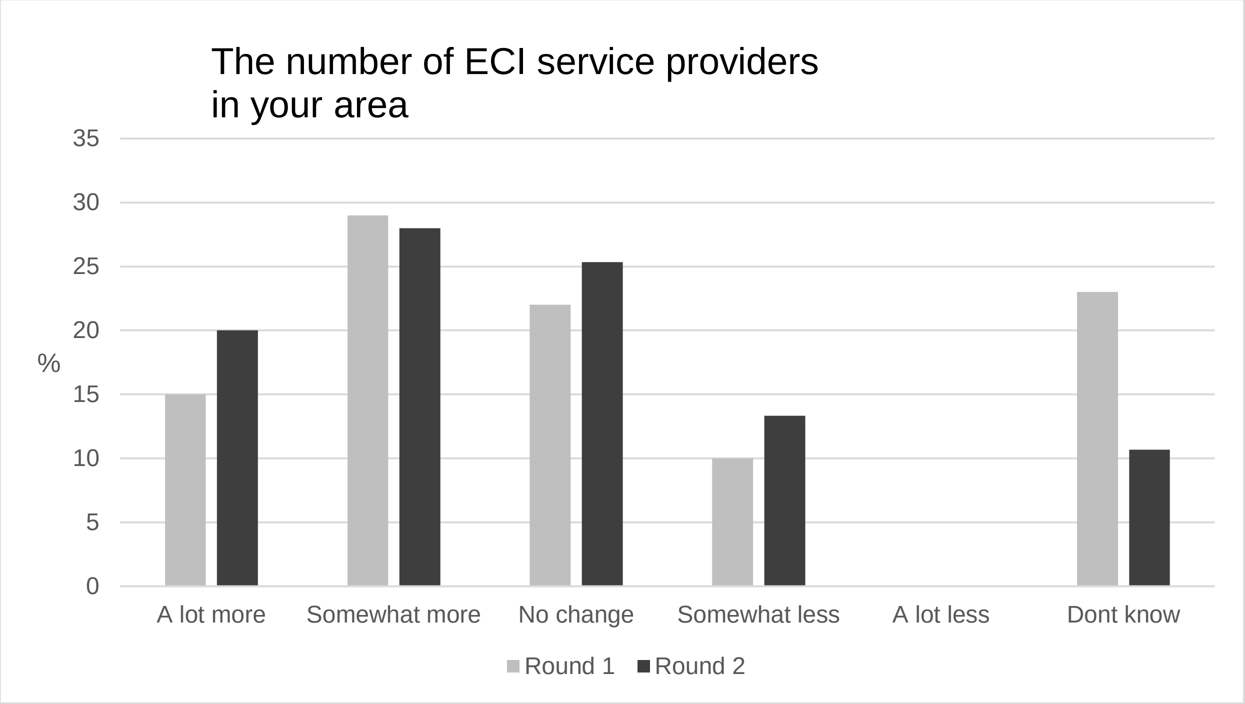


Figure B- 12 The number of ECI places available in your area

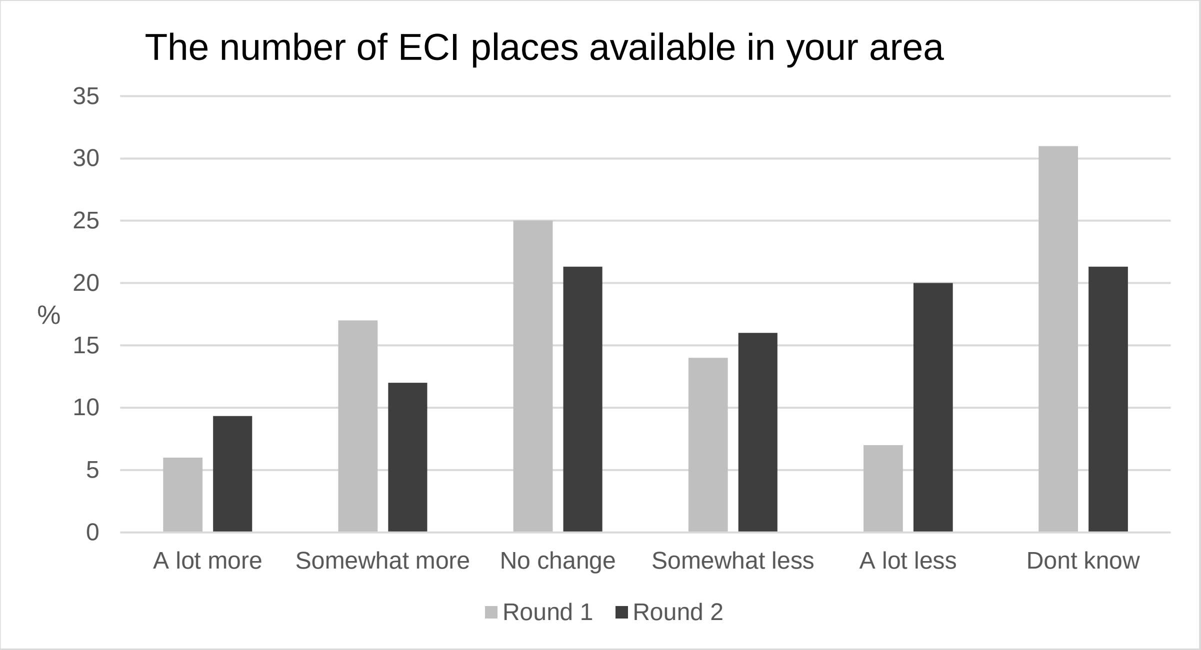


Figure B- 13 Staff turnover in your organisation

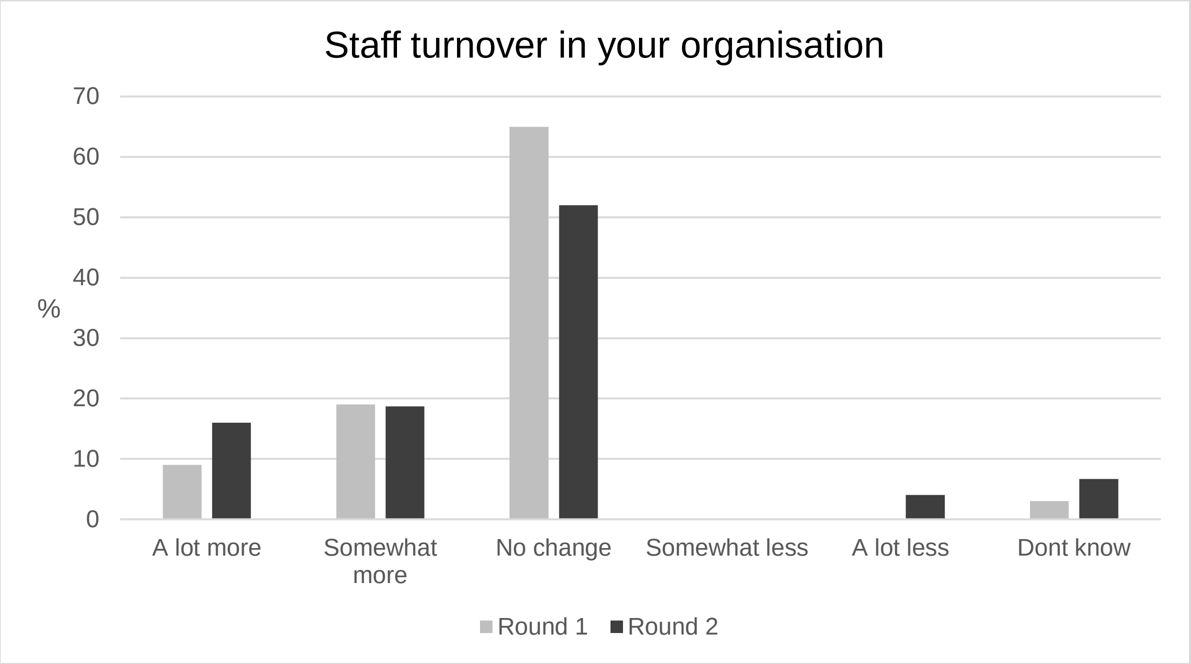


Figure B- 14 The workload in your organisation

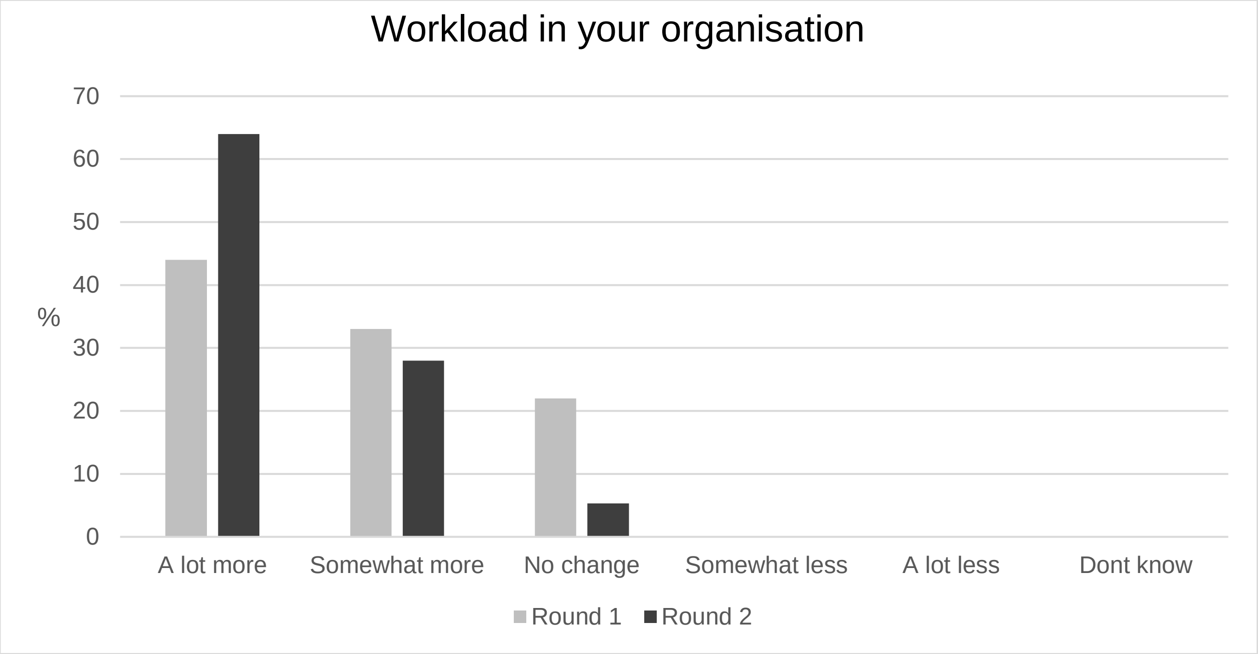


Figure B- 15 The number of staff your organisation employs now

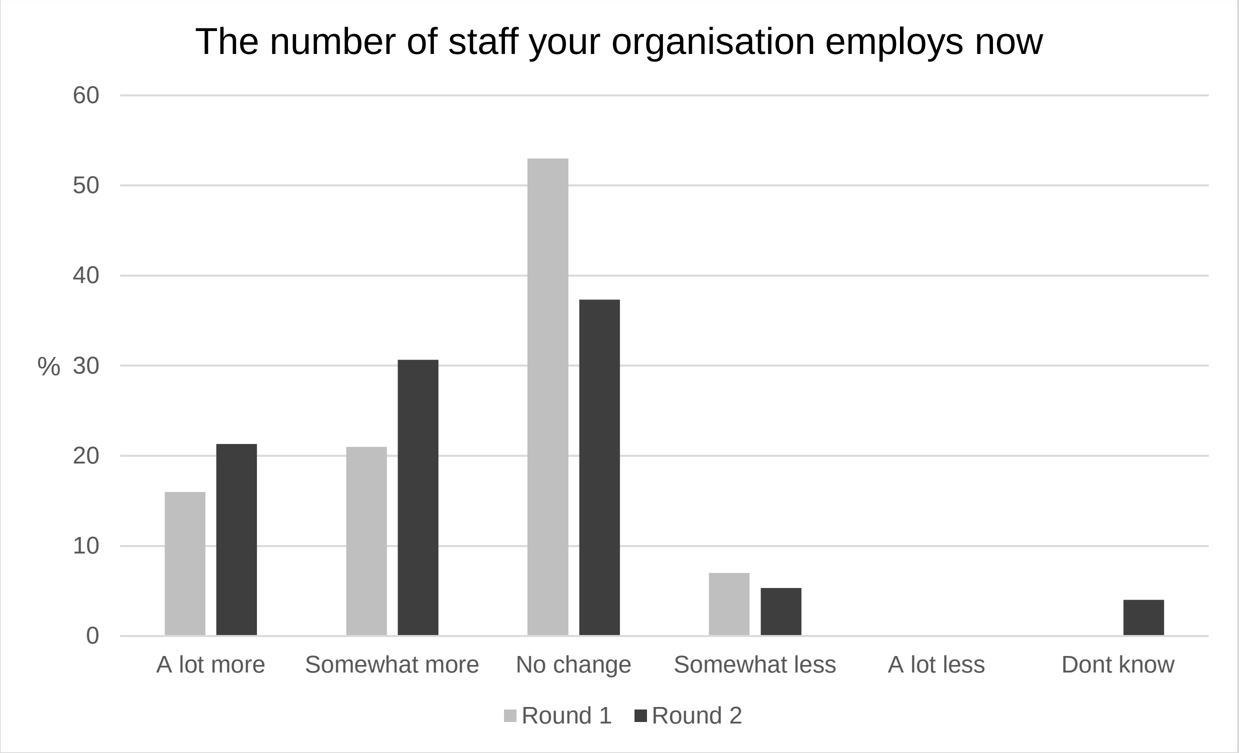


Figure B- 16 The amount of supervision staff at your organisation need

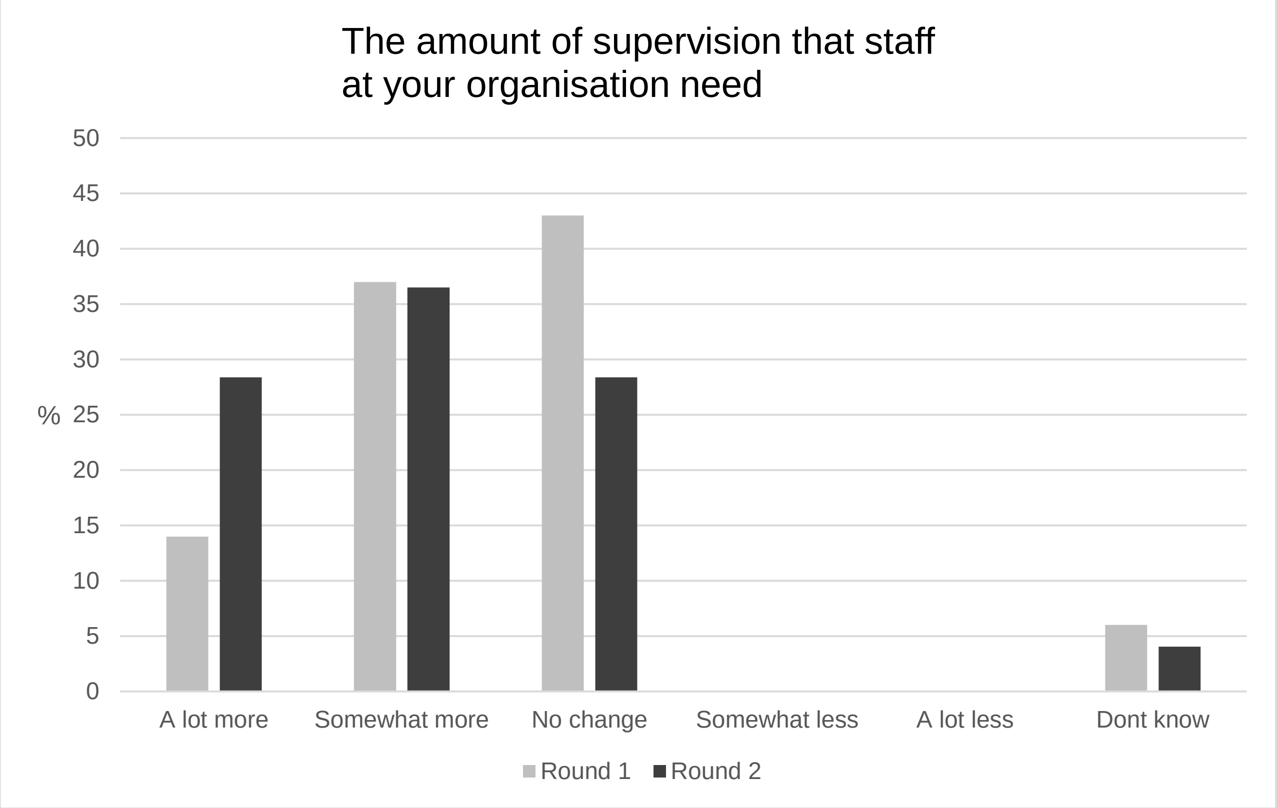
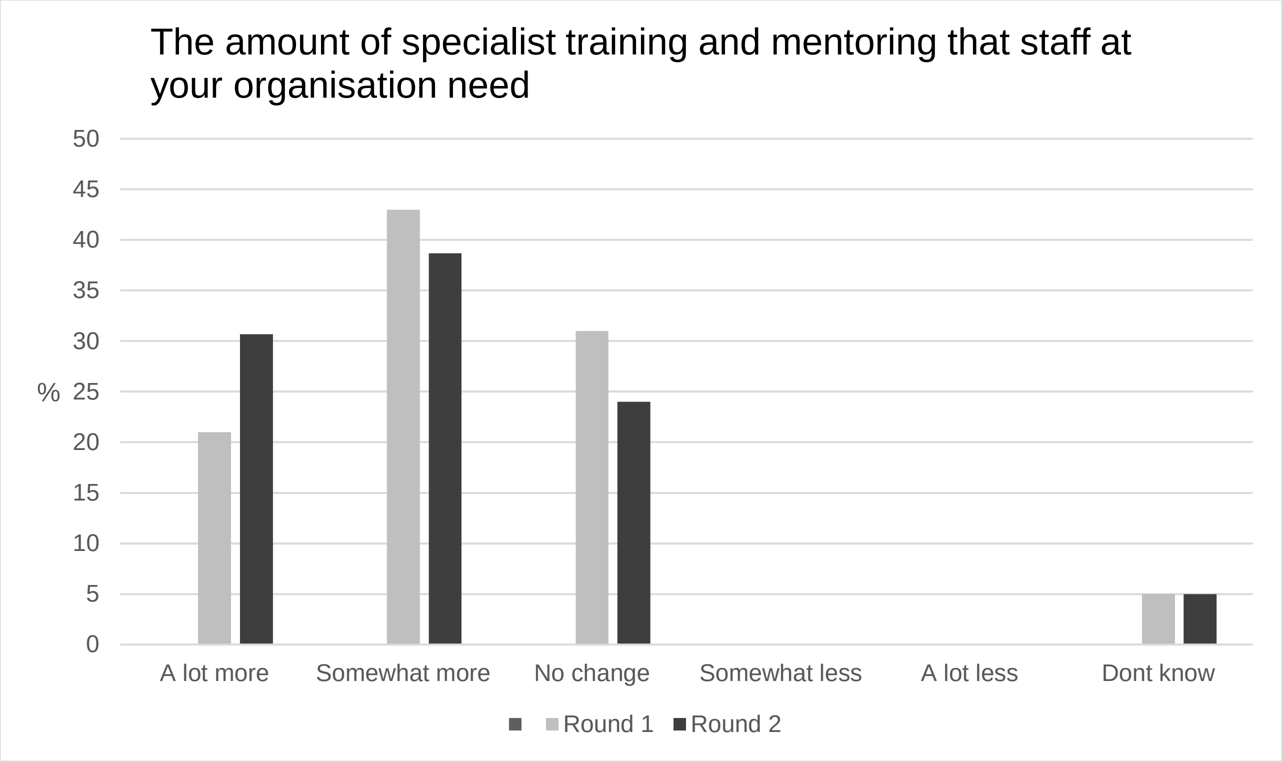


Figure B- 17 The amount of specialist training and mentoring staff at your organisation need



Respondents were asked about changes in aspects of their ECI services, which are outlined in Table B- 33 to Table B- 37 and Figure B- 18 to Figure B- 25. A relatively small number of respondents in both rounds replied to these questions (16-17 in Round 1 and 29 in Round 2), as they had to be both providing ECI services (Table B- 22) and providing services in areas currently in the NDIS (or not sure if they were) (Table B- 25). Therefore, the answers must be interpreted with caution. Overall, among this small number of respondents in both rounds, there was an indication of increases in relation to:

- amount of collaboration the service has with families
- number of children on the service's waiting list
- number of children on the waiting lists of health services they refer to.

In Round 2 there was also an increase in:

- the number of children the service supports.

Among these respondents in both rounds there was a tendency to report a decrease in:

- ease of understanding a child's needs based on the plans provided
- ease of travelling to support children in their natural environments
- ease of covering no-show/cancellation costs
- sustainability of the service as an organisation
- ease of filling vacant positions.

As noted above, a small number of respondents answered these questions, so the answers cannot be considered broadly representative.

Table B- 35 outlines the percentages for these responses in Round 2 for the ECI and disability specialist services, as in that round the questions were asked of both types of services. The responses show a similar pattern to those from the ECI providers only, with the same factors showing tendencies for increases and decreases.

Table B- 33 Changes in ECI services (numbers) Round 1

Since the NDIS started in your area, what changes have you observed to the following aspects of your ECI service?	A lot more	Some-what more	No change	Some-what less	A lot less	Don't know	n
Ease of servicing families, given the billable hours model	n/a	5*	7	4	n/a	n/a	16
The number of children your service support	n/a	7*	4	5*	n/a	n/a	16
The amount of collaboration your service has with families	3	4	8	n/a	n/a	n/a	17
The number of children on your service's waiting list	3	4	4	4*	n/a	n/a	17
The number of children on the waiting lists of health services you refer to	4	3	n/a	n/a	n/a	8	17
Ease of understanding a child's needs based on the plans provided	n/a	n/a	7	3	4	n/a	17
Ease of travelling to support children in their natural environments	n/a	n/a	6	5	4	n/a	17
Ease of covering no show/cancellation costs	n/a	n/a	n/a	5	6	3	17
Sustainability of your service as an organisation	n/a	n/a	n/a	6	6	n/a	17
Ease of filling vacant positions	n/a	n/a	4	4	4	4	17

Notes: 'n/a' indicates fewer than 3 respondents, including zero. This table does not report percentages since overall response numbers were low. Questions asked only of respondents who indicated that they were both providing ECI services (Table B- 22) and who indicated 'yes in all areas we service', 'yes - in some areas we service' or 'not sure' to the question about providing services in areas currently in the NDIS (Table B- 25).

Table B- 34 Changes in ECI services (numbers) Round 2

Since the NDIS started in your area, what changes have you observed to the following aspects of your ECI service?	A lot more	Some-what more	No change	Some-what less	A lot less	Don't know	n
Ease of servicing families, given the billable hours model	na	3	4	10	na	4	29
The number of children your service support	8	10	na	7	na	na	29
The amount of collaboration your service has with families	6	6	11	4	na	na	29
The number of children on your service's waiting list	14	4	5	na	na	3	29
The number of children on the waiting lists of health services you refer to	10	7	5	na	na	7	29
Ease of understanding a child's needs based on the plans provided	na	9	7	6	na	5	29
Ease of travelling to support children in their natural environments	na	4	7	8	7	na	29
Ease of covering no show/cancellation costs	3	na	5	5	10	6	29
Sustainability of your service as an organisation	na	4	4	7	6	6	29
Ease of filling vacant positions	3	na	8	4	9	4	29

Notes: 'n/a' indicates fewer than 3 respondents, including zero. This table does not report percentages since overall response numbers were low. Questions asked only of respondents who indicated that they were both providing ECI services (Table B- 22) and who indicated 'yes in all areas we service', 'yes - in some areas we service' or 'not sure' to the question about providing services in areas currently in the NDIS (Table B- 25).

Table B- 35 Changes in ECI services (percentages) for both ECI and Specialist Disability Services

Since the NDIS started in your area, what changes have you observed to the following aspects of your ECI service?	**A lot more**	**Some-what more**	**No change**	**Some-what less**	**A lot less**	**Don't know**	**%**	**n**
Ease of servicing families, given the billable hours model	*6*	*12*	*12*	*34*	*22*	*14*	*100*	50
The number of children your service support	*24*	*37*	*8*	*18*	*na*	*8*	*99*	49
The amount of collaboration your service has with families	*18*	*22*	*38*	*12*	*na*	*6*	*100*	50
The number of children on your service's waiting list	*40*	*18*	*24*	*6*	*na*	*8*	*100*	50
The number of children on the waiting lists of health services you refer to	*38*	*18*	*14*	*na*	*na*	*30*	*100*	50
Ease of understanding a child's needs based on the plans provided	*na*	*26*	*26*	*18*	*12*	*16*	*100*	50
Ease of travelling to support children in their natural environments	*6*	*14*	*26*	*26*	*20*	*8*	*100*	50
Ease of covering no show/cancellation costs	*6*	*10*	*18*	*14*	*33*	*18*	*99*	49
Sustainability of your service as an organisation	*6*	*18*	*12*	*24*	*20*	*20*	*100*	50
Ease of filling vacant positions	*6*	*10*	*18*	*12*	*38*	*16*	*100*	50

Notes: 'n/a' indicates fewer than 3 respondents, including zero. This table reports percentages since overall response numbers were higher in Round 2. Questions asked only of respondents who indicated that they were both providing ECI services or Specialist disability services (with ECI being part, but not all, of support provided) (Table B- 22) and who indicated 'yes in all areas we service', 'yes - in some areas we service' or 'not sure' to the question about providing services in areas currently in the NDIS (Table B- 25).

Table B- 36 and Table B- 37 and Figure B- 18 to Figure B- 25 report on perceived changes in support for specific groups since the introduction of the NDIS. Overall, the responses suggest that there has been increased ease between Rounds 1 and 2 in providing support for children with an NDIS individualised package. However, the responses in Round 2 suggest that it has become harder to access support for children:

- accessing ECEI funding only
- not accessing NDIS but who will be eligible
- who are not eligible for the NDIS

- from culturally and linguistically diverse communities
- from Aboriginal and Torres Strait Islander backgrounds
- with complex needs
- in families at risk.

Table B- 36 Support for specific groups since NDIS (percentages) Round 1

Since the NDIS started in your area, how easy or hard has it been to provide appropriate support for the following groups?	Very easy	Easy	Neither easy nor hard	Hard	Very hard	Don't know	N/A	Total %	n
Children with an NDIS individualised package	*n/a*	*13*	*38*	*17*	*9*	*13*	*8*	*100*	87
Children accessing ECEI funding only	*n/a*	*6*	*21*	*30*	*9*	*21*	*12*	*100*	86
Children not accessing NDIS but who will be eligible	*n/a*	*6*	*15*	*29*	*30*	*15*	*5*	*100*	87
Children who are not eligible for the NDIS	*3*	*3*	*21*	*23*	*34*	*10*	*5*	*100*	87
Aboriginal and Torres Strait Islander children	*n/a*	*5*	*47*	*7*	*8*	*21*	*12*	*100*	85
Culturally and linguistically diverse children	*n/a*	*n/a*	*45*	*16*	*13*	*14*	*9*	*100*	86
Children and families who are at risk	*n/a*	*n/a*	*23*	*27*	*23*	*13*	*12*	*100*	86
Children with complex needs	*n/a*	*n/a*	*18*	*37*	*26*	*11*	*7*	*100*	87

Notes: ‘n/a’ indicates fewer than 3 respondents, including zero. Questions asked only of respondents who indicated ‘yes in all areas we service’, ‘yes - in some areas we service’ or ‘not sure’ to the question about providing services in areas currently in the NDIS (Table B- 25).

Table B- 37 Support for specific groups since NDIS (percentages) Round 2

Since the NDIS started in your area, how easy or hard has it been to provide appropriate support for the following groups?	Very easy	Easy	Neither easy nor hard	Hard	Very hard	Don't know	N/A	Total %	n
Children with an NDIS individualised package	*7*	*16*	*36*	*19*	*8*	*8*	*7*	*101*	75
Children accessing ECEI funding only	*na*	*7*	*17*	*39*	*27*	*5*	*5*	*100*	75
Children not accessing NDIS but who will be eligible	*na*	*na*	*16*	*40*	*33*	*5*	*na*	*100*	75
Children who are not eligible for the NDIS	*na*	*4*	*19*	*29*	*41*	*4*	*na*	*100*	75
Aboriginal and Torres Strait Islander children	*na*	*5*	*39*	*25*	*16*	*8*	*5*	*100*	75
Culturally and linguistically diverse children	*na*	*4*	*32*	*28*	*17*	*9*	*8*	*100*	75
Children and families who are at risk	*na*	*na*	*27*	*32*	*31*	*na*	*4*	*100*	74
Children with complex needs	*na*	*na*	*28*	*28*	*36*	*na*	*na*	*100*	75

Notes: ‘n/a’ indicates fewer than 3 respondents, including zero. Questions asked only of respondents who indicated ‘yes in all areas we service’, ‘yes - in some areas we service’ or ‘not sure’ to the question about providing services in areas currently in the NDIS (Table B- 25).

The following figures compare responses in Rounds 1 and 2:

Figure B- 18 Supporting children with an NDIS package

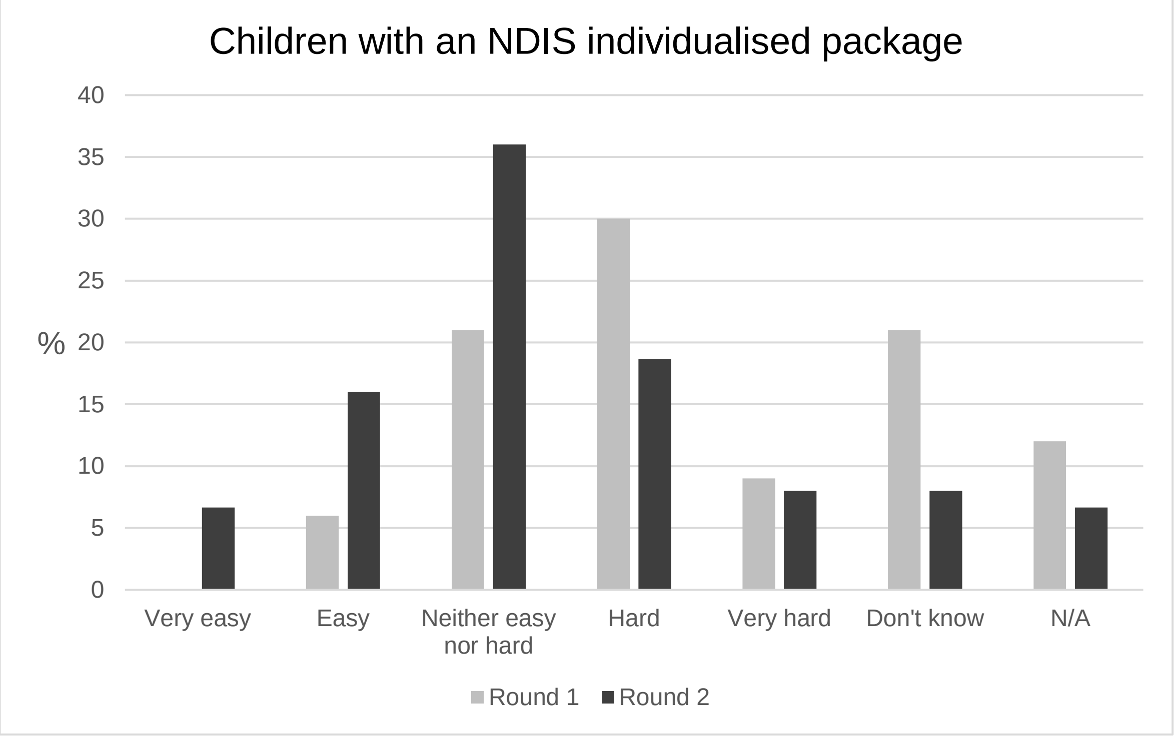


Figure B- 19 Supporting children accessing ECEI funding only

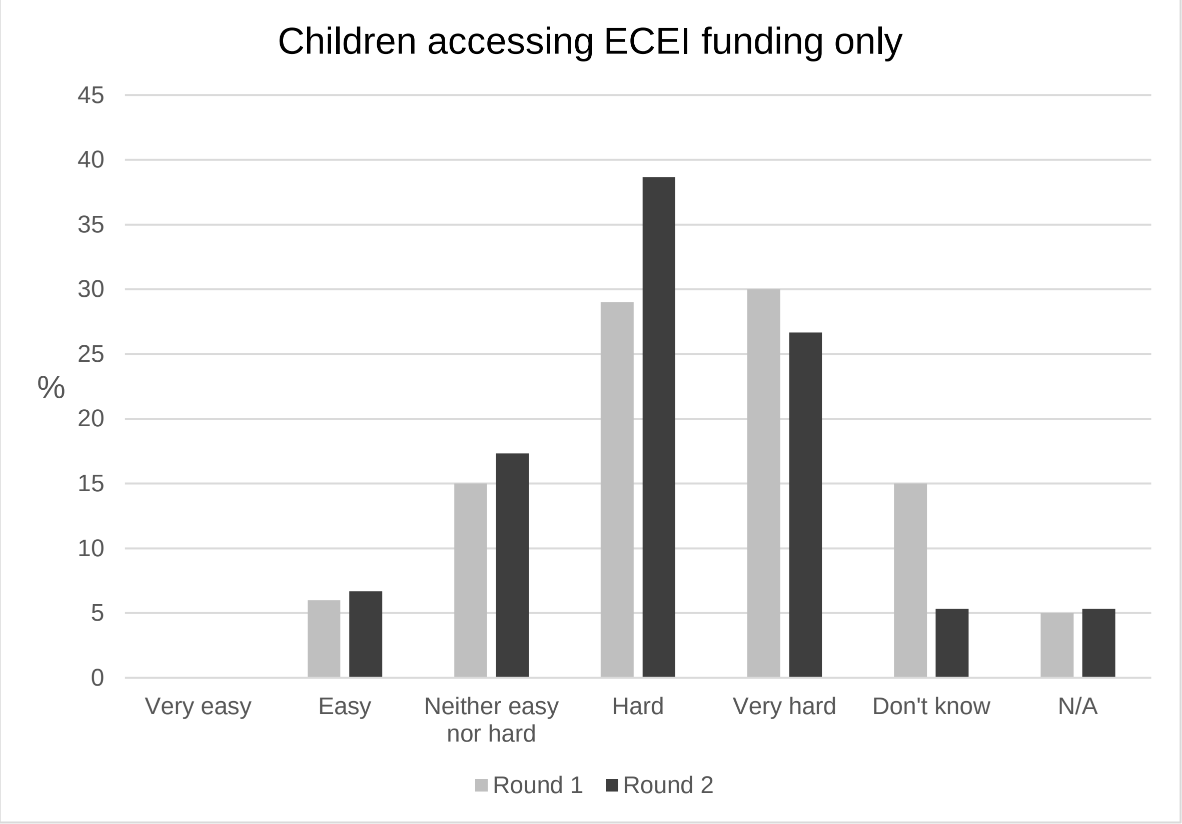


Figure B- 20 Supporting children who are not eligible for the NDIS

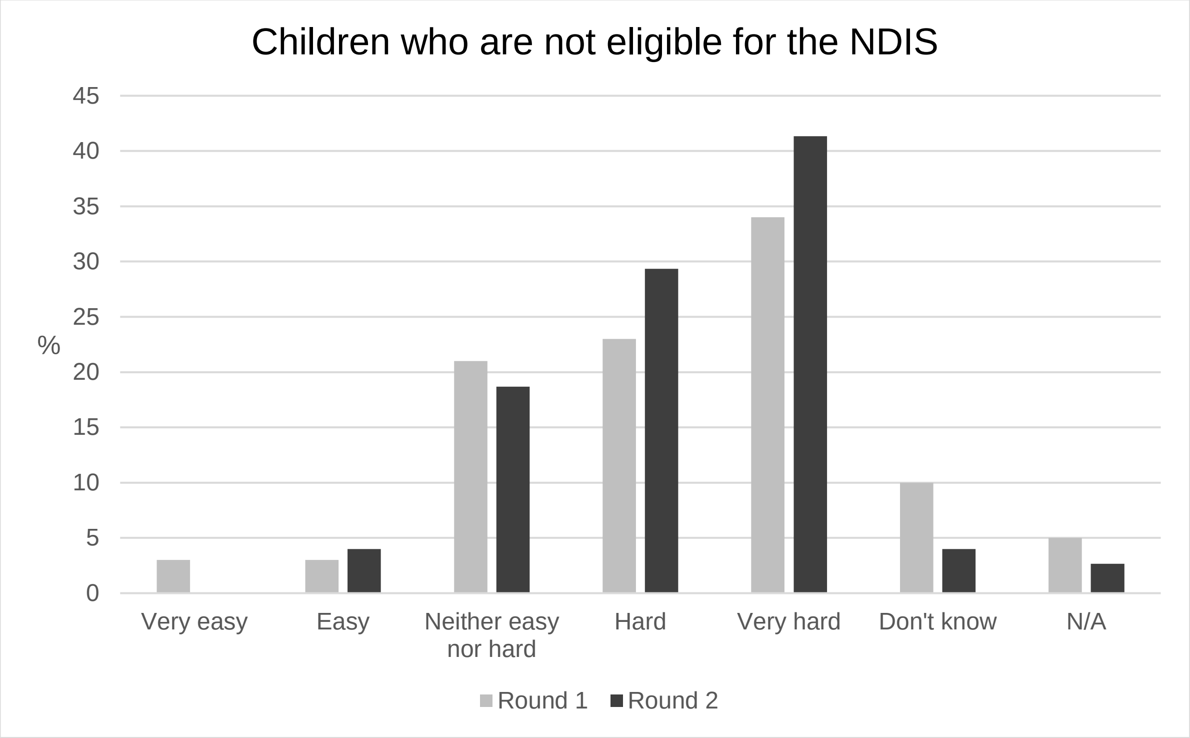


Figure B- 21 Supporting children who are not accessing NDIS but who will be eligible

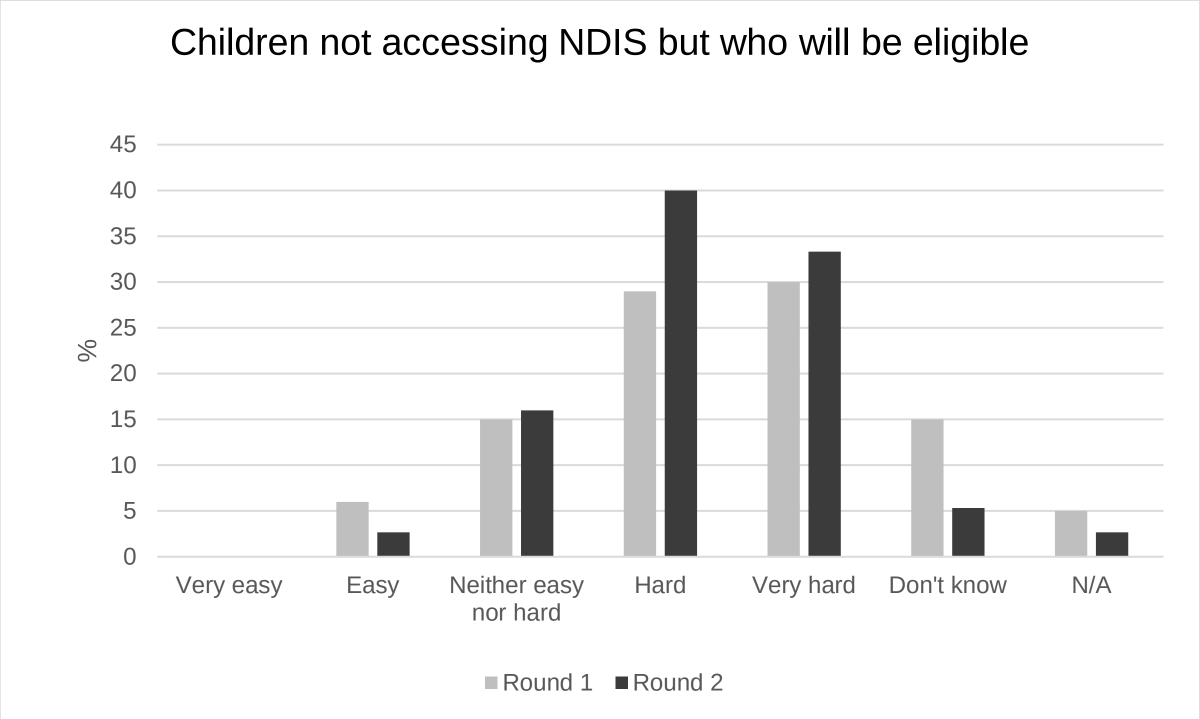


Figure B- 22 Supporting Aboriginal and Torres Strait Islander children

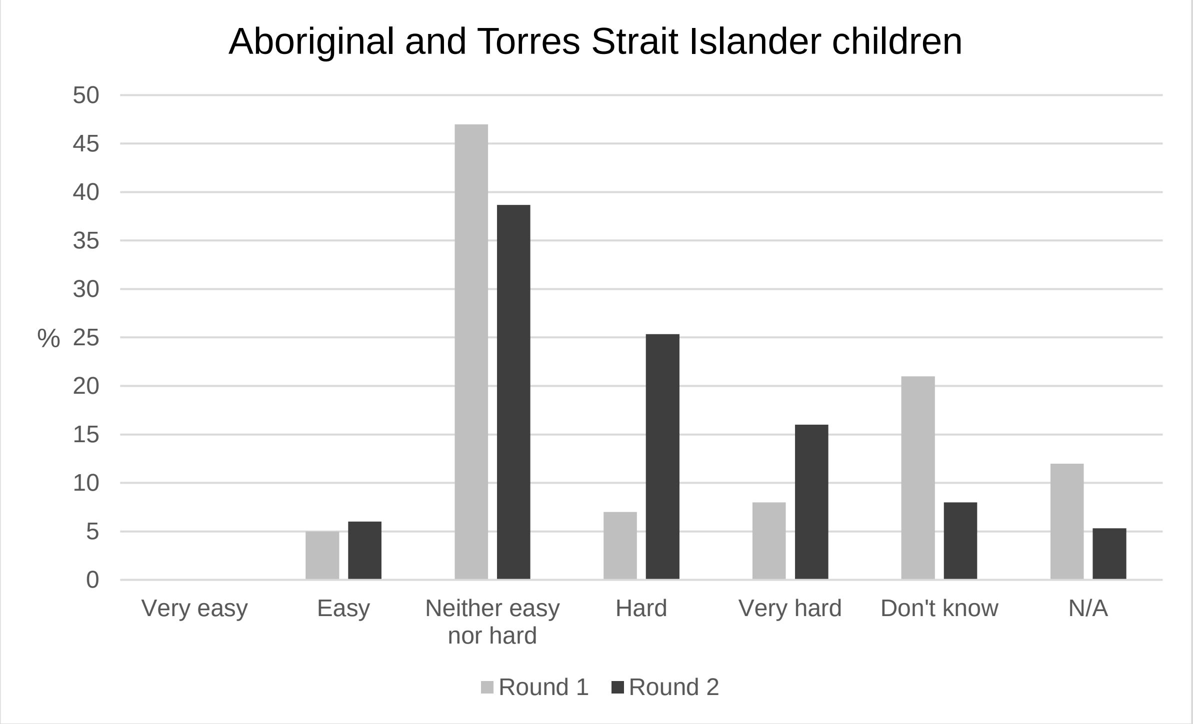


Figure B- 23 Supporting culturally and linguistically diverse children

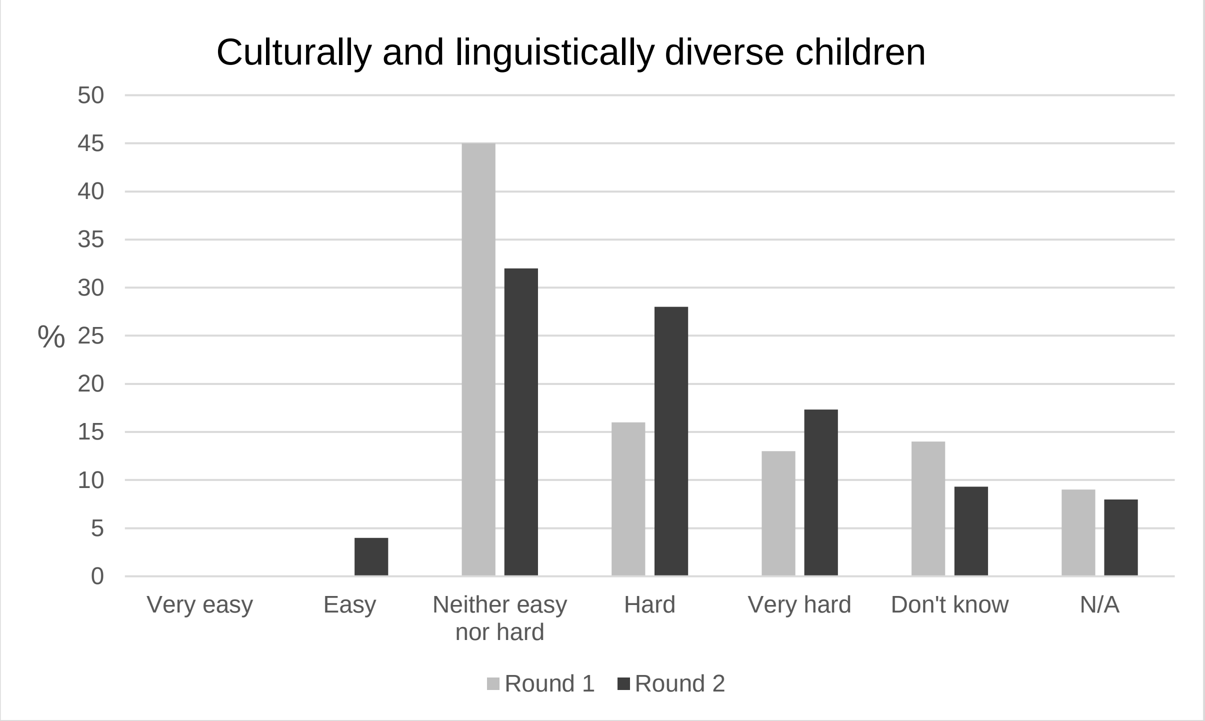


Figure B- 24 Supporting children and families who are at risk

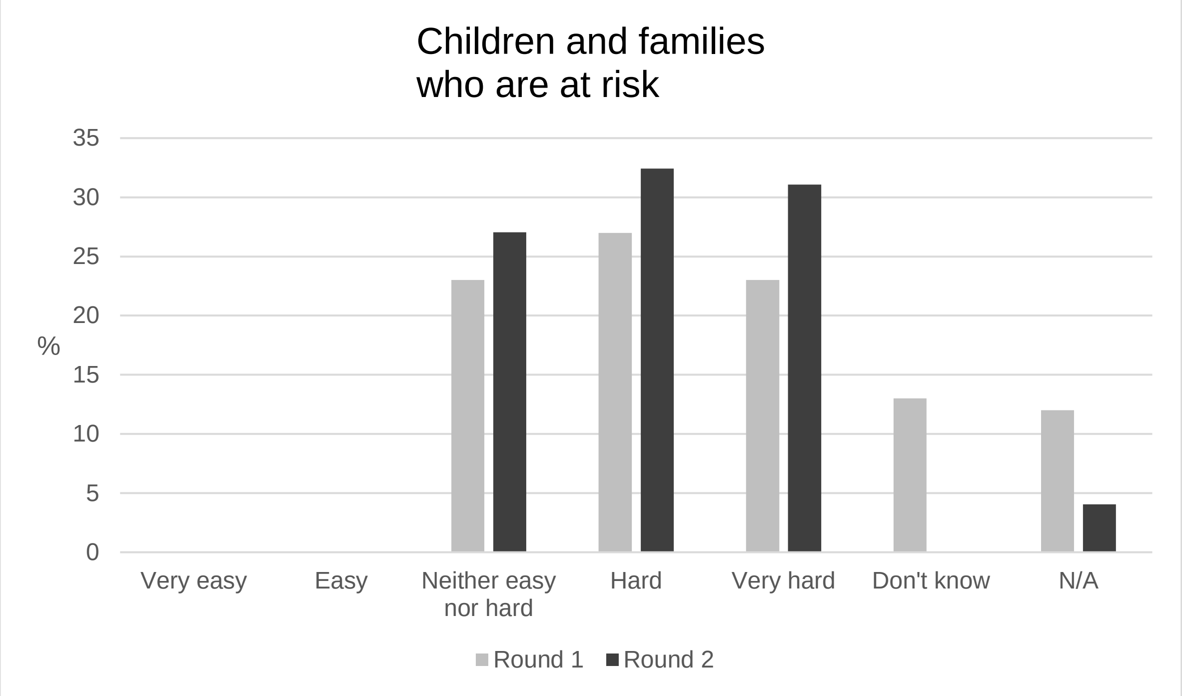


Figure B- 25 Supporting children with complex needs

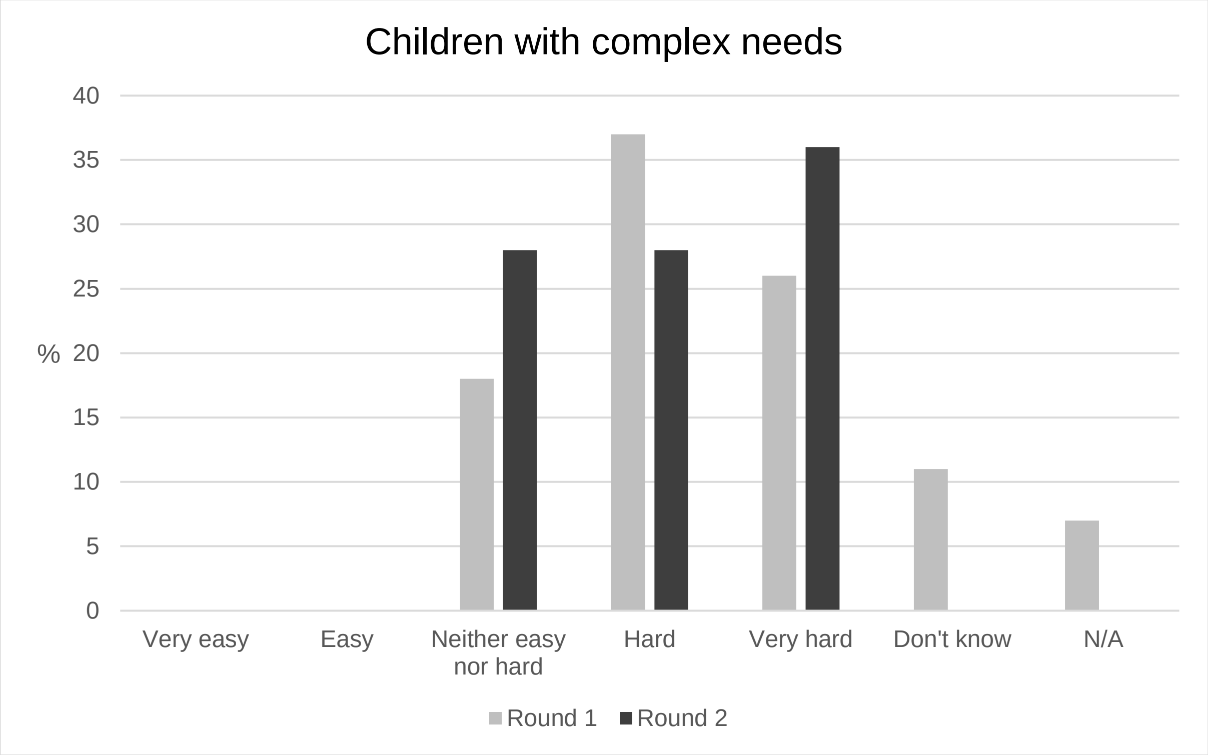


Table B- 38 to Table B- 41 outline the responses relating to changes in referrals to other services for ECI service providers and other services. Only small numbers responded in some cases, so the data should be interpreted with caution. Table B- 38 shows that the responses tended to indicate that there was not much change or it had become harder to refer to other services since the NDIS started in their area, but the numbers are small, so these findings are inconclusive.

Table B- 38 Ease of referral to other services since NDIS

Since the NDIS started in your area, how easy or hard has it been to refer out to other services?	Round 1 ECI services only Number	Round 2 ECI Services only Number	Round 2 ECI Services and specialist disability services Number
Very easy		n/a	n/a
Easy	n/a	n/a	n/a
Neither easy nor hard	7	13	25
Hard	7	11	16
Very hard	n/a	na	3
Total responses	**17**	**28**	**48**

Notes: 'n/a' indicates fewer than 3 respondents or data confidentialised. In Round 1 question was asked only of respondents who indicated that they were both providing ECI services (Table B- 22) and who indicated 'yes in all areas we service', 'yes - in some areas we service' or 'not sure' to the question about providing services in areas currently in the NDIS (Table B- 25).

Respondents who were from ECI services and had indicated that they were not yet in areas currently in the NDIS were asked how hard or easy it was to refer out to other services. In Round 1, the numbers of respondents were low (8), and half of this group indicated that it was easy (4). In Round 2,+ there were insufficient numbers to report a response to this question (Table B- 39).

Table B- 39 Current ease of referral to other services

At the moment, how easy or hard is it to refer out to other services?	Round 1 Number	Round 2 number
Easy	4	n/a
Neither easy nor hard	n/a	n/a
Hard	n/a	n/a
Total responses	**8**	**n/a**

Notes: 'n/a' indicates fewer than 3 respondents. Question asked only of respondents who indicated that they were both providing ECI services (Table B- 22) and who indicated 'not yet' to the question about providing services in areas currently in the NDIS (Table B- 25).

Other service providers

Organisations that were not ECI service providers exclusively but were in areas currently in the NDIS or not sure, responded to the question about how easy or hard it had been to refer to ECI services since the NDIS started. Of these, in Round 1 around half (53%) reported that it was neither easy nor hard, and 35% indicated that it had become harder (Table B- 40). The numbers in this category in Round 2 were much smaller, and most respondents indicated it had become harder or very hard.

Among the small number of other service providers in Round 1 who were not yet in areas in the NDIS, most indicated that they generally found it very easy, easy or neither easy nor hard to refer to ECI services (Table B- 41).

Table B- 40 Ease of referral to ECI services since NDIS (Non ECI services and Specialist disability services)

Since the NDIS started in your area, how easy or hard has it been to refer to ECI services?	Round 1		Round 2	
	Number	**Per cent**	**Number**	**Per cent**
Very easy	n/a	n/a	n/a	n/a
Easy	-n/a	n/a	n/a	n/a
Neither easy nor hard	28	60	7	28
Hard	11	23	9	36
Very hard	4	9	8	32
Total responses	**47**	**100**	**25**	**100**

Notes: Missing = 1. 'n/a' indicates fewer than 3 respondents or data confidentialised. Question was asked only of respondents who had indicated that they were not providing ECI services in Table B- 22 and who indicated 'yes in all areas we service', 'yes - in some areas we service' or 'not sure' to the question about providing services in areas currently in the NDIS (Table B- 25).

Table B- 41 Current ease of referral to ECI services

At the moment, how easy or hard is it to refer to ECI services?	Round 1 Number	Round 2 Number
Very easy	n/a	
Easy	3	
Neither easy nor hard	8	
Hard	n/a	
Total responses	**17**	**0**

Notes: 'n/a' indicates fewer than 3 respondents or data confidentialised. Question was asked only of respondents who had indicated that they were not providing ECI services in Table B- 22 and who indicated 'not yet' to the question about providing services in areas currently in the NDIS (Table B- 25).

ECI service providers

Table B- 42 and Table B- 43 report on changes in the amount and quality of collaboration with other service providers since the NDIS. A relatively small number of service providers who were from ECI services and in the areas currently in the NDIS responded to these questions. In Round 1 the majority of respondents to these questions reported no change to the amount or quality of collaboration, whereas in Round 2, most respondents reported no change or more or better-quality collaboration.

Table B- 42 Amount of collaboration since NDIS

Since the NDIS started in your area, how has your *amount* of collaboration with other service providers changed?	Round 1 ECI services only	Round 2 ECI Services only	Round 2 ECI Services and Specialist disability services
	Number	Number	Number
Much more collaboration	n/a	n/a	n/a
More collaboration	n/a	10	15
Neither more nor less collaboration	8	9	19
Less collaboration	4	n/a	6
Much less collaboration	4	5	/n/a
Total responses	**17**	**28**	**49**

Notes: 'n/a' indicates fewer than 3 respondents or data confidentialised. Question asked only of respondents who indicated that they were both providing ECI services (Table B- 22) and who indicated 'yes in all areas we service', 'yes - in some areas we service' or 'not sure' to the question about providing services in areas currently in the NDIS (Table B- 25).

Table B- 43 Quality of collaboration since NDIS

Since the NDIS started in your area, how has the quality of your collaboration with other service providers changed?	Round 1 ECI services only	Round 2 ECI Services only	Round 2 ECI Services and Specialist disability services
	Number	Number	Number
Much better collaboration	n/a	n/a	n/a
Better collaboration	n/a	7	11
Neither better nor worse collaboration	9	12	22
Worse collaboration	4	4	10
Much worse collaboration	n/a	n/a	n/a
Total responses	**16**	**28**	**49**

Notes: Missing = 1. 'n/a' indicates fewer than 3 respondents or data confidentialised. Question asked only of respondents who indicated that they were both providing ECI services (Table B- 22) and who indicated 'yes in all areas we service', 'yes - in some areas we service' or 'not sure' to the question about providing services in areas currently in the NDIS (Table B- 25).

Table B- 44 and Table B- 45 report on responses to the extent and quality of current collaboration. Few service providers responded to these questions (8 in Round 1 only), as they were only asked of service providers who were ECI services and not yet in areas in the NDIS.

Table B- 44 Extent of current collaboration

At the moment, how much do you collaborate with other service providers?	Round 1 Number	Round 2 Number
Very much - 1	4	n/a
2	n/a	n/a
3	n/a	n/a
Total responses	**8**	**n/a**

Notes: Scale of 1 'very much' to 5 'not at all'. 'n/a' indicates fewer than 3 respondents. Questions asked only of respondents who indicated that they were both providing ECI services (Table B- 22) and who indicated 'not yet' to the question about providing services in areas currently in the NDIS (Table B- 25).

Table B- 45 Quality of current collaboration

At the moment, how would you rate the quality of your collaboration with other service providers?	Round 1 Number	Round 2 Number
Very good quality	n/a	n/a
Good quality	5	n/a
Neither good	n/a	n/a
Total responses	**8**	n/a

Notes: 'n/a' indicates fewer than 3 respondents. Questions asked only of respondents who indicated that they were providing ECI services (Table B- 22) and indicated 'not yet' to the question about providing services in areas currently in the NDIS (Table B- 25).

Other service providers

Table B- 46 and Table B- 47 report on changes in the amount and quality of collaboration with ECI providers since the NDIS for other service providers. Relatively small numbers of services providers were in these categories, so results must be interpreted with caution. In Round 1, most respondents reported no change in the amount or quality of collaboration, and in Round 2, the responses were mostly no change or less or worse collaboration.

Table B- 46 Change in amount of collaboration with ECI providers since the NDIS

Since the NDIS started in your area, how has your amount of collaboration with ECI providers changed?	Round 1		Round 2	
	Number	Per cent	Number	Per cent
Much more collaboration	n/a	*n/a*	n/a	*n/a*
More collaboration	7	*15*	3	*12*
Neither more nor less collaboration	27	*59*	7	*28*
Less collaboration	7	*15*	7	*28*
Much less collaboration	/na	*n/a*	/na	*n/a*
Total responses	**46**	***100***	**27**	***100***

Notes: Missing = 3. Question was asked only of respondents who had indicated that they were not providing ECI services or Specialist Disability Services in Table B- 22 and who indicated 'yes in all areas we service', 'yes - in some areas we service' or 'not sure' to the question about providing services in areas currently in the NDIS (Table B- 25). 'n/a' indicates fewer than 3 respondents or data confidentialised.

Table B- 47 Change in quality of collaboration with ECI providers since the NDIS

Since the NDIS started in your area, how has the quality of your collaboration with ECI providers changed?	Round 1		Round 2	
	Number	Per cent	Number	Per cent
Much better collaboration	n/a	*n/a*	n/a	*n/a*
Better collaboration	5	*11*	n/a	*n/a*
Neither better nor worse collaboration	31	*67*	10	*40*
Worse collaboration	8	*17*	7	*28*
Much worse collaboration	n/a	*n/a*	6	*24*
Total responses	**46**	***100***	**25**	***100***

Notes: Missing = 3. Question was asked only of respondents who had indicated that they were not providing ECI services in Table B- 22 and who indicated ‘yes in all areas we service’, ‘yes - in some areas we service’ or ‘not sure’ to the question about providing services in areas currently in the NDIS (Table B- 25).

Table B- 48 and Table B- 49 describe the responses to questions on current amount and quality of collaboration with ECI providers. In Round 1, 17 service providers who were not from ECI services and not yet in areas currently in the NDIS gave responses to these questions. Around half (7) indicated no change in the amount of collaboration, while 6 indicated that the quality of their collaboration was good, and 5 indicated that it was neither good nor poor quality.

Table B- 48 Current amount of collaboration with ECI providers

At the moment, how much do you collaborate with ECI providers?	Round 1 Number	Round 2 Number
Much more collaboration	n/a	
More collaboration	n/a	
Neither more nor less collaboration	7	
Less collaboration	n/a	
Much less collaboration	n/a	
Total responses	**14**	**0**

Notes: ‘n/a’ indicates fewer than 3 respondents. Question asked only of respondents who indicated that they were not providing ECI services or Specialist Disability Services (Table B- 22) and who indicated ‘not yet’ to the question about providing services in areas currently in the NDIS (Table B- 25).

Table B- 49 Current quality of collaboration with ECI providers

At the moment, how would you rate the quality of your collaboration with ECI providers?	Round 1 Number	Round 2 Number
Very good quality	n/a	
Good quality	6	
Neither good nor poor quality	5	
Very poor quality	n/a	
Total responses	**14**	**0**

Notes: ‘n/a’ indicates fewer than 3 respondents. Question asked only of respondents who indicated that they were not providing ECI services (Table B- 22) and who indicated ‘not yet’ to the question about providing services in areas currently in the NDIS (Table B- 25).

Appendix C NDIA quarterly reports data

The following tables report on data drawn from the *National Disability Insurance Scheme COAG Disability Reform Council Quarterly Reports* prepared by the NDIA. The tables compare the data for Australia with the data for NSW as recorded in these reports. Exact sources for the data are outlined below each table. The NDIS Quarterly Report data contain information from July 2016 for each quarter about four different populations and the different tables refer to these different populations:

- ECEI participants
- children aged 0 to 6 years
- children 0 to school age (before school age)
- parents and carers of children aged 0-14 years

Table C- 1 shows that the number of children with plans through the ECEI gateway for NSW was reported as 1,807 in 2016-17 (Quarter 2) and in the 2017-18 Quarter 1 report this was 4,926. A total of 6,716 children in Australia were recorded with plans in the 2017-18 Quarter 1 report.

Table C- 1 Number of children with plans through the ECEI gateway by quarter, Australia and NSW (cumulative)

Quarter	Australia	NSW
2016-17 Q2	2,267⁽¹⁾	1,807⁽¹⁾
2016-17 Q3	2,439 ⁽²⁾	2,125 ⁽³⁾
2016-17 Q4	6,134 ⁽²,⁴⁾	4,330 ⁽³⁾ / 4,324 ⁽⁵⁾
2017-18 Q1	6,716 ⁽⁴⁾	4,926 ⁽⁵⁾

Sources:

(1) National Disability Insurance Scheme Launch Transition Agency (2016) *National Disability Insurance Scheme COAG Disability Reform Council Quarterly Report 31 December 2016,* Table 2-15 Approved Plans against bilateral estimates by jurisdiction - Q1 2013-14 to Q2 2016-17, page 59.

(2) National Disability Insurance Scheme Launch Transition Agency (2017) *National Disability Insurance Scheme COAG Disability Reform Council Quarterly Report 30 June 2017* Table 1.1 Quarterly intake (national), split by plan and entry type**,** page 15.

(3) National Disability Insurance Scheme Launch Transition Agency (2017) *National Disability Insurance Scheme COAG Disability Reform Council Quarterly Report 30 June* 2017, Table C.2 Quarterly intake split by plan and entry type – NSW, page 49.

(4) National Disability Insurance Scheme Launch Transition Agency (2017) *National Disability Insurance Scheme COAG Disability Reform Council Quarterly Report 30 September 2017*, Table 1.1 Quarterly intake (national), split by plan and entry type, since 1 July 2013, page 19.

(5) National Disability Insurance Scheme Launch Transition Agency (2017) *National Disability Insurance Scheme COAG Disability Reform Council Quarterly Report 30 September 2017* Table C.2 Quarterly intake split by plan and entry type since 1 July 2013 – NSW, page 57.

Notes: The NDIS reports cited above for June 2017 and September 2017 state in relation to Table 1.1 that 'The number of children supported in the ECEI gateway cannot be summed across quarters as they can transition to NDIS plans, hence the ECEI figure shown is cumulative'.

Table C- 2 outlines the number of participants in the NDIS who are aged 0-6 years. In total, there were 5,015 participants aged 0-6 years in NSW and 14,061 in Australia recorded in 2017-18 Quarter 1.

Table C- 2 Active participant profile per quarter for 0-6 years, Australia and NSW

	Prior quarters		2017-18 Q1		Total	
	N	**% of total participants**	**N**	**% of total participants**	**N**	**% of total participants**
Australia(1)	11,357	13%	2,704	12%	14,061	13%
NSW(2)	3,761	9%	1,254	9%	5,015	9%

Sources:

(1) National Disability Insurance Scheme Launch Transition Agency (2017) *National Disability Insurance Scheme COAG Disability Reform Council Quarterly Report* 30 *September 2017.* Table 1.8 Active participant profile per quarter by age group page 23.

(2) National Disability Insurance Scheme Launch Transition Agency (2017) *National Disability Insurance Scheme COAG Disability Reform Council Quarterly Report* 30 *September 2017.* Table C.9 Participant profile per quarter by Age group – NSW page 59.

Table C- 3 provides data on the selected key indicators for participants aged 0-6 years in Australia and NSW for the 30 September 2017 Quarter. Overall, the data shows that the findings for Australia and NSW are very similar, except for the percentage of respondents with concerns for 6 or more areas of daily living: 69% in NSW and 62% in Australia. Other results for NSW showed that

- 77% say their child is able to tell them what he/she wants
- 66% of children can make friends with people outside the family
- 57% of children participate in age appropriate community, cultural or religious activities, and of these, 61% are welcomed or actively included.

Table C- 3 Selected key indicators for participants 0 to before school, Australia and NSW (30 September 2017 Quarter)

Key indicator	Percentage of participants 0 to before school	
	Australia	**NSW**
Daily living (DL) % with concerns in 6 or more of the areas: gross motor skills, fine motor skills, self-care, eating, social interaction, communication, cognitive development, sensory processing.	62 (1)	69 (4)
Choice and Control (CC) % who say their child is able to tell them what he/she wants.	78 (1)	77 (4)
Relationships (REL) % of children who can make friends with people outside the family.	66 (2)	66 (5)
Social/Community Participation (S/CP) % of children who participate in age appropriate community, cultural or religious activities.	57 (2)	57 (5)
Relationship (REL) Of these, % who are welcomed or actively included	63 (2)	61 (5)
Number of questionnaires completed SFOF version 'Participant 0 to school'	**10, 937 (3)**	**4,496 (6)**

Sources:

(1) National Disability Insurance Scheme Launch Transition Agency (2017) *National Disability Insurance Scheme COAG Disability Reform Council Quarterly Report* 30 *September 2017.* Table 1.17 Selected key indicators for participants – Daily Living (DL) and Choice and Control (CC) page 28;

(2) National Disability Insurance Scheme Launch Transition Agency (2017) *National Disability Insurance Scheme COAG Disability Reform Council Quarterly Report* 30 *September 2017*, Table 1.18 Selected key indicators for participants – Relationships (REL) and Social/ Community Participation (S/CP), page 28;

(3) National Disability Insurance Scheme Launch Transition Agency (2017) *National Disability Insurance Scheme COAG Disability Reform Council Quarterly Report* 30 *September 2017* Data from Table 1.16 Number of questionnaires completed by SFOF version, page 27;

(4) National Disability Insurance Scheme Launch Transition Agency (2017) *National Disability Insurance Scheme COAG Disability Reform Council Quarterly Report* 30 *September 2017* Table C.18 Selected key indicators for participants – Daily Living (DL) and Choice and Control (CC) – NSW, page 61.

(5) National Disability Insurance Scheme Launch Transition Agency (2017) *National Disability Insurance Scheme COAG Disability Reform Council Quarterly Report* 30 *September 2017* Table C.19 Selected key indicators for participants – Relationships (REL) and Social/ Community Participation (S/CP) – NSW, page 61.

(6) National Disability Insurance Scheme Launch Transition Agency (2017) *National Disability Insurance Scheme COAG Disability Reform Council Quarterly Report* 30 *September 2017* Table C.17 Number of questionnaires completed by SFOF version – NSW, page 60.

Notes: Number of questionnaires refers to the transition period July 2016 - September 2017.

In the September 2017 Quarterly Report, data was published on whether the NDIS had helped. Table C- 4 reports the findings for Australia and NSW. Ninety-two respondents with children age 0 to school completed this questionnaire in NSW. NSW has generally higher or similar results to the results for Australia overall. In NSW, nearly all respondents indicated that the NDIS had: improved their child's development (98%), improved their child's access to specialist services (99%) and helped increase your child's ability to communicate what they want (94%). Around three quarters (76%) reported that the NDIS had improved how their child fit into family life, but only 65% reported that the NDIS had improved how their child fit into community life.

Table C- 4 Results for 'has the NDIS helped?' questions answered at review, for SFOF versions 'Participant 0 to school', Australia and NSW (30 September 2017 Quarter)

	Question	**Percentage responding Yes**	
		Australia (1)	**NSW**(2)
DL	Has the NDIS improved your child's development?	93	98
DL	Has the NDIS improved your child's access to specialist services?	93	99
CC	Has the NDIS helped increase your child's ability to communicate what they want?	87	94
REL	Has the NDIS improved how your child fits into family life?	78	76
S/CP	Has the NDIS improved how your child fits into community life?	65	65
	Number of respondents	**381**	**92**

Sources:

(1) National Disability Insurance Scheme Launch Transition Agency (2017) National Disability Insurance Scheme COAG Disability Reform Council Quarterly Report 30 September 2017, Table 1.21 Results for 'has the NDIS helped?' questions answered at review, for SFOF versions 'Participant 0 to school (n=381), page 31;

(2) National Disability Insurance Scheme Launch Transition Agency (2017) National Disability Insurance Scheme COAG Disability Reform Council Quarterly Report 30 September 2017, Table C.22 Results for 'Has the NDIS helped?' questions answered at review, for SFOF version 'Participant 0 to school' (n=92) – NSW, page 63.

Table C- 5 provides data on the profile of the families and carers of participants aged 0-14 years. Profiles on the families or carers of only those in receipt of ECEI were not available in the Quarterly reports. Once again, the results for Australia and NSW were fairly similar. The data for NSW is as follows:

- Around one quarter of this group (28%) were in receipt of carer payment and over half (60%) received carer allowance.
- 46% were in a paid job and around three quarters of the employed group were in permanent employment and working more than 15 hours per week.

- Only 39% indicated that they and their partner are able to work as much as they want. The reported barriers to work for the rest of the group included the situation of their child/family member (89%) and insufficient flexibility with the job (42%).
- Over three quarters (78%) felt they were able to advocate for their family member and 85% expressed confidence in supporting their child's development.
- 71% reported good, very good or excellent health.
- However, only 43% reported that they have friends and family that they could see as often as they liked.

Table C- 5 Selected key indicators for families/carers of participants aged 0-14 years, Australia and NSW (September 2017)

	Australia (1) Percentage	**NSW (2) Percentage**
% receiving Carer Payment	25	28
% receiving Carer Allowance	55	60
% working in a paid job	45	46
Of those in a paid job, % in permanent employment	74	73
Of those in a paid job, % working 15 hours or more	78	78
% who say they (and their partner) are able to work as much as they want	42	39
Of those unable to work as much as they want, % who say the situation of their child/family member with disability is a barrier to working more	87	89
Of those unable to work as much as they want, % who say insufficient flexibility of jobs is a barrier to working more	39	42
% able to advocate for their child/family member	78	78
% who have friends and family they see as often as they like	45	43
% who feel very confident or somewhat confident in supporting their child's development	86	85
% who rate their health as good, very good or excellent	72	71

Sources:

(1) National Disability Insurance Scheme Launch Transition Agency (2017) *National Disability Insurance Scheme COAG Disability Reform Council Quarterly Report* 30 *September 2017.* Table 1.20 Selected key indicators for families/ carers of participants, page 30.

(2) National Disability Insurance Scheme Launch Transition Agency (2017) *National Disability Insurance Scheme COAG Disability Reform Council Quarterly Report* 30 *September 2017.* Table C.21 Selected key indicators for families/ carers of participants – NSW, page 63

Appendix D Literature review update

Introduction

In March-June 2016, a brief literature review conducted for previous research (Meltzer et al. 2016a) examined early childhood intervention (ECI) service transition and integration, including research on how ECI operated in other service contexts similar to the National Disability Insurance Scheme (NDIS), as well as family and service provider perspectives on effective ECI services.

The literature review conducted in 2016 showed few studies specifically included the perspectives of families of children with disabilities, and of ECI service providers. Regarding family experiences, five key themes were mentioned in the literature: information, coordination, access, quality and advocacy. Less had been published about service providers' experiences in providing best practice. Key themes were: information, workforce, cultural competence and business models.

The updated literature review of academic and grey literature below is presented in two parts, similar to the previous literature review. The first part shows updates on ECI service transition and integration into and with the NDIS, and the second part focuses on experiences of families and service providers with the NDIS after 2016.

Part 1: ECI service transition and integration

The first part of the previous literature review examined ECI service transition and integration and included exploring literature on how ECI had transitioned to, integrated with, and operated in other service contexts similar to the NDIS. This updated literature review discusses service transition and integration post NDIS implementation and challenges with maintaining a family-centred approach.

Service transition and integration with and into the NDIS

The NDIS will transform how the disability services market in Australia operates. The Scheme will enable people to purchase their own services, referred to as 'consumer-centred disability funding', (CCDF schemes, McDonald Davis & Mahar 2016 pp. 277). Consumer 'choice and control' is a central pillar of the NDIS changing the relationship between consumers and service providers (Australian National Audit Office (ANAO) Report No.24, 2016–17). The ANAO Report (2016–17) adds:

> Many service providers will also need to adapt their systems and processes to manage the shift from block funding (in advance) to fee-for-service arrangements. Due to the scale of the reform, the maturing of the new NDIS disability services market is expected to take up to ten years, and perhaps longer…

The disability services market is expected to grow significantly with new and different forms of suppliers anticipated to enter the market (The ANAO Report, 2016–17). The increase in demand and various practitioners and service providers entering the scheme continues to raise concerns about quality control, coordination and collaboration in the ECI sector (Sukkar, 2013), as mentioned in the previous literature review. Pierce (2017) explains:

> The NDIS rollout across NSW has brought massive growth in the ECI industry, leading to a range of specialist practitioners visiting early childhood education and care settings who may have varying knowledge and experience of inclusive practices… and the variability of practices and the sudden increase in numbers of visiting practitioners that has [sic] led to some challenges.

Apart from making it difficult for parents to navigate and coordinate the system, this raises issues with collaboration and quality control, calling for an ‘explicit national commitment to work together with a child’s early childhood intervention provider to support the child’s inclusion and meaningful participation at the service’ (Brien 2016, p.24).

Collaboration within the ECI sector is crucial for the NDIS to succeed, yet the previous research by the SPRC in 2016 shows that the introduction of the NDIS has ‘disrupted organisational collaboration and in some cases disbanded professional networks’ (Carey & Reeders 2016). For example, in NSW, the ECEI approach is transitional until the Early Childhood Partners have been established and finalised across Australia by June 2018 (ECIA, 2017). In a media release in October 2017, Early Childhood Intervention Australia (ECIA) argued against the decision where none of the current ECEI transition providers in NSW could tender to be an Early Childhood Partner within their local communities. They explained that ‘ECI services have gone to considerable expense to set up business systems and processes to support the NDIA’s approach in NSW over the last two years, and this will all be lost’ (2017) if collaboration with service providers was not part of the NDIS integration.

One way in which ECIA addressed concerns with quality control and collaboration across the sector was through establishing a working group of key stakeholders who:

> recognised a need to help everyone involved to understand the priorities for families and objectives of each sector, and to have a universal means of clarifying what the focus and approach to early childhood intervention in inclusive settings would be. The Working Together Agreement is a package of practical resources, including the agreement itself, a wall poster, an outline of the relevant standards and guidelines for ECI practitioners and early childhood (Pierce 2017).

McDonald, Davis & Mahar (2016, p.283) added that collaboration between parents and therapists was a key characteristic of contemporary therapeutic approaches to ECI, compared to more traditional therapeutic approaches which place little emphasis on parental and family participation. The importance of maintaining a family-centred approach will be discussed next.

Maintaining a family-centred approach

Literature highlights a long history of service transitions within ECI aimed at moving away from an impairment-focused and medicalised approach towards child-, family- and community-focused models. Recent literature shows early childhood intervention providers intend to continue to focus on working with families to build child and family capacity at home and in mainstream settings, using a family-centred and evidence-based approach (Brien 2016). The recent Joint Standing Committee on the National Disability Insurance Scheme (2017) strongly believes access to supports for families and carers should be integral to the ECEI approach, and ‘guidelines on the NDIS ECEI approach are available and emphasise evidence-based interventions using family-centred approaches' (May, Roberts, Webber, Spreckley, Scheinberg, Forrester & Williams 2018, p.117).

Marchbank (2017, p.51) reported that some new practices, emerging out of transitioning into NDIS, conflict with previous principles underpinning a family-centred approach, and these new practices were identified contextually as 'inflexible' or 'no choice', 'therapy driven' or 'child centred', consequently revealing a 'disconnect' with the family-centred approach. A few service providers in Marchbank's (2017, p.51) study commented on NDIS implications on a family-centred approach:

> I don't think it is a priority. They [NDIS processes] are an insurance scheme to assess families' eligibility and set fees for service…
>
> If it got to the point that we would have to compromise family-centredness … then we would get out… I guess as a professional it is a struggle for me between family centred and the way it sits now with … so that it's a bit muddled up.

Summary of ECI service transition and integration

To summarise, ECI service transition and integration with the NDIS shows the following key points:

- transition for the ECI sector is not easy and might take a while
- a growing market and increase in demand carries ongoing concerns about quality control, coordination and collaboration in the ECI sector
- collaboration is essential
- maintaining a family-centred approach is important but challenging.

Part 2: Family and service provider perspectives on effective ECI services

The second section of the previous literature review focused on the perspectives of families and service providers: what was known about their experiences with receiving (families) or providing (service providers) ECI services respectively. It concentrated on studies from the last few years before 2016, just before the introduction of the NDIS and, as available, families' and service providers' early experiences with the NDIS and how the ECI sector was changing under the Scheme.

Since 2016, more has been published about service providers' experiences and transitions than about family experiences. Research and themes overlap between the two perspectives, but like the previous literature review, the family experiences will focus on five themes (information, coordination, access, quality and advocacy), and service provider experiences will outline key themes (information, workforce, cultural competence and business models) to illustrate changes or progress. No other major themes were found in recent literature.

Family experiences

Experiences of families transitioning into the NDIS differ. Focusing on experiences of a small group of families in Australia and their relation to the NDIS, Whitburn, Moss & O'Mara (2017, p.11) indicated that 'families navigate the possibilities and restraints in patchy, uneven ways'. Some families in the study expressed continued dissatisfaction with the Scheme two years after the NDIS implementation began, and all participants described feeling ‘immobilised by their interaction with the NDIS at one time or another’ (Whitburn, Moss & O’Mara 2017, p.10). Family experiences regarding information, coordination, access, quality and advocacy will be discussed next.

Information

As stated in the previous literature review, families often reported having inadequate information about their child’s support needs and support options, while studies also found that adequate information provision was correlated with feelings of empowerment among the families. Marchbank (2017) noted that the parents’ capacity to remain positive about their changed circumstances was highly variable and depended on the quality of information they received. McDonald, Davis & Mahar (2016, p.283) added:

> if we want families to have meaningful choices… we need to be able to communicate evidence about therapeutic treatments to them and provide them with support to interpret that evidence (or the lack of it). Doing this without overwhelming parents is a challenging task, but the risk of not doing so is that consumers are unaware of the range of options available.

Coordination

Many families, as mentioned above, find it stressful to navigate a fragmented and complex service system (Moore 2011, Muir et al. 2008). Recent literature reported similar experiences, where some families with young children with disability were ‘feeling adrift’ and overwhelmed by the decisions they were required to make (McDonald, Davis & Mahar 2016 p.283). Whitburn, Moss & O’Mara (2017, p.5) reported their participants were initially enthusiastic about the promises of the Scheme, yet once entering the initial planning phase, they realised that provisions may not match their original expectations. Additionally, ‘some parents have found it difficult to accept that funding for their child's therapy for what they are hoping is a transient problem comes under a “disability” scheme’ (May, et al. 2018, p.116). Therefore, uncertainty and ambivalence among families when accessing the Scheme and about how they can navigate and control their participation, appears to limit the capacity of the NDIS to positively impact their lives (Whitburn, Moss & O’Mara 2017).

Access

May et al. (2018) explained that access to ECEI through the NDIS was through a functional impairment or a medical diagnosis assessment, which was ‘a change from the diagnostic entry’ required by previous funding schemes such as HCWA and Better Start. ‘This functional approach aims to provide timely intervention, which was monitored to ensure it is effective and provided for the appropriate duration’ (p.116). According to the Joint Standing Committee on the National Disability Insurance Scheme (2017, p ix), while the NDIA has recently made significant improvements to the Participant Pathway to improve access for families:

> The committee is concerned by reports that the PEDI-CAT tool is unsuited to assessing the functional capacity of children with a developmental delay, including those with Autism Spectrum Disorder (ASD), yet it is being used by the NDIA and its

> Partners to inform access and funding decisions and track children's developmental progress. (2017, p.ix)

The committee added there was concern that 'families of children with disability or developmental delay are facing extensive waiting lists for first contact with an ECEI Partner' (2017, p.29), voicing further concerns about whether the number of children with developmental delay accessing the NDIS and the level of their delay was correct.

Quality

McDonald Davis & Mahar (2016 p.282) stated that:

> parents need a framework for understanding the quality of different types of evidence and they need to know which types of treatment are effective. However, a consumer centred funding model that requires parents to make decisions about treatment and presents them with a particular means of interpreting evidence (i.e. the concept of "gold standard" treatments) has the potential to undermine contemporary therapeutic approaches.

They added that contemporary and new approaches to ECI were often challenging to evaluate using 'gold standard' research designs (McDonald Davis & Mahar 2016, p.282). The Joint Standing Committee 'remains troubled by reports that Planners have poor understanding of the needs of the children they are developing Plans for' (2017, p ix), which raises concerns about the quality of service for families.

Advocacy

The Joint Standing Committee (2017, p.69) reported that parental competence and advocacy skills could directly impact the level of funding allocated to a child, causing disadvantage for vulnerable families and creating inconsistencies between experiences and the levels of funding allocated to families that could clearly communicate their child's needs and those that struggled to articulate the services required. Whitburn, Moss & O'Mara (2017, p.11) exemplified that a family:

> who was resourced with extensive knowledge and experience of disability, and who could draw on strong relationships in their local community, was able to… take full advantage of the possibilities of their Scheme participation.

Summary

Family perspectives can be summarised as:

- parents experience dissatisfaction, stress and anxiety with navigating a complex new system
- experiences of families differ and depend on their level of knowledge and access to information and advocacy skills
- assessments and long waiting times are key issues undermining quality of service.

Service provider experiences

The transition experiences of service providers were widely variable as well, but generally ECI transition and integration into the NDIS has been difficult for many service providers. Marchbank (2017, p.49) stated:

> The administrators wanted the new system to integrate smoothly with the previous ways services were funded. This was not the case. Leftover income from earlier systems such as Helping Children with Autism (HCWA), Better Start, or state 'in kind' funding, needed to be completely disbursed before further monies could be expected from the NDIS.

As in the previous literature review, themes of information, workforce, cultural competence and business models will be addressed here.

Information

The previous literature review showed that, similar to families, service providers reported confusion and lack of information about funding policies and the NDIS (Meltzer et al. 2016). There has been little research confirming whether, and what, confusion and lack of information still exists among service providers. Recent studies, however, highlighted the important role service providers have in explaining information and helping families navigate the NDIS and the ECI sector as a whole, as briefly mentioned above in the family experience section (Marchbank 2017; McDonald, Davis & Mahar 2016). For example, May at al. (2018, p.116) reported:

> Paediatricians and other health professionals can play an important part in explaining to families that some developmental and behavioural differences may be transient, requiring a period of early intervention, with this intervention now funded under the NDIS model.

Workforce

Workforce training is considered important to ensure services provide effective support (Moore 2011) and therefore bridge the gap between the theory of family-centred approaches and its patchy realisation in practice (see family experience section above). The ANAO Report (2016–17, p.7) states: 'Estimates suggest that the disability care workforce will need to more than double in size between 2013 and 2019–20'.

The Joint Standing Committee on the National Disability Insurance Scheme reported that ECI partners and providers were struggling with the variety of roles they were required to fulfil and the sheer volume of children they must support, highlighting that capacity issues may be resulting in providers delaying less urgent cases, further lengthening some families' wait times (2017, p.31). Waiting times emerged as a key issue (Marchbank 2017). Marchbank (2017, p.51) added that conventional timetabling, case management and allocation demanded different organisational procedures without budgetary safety nets to ensure service delivery.

Cultural competence

It appears that cultural competence of service providers needs to be further developed. The Joint Standing Committee (2017, p.ix):

> is troubled by reports that there are Aboriginal and Torres Strait Islander families unable to use allocated funding because they are unsure how to access services. The committee considers that resources should be developed in codesign with people with disability, Aboriginal and Torres Strait Islander populations, and CALD communities to assist them to understand the Scheme, and how to use their funds to access services.

Business models

The NDIS and other individual funding approaches challenge traditional ECI service models based on block funding. As mentioned in part 1, this transition means 'different agencies needed to adopt a different way of looking at service delivery consistent with a new business model that administrators viewed as a "business opportunity" or as an "'opportunity for growth"' (Marchbank 2017, p.48). Marchbank (2017, p.47) offers a service provider perspective about the transition: 'Administrators had little time to prepare for change; the process was quick and needed an immediate response to become a financially viable commercial organisation'. May et al. (2018, p.116) agreed that:

> Paediatricians will soon be using NDIS mechanisms to assist and support children with disabilities and will help their families receive the services they need, but some frustrations are likely, especially during the roll-out where multiple systems will be in operation simultaneously, and also during the learning phase and while change within the NDIS is still occurring.

One issue arising out of the transition were reports of underfunded plans, which was a major concern of the Joint Standing Committee (2017, p.) stating that:

> Alarmingly, the committee heard that NDIS funding levels are often lower than previous national funding models such as Helping Children With Autism. It is concerning that some participants and their families are potentially worse off than under previous funding models.

Service providers reported that individual packages, which often provided less per child than the previous block funding, were putting their programs and businesses at risk, and O'Tarpey (2016) explained that "under the scheme, early childhood intervention (ECI) service providers are asked to estimate the cost of delivering a 'typical' suite of interventions for the nominated period for a child". Marchbank (2017, p.49), on the other hand, reported an increase in individual funding packages and workload, saying that:

> At the moment they [the families] have packages all about $12 000. If and when they come to us, we have to provide a $12 000 service. One of the issues is that block government funding was less than $8000. The staff are used to providing this $8000 service, so now they have to provide a $12 000 service.

Regardless of the increase or decrease of funding, increased workload and shifting business models are challenges faced by service providers transitioning into the NDIS.

Summary

Available recent literature about service provider experiences indicates:

- Service providers experience a difficult transition to a more business-oriented and consumer-centred model.
- A growing market means increased workload and limited workforce resources.
- Underfunded plans due to the change in funding system are a key issue.

Conclusion

This literature review updated a previous one about ECI service transition and integration into the NDIS and about experiences of families and service providers with the NDIS after 2016. Major themes and issues have remained. This includes changes in funding models making it difficult for providers to transition and integrate into the NDIS, and the importance of collaboration within the ECIA sector. Maintaining a family-centred approach and long waiting times were key issues that emerged for both families and service providers in this literature review. Experiences differed within both family and service provider groups, and more research is needed to understand their experiences in trying to transition and integrate into the new system.

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