

4. Participants from birth to before starting school: overview of results

4.1 Key findings

Box 4.1: Key findings for participants from birth to before starting school

- In the longitudinal analysis, significant improvements were observed across a number of indicators¹⁴, particularly in the areas of:
 - Communication: the percentage who say their child is able to tell them what he/she wants has increased by 9.4%, from 70.2% at baseline to 79.6% approximately one year later.
 - Making friendships: the percentage of children who can make friends with people outside the family has increased by 5.8% (from 61.6% to 67.4%), and the percentage who have friends that they enjoy playing with has increased by 10.6% (from 46.7% to 57.3%).
 - Participating in family life and community activities: the percentage who say their child fits in with the everyday life of the family has increased by 5.6% (from 67.1% to 72.7%), and the percentage of those participating in community, cultural or religious activities who feel welcomed has increased by 6.0% (from 63.6% to 69.6%).
- Understandably, their child's progress in major developmental areas is a key concern of parents and carers. From the longitudinal analysis, the proportion of parents/carers expressing concern about their child's development in six or more of eight areas surveyed has increased by 6.5%, from 60.8% to 67.3%.
- Baseline and longitudinal outcomes vary with participant level of function. Participants with higher level of function tend to have better baseline outcomes and exhibit higher rates of improvement than those with lower level of function.
- Participants with a hearing impairment generally experience better outcomes than those with other disabilities, both baseline and longitudinal.
- Participants from regional and remote locations, compared to those from major cities, show more positive results on some indicators – both at baseline and for longitudinal change. For example, children in regional and remote areas are more likely to improve in their ability to tell their parents/carers what they want, and in their ability to make friends outside the family.
- Indigenous children tend to exhibit slightly worse outcomes at baseline. They are also less likely to live with their parents than non-Indigenous children, and more likely to live in public housing. For longitudinal change, small numbers make it difficult to identify differences.
- Baseline outcomes for children from a CALD background are mixed. They are more likely to live with their parents, and parents/carers are less likely to express concerns about their child's development, however they tend to fare worse on some of the relationship and participation indicators. For longitudinal change, small numbers make it difficult to identify differences.

¹⁴ Note that at least some of the observed change may be attributable to normal age-related development, since the children will be one year older at the second time point.

Box 4.1: Key findings for participants from birth to before starting school (continued)

- NDIS participants' use of childcare appears to be lower than for the general population, and participants with higher/complex needs are less likely to attend childcare. Higher use of specialist services tends to be associated with increased use of childcare. Participation in community and the ability to make friends are also associated with increased use of childcare: these attributes could be either a driver of childcare use (parents/carers feel more comfortable sending their child to childcare once they have the necessary social skills) or an outcome of using childcare (use of childcare fosters social skills).
- Use of specialist services is widespread amongst NDIS participants. Usage has increased between baseline (72%) and review (90%). Increases are observed for both existing and new participants, but more so for new participants. Satisfaction with specialist services is high, and has also increased between baseline and review. Early intervention participants are more likely to use specialist services. Participants with a developmental delay, those living in South Australia, and those living in a high unemployment Local Government Area, are less likely to use specialist services.
- Opinions on whether the NDIS has helped tend to be positive for this cohort. In particular, there is widespread agreement that the NDIS has helped in areas related to the child's development (91%) and access to specialist services (89%). Higher baseline plan utilisation is a strong predictor of a positive response across all five areas surveyed. Participants entering the Scheme for early intervention are more likely to think that the NDIS had helped than those entering due to disability.

4.2 Results overview

4.2.1 Outcomes framework questionnaire domains

For children in the pre-school age range, the outcomes framework seeks to measure the extent to which participants are:

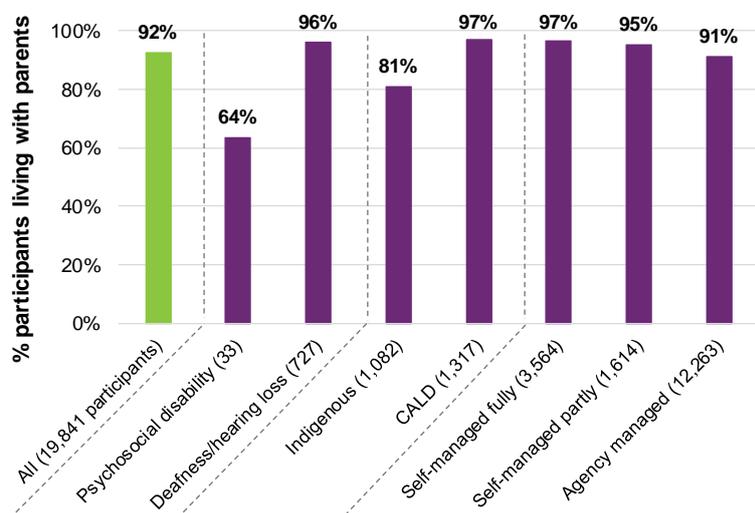
- Gaining functional, developmental and coping skills appropriate to their ability and circumstances
- Showing evidence of autonomy in their everyday lives
- Participating meaningfully in family life
- Participating meaningfully in community life
- Using specialist services that assist them to be included in families and communities.

The LF includes 11 extra questions related to childcare, four related to specialist services, three about developmental/coping skills, two about effects on family, and one about developing autonomy.

4.2.2 Participant living arrangements

Overall, 92% of children live with their parents. 3% live with other family members and 2% with non-relatives, such as foster carers. The percentage living with their parents is much lower for the small number of participants with a psychosocial disability (64% of the 33 participants) and higher for those with deafness/hearing loss (96%). Indigenous children are less likely to live with their parents (81%), however children from a culturally and linguistically diverse background are more likely to do so (97%). Children whose plan is self-managed, either partly or fully, are more likely to live with their parents (95-97% compared to 91% for agency-managed).

Figure 4.1 Proportion of participants living with parents



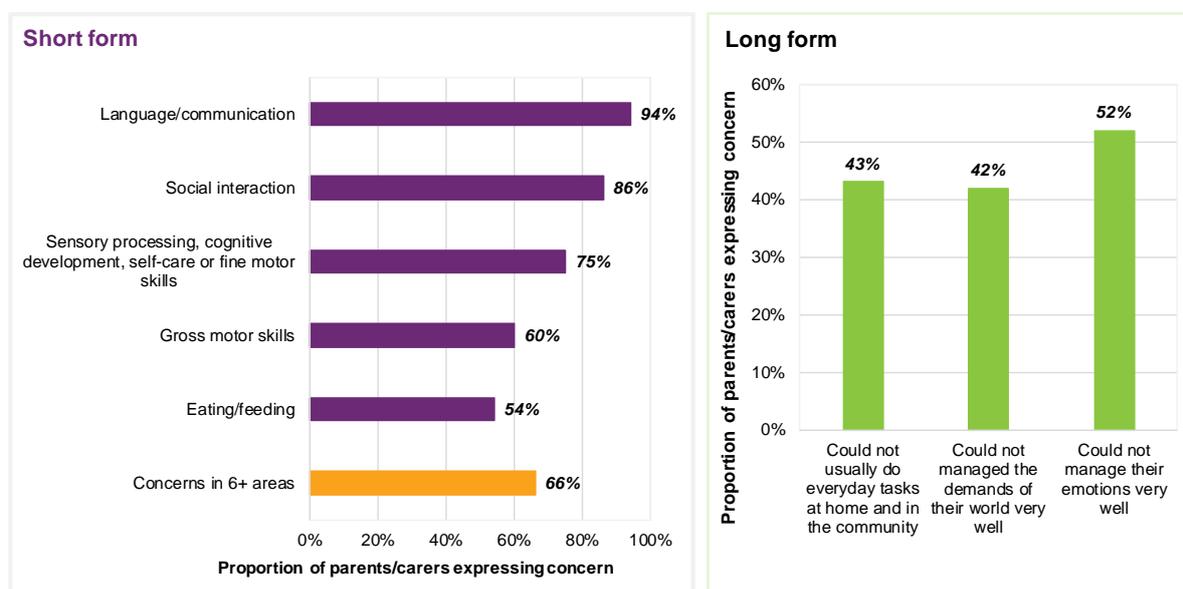
Most participants (89%) are in a private home either owned or rented from a private landlord. 8% of participants live in a private home rented from a public authority, but this percentage is much higher for Indigenous participants (29%) and in the Northern Territory (60%).

4.2.3 Baseline indicators – aggregate

Areas of development

The SF asks parents/carers whether they have concerns about their child's development in eight different areas (multiple areas can be chosen). For each of the eight areas surveyed, more than half of parents/carers expressed concerns at baseline. The area with the highest level of concern was language/communication, where 94% of parents/carers had concerns, followed by social interaction (86%). Around three-quarters had concerns with sensory processing, cognitive development, self-care or fine motor skills. Lower proportions had concerns regarding gross motor skills (60%) or eating/feeding (54%). Most parents/carers had concerns in multiple areas, with 66% expressing concerns in six or more of the eight areas.

Figure 4.2 Proportion of parents/carers expressing concern



The LF asks parents/carers whether their child can usually manage their emotions, and the demands of their world. At baseline, 52% thought that their child could not manage their emotions very well, and 42% thought that they could not manage the demands of their world very well. 43% thought that their child could not usually do everyday tasks at home and in the community.

Autonomy

Most children exhibited evidence of growing autonomy, with 74% of SF respondents saying that their child was able to tell them what they want, and 89% of LF respondents saying that their child takes action once they have decided to do something.

In relation to family life, 55% of parents/carers think there is enough time to meet the needs of all family members. 55% of those with more than one child expressed some concern about the effect of having a sibling with disability on their other children. However, 80% say that their child with disability gets along with their siblings. Overall, 66% say that their child fits into everyday family life. Evidence of integration into family life is provided by children assisting their parents/carers with tasks at home (74%) and outside the home (81%). 64% of children are able to make friends with people outside the family.

Childcare

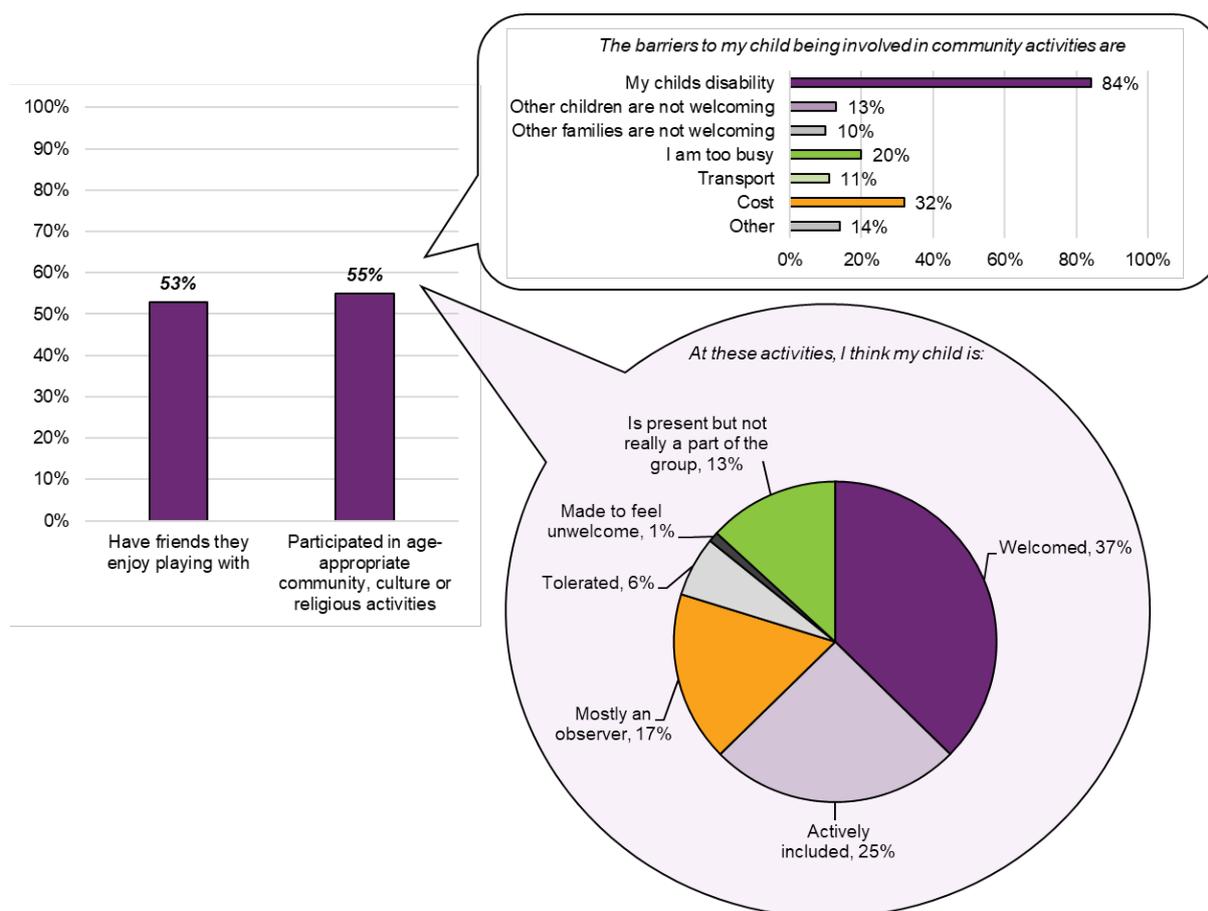
The LF includes a number of extra questions related to childcare. For this relatively small cohort of 320 participants, 55% used some form of childcare. It was not uncommon for parents/carers to experience a lot of difficulty in finding good quality childcare (21%), finding the right person to take care of their child (18%), and finding childcare at short notice (30%). The most common form of childcare used was centre-based, including family day care, long day care, or any other care at a childcare centre. 78% of parents/carers used this form of childcare either while at work or while not at work, with a higher proportion using it while at work (53%) than while not at work (37%).

Children's experiences at childcare were generally positive, with 94% of those using group childcare saying that other children and other families were welcoming, 90% thinking that their child was asked to do tasks at an appropriate level, and 97% feeling that their cultural heritage was respected (where applicable). Evidence of childcare services working together with the parent/carer to support the child was less strong, with 76% thinking the childcare helped them assist their child, 65% thinking they involved them in planning for their child, and 56% saying they helped them to plan for the future. 57% thought their childcare service was being assisted by their early intervention service (where applicable) to support their child.

Participation

Evidence of social and community participation outside childcare comes from the SF. 53% of children have friends they enjoy playing with, most often at social or family gatherings (57%) or pre-school (52%). 55% of children participated in age-appropriate community, cultural or religious activities, with 62% of parents/carers feeling that their child was welcomed or actively included in these activities. 77% of parents wanted their child to be more involved in community activities, with 84% perceiving their child's disability as a barrier to being more involved. Community activities appear less welcoming than childcare, with barriers to greater involvement including non-welcoming behaviour of other children (13%) or other families (10%). Cost is also a considerable barrier (32%).

Figure 4.3 Social and community participation, barriers and inclusion



Specialist services

About three-quarters of children use specialist services (such as speech pathology, occupational therapy) to assist their learning and development. From the SF, 93% thought that these services helped their child's skill development and 93% thought they supported them to assist their child. From the LF, 97% thought that the services involved them, 93% that they respected the family/carer's cultural heritage, and 86% that they helped plan for the future. However the percentage thinking that the services assisted staff at their child's other activities (such as childcare/pre-school) to support their child was lower, at 61%.

4.2.4 Baseline indicators – participant characteristics

Baseline indicators have been analysed by participant characteristics using one-way analyses and multiple logistic regression modelling. Key findings from these analyses include:

- Level of function**

Baseline indicators are generally better for participants with higher level of function. An exception is the percentage of families/carers using childcare while not at work, which is similar for children with high, medium and low levels of function. However the percentage using childcare while at work decreases with level of function, from 67% for children with high level of function, to 47% for those with low level of function, probably reflecting decreasing employment rates for parents/carers with child's level of function. Whilst use of specialist services is more prevalent amongst children with low

levels of function (81% compared to 74-77% for medium and high levels of function), satisfaction with services is similar (93%).

- **Disability**

By disability, developmental concerns are highest amongst children with Down syndrome and global developmental delay, and lowest by a considerable margin for children with deafness/hearing loss. Children with autism are much less likely to be able to make friends outside the family than children with other disability types. Participation in community, cultural or religious groups is lowest for children with global developmental delay, and these children, together with those with autism, are the least likely to be welcomed or actively included in these activities. Children with deafness/hearing loss and those with Down syndrome have better participation outcomes. Children with autism are less likely to get on with their siblings, and from the LF, parents/carers of children with autism are more likely to be worried about the effect on their other children of having a sibling with disability.

- **Culturally and linguistically diverse backgrounds**

Controlling for other factors, parents/carers of children from a culturally and linguistically diverse background are less likely to have concerns in six or more developmental areas than those from a non-CALD background. However, children from a CALD background are much less likely to be able to communicate what they want, to make friends outside the family, and to be welcomed in community activities. Whilst based on small numbers, LF responses also suggest that children from a CALD background are less likely to be able to manage their emotions and the demands of their world, and to be able to do everyday tasks. Children from a CALD background are also less likely to join in tasks within and outside the home, and less likely to fit into family life. However (based on smaller numbers in the LF), parents/carers of children from a CALD background are more likely to think there is enough time to meet the needs of all family members, and less likely to express concerns about the effect of the child's disability on siblings.

- **Indigenous**

Indigenous children also have different experiences on some indicators, and generally slightly worse than non-Indigenous children. For example, controlling for other factors in a multiple regression model, Indigenous children are less likely to participate in community, cultural or religious activities, and less likely to be welcomed or actively included when they do.

- **Age**

Some trends by age reflect normal childhood development. For example, the percentage who say their child can tell them what they want increases with age. Older children are also more likely to make friends outside the family, to have friends they enjoy playing with, and to participate in community, cultural or religious activities. However, between the ages of 0 and 4, the likelihood of being welcomed or actively included in these activities declines with age. Parents/carers of older children are more likely to want their child to be more involved in community activities, and more likely to see their child's disability as a barrier to greater involvement. Use of specialist services tends to increase with the child's age.

- **Gender**

In multiple regression models, parents/carers of girls are less likely to have concerns in six or more of the eight areas surveyed, and girls are more likely to participate in community, cultural or religious activities.

- **Geography**

Children from regional and remote locations show more positive results on some indicators. For example, parents/carers are less likely to have concerns in six or more of the eight areas surveyed, their children are more likely to be able to tell them what they want, and are more likely to make friends outside the family. Use of specialist services is less prevalent in outer regional/remote/very remote locations, being 69% compared to 76% for less remote locations.

- **Relationships**

Integration into family life (fitting into family life, joining in completing tasks within and outside the home), and friendships (the ability to make friends outside the family, and having friends to play with) are associated with better outcomes on key indicators.

4.2.5 Longitudinal indicators – aggregate

Longitudinal analysis describes how outcomes have changed for participants during the time they have been in the Scheme. Included here are participants entering the Scheme in the first year of transition (from 1 July 2016 to 30 June 2017) for whom a record of outcomes is available at two time points: at scheme entry and at approximately one year following scheme entry.

As expected during this relatively short period, many indicators have not changed a great deal. For this summary we select indicators based on a combination of statistical significance and magnitude of change^{15,16}.

Table 4.1 summarises changes for the 13 selected indicators.

Table 4.1 Selected longitudinal indicators for participants from birth to before starting school

SF/LF	Domain	Indicator	Baseline	Review	Change	Improvement/ Deterioration
SF	2	% who say their child is able to tell them what he/she wants	70.2%	79.6%	9.4%	Improvement
SF	3	% of children who can make friends with people outside the family	61.6%	67.4%	5.8%	Improvement
SF	3	% of parents/carers who say their child joins them when they complete tasks at home	74.3%	77.4%	3.1%	Improvement
SF	3	% who say their child fits in with the everyday life of the family	67.1%	72.7%	5.6%	Improvement
SF	4	% of children who have friends that they enjoy playing with	46.7%	57.3%	10.6%	Improvement
SF	4	Of those who participate in community, cultural or religious activities, % who are welcomed or actively included	63.6%	69.6%	6.0%	Improvement
SF	5	% who say specialist services help their child gain skills to participate in everyday life	88.7%	95.1%	6.5%	Improvement

¹⁵ Since there is much more data available for the SF, with more than 2000 participants contributing to the analysis, statistical testing would identify indicators where the magnitude of change is unimportantly small, so we only consider SF indicators where the absolute magnitude of change in the indicator is greater than 0.02 (all of these changes are statistically significant). For the LF, where the quantity of data is much smaller (less than 70 participants), selection is based on statistical significance.

¹⁶ Note that at least some of the observed change may be attributable to normal age-related development, since the children will be one year older at the second time point.

SF/LF	Domain	Indicator	Baseline	Review	Change	Improvement/ Deterioration
SF	5	% who say specialist services support them to assist their child	89.1%	95.6%	6.5%	Improvement
SF	4	% who say they would like their child to be more involved in community activities	68.4%	76.1%	7.7%	Context dependent
SF	5	% who use specialist services	73.1%	90.1%	16.9%	Context dependent
SF	1	% 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	60.8%	67.3%	6.5%	Deterioration
LF	3	% who say there is enough time each week for all members of their family to get their needs met	70.3%	48.4%	-21.9%	Deterioration
SF	4	Of those who would like their child to be more involved in community activities, % who see their child's disability as a barrier	80.7%	84.6%	3.9%	Deterioration

Key findings from Table 4.1 include:

- More children are able to communicate what they want, however this would be expected for children who are one year older.
- Making friendships, and participation in family life and community activities, has improved. The use of informal childcare, such as relatives, friends and neighbours, may also reflect improvement in relationships outside the immediate family.
- Use of specialist services has increased markedly (possibly due to new entrants to the Scheme), as has satisfaction with those services.
- Three indicators exhibit significant deterioration. More parents/carers have concerns in six or more of the eight areas surveyed, fewer feel there is enough time to meet the needs of all family members, and more see their child's disability as a barrier to greater involvement in community activities.

4.2.6 Longitudinal indicators – participant characteristics

Analysis by participant characteristics has been examined in two ways:

1. A simple comparison of the percentage meeting the indicator at review with the percentage meeting the indicator at baseline. The difference (review-baseline) is compared for different subgroups.
2. Multiple regression analyses modelling improvement (or sometimes deterioration) in the indicator. That is, for the subset without the indicator at baseline, the probability of meeting the indicator at review is modelled as a function of participant characteristics.

It should be noted that these two analyses can produce different results, particularly where there is a large difference in the indicator at baseline between subgroups.

Some key features of the analyses for selected indicators are summarised below.

My child is able to tell me what he/she wants (overall improvement of 0.094)

Based on the logistic regression model for improvement:

- The likelihood of improvement decreased with level of function, and as plan cost increased from \$20,000 to \$50,000.
- Girls were less likely to improve than boys.
- Participants from SA and NSW, and those from regional and remote areas, were more likely to improve.
- The likelihood of improvement increased from birth to age 4, then declined between ages 5 and 6.
- Participants coming in from an existing State scheme were less likely to improve.
- Children participating in community activities, and those joining in tasks at home, were more likely to improve. However, respondents using childcare were less likely to improve.

My child can make friends with people outside the family (overall improvement of 0.058)

Based on the logistic regression model for improvement, the likelihood of improvement decreased with level of function, and as plan cost increased from \$10,000 to \$15,000. Participants from regional and remote areas were more likely to improve.

My child participates in age-appropriate community, cultural or religious activities, and at these activities I think my child is welcomed or actively included (overall improvement of 0.060)

Based on the logistic regression model for improvement, the likelihood of improvement decreased with level of function. Girls were more likely to improve than boys, and participants from NSW were more likely to improve than those from other States/Territories.

Percentage with concerns in six or more areas (overall deterioration of 0.065)

Based on the logistic regression model, deterioration was more likely for participants with lower level of function and those with autism or global developmental delay, and less likely for those with a hearing impairment. Deterioration was more likely for older participants. Participants in ACT, and those entering the Scheme through early intervention, are less likely to exhibit deterioration. Increasing cost of baseline plan, and utilisation, are associated with increased likelihood of deterioration. Participants who are welcomed in community activities, and those who can make friends outside the family, are less likely to experience deterioration.

Use of specialist services (overall increase of 0.169)

Multiple regression analysis of usage at review, controlling for usage at baseline, found lower usage for SA and higher usage for early intervention participants. Additionally, participants with developmental delay or global developmental delay, and those living in an area with high unemployment, were found to be less likely to increase their use of specialist services.