



Participant and family/carer outcomes: COVID-19 impact | Executive summary

To 30 June 2020

National Disability Insurance Agency

ndis

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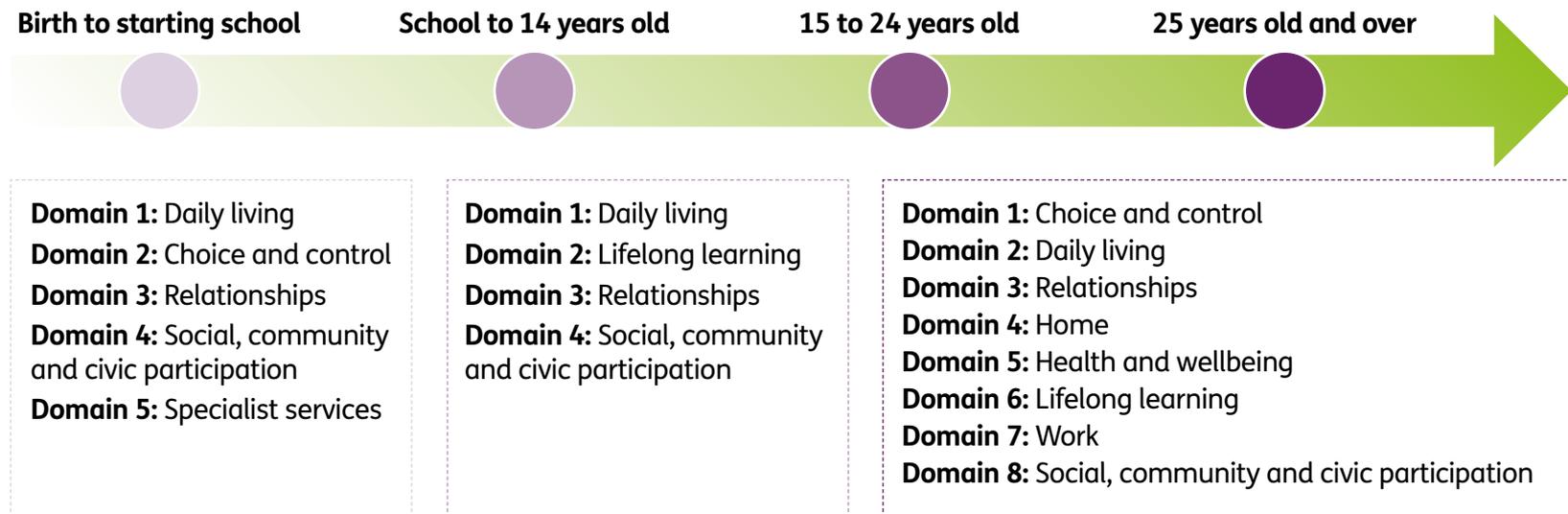
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 - 0 to 14
 - 15 to 24
 - 25 and over

Outcomes framework questionnaires

Outcomes framework: Participants

A lifespan approach to measuring participants' goals and outcomes across main life domains has been used.

Lifespan approach: four age-based cohorts



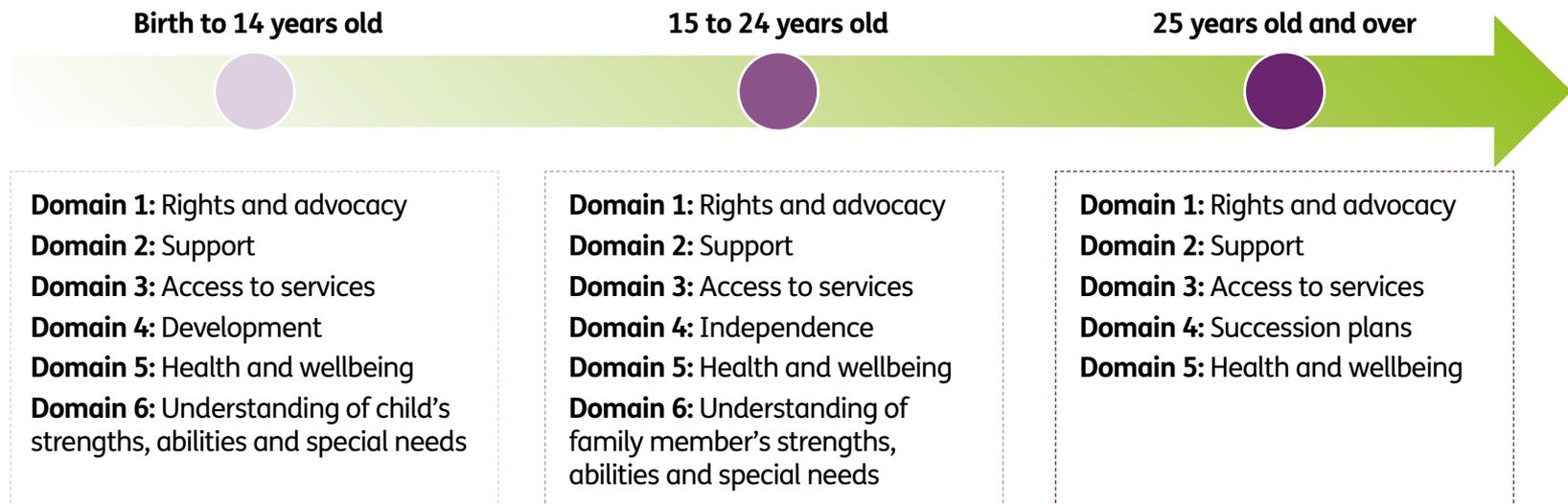
While most domains overlap, goals and outcomes may differ depending on the age group.

This approach facilitates monitoring of participants' progress over time, as well as benchmarking to Australians without disability and to other OECD countries.

Outcomes framework: Families and carers

A lifespan approach to measuring family/carer outcomes across main life domains has also been used:

Lifespan approach: three cohorts, based on participant age:



Many of the issues faced by families and carers are similar regardless of participant age (for example, being able to work as much as they want), however there are some differences (for example, families and carers of young children will be focussed on helping their child's early development and learning, whereas families and carers of young adults will want to help their family member to become as independent as possible). As for participants, the approach facilitates monitoring of progress for families/carers, as well as benchmarking, for example, against the Australian population as a whole.

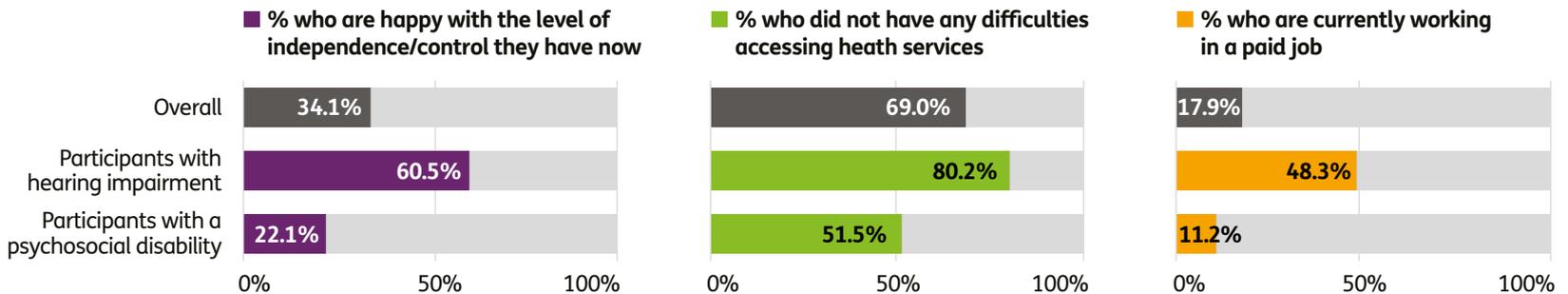
Baseline outcomes (at Scheme entry)

Baseline outcomes for participants and families/carers vary by a number of factors, including:

- the nature and severity of the participant’s disability
- the extent of support networks
- local community inclusiveness
- their general health

Example:
Participants with a hearing impairment are more likely to experience better baseline outcomes, and those with a psychosocial disability are less likely.

Participants aged 15 to 24

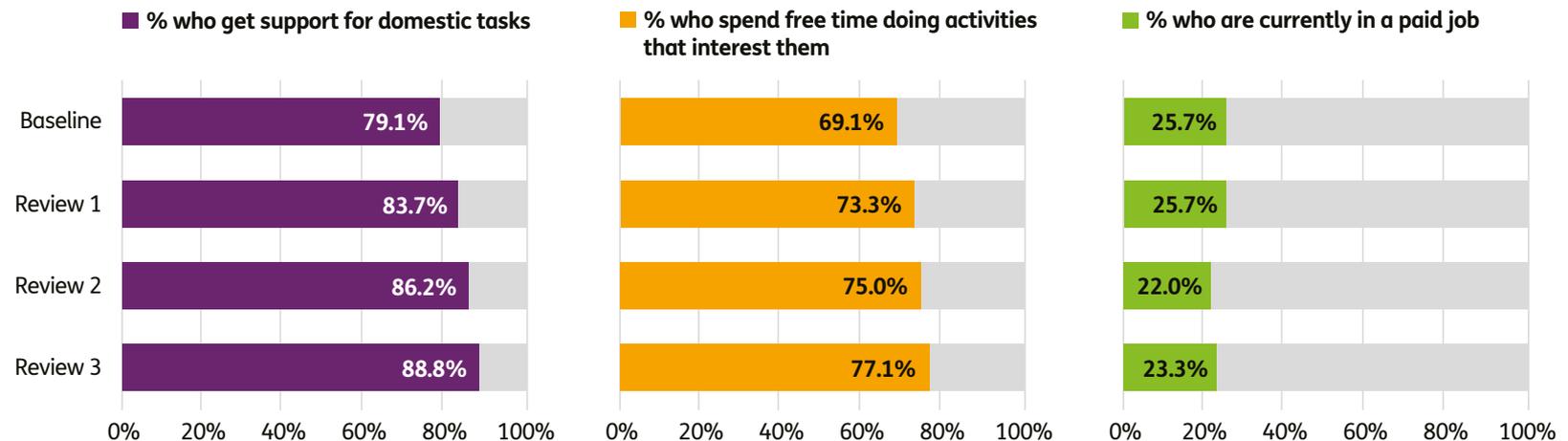


Progression towards better outcomes

Success should be measured on how far participants and their families and carers have come since entering the Scheme, acknowledging different starting points.

Whilst some outcomes should improve relatively quickly (for example, daily living and access to services), others are much more long-term in nature (for example, employment), and measurable progress may take some years to emerge.

Participants age 25 and over



Longitudinal cohorts

Longitudinal results for participant and family/carer outcome indicators are considered separately for three cohorts of participants:

- Participants who have been in the Scheme for three years at 30 June 2020 (C3 cohort)
- Participants who have been in the Scheme for two years at 30 June 2020 (C2 cohort)
- Participants who have been in the Scheme for one year at 30 June 2020 (C1 cohort)

These three cohorts are distinct (that is, a participant or family member/carer contributing to the longitudinal analysis belongs to one cohort only).

The family/carer longitudinal analysis is also restricted to instances where the same person responded at each of the time points being considered.

For the regression models which consider factors affecting changes in outcomes (such as going from not having a paid job to having a paid job), the analysis includes changes from all three cohorts.

COVID-19 modelling approach

The global pandemic that took hold from early 2020 is likely to have had an impact on at least some participant and family/carer outcomes, such as employment and community participation.

To investigate which outcomes may have been affected by the pandemic via quantitative modelling, additional time-related terms were included in the regression models.

These terms allow for:

1. A step change in the response probability at the date the pandemic is assumed to start affecting outcomes (23 March 2020 – the date that stronger restrictions were announced by the Prime Minister, such as closure of restaurants and gyms)
2. A general time trend (not related to the pandemic)
3. Different time trends before and after the start of the pandemic.

The baseline modelling investigates factors that are associated with participant and family/carer outcomes at the time participants enter the Scheme. For example, at the time participants enter the Scheme, what are the factors associated with them having a paid job?

For the baseline modelling, the time-related terms are defined in relation to the participant's time of entry to the Scheme, and there is a single model for each indicator.

For example, for Scheme entry dates up until 23 March 2020, the probability of being in a paid job depends on a combination of the pre-COVID constant level, and the pre-COVID time-trend applicable at the Scheme entry date.

The baseline model allows for a change in both the pre-COVID constant level and the pre-COVID time trend, from 23 March 2020.

Hence for Scheme entry dates after 23 March 2020, the probability of being in a paid job depends on a combination of the post-COVID constant level, and the post-COVID time-trend applying at the Scheme entry date, where both the post-COVID constant level and the post-COVID time trend are potentially different to their corresponding pre-COVID values.

Longitudinal modelling



The longitudinal modelling investigates factors that are associated with changes in participant and family/ carer outcomes (such as going from not having a paid job to having a paid job, or vice versa). For example, for participants who do not have a paid job when they enter the Scheme, what are the factors associated with them having a paid job after one year in the Scheme?

The longitudinal models look at changes between two time points, either from baseline to first, second or third review, or from an earlier review to a later review. Separate models are used for improvement and deterioration in the indicator. Hence multiple models are considered for each indicator.

In all situations, only the later review can have occurred after the assumed COVID-19 date of 23 March 2020, and the time variables are measured with reference to that later review.

Longitudinal results summarise the COVID-19 impact across all models considered for each indicator. The table below defines the symbols used in the summary tables.

| Symbol | COVID-19 effect | Type of indicator | Meaning |
|---|-------------------------------------|--|--|
|  | Positive | Positive (e.g. working in a paid job) or negative (e.g. have been to hospital in the last 12 months) | More likely to respond favourably ¹ (“Yes” for positive indicator, “No” for negative indicator) in all models where COVID terms are significant |
|  | Negative | Positive or negative | Less likely to respond favourably in all models where COVID terms are significant |
|  | Mixed | Positive or negative | Effect is positive in some models and negative in others |
|  | More likely to respond “Yes” | Depends on context (e.g. I would like my child to be more involved in community activities) | More likely to respond “Yes” in all models where COVID terms are significant |
|  | More likely to respond “No” | Depends on context | More likely to respond “No” in all models where COVID terms are significant |
|  | Mixed | Depends on context | More likely to respond “Yes” in some models; more likely to respond “No” in others |

¹ At second time point (for COVID-19 step-change term) or over time (for the time trend terms).

COVID-19 modelling: Limitations

-
- The modelling is based on data as at 30 June 2020, so only includes about three months of experience during the pandemic (23 March 2020 to 30 June 2020).
 - Some of the effects detected are only slight.
 - Some of the indicators where the pandemic might be thought to have an effect have a time frame specified. For example, for social and community participation, adult participants are asked “**Have you been actively involved in a community, cultural or religious group in the last 12 months?**”. At least nine months of this period will be prior to the start of the pandemic.
 - Significance of the COVID-related terms in the model does not imply causality: it is not possible to say that changes in the indicator were caused by the COVID-19 pandemic.
 - The full impact of the pandemic cannot be evaluated using quantitative methods alone: qualitative research (such as focus groups and interviews with participants) would also be needed. Some qualitative research into economic and social participation outcomes, including the effect of the pandemic, is being undertaken.

Nonetheless, the modelling provides some valuable insights into the impact of the COVID-19 pandemic on the lives of NDIS participants and their families and carers.

Results

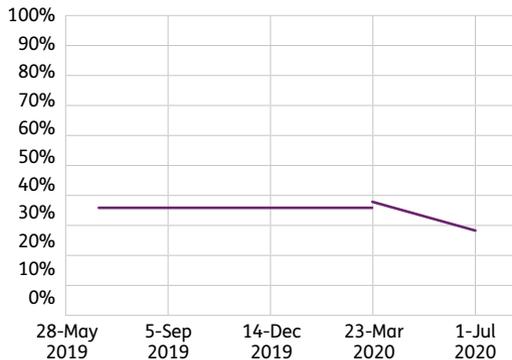
Participants
**from birth to before
starting school**

Baseline outcomes

Participants from birth to before starting school: Impact of COVID-19 - Baseline

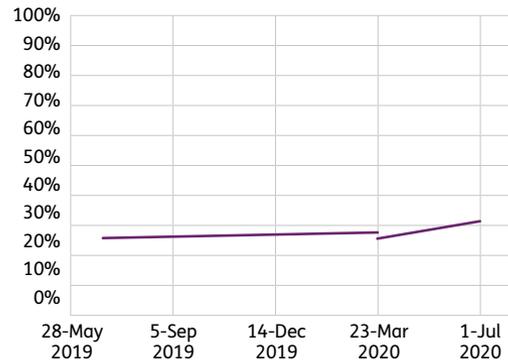
COVID-19 was identified as a significant¹ factor for six indicators, and effects were mixed.

Participates in age appropriate community, cultural or religious activities



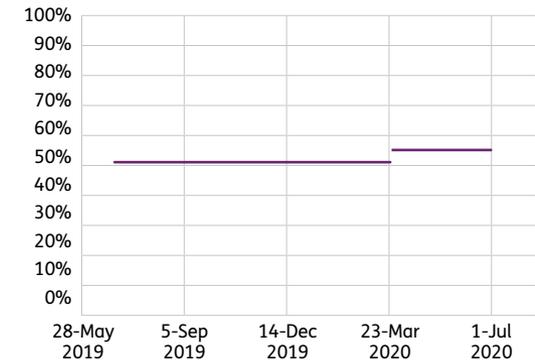
The percentage of parents/carers who say their child participates in age appropriate community, cultural or religious activities remained relatively constant until the start of the pandemic, but has declined over time since then.

Has friends he/she enjoys playing with



The percentage of children who have friends they enjoy playing with also remained relatively constant until the start of the pandemic, but showed a slight increasing trend over the post-COVID period.

Fits in with the everyday life of the family

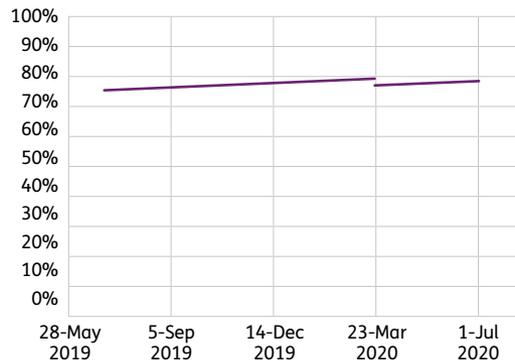


The percentage of parents/carers who say their child fits in with the everyday life of the family rose to a higher level at the start of the pandemic, and remained at this level during the pandemic.

¹ Indicators for which there was a significant step change or a significant change in time trend at 23 March 2020.

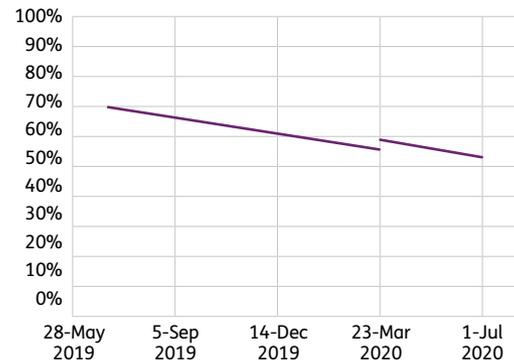
Participants from birth to before starting school: Impact of COVID-19 - Baseline

Joins in completing tasks outside home



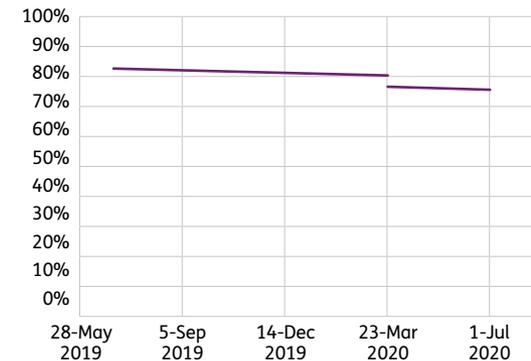
The percentage of children who join their parent/carer in completing tasks outside the home dropped to a lower level at the start of the pandemic, but then increased over time at a similar rate to that observed in the pre-COVID period.

Uses specialist services



The percentage of children who use specialist services rose to a higher level at the start of the pandemic, but then decreased over time at a similar rate to that observed in the pre-COVID period.

Parent/carer has concerns in six or more areas of development



The percentage of parents/ carers with concerns in six or more areas of their child's development dropped to a lower level at the start of the pandemic, and then declined over time at a similar rate to that observed in the pre-COVID period.

Participants
**from birth to before
starting school**

Longitudinal outcomes

Participants from birth to before starting school: Impact of COVID-19 – longitudinal – summary

For the nine indicators modelled, results were generally negative, with participants being less likely to improve and/or more likely to deteriorate in their response compared to the pre-COVID period:

- The COVID-19 step-change variable was significant in at least one model for all but one indicator (“**My child fits in with the everyday life of the family**”), and had a negative impact for all but one of these models, with responses being less likely to improve or more likely to deteriorate between the two time points when the later time point occurred during the COVID-19 period. For example, participants were less likely to improve between baseline and first or second review with regard to:
 - Participating in age-appropriate community, cultural or religious activities.
 - Being able to make friends with people outside the family.
- The one indicator where there was a positive step change was “**My child joins me when I complete tasks at home**”, where participants were less likely to deteriorate between baseline and first review, when the review occurred during the COVID period.
- Two indicators exhibited a favourable change in the time trend after the COVID-19 date: “**My child fits in with the everyday life of the family**” and “**My child’s disability is a barrier to being more involved**”.

More detail is provided in the table on the next slide.

Participants from birth to before starting school: Impact of COVID-19 – longitudinal

| Indicator | COVID step change | Time trend pre-COVID | Time trend post-COVID | Description of effect during COVID period |
|---|-------------------|----------------------|-----------------------|--|
| My child participates in age-appropriate community, cultural or religious activities | ↓ | ↓ | ↓ | Less likely to improve between baseline and first review (improvement also becomes less likely over time), and between baseline and second review. |
| My child feels welcomed or actively included when they participate in community activities | ↓ | | | Less likely to improve between baseline and first review. |
| I would like my child to be more involved in community activities | ↓ | ↑ | ↑ | Less likely to change from “No” at baseline to “Yes” at first or third review. Likelihood of changing from “Yes” to “No” between baseline and first review declines over time. |
| My child’s disability is one of the barriers to being more involved in community activities | ↓ | | ↑ | Less likely to improve between baseline and first review. Likelihood of deterioration in the latest year initially increases post-COVID, but then declines over time. |
| Parents/carers with concerns in six or more areas | ↓ | | | Less likely to improve between baseline and first review. |
| My child is able to tell me what he/she wants | ↓ | | | Less likely to improve between baseline and first review. |
| My child can make friends with people outside the family | ↓ | ↑ | ↑ | Less likely to improve between baseline and first review and over latest year. Likelihood of deterioration decreases over time (for 1-step transitions). |
| My child joins me when I complete tasks at home | ↕ | | | Less likely to improve or deteriorate between baseline and first review. More likely to deteriorate in latest year. |
| My child fits in with the everyday life of the family | | | ↑ | Likelihood of deterioration between baseline and first review declines over time post-COVID. |

Participants

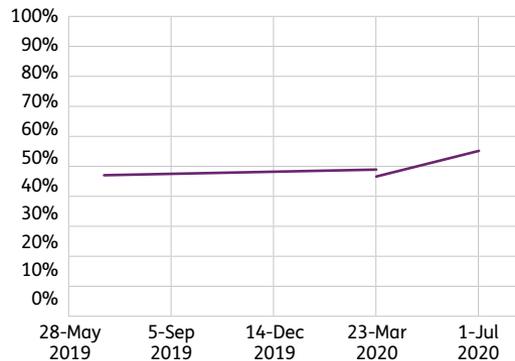
**from starting
school to age 14**

Baseline outcomes

Participants from starting school to age 14: Impact of COVID-19 – baseline

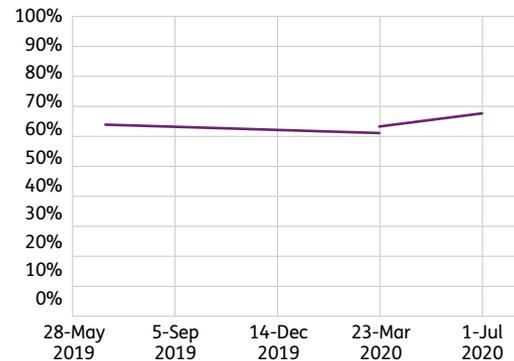
COVID-19 was associated with a number of changes to participant outcomes, with most changes being positive. For three indicators, there was a change in time trend:

Attends school in a mainstream class



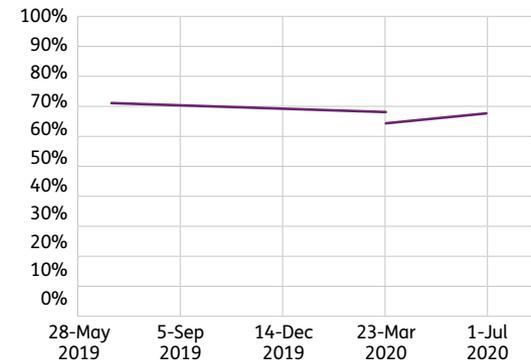
The percentage of children who attend school in a mainstream class increased at a slightly greater rate over the post-COVID period.

Gets along with his/her siblings



The percentage of children who get along with their siblings was declining slightly over time until the start of the pandemic, but since then has been increasing.

Parent/carer would like their child to be more involved

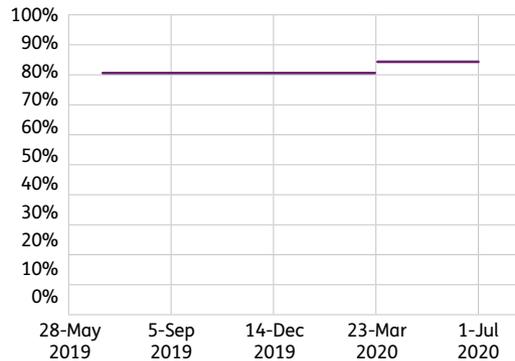


The percentage of parents/carers who say they would like their child to be more involved in activities with other children was declining slightly over time until the start of the pandemic. The percentage dropped after the pandemic started, but has since shown an increasing trend.

Participants from starting school to age 14: Impact of COVID-19 – baseline

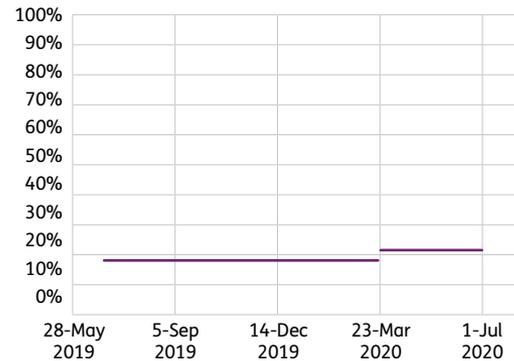
For six indicators, there was a step-change, as shown on this slide and the following slide:

Fits in with the everyday life of the family



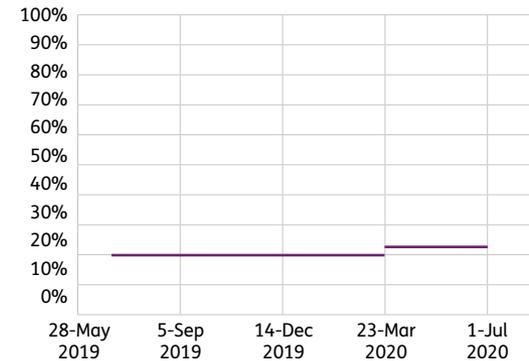
The percentage of parents/carers who say their child fits in with the everyday life of the family increased to a higher level during the pandemic.

Parent/carer thinks there is enough time to meet the needs of all family members



The percentage of parents/carers who think there is enough time to meet the needs of all family members increased to a higher level during the pandemic.

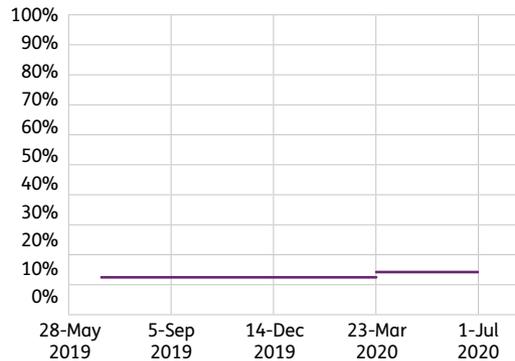
Developing functional, learning and coping skills



The percentage of children developing functional, learning and coping skills appropriate to their ability and circumstances also increased to a higher level during the pandemic.

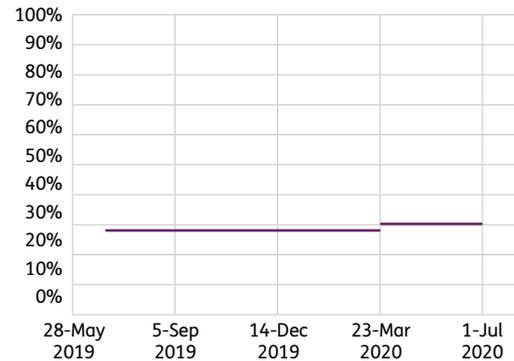
Participants from starting school to age 14: Impact of COVID-19 – baseline

Manages their emotions well



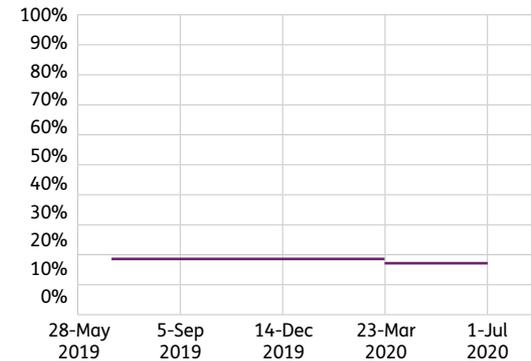
The percentage of children who manage their emotions well increased to a higher level during the pandemic.

Becoming more independent



The percentage of children becoming more independent also increased to a higher level during the pandemic.

Spends time away from parents/carers other than at school



However, the percentage of children who spend time away from their parents/carers other than at school has dropped to a lower level during the pandemic.

Participants

**from starting
school to age 14**

Longitudinal outcomes

Participants from starting school to age 14: Impact of COVID-19 – longitudinal – summary

There were some significant changes to participants' longitudinal outcomes during the pandemic, and results were mixed, being favourable in some models but unfavourable in others. For example:

- For the indicator “**My child gets along with his/her siblings**”, parents/carers were less likely to change their response (either improve or deteriorate) in all one-year transitions, when the later review occurred during the COVID period. In addition, responses were less likely to improve over three years when the third review occurred during the COVID period.
- For the indicator “**There is enough time each week for all members of the family to get their needs met**”, parents/carers were less likely to change their response (either improve or deteriorate) between baseline and first review, and they were less likely to deteriorate between second and third review.
- With respect to their child becoming more independent, parents/carers were less likely to change their response (either improve or deteriorate) between baseline and first review, but were less likely to improve between second and third review. There was also a negative change in time trend post-COVID, with improvement becoming less likely over time for some transitions.
- However, parents/carers were less likely to deteriorate with respect to perceiving their child's disability as a barrier to being more involved between baseline and first review, where the review occurred during the COVID period.

More detail is provided in the tables on the following slides.

Participants from starting school to age 14: Impact of COVID-19 – longitudinal

| Indicator | COVID step change | Time trend pre-COVID | Time trend post-COVID | Description of effect during COVID period |
|--|-------------------|----------------------|-----------------------|---|
| My child is becoming more independent | ↕ | ↕ | ↕ | Parents/carers were less likely to change their response (either improve or deteriorate) between baseline and first review, but were less likely to improve between second and third review. Deterioration becomes less likely over time (both pre- and post-COVID). However, improvement becomes less likely over time for some transitions (with a stronger decline during the COVID period). |
| My child spends time away from parents/carers other than at school | ↕ | ↕ | ↘ | Less likely to deteriorate between first and second review. Deterioration between baseline and first or second review becomes less likely over time (both pre- and post-COVID). However, improvement becomes less likely over time for some transitions (with a stronger decline during the COVID period for baseline to first review). |
| My child has a genuine say in decisions about themselves | ↕ | ↕ | ↕ | Less likely to deteriorate between baseline and first review, but less likely to improve between baseline and second or third review. Time trends are mixed, but do not change post-COVID. |
| My child attends school in a mainstream class | ↕ | ↘ | ↘ | Less likely to deteriorate between baseline and first review. Improvement between baseline and first review becomes less likely over time. |
| My child gets along with his/her siblings | ↕ | ↕ | ↕ | Parents/carers were less likely to change their response (either improve or deteriorate) in all one-year transitions, and less likely to improve over three years. Deterioration becomes less likely over time (both pre- and post-COVID) for some transitions. |

Participants from starting school to age 14: Impact of COVID-19 – longitudinal

| Indicator | COVID step change | Time trend pre-COVID | Time trend post-COVID | Description of effect during COVID period |
|--|---|---|---|---|
| There is enough time each week for all members of the family to get their needs met |  |  |  | Parents/carers were less likely to change their response (either improve or deteriorate) between baseline and first review, and were less likely to deteriorate between second and third review. Changing their response became less likely over time for most transitions. |
| My child has friends that he/she enjoys spending time with |  |  |  | Less likely to deteriorate between baseline and first review, but less likely to improve between second and third review. Time trends are mixed, but do not change post-COVID. |
| I would like my child to have more opportunity to be more involved in activities with other children |  |  |  | Less likely to change from “No” to “Yes” between baseline and first review. Changing from “No” to “Yes” becomes less likely over time for most transitions. |
| My child’s disability is a barrier to being more involved |  |  |  | Less likely to deteriorate between baseline and first review. Time trends are mixed, but do not change post-COVID. |

Participants

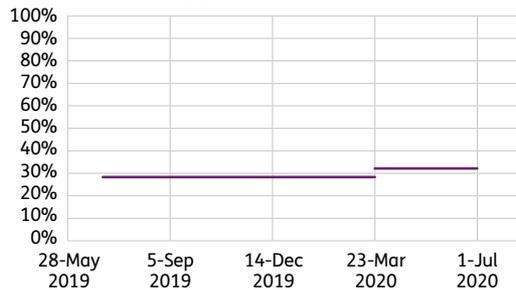
aged 15 to 24

Baseline outcomes

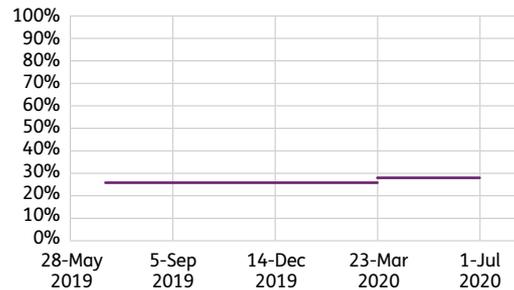
Participants aged 15 to 24: Impact of COVID-19 – baseline

COVID-19 was associated with a number of changes to participant outcomes, with most changes being positive. During the COVID period, participants were more likely to choose who supports them, to be able to have a say with their support services, and to be able to advocate for themselves. They were also more likely to want to live in their current home in five years' time, and to feel safe in their home as well as getting out and about in their community.

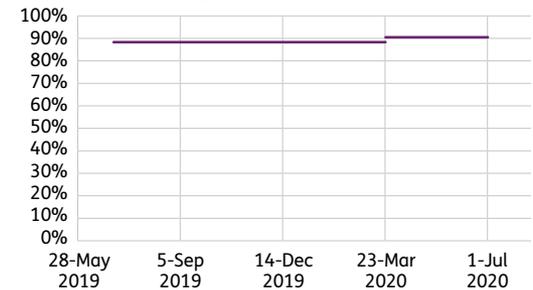
Choose who supports them



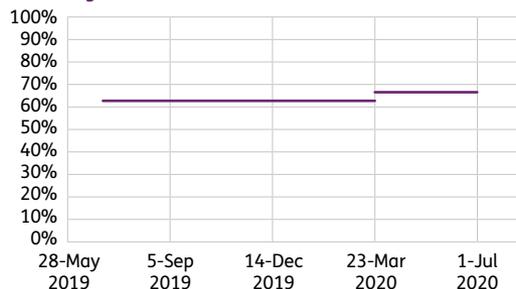
Able to advocate for themselves



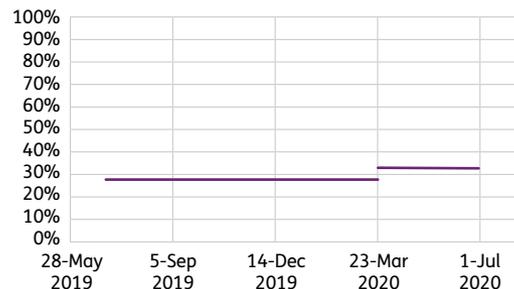
Feel safe or very safe in their home



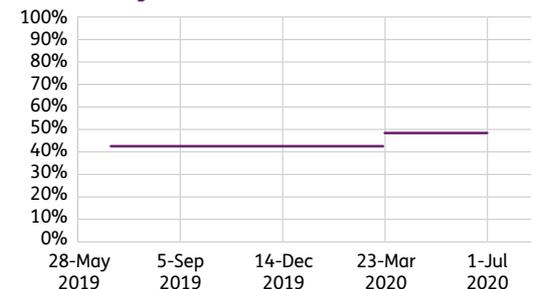
Would like to live in their current home in five years time



Able to have a say with their support services most of the time or all of the time



Feel safe getting out and about in their community

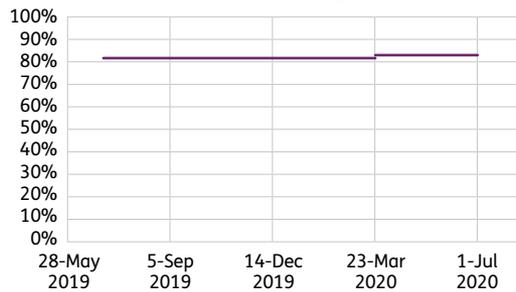


Participants aged 15 to 24: Impact of COVID-19 – baseline

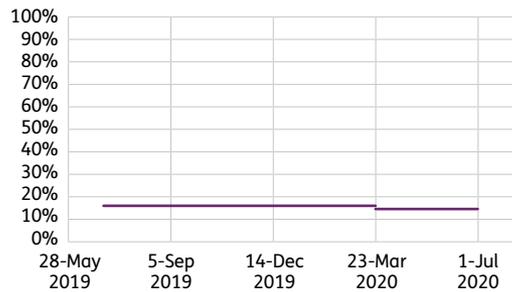
In addition, participants were more likely to:

- Rate their health as excellent, very good or good, and have no difficulty accessing health services. They were also less likely to have been to hospital in the last 12 months.
- Participate in education, training or skill development, spend their free time doing activities that interest them, and know people in their community

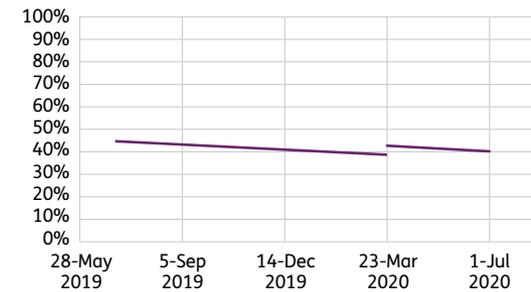
Have no difficulties accessing health services



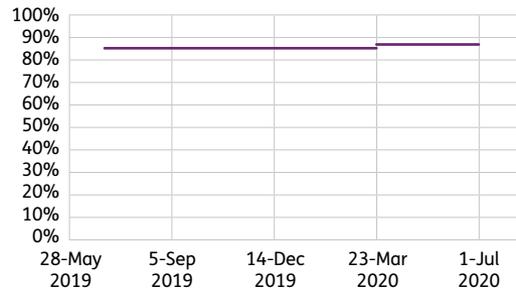
Have been to hospital in the last 12 months



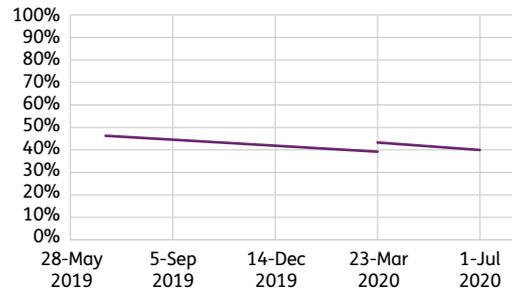
Know people in the community



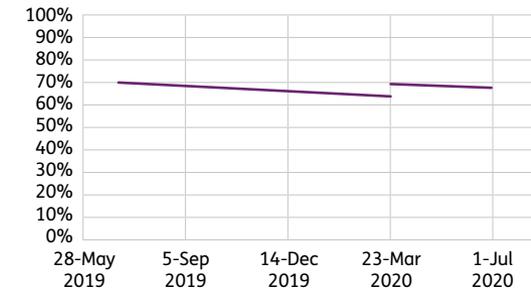
Rate their health as excellent, very good or good



Participate in education, training or skill development



Spend their free time doing activities that interest them

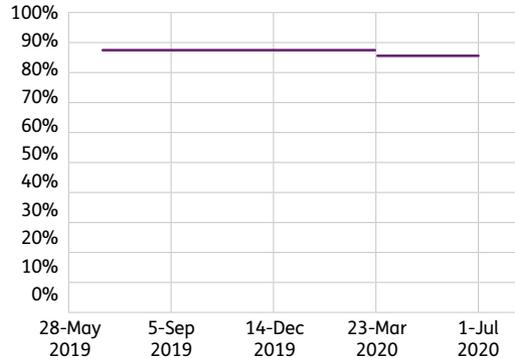


Participants aged 15 to 24: Impact of COVID-19 – baseline

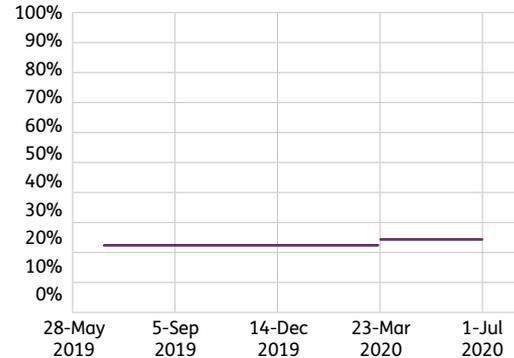
Negative results were observed for only two indicators, indicating that during the pandemic, participants were:

- Less likely to have someone outside their home to call on for help when needed.
- More likely to want to see their family more often.

Have someone outside their home to call when they need help



Would like to see their family more often



Participants

aged 15 to 24

Longitudinal outcomes

Participants aged 15 to 24:

Impact of COVID-19 – longitudinal – summary

There were some significant changes to participants' longitudinal outcomes during the pandemic, and results were mixed, being favourable in some models but unfavourable in others. For example:

- Participants were generally less likely to report an improvement between reviews with respect to making more decisions than they did two years ago, when the later review occurred during the pre-COVID period.
- Participants who gave their second response during the COVID period were less likely to change their response from “Yes” (wanting to see their friends more often) to “No” (not wanting to see them) in all transitions from baseline.
- However, participants were less likely to deteriorate between baseline and second review in relation to wanting to do certain things in the last 12 months but being unable to, when the later response occurred during the COVID period.

More detail is provided in the tables on the following slides.

Participants aged 15 to 24: Impact of COVID-19 – longitudinal

| Indicator | COVID step change | Time trend pre-COVID | Time trend post-COVID | Description of effect during COVID period |
|---|---|---|---|---|
| I make more decisions in my life than I did two years ago |  |  |  | Participants who had a review in the COVID period were less likely to improve from baseline to second or third review, and between first and second review. Deterioration becomes less likely over time (both pre- and post-COVID) for most transitions, however improvement between baseline and first review becomes less likely. |
| I make most decisions in my life |  |  |  | Participants were less likely to change their response (either improve or deteriorate) between baseline and first review, and were less likely to deteriorate between baseline and second review. Change between baseline and first review became less likely over time (both pre- and post-COVID). |
| I want more choice and control in my life |  |  |  | Participants were less likely to change from “Yes” to “No” between first and second review, and between baseline and second review, but less likely to change from “No” to “Yes” between baseline and first review. Changing from “Yes” to “No” becomes more likely over time (both pre- and post-COVID). |
| I would like to see my friends more often |  |  |  | Participants are generally more likely to continue to say they want to see their friends more often during the COVID period. This tendency has been increasing over time (both pre- and post-COVID). |

Participants aged 15 to 24: Impact of COVID-19 – longitudinal

| Indicator | COVID step change | Time trend pre-COVID | Time trend post-COVID | Description of effect during COVID period |
|---|-------------------|----------------------|-----------------------|---|
| I have a doctor I see on a regular basis | | ↓ | ↕ | Improvement was generally less likely over time prior to COVID. This trend continued unchanged after COVID, with the exception that between second and third review, improvement started to become more likely over time. |
| I have been to the hospital in the last 12 months | ↓ | ↑ | ↑ | Participants were less likely to improve between baseline and first review. Improvement between baseline and first or second review becomes more likely over time (both pre- and post-COVID). |
| I have wanted to do certain things in the last 12 months, but could not | ↑ | ↕ | ↕ | Participants were less likely to deteriorate between baseline and second review. Improvement over time becomes less likely over time for most transitions, but deterioration between baseline and first review becomes less likely over time (both pre- and post-COVID). |
| I know people in my community | ↕ | ↕ | ↕ | Participants were less likely to deteriorate between baseline and first review, but were less likely to improve between baseline and second review. Improvement becomes less likely over time for most transitions, but deterioration becomes less likely between baseline and first or second review (both pre- and post-COVID). |

Participants
aged 25 and over
Baseline outcomes

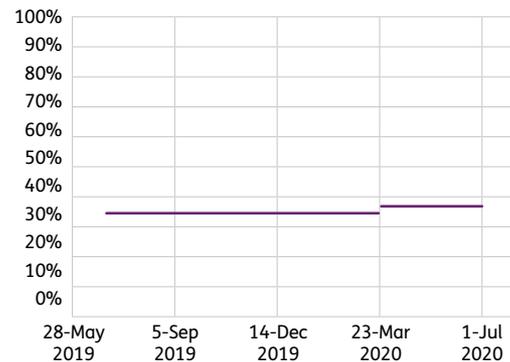
Participants aged 25 and over: Impact of COVID-19 – baseline

COVID-19 was associated with a number of changes to participant outcomes. Most changes were positive, as shown on this slide and the next slide.

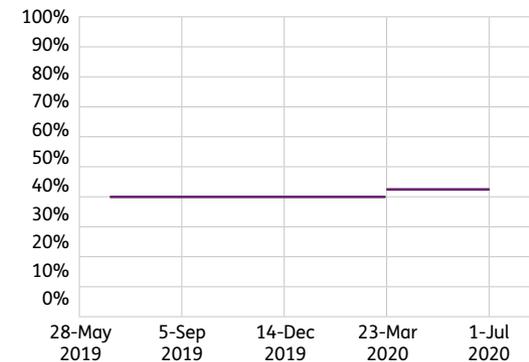
During the COVID period, participants were more likely to:

- Choose who supports them, make most decisions in their life, and be able to have a say with their support services most of the time or all of the time.
- Be able to advocate for themselves.

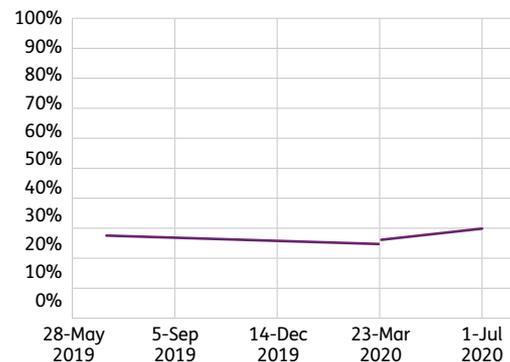
Choose who supports them



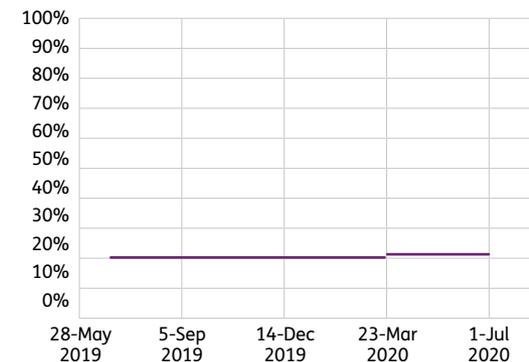
Make most decisions in their life



Able to have a say with their support services most of the time or all of the time



Able to advocate for themselves

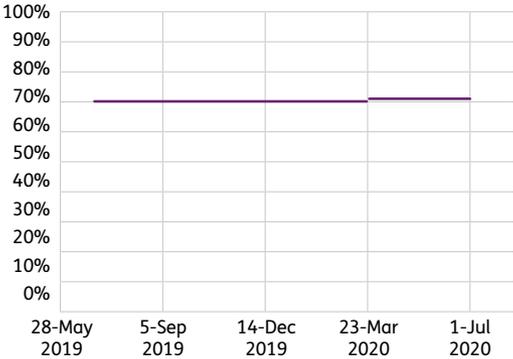


Participants aged 25 and over: Impact of COVID-19 – baseline

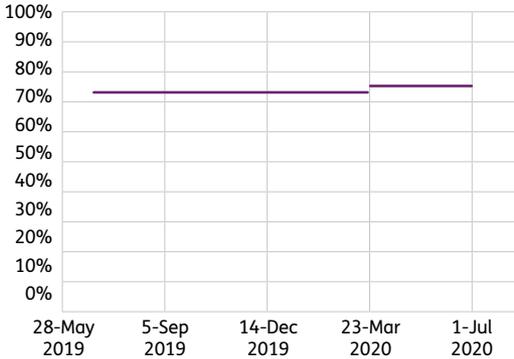
During the COVID period, participants were more likely to:

- Be happy with their current home.
- Want to live in their current home in five years' time, and to feel safe or very safe in their home.
- Feel safe getting out and about in their community

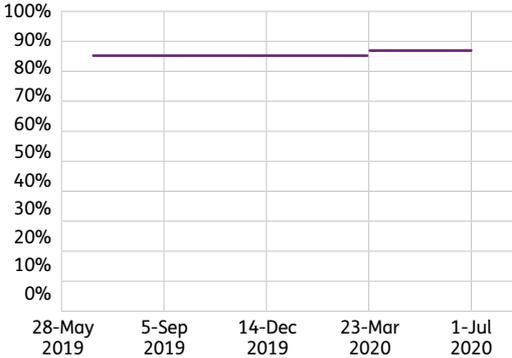
Happy with the home they live in



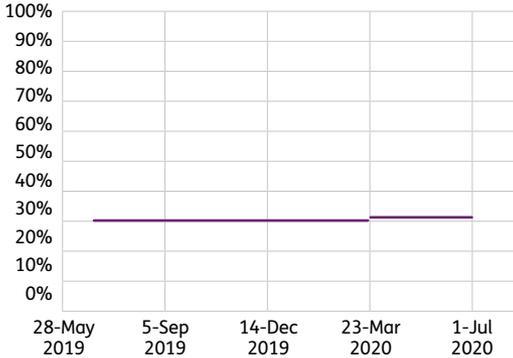
Feel safe or very safe in their home



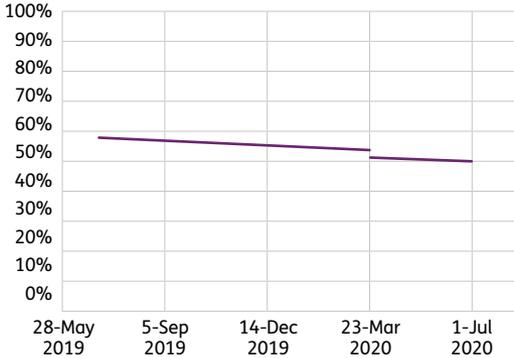
Would like to live in their current home in five years time



Feel safe getting out and about in their community



Wanted to do certain things in the last 12 months but could not

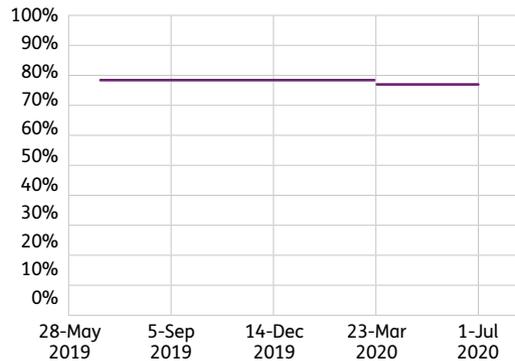


Participants were also less likely to have been unable to do certain things that they wanted to do in the last 12 months.

Participants aged 25 and over: Impact of COVID-19 – baseline

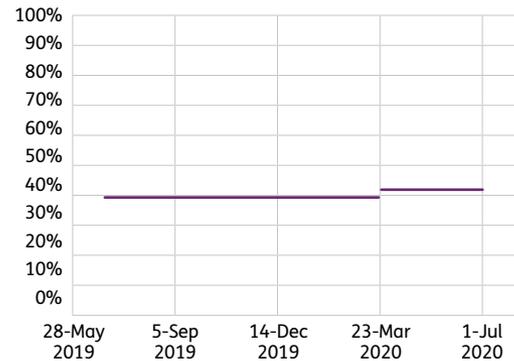
Negative results were observed for only three indicators, indicating that during the pandemic, participants were:

Have someone outside their home to call when they need help



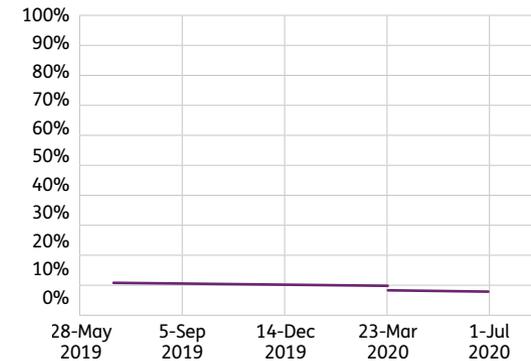
- Less likely to have someone outside their home to call on for help when needed.

Would like to see their family more often



- More likely to want to see their family more often.

Currently volunteer



- Less likely to currently be a volunteer.

Participants

aged 25 and over

Longitudinal outcomes

Participants aged 25 and over:

Impact of COVID-19 – longitudinal – summary

There were some significant changes to participants' longitudinal outcomes during the pandemic, and results were mixed, being favourable in some models but unfavourable in others. For example.

- With respect to having a regular doctor, participants were less likely to deteriorate between baseline and second or third review, when the review occurred during the COVID period. There was also a favourable change in time trend post-COVID, with deterioration becoming less likely over time, for the transition from baseline to third review.
- However, participants were less likely to improve with respect to knowing people in their community between baseline and second review, and between second and third review, when the later review took place during the COVID period.
- Participants who gave their second response during the COVID period were less likely to change their response from “Yes” (wanting to see their family more often) to “No” (not wanting to see them) between baseline and first or second review, as well as between first and second review.

More detail is provided in the tables on the following slides.

Participants aged 25 and over: Impact of COVID-19 – longitudinal

| Indicator | COVID step change | Time trend pre-COVID | Time trend post-COVID | Description of effect during COVID period |
|---|---|---|---|--|
| I feel able to advocate for myself |  |  |  | Participants who had a review in the COVID period were less likely to deteriorate between baseline and third review, and between second and third review. However, they were less likely to improve from baseline to third review. Time trends were mixed, but improvement between baseline and third review became more likely over time during the COVID period. |
| I want more choice and control in my life |  |  |  | Participants were more likely to change from “No” to “Yes” between first and second review, and less likely to change their answer between baseline and third review. Time trends were mixed. Post-COVID, changes from “No” to “Yes” become less likely over time. |
| I would like to see my family more often |  |  |  | Participants are generally more likely to continue to say they want to see their family more often during the COVID period. This tendency has been increasing over time (both pre- and post-COVID). |
| I would like to see my friends more often |  |  |  | Participants are generally more likely to continue to say they want to see their friends more often during the COVID period. This tendency has been increasing over time (both pre- and post-COVID). |
| I have a doctor I see on a regular basis |  |  |  | Participants were less likely to deteriorate between baseline and second or third review. General time trends were mixed. However, there was one favourable change in time trend post-COVID, with deterioration becoming less likely over time, for the transition from baseline to third review. |

Participants aged 25 and over: Impact of COVID-19 – longitudinal

| Indicator | COVID step change | Time trend pre-COVID | Time trend post-COVID | Description of effect during COVID period |
|---|---|---|---|---|
| I have been to the hospital in the last 12 months |  |  |  | Participants were less likely to improve between baseline and first or second review, and between first and second review. However, they were less likely to deteriorate between baseline and first review. Deterioration between baseline and third review becomes more likely over time (both pre- and post-COVID). However, post-COVID, improvement between baseline and first review becomes more likely. |
| I get opportunities to learn new things |  |  |  | Participants were less likely to improve in most transitions, however they were less likely to deteriorate between baseline and second review, and between first and second review. Over time, improvement has become less likely (both pre- and post-COVID). |
| I have wanted to do certain things in the last 12 months, but could not |  |  |  | Participants were less likely to deteriorate between baseline and first or second review, but less likely to improve between baseline and second review or between first review and second review. Time trends were mixed, but there was one negative change during COVID, with deterioration between baseline and second review becoming more likely over time. |
| I know people in my community |  |  |  | Participants were less likely to improve between baseline and second review, and between second and third review. Participants become less likely to change their response over time for some transitions (both pre- and post-COVID). |

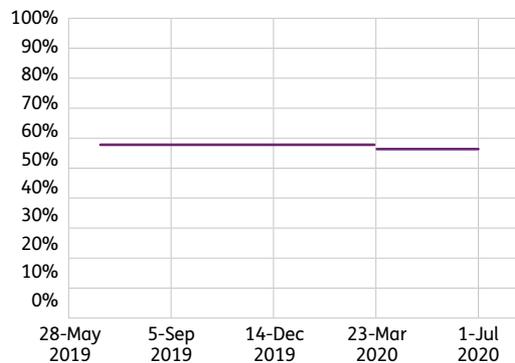
Families/carers of participants
from birth to age 14
Baseline outcomes

Families/carers of participants from birth to age 14: Impact of COVID-19 – baseline

There were some significant changes to family/carer outcomes during the pandemic, and results were mixed.

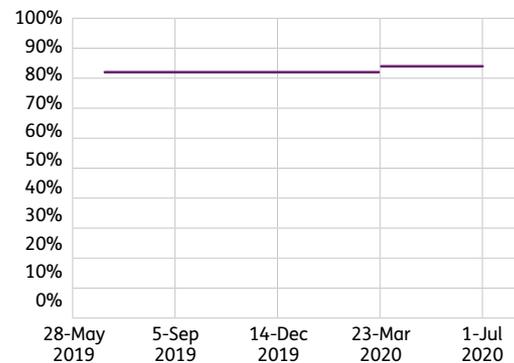
Employment-related indicators:

% of families/carers in a paid job



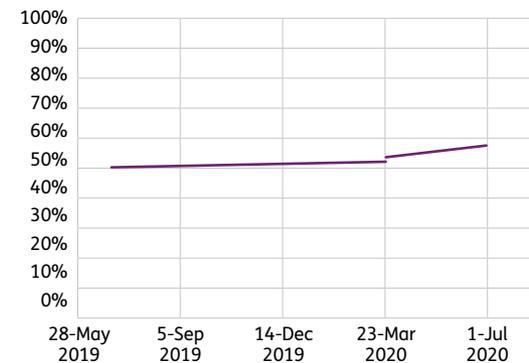
There was a significant drop in the percentage of families/ carers who have a paid job at the COVID-19 date.

Of those in a paid job, % who work 15 hours or more per week



However, there was a significant step increase in the percentage working 15 hours or more per week.

% of families or carers and their partners who are able to work as much as they want

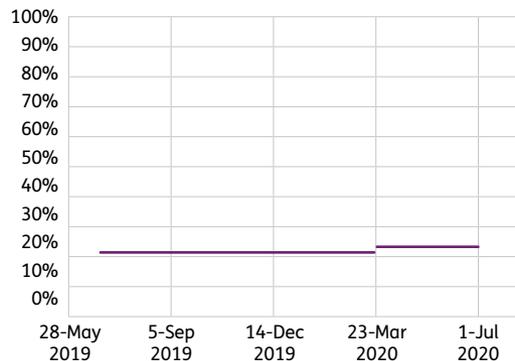


The percentage who say that they (and/or their partner) are able to work as much as they want increased more strongly over time during the pandemic.

Families/carers of participants from birth to age 14: Impact of COVID-19 – baseline

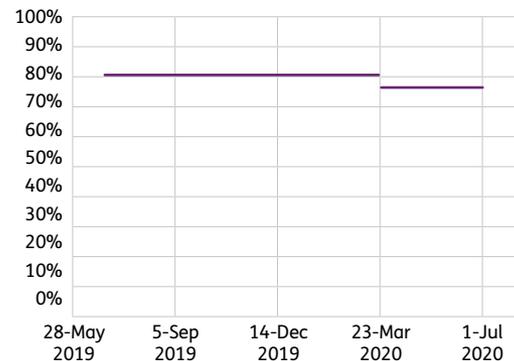
Employment-related indicators:

Of those unable to work as much as they want, % who say availability of jobs is a barrier to working more



Of those unable to work as much as they want, the percentage who say that availability of jobs is a barrier to working more rose to a higher constant level during the pandemic.

Of those unable to work as much as they want, % who say the situation of their child with disability is a barrier to working more



However, the percentage saying the situation of their child with disability was a barrier dropped to a lower constant level.

% of families / carers who are receiving Carer Allowance



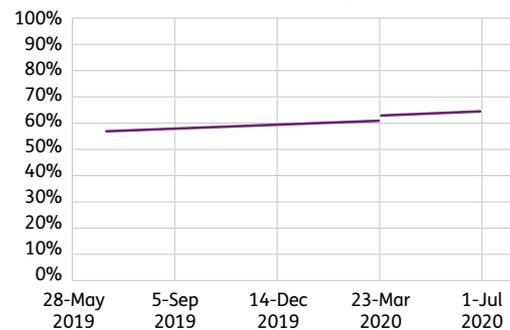
The percentage receiving Carer Allowance had been declining over time prior to the pandemic, but this decreasing trend levelled off during the pandemic

Families/carers of participants from birth to age 14: Impact of COVID-19 – baseline

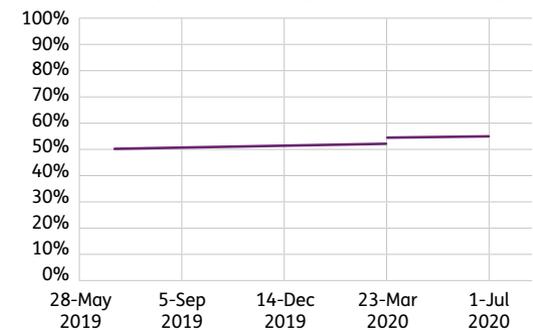
For the four indicators related to families feeling supported (having friends they can see as often as they like; having people they can ask for practical help, childcare, and emotional support as often as they need): there was a general increasing trend in these indicators prior to the start of the pandemic, a significant step increase at the start date, and a continuation of the same increasing trend post-onset of the pandemic.

Indicators related to support for families/carers and their child:

% of families or carers who have friends they can see as often as they'd like



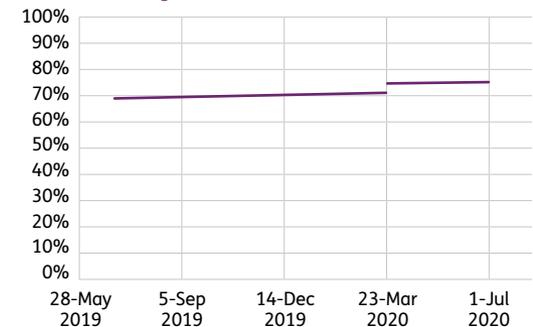
% of families or carers who have people they can ask for practical help as often as they need



% of families or carers who have people they can ask for childcare as often as they need



% of families or carers who have people they can talk to for emotional support as often as they need

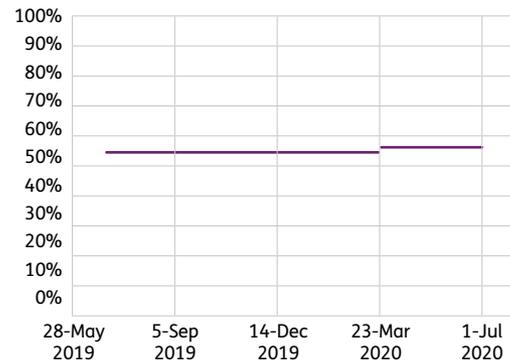


Families/carers of participants from birth to age 14: Impact of COVID-19 – baseline

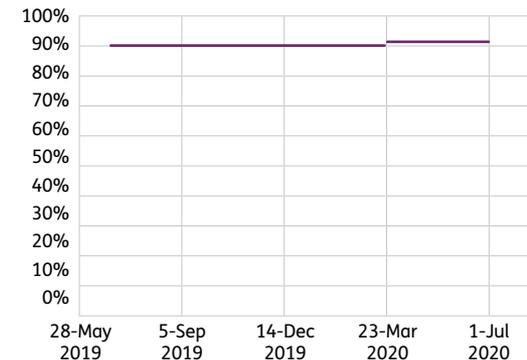
For the two indicators related to families/carers being supported in helping their child develop and learn (getting enough support in parenting their child, and feeling confident in supporting their child’s development): there was a significant improvement in these indicators to a new constant level post-onset of the pandemic.

Indicators related to support for families/carers and their child:

% of families or carers who get enough support in parenting their child



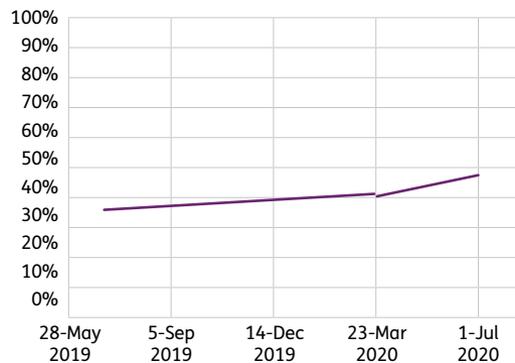
% of families or carers who feel very confident or somewhat confident in supporting their child’s development



Families/carers of participants from birth to age 14: Impact of COVID-19 – baseline

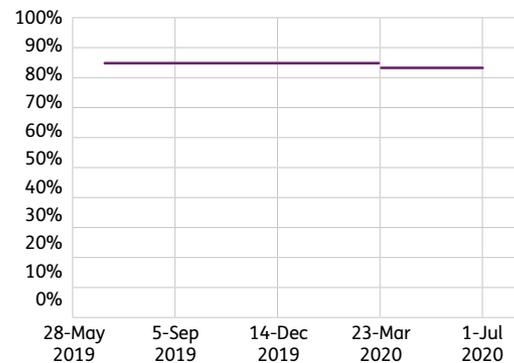
Indicators related to social and community engagement, and self-rated health:

% of families or carers and their partners who are able to engage in social interactions and community life as much as they want



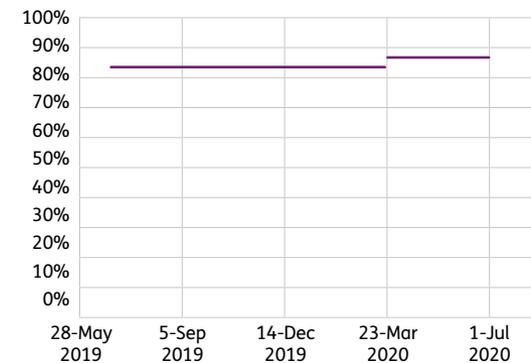
The percentage of families/ carers who are able to engage in social interactions and community life as much as they want showed an increasing trend prior to the pandemic. The increasing trend persisted, but at a higher rate, after the start of the pandemic.

Of those unable to engage in social interactions/community as much as they want, % who say the situation of their child is a barrier to engaging more



For those unable to engage as much as they want, the percentage who see the situation of their child with disability as a barrier to engaging more dropped to a lower constant level during the pandemic.

% of families or carers who rate their health as excellent, very good or good



The percentage of families/carers rating their health as excellent, very good or good rose to a new constant level during the pandemic.

Families/carers of participants
from birth to age 14
Longitudinal outcomes

Families/carers of participants from birth to age 14: Impact of COVID-19 – longitudinal – summary

There were some significant changes to families' and carers' longitudinal outcomes during the pandemic. The COVID-19 step-change variable was significant in at least one model for all 14 indicators considered. In addition, there were five indicators for which a change in time trend was detected in at least one model. Results were mixed, being favourable for some indicators but unfavourable for others. For example:

- When the later response occurred during the COVID period, deterioration over two years was more likely for having a paid job, and deterioration between second and third review was more likely for working 15 or more hours per week.
- Deterioration was less likely in transitions from baseline for having people to ask for practical help, and for being able to engage in social interactions and community life.
- There was a drop in the likelihood of improvement between baseline and first review with respect to getting enough support to feel confident in parenting their child at the start of the pandemic, however this was accompanied by a favourable change in time trend, with improvement becoming more likely over time during the pandemic.

More detail is provided in the tables on the following slides.

Families/carers of participants from birth to age 14: Impact of COVID-19 – longitudinal



| Indicator | COVID step change | Time trend pre-COVID | Time trend post-COVID | Description of effect during COVID period |
|---|-------------------|----------------------|-----------------------|---|
| I work in a paid job | ↓ | ↓ | ↓ | More likely to deteriorate (change from having a paid job to not having one) between baseline and second review. Improvement between baseline and first or second review, and between first and second review, becomes less likely over time, and deterioration between second and third review becomes more likely (same trends pre- and post-COVID). |
| I work 15 or more hours per week | ↓ | ↓ | ↓ | Families/carers whose second response was given after the onset of the COVID-19 pandemic were more likely to deteriorate between first and second review. Deterioration between baseline and second review becomes more likely over time (same trend pre- and post-COVID). |
| I have friends I can see as often as I like | ↕ | ↕ | ↕ | Families/carers whose second response was given after the onset of COVID-19 were less likely to deteriorate in all transitions from baseline, and more likely to improve between first and second review. However, they were more likely to deteriorate between first and second review. Time trends were mixed, however there was a stronger favourable time trend during the COVID period, with the likelihood of deteriorating in all transitions from baseline, and between first and second review, becoming increasingly less likely. |
| I have people I can ask for practical help as often as I need | ↕ | ↕ | ↕ | Families/carers who gave their later response during the COVID period were less likely to deteriorate in all transitions from baseline, however they were more likely to deteriorate between first and second review. Changing their response between baseline and first review becomes less likely over time. There was a favourable change in time trend post-COVID for two models, with the likelihood of deterioration between baseline and first or second review becoming increasingly less likely. |

Families/carers of participants from birth to age 14: Impact of COVID-19 – longitudinal

| Indicator | COVID step change | Time trend pre-COVID | Time trend post-COVID | Description of effect during COVID period |
|---|---|---|---|--|
| I get the services and supports I need to care for my child |  |  |  | Families/carers who responded during COVID were less likely to deteriorate from baseline to first review, baseline to second review and from first review to second review. However the general time trend pre-COVID19 was less likely to improve between baseline and first review, and this trend did not change post-COVID. |
| I know what specialist services are needed to promote my child's learning and development |  |  |  | Families/carers were less likely to change their response between baseline and first review, and were less likely to deteriorate between first and second review. Improvement between baseline and first or second review becomes less likely over time, however improvement between second and third review becomes more likely over time (same trend pre- and post-COVID). |
| I know what my family can do to support my child's learning and development |  |  |  | Families/carers were less likely to improve between baseline and first review and more likely to improve between baseline and third review when the review occurred during the COVID period. Improvement between baseline and first or second review, and between first and second review, becomes less likely over time, however improvement between second and third reviews becomes more likely (same trend pre- and post-COVID). |
| I get enough support to feel confident in parenting my child |  |  |  | Families/carers were more likely to improve between baseline and second review, and between first and second review, and less likely to deteriorate between baseline and first review. However, they were also less likely to improve between baseline and first review. The pre-COVID time trends were mixed, with improvement between baseline and first or second review, and between first and second review, becoming less likely over time, but deterioration between baseline and first review also becoming less likely. There were favourable changes in time trends for baseline to first review transitions, with the likelihood of improvement changing from being less likely to being more likely over time during the COVID period, and the likelihood of deterioration reducing more strongly during the COVID period. |

Families/carers of participants from birth to age 14: Impact of COVID-19 – longitudinal

| Indicator | COVID step change | Time trend pre-COVID | Time trend post-COVID | Description of effect during COVID period |
|--|---|---|---|---|
| I feel very confident or somewhat confident in supporting my child's development |  | | | Less likely to improve, but also less likely to deteriorate between baseline and first review. Less likely to improve between first and second review. |
| In general, my health is excellent, very good or good |  |  |  | Less likely to deteriorate from baseline to first and second review, however more likely to deteriorate from baseline to third review. Deterioration between baseline and second or third review, and between first and second review, becomes more likely over time, but deterioration between baseline and first review becomes less likely. There were three favourable changes in time trends at the onset of COVID-19, with families/carers becoming increasingly less likely over time to deteriorate between baseline and second review, and between first and second review, and more likely to improve between baseline and second review. The trend for deterioration between baseline and second review to become more likely over time persists in the post-COVID period. |
| One of the barriers to working more is the situation of my child with disability |  |  |  | Less likely to deteriorate between baseline and first review, and more likely to improve between baseline and second review. Improvement between baseline and first review becomes less likely over time, but improvement between first and second review becomes more likely (same trends pre- and post-COVID). |
| One of the barriers to working more is the insufficient flexibility of jobs |  |  |  | Less likely to deteriorate for all one-year transitions, however less likely to improve between baseline and first or second review. Deterioration between second and third review becomes more likely over time (both pre- and post-COVID). However, during the COVID period, improvement between second and third review becomes more likely over time. |

Families/carers of participants from birth to age 14: Impact of COVID-19 – longitudinal

| Indicator | COVID step change | Time trend pre-COVID | Time trend post-COVID | Description of effect during COVID period |
|---|---|---|---|---|
| I am able to engage in social interactions and community life as much as I want |  |  |  | Less likely to deteriorate between base and first or second review. Time trends were mixed, with improvement between baseline and first review, and deterioration between first and second review, both becoming less likely over time. |
| One of the barriers to engaging more in social interactions and community life is the situation of my child with disability |  |  |  | Families/carers were less likely to deteriorate between baseline and first review. Changing their response between baseline and first review became less likely over time. |

Families/carers of participants
aged 15 to 24

Baseline outcomes

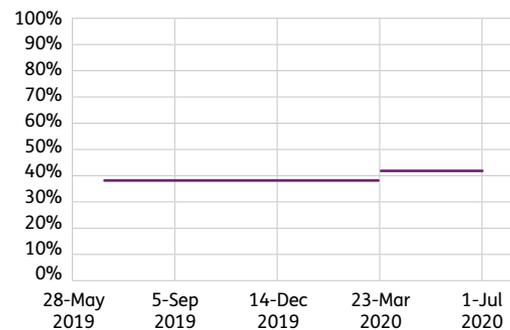
Families/carers of participants aged 15 to 24: Impact of COVID-19

COVID-19 was associated with positive changes to family/carer outcomes for five indicators.

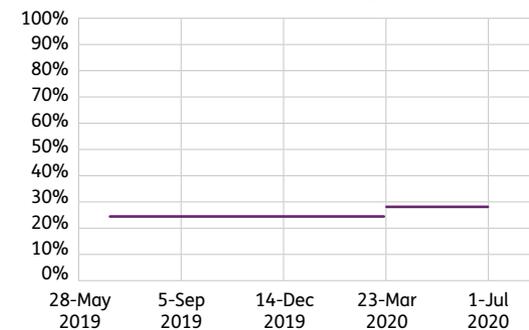
The baseline outcomes related to families feeling supported have become more positive, with increases during the pandemic being observed for the percentage of families/carers who:

- have friends they can see as often as they'd like.
- have people they can ask to support their family member with disability as often as they need
- have people they can talk to for emotional support as often as they need
- feel that the services they use for their family member with disability listen to them

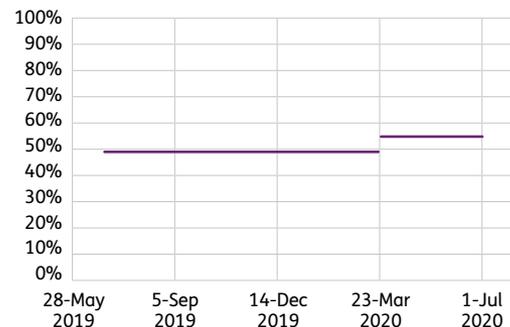
% of families or carers who have friends they can see as often as they'd like



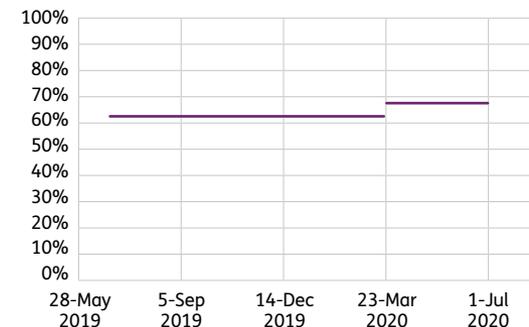
% of families or carers who have people they can ask to support their family member with disability as often as they needed



% of families or carers who have people they can talk to for emotional support as often as they need



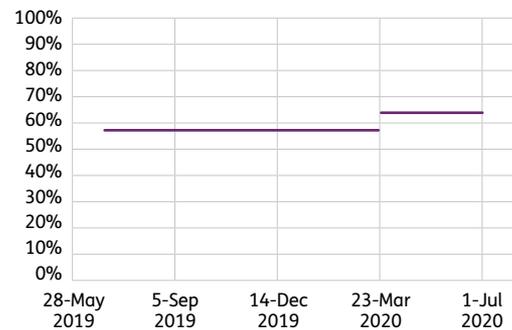
% of families or carers who feel that the services they use for their family member with disability listen to them



Families/carers of participants aged 15 to 24: Impact of COVID-19 – baseline

In addition, more families/carers rated their health as excellent, very good or good compared to the pre-COVID period.

% of families or carers who rate their health as excellent, very good or good



Families/carers of participants
aged 15 to 24

Longitudinal outcomes

Families/carers of participants aged 15 to 24: Impact of COVID-19 – longitudinal – summary

There were a few significant changes to families' and carers' longitudinal outcomes during the pandemic, and results were mixed, being favourable in some indicators but unfavourable in others. For example:

- Families and carers whose latest response was collected during the COVID period were more likely to show deterioration from baseline to first review in working 15 or more hours per week, however, they were more likely to show improvement from baseline to third review.
- Families and carers are less likely to deteriorate between baseline and first review in thinking that the services they use listen to them when their latest response is given during the COVID period.
- Families and carers who are unable to work as much as they want are more likely to start citing lack of job availability as a reason for not working more between baseline and third review, when the third review happened during the COVID period.

More detail is provided in the table on the next slide.

Families/carers of participants aged 15 to 24: Impact of COVID-19 – longitudinal

| Indicator | COVID step change | Time trend pre-COVID | Time trend post-COVID | Description of effect during COVID period |
|---|---|---|---|--|
| I work 15 or more hours per week |  |  |  | Families/carers were more likely to show improvement from baseline to third review, however they were also more likely to show deterioration from baseline to first review. Improvement between baseline and third review became less likely over time (both pre- and post-COVID). |
| I get the services and supports I need to care for my family member with a disability |  |  |  | Families and carers with latest review response collected during the COVID period were more likely to improve from baseline to third review. Deterioration between baseline and first review becomes less likely over time, however improvement between baseline and third review also becomes less likely, with these trends being the same pre- and post-COVID. |
| I feel that the services I use for my family member with disability listen to me | |  |  | Time trends were mixed, with the likelihood of both deteriorating and improving between baseline and first review becoming less likely over time. Also, the likelihood of improving in the latest year became less likely. There was one positive change in time trend post-COVID, with the probability of deterioration between baseline and first review decreasing at a stronger rate post-COVID. (The two negative time trends were maintained). |
| The availability of jobs is a barrier to working more |  |  |  | Deterioration was more likely between baseline and third review for families and carers whose interview took place after COVID impact. Deterioration between baseline and first review became less likely over time, but improvement between baseline and second review also became less likely, with the same trends observed pre- and post-COVID. |

Families/carers of participants
aged 25 and over

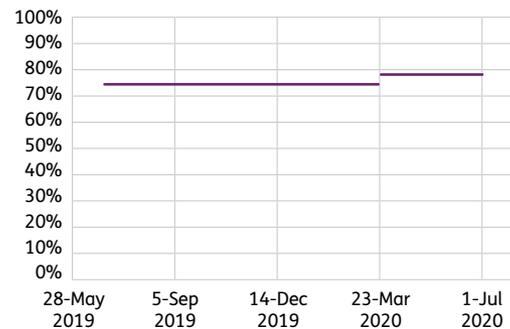
Baseline outcomes

Families/carers of participants aged 25 and over: Impact of COVID-19 – baseline

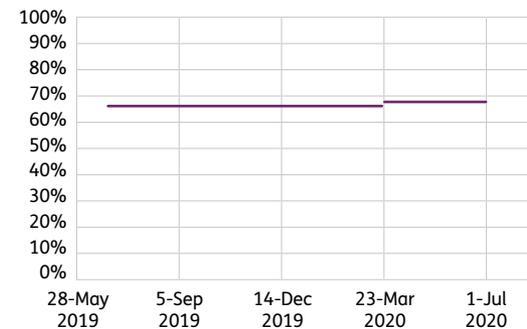
COVID-19 was associated with a number of changes to family/carer outcomes, with most being positive:

- For families/carers who have a paid job, the percentage working 15 hours or more per week increased.
- The percentage who say that those providing informal care to their family member with disability are able to work as much as they want also increased
- A higher percentage of families/carers reported having people they can talk to for emotional support as often as they need during the pandemic
- A higher percentage of families/carers said that the services they use listen to them

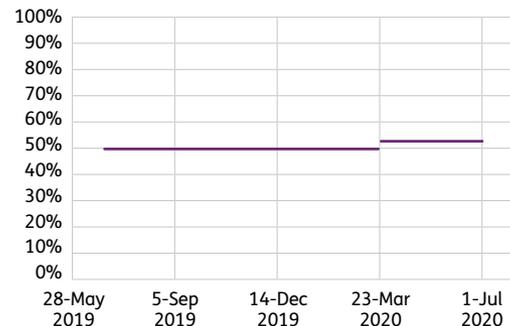
Of those in a paid job, % who work 15 hours or more per week



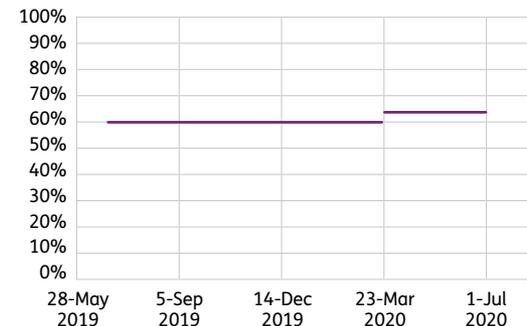
% of families or carers who provide informal care to their family member with disability and are able to work as much as they want



% of families or carers who have people they can talk to for emotional support as often as they need

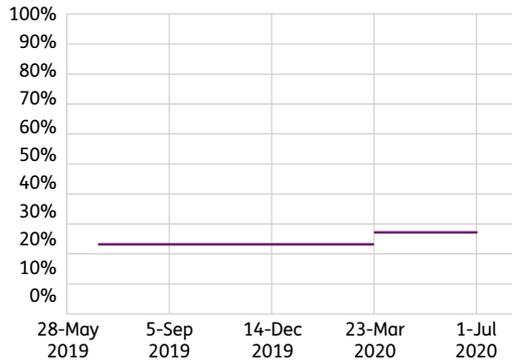


% of families or carers who feel that the services they use for their family member with disability listen to them



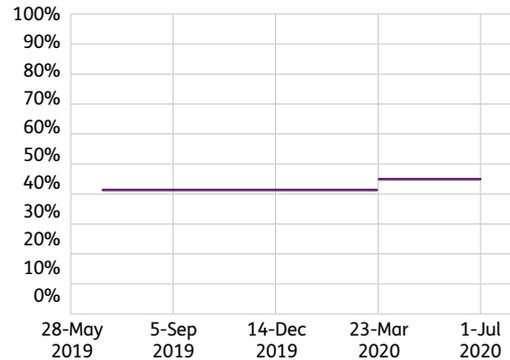
Families/carers of participants aged 25 and over: Impact of COVID-19 – baseline

% of families or carers who feel their family member with disability gets the support they need



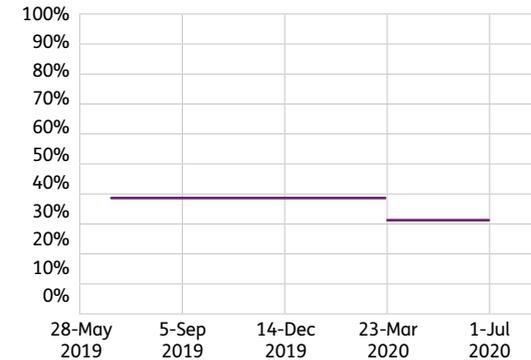
A higher percentage of families/carers thought that their family member with disability gets the support they need.

% of families or carers who rate their health as excellent, very good or good



The percentage of families/ carers rating their health as excellent, very good or good increased.

Of those who made or have begun making plans, % of families or carers who have asked for help from service providers, professionals or support workers



For families/carers who have begun to make plans for the future support of their family member, the percentage who have asked for help from service providers, professionals or support workers decreased.

Families/carers of participants
aged 25 and over

Longitudinal outcomes

Families/carers of participants aged 25 and over: Impact of COVID-19 – longitudinal – summary

There were only two indicators where there were significant changes to families' and carers' longitudinal outcomes during the pandemic:

- Families and carers who gave their later response during the COVID period were more likely to improve between baseline and first review in thinking that the services their family member with disability and their families receive meet their needs.
- Families and carers who had their review during the COVID period were less likely to deteriorate between baseline and first review but less likely to improve between baseline and second review in thinking that their family member gets the support they need.

More detail is provided in the table on the next slide.

Families/carers of participants aged 25 and over: Impact of COVID-19 – longitudinal

| Indicator | COVID step change | Time trend pre-COVID | Time trend post-COVID | Description of effect during COVID period |
|---|---|---|---|---|
| <p>The services my family member with a disability and my family receive meet our needs</p> |  |  |  | <p>Families and carers who gave their later response during the COVID period were more likely to improve between baseline and first review in thinking that the services their family member with disability and their families receive meet their needs. Improvement between baseline and first review became less likely over time, and deterioration between baseline and second review became more likely over time (same trends both pre- and post-COVID).</p> |
| <p>I feel my family member with a disability gets the support they need</p> |  |  |  | <p>Families and carers who had their review during the COVID period were less likely to deteriorate between baseline and first review but less likely to improve between baseline and second review. Improvement between baseline and first review became less likely over time (same trend both pre- and post-COVID).</p> |



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