



## **Autism Specific Transition Resources (T-Res Study) Report 2<sup>12</sup>**

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### **Highlights**

- Despite the return to school being a major concern that crossed from Time 1 of our study, overall this was a successful transition with most children returning in Time 2.
- Notably, 30.1% (28/93) that returned to school found this experience more positive than in previous years and 30.1% found this experience to be more or less the same kind of experience as in previous years.
- However, the proportion of students who engaged in frequent school refusal levels more than doubled from pre-March levels of 9.7% to 19.4% between September and March 2020.
- Similar levels of skills gains were reported as at Time 1 (July 2020), with daily living skills increasing most.
- Regarding skills regressions, the ability to self-regulate emotions was the most common with a decline reported for 44.2% of children. This was followed by a decline in social skills for 27.9% children.
- Similar to Time 1, many behaviours increased in frequency: verbal protests (63.3%) and rigid behaviours (54.1%), repetitive behaviours (51%), acting out aggressively, (45.9%) and self-injury (38.8%).

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<sup>2</sup> Information correct as of August 2021

## **Intro**

### **Background**

The Covid-19 pandemic has brought great upheaval to people's lives in Ireland and its true impact may not be seen for years. Vulnerable groups have been disproportionately affected by the restrictions imposed and one of the more significantly affected groups are autistic students and children. Many changes made the lives of children with a diagnosis of ASD more difficult. Schools in Ireland were closed in March 2020 with business closures, the introduction of social distancing, masks and other preventative measures coming gradually in the following weeks and months.

### **Aims**

The overall aim of the T-Res Project is to investigate the impact of Covid-19 related restrictions and the pandemic more broadly on autistic children and their families. Based on these findings, appropriate resources will be created and disseminated widely through an online repository. Within this, specific objectives of the Phase 2 survey were to 1) assess and gain further insights into the immediate and anticipated challenges faced by families, children and young people with autism, as a result of cycling in and out of the COVID-19 restrictions and 2) to compare these findings over time against the effects of the restrictions in March and Summer 2020.

## **Methods**

### **Participants**

Parents of children and young people with autism (up to the age of 18 years) were invited to take part in wave 2 of a longitudinal, anonymous, online survey. Demographic information for the subset of participants who were returning from Wave 1 were as follows. Forty one parents responded in relation to 46 children (age  $M (SD) = 10.8$

(3.051)). Of the 41 parents surveyed 7.3% provided data separately for two children with a diagnosis of autism, while 2.3% provided data for three children with a diagnosis. 95.1% participants in this subset identified as female.

Given a low wave 2 response rate from wave 1 participants ( 38.3%), it was decided to open the survey wider to new participants at Wave 2. Forty-four new parents took part and in total, therefore, participants consisted of 85 parents (age  $M (SD) = 42.24 (5.903)$ ) of child(ren) with autism, who responded with respect to 98 children aged eighteen and under (age  $M (SD) = 10.17 (3.604)$ ). Of the 85 parents surveyed, 12.9% provided data separately for two children with a diagnosis of autism, while 1.2% provided data for three children with a diagnosis. The majority of participants who took part in the survey identified as female (Female = 94.1%).

**Table 1**

*Number of children with a diagnosis of ASD answered for*

<b>No. of children</b>	<b>%</b>
1 child	85.9
2 children	12.9
3 children	1.2

### **Measures**

Many of the survey items were similar to at Time 1 with questions on topics such as the challenges of the restrictions, behavioural change, skills and abilities. These were updated to the relevant timeline (e.g. Sept- Dec 2020). A number of questions were added on areas such as the return to school, attitudes towards school, school refusal and communication

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from schools. There were new questions on new Covid-19 related behaviours that may have begun during the lockdown, Covid-19 supports, routine and verbal ability.

The remaining questions were those from Wave 1 of the survey. Some of these questions included predicted and current challenges faced by their child(ren) due to COVID-19 restrictions, resources and/or strategies parents found helpful during the restrictions and decline and/or improvements parents observed in their child's abilities/skills in recent months. In addition to this, parents completed a measure of behaviour regulation.

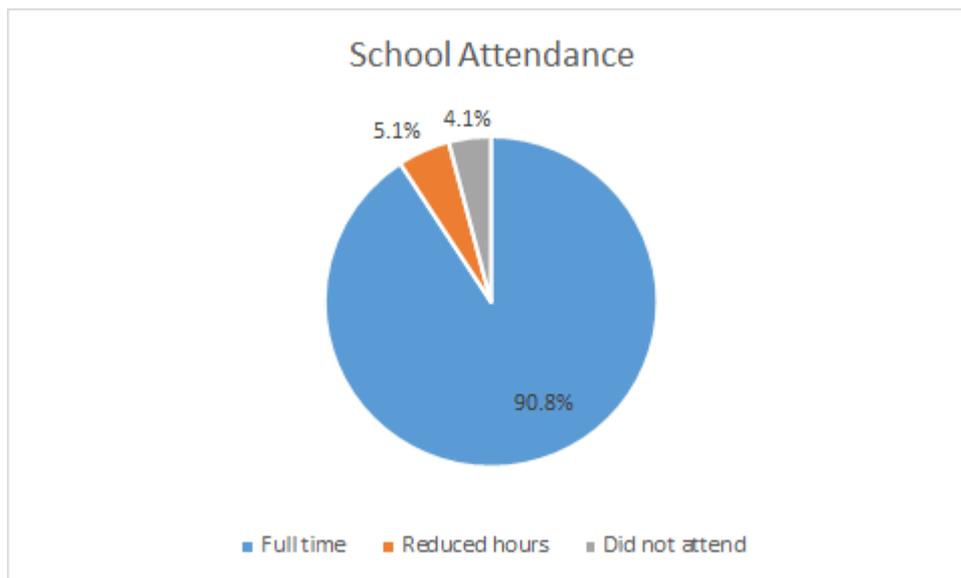
Parental stress levels were measured using the Parenting Stress Index, (deSilva & Schalock, 2012) and children's levels of anxiety were measured using the Anxiety Scale for children with autism spectrum disorder (ASC-ASD) (Rodgers, Wigham, McConachie, Freeman, Honey & Parr, 2016). If participant's children were aged 8 or above, were verbal and consented to take part, they were invited to complete the Anxiety Scale for children (ASC-ASD) to assess their own anxiety levels. If this was not the case, a parent was instructed to complete the anxiety scale on behalf of their child.

New participants were asked to fill in some demographic information while follow-up participants were not asked for that information as it had already been gathered.

### **Findings**

Both quantitative and qualitative methods were used to analyse the data collected. Descriptive and frequency analyses were conducted using SPSS. Content analysis was used to analyse qualitative data provided by participants in relation to challenges and improvements/decline in skills and abilities.

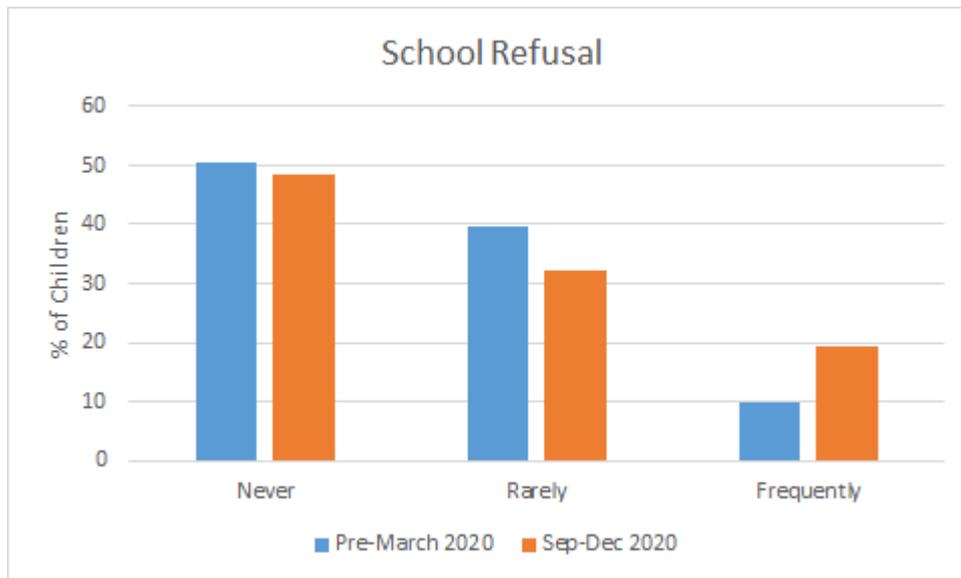
## Return to school



**Figure 1.** The % of children returned school on full, reduced hours or did not attend

Schools in Ireland closed in March 2020 and did not reopen until after the school holidays in September of that year. By this time, children had been out of school for approximately six months. 90.8% of children returned to school full-time on reopening following the summer holidays in September 2020. 5.1% of children returned on reduced hours. 4.1% of children did not attend school in this period. This break had differential impacts on individuals and the experience of the return to school varied throughout the cohort included in the current study.

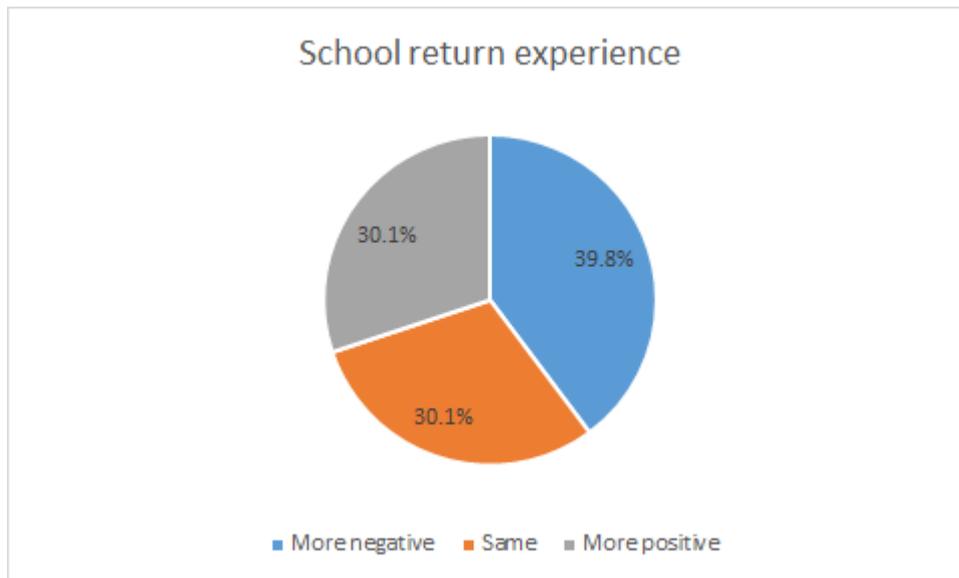
Parents reported that before March 2020 that 50.5% of the children included in this study had never refused to go to school. 39.8% had rarely or occasionally refused to attend and only 9.7% had frequently or very frequently refused. In comparison, between September-December 2020, following the return to school after a period of remote learning, 19.4% had either frequently or very frequently refused to attend school, a more than twofold increase.



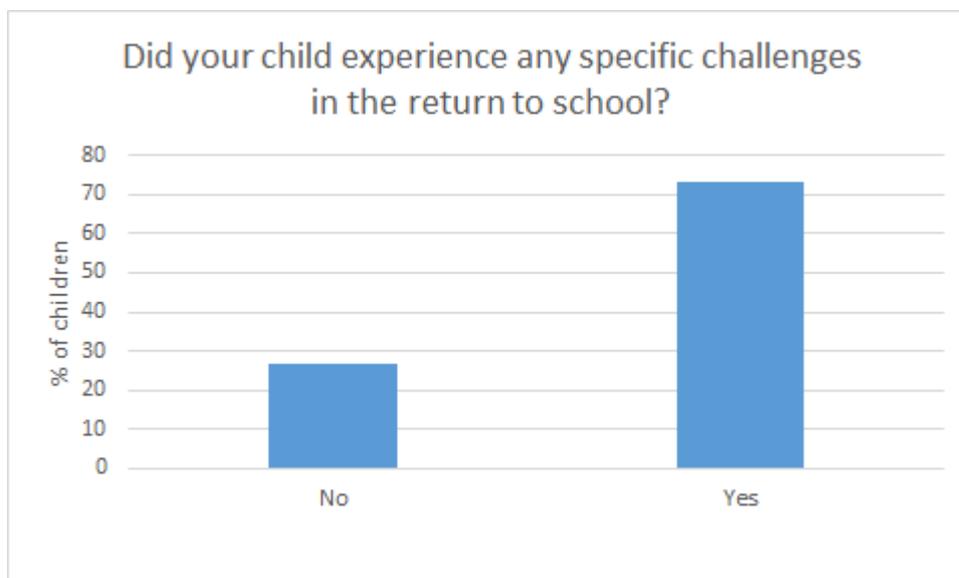
**Figure 2.** School refusal levels pre-pandemic versus the return to school

Attitudes towards school were also measured. Retrospective parent reports of children’s attitudes towards school were rated on a 10-point scale (1 being a very negative attitude with 10 being a very positive attitude). Attitudes prior to the lockdown in March 2020 had a mean score of 6.77. Attitudes on the return to school from September to December 2020 were slightly lower with a mean of 6.05.

Similar to the attitudes to school, the experience of returning to school itself was also measured. Participants were asked to rank the return experience between negative and positive. Nearly one third of children who returned to school (30.1%) found this experience to be more or less the same kind of experience as in previous years, while 39.8% found it to be a more negative experience and 30.1% found it to be a more positive experience.



**Figure 3.** School refusal levels pre-pandemic versus the return to school



**Figure 4.** % of children who experienced specific challenges in the return to school

With the many adjustments to everyday life made during lockdown and the changes to the school environment, on return, children faced a potentially onerous transition back to school in September 2020. Despite this, parents of 26.9% of children did not report any specific challenges. Parents of 73.1% of the students who returned to school did report that their child(ren) faced specific challenges in the weeks leading up to and after the return. Following a content analysis of the answers provided, anxiety was the most prevalent issue

raised by participants with 50% participants highlighting it as an issue. Issues around routine and sleep were raised by 36.8% participants. Emotional regulation was of concern for 30.8% students. In addition, 14.7% participants reported regression of skills and abilities and 14.7% reported difficulties in understanding and adhering to social distancing & public health guidelines. Other challenges less frequently experienced can be seen in Table 2. These challenges may have contributed to the development of skills and abilities in children.

**Table 2**  
*Types of challenges reported*

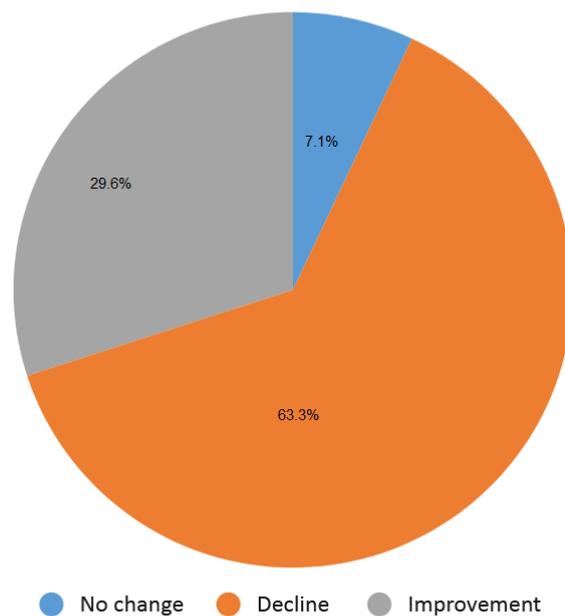
Challenges	% of children
Anxiety	50
Routine & Sleep	36.8
Emotional Regulation	30.8
Regression of skills & abilities	14.7
Understanding and adhering to public health guidelines	14.7
Social Skills	7.4
Behavioural issues	4.4

### **Skills, abilities and behaviours**

During lockdown many children’s learning and development environment was altered. This had an impact on skills and abilities for the majority of cases. Parents were asked if they had observed any changes in their child(ren)’s skills and abilities over the second school closure period (January-February 2021). An overall decline in skills and abilities was

reported for 63.3% of children. Improvements in skills and abilities was reported for 29.6% of children, while no change in abilities and skills was observed in 7.1% of children.

### Skills & abilities



**Figure 5.** % change in skills and abilities for children

When asked to give details of the changes in skills and abilities noted, it was reported that the ability to self-regulate emotions declined in 44.2% children in recent months. This included examples such as, deterioration in motivation, mood, meltdowns and self-regulation. In keeping with the anticipated challenges identified, parents reported social skills declined for 27.9% of children. Deterioration in anxiety levels was observed in 12.8% of children. Issues also arose around the return to school for 25.6% children in areas such as academics and school refusal. Daily living skills such as general independence and toileting declined for 20.9% of students. Finally, problems with routine and sleep were observed in 23.3% of children.

**Table 3***Types of skills and abilities that have declined.*

<b>Ability/Skill</b>	<b>% of children</b>
Emotional- & Self-regulation	44.2
Social skills	27.9
Anxiety	12.8
Return to school	25.6
Independence	20.9
Routine & sleep	23.3

While a decline in skills and abilities was most frequently reported, an improvement in abilities and skills was reported for a significant minority of children. Daily living skills were the most highly reported skills to improve in recent months which were reported by 19.8% of children. Improvements in academic skills were observed in 14% of children. Emotional and self regulation issues improved in 7% of children while anxiety levels also improved in 4.7%. Both social skills and routine related issues improved in 2.3% of children respectively.

**Table 4***Skills and abilities observed that have improved*

<b>Ability/Skill</b>	<b>% of children</b>
Daily living skills	19.8
Academic skills	14
Emotional- and self-regulation	7
Anxiety	4.7
Social skills	2.3
Routine	2.3

Post Covid-19 society is a much changed environment. For autistic children the transition led to new behaviours for many but not all. When asked about new Covid-19 related behaviours in their children since the onset of school closures in January 2021, parents indicated that 34.7% of children did not engage in any new behaviours. For 65.3 % of children, parents indicated that their child had engaged in new Covid related behaviours. The most common issue was a refusal to leave home 27.6%, followed by fear of death related to Covid-19 23.5% and repetitive questioning 22.4%. Excessive hygiene routines were highlighted by 17.3% individuals, while obsessions with the news were reported by 11.2% participants and refusal to allow visitors was reported by 9.2%.

Different levels of new behaviours were observed in individuals. Of the 50 participants that selected a provided option in terms of new behaviours engaged in, 42% selected one new behaviour, 26% selected two new behaviours and 32% selected three or more new behaviours

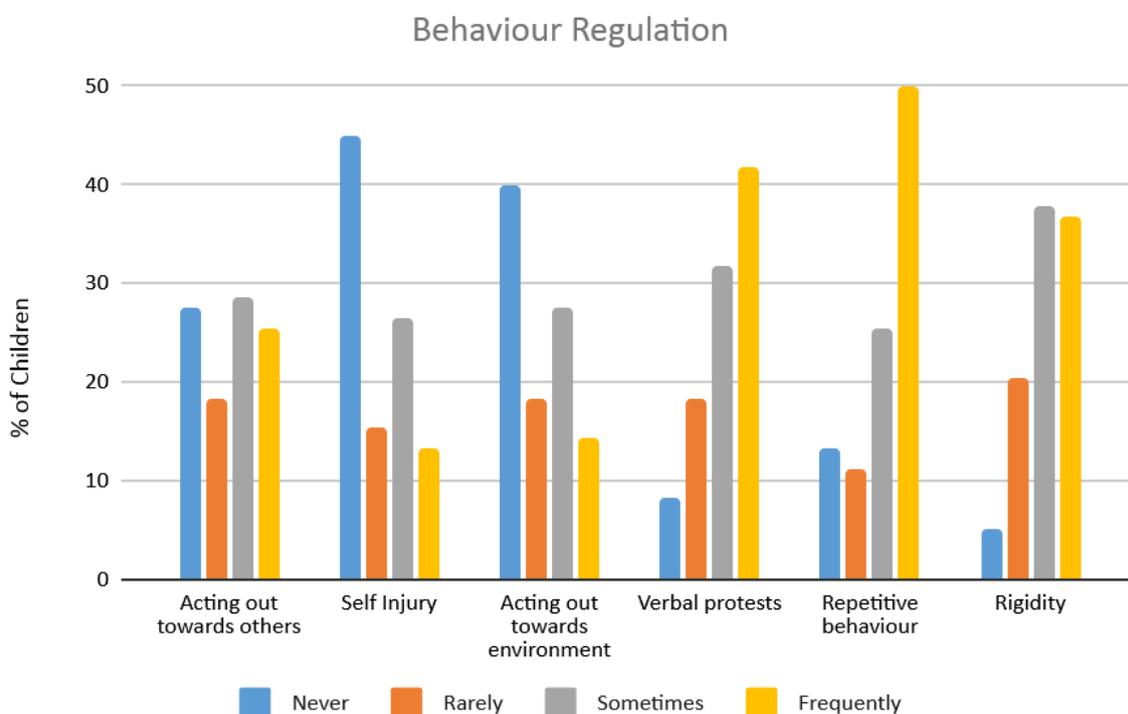
**Table 5**  
*New Covid-19 related behaviours*

<b>Behaviour</b>	<b>% of children</b>
Repetitive questioning	22.4
Fear of loss or death as a result of Covid-19	23.5
Excessive hand washing and hygiene routines	17.3
Obsession with the news	11.2
Refusal to leave home	27.6
Refusing to allow others visit the family home	9.2
No. My child has not engaged in any new behaviours as listed above	34.7

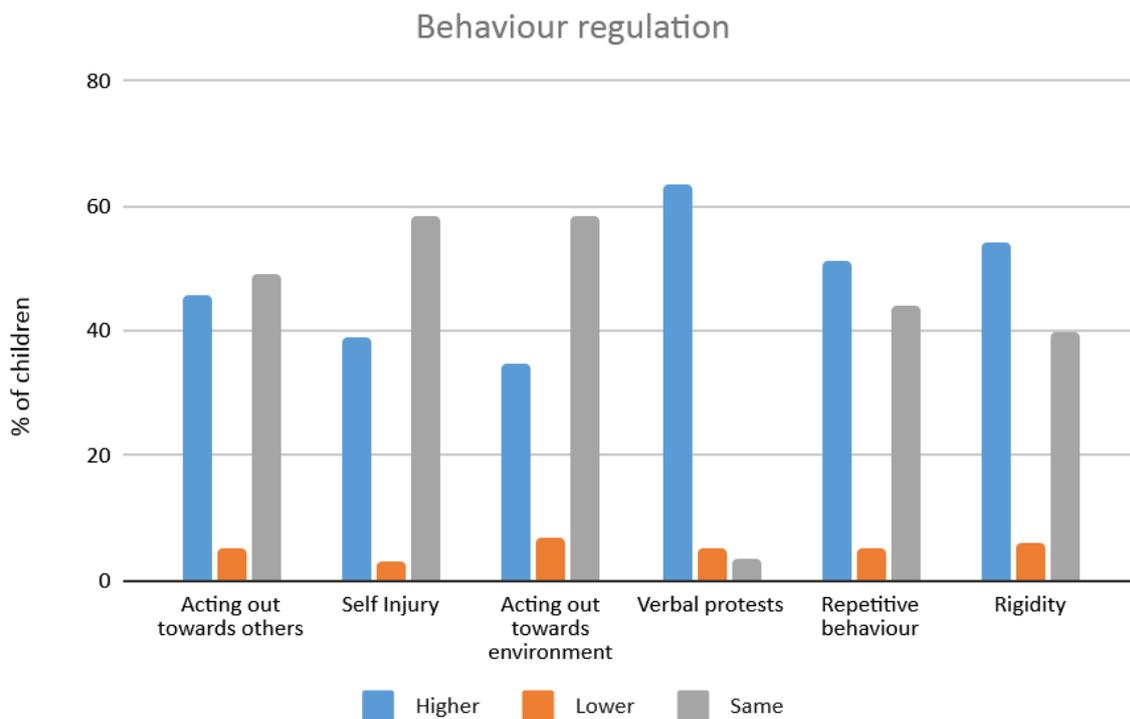
The changes and anxiety caused by the pandemic led to more behaviour regulation issues amongst some children. Parents completed a series of questions specific to behaviours, exhibited by their child(ren) in the past month. Behaviours exhibited by children “frequently”

included; repetitive behaviour (50% of children), rigid (routine type) behaviours (36.7% of children) and verbal protests (41.8% of children). Aggressive behaviour (towards others) was also frequently reported for 25.5% of children.

Parents were also asked if occurrences of these behaviours were higher, lower or the same in the past month. Parents reported that verbal protests (63.3% of children) and rigid behaviours (54.1% of children) were higher in the past month. This was followed by higher instances in repetitive behaviours for 51% of children and acting out aggressively (towards others) for 45.9% of children. 38.8% of children were reported to have engaged in higher levels of self injury. Parents reported that Acting out (towards the environment), displayed lower instances in 7.1% of children. Similarly, 6.1% of children exhibited lower levels of rigidity (reliance on routine).

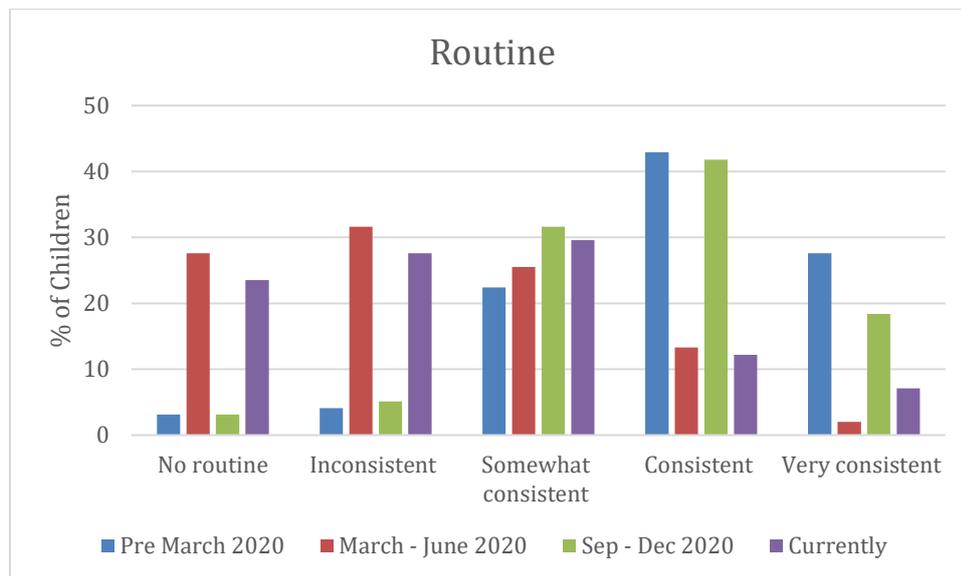


**Figure 6.** Levels of behaviours exhibited



**Figure 7.** % change in levels of behaviours since the pandemic onset

People with a diagnosis of ASD tend to have more problems with transitions and in turn are more reliant on routine. The pandemic caused significant changes to routine for many. Pre-March 2020 92.9% of children were reported as having a somewhat consistent or better routine. Only 4.1% had an inconsistent routine and 3.1% of children had no routine at all. Between March and June 2020, 59.2% of children had an inconsistent routine or no routine at all. 25.5% had a somewhat consistent routine while only 15.3% had a consistent or very consistent routine. Between September and December 2020, only 8.2% of children had an inconsistent routine or no routine at all. 91.8% had a somewhat consistent routine or better. When asked about their children’s current routine at the time of the second round of the survey in the Spring of 2021, 48.9% had a somewhat consistent routine or better while 51.1% had an inconsistent routine or no routine at all. This shows that although children have had their routines drastically disrupted by school closures, they quickly return to routine on the resumption of in-person schooling.



**Figure 8.** Routine before and across the pandemic

### Parenting stress & Child anxiety

With all of the changes and stress induced by the pandemic, coupled with the continued uncertainty over a prolonged period, it may have been expected that stress and anxiety levels would deteriorate for both caregivers and children as the pandemic, restrictions and lockdowns remained in sight. A Wilcoxon signed-rank test showed that of those who partook in both time points, there was not a statistically significant change in stress ( $Z = -.780, p = 0.435$ ) or anxiety scores ( $Z = -.943, p = 0.345$ ) in individuals between Phase 1 and Phase 2. Median Stress Score rating was 20.0 for phase 1 and 21.0 for phase 2. Median Anxiety score was 30.0 for phase 1 and 27.0 for phase 2. These scores represent relatively high levels of anxiety (ASC-ASD) as a score greater than 20 may indicate the presence of significant levels of anxiety (Adams, Clark and Keen, 2019). In terms of the stress scores (APSI), participants had a much higher score than what would be expected of normally developing populations (5.41 mean score; deSilva & Schalock, 2012) or other developmental disabilities (11.75 mean score; deSilva & Schalock). However, when compared to ASD populations the scores are not very different to non-pandemic situations when deSilva and Schalock reported a mean of 22.93.

## **Conclusion**

Wave 2 of our online survey aimed to investigate the impacts of COVID-19 restrictions and the subsequent cycling in and out of restrictions on autistic children and their families. Findings suggest a number of challenges faced by both children and their families.

As had been expected based on Wave 1 of this study, the return to school posed a significant challenge to families in September 2020 with almost 40% of students finding it to be a more negative experience compared with other school returns. A contributing factor to this may be the increased disruption to routine caused by school closures and other restrictions. Levels of school refusal also increased on the return with almost a twofold increase in comparison to previous years.

For some children, both skills and abilities improved in certain areas with daily living skills the most improved. However, a decline in skills and abilities was reported by a majority. There were increased challenges faced by many participants, especially in anxiety, routine, sleep and emotional regulation. In addition, some new behaviours emerged during the pandemic such as refusal to leave home, Covid-19 fears, repetitive questioning and excessive hand washing. Relatedly, other problematic behaviours increased in frequency such as verbal protests and rigid and repetitive behaviours, aggression and self-injury.

It is clear from these findings that children and their parents are experiencing a multitude of unique challenges, as a result of the COVID-19 restrictions, continuous uncertainty amid imposition, relaxation and re-imposition of restrictions and closures. It is also noted that these findings reflect children and young people of various age ranges and abilities. It is evident that the broader transition-based resources project, of which this report forms part, needs to take account of the impact of extended and extensive changes.

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## References

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