



## **Autism Specific Transition Resources (T-Res Study) Report 3**

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### **T3 Highlights**

- Despite the return to school following the first closures being broadly a success (See Report for survey 2), the return to school after the second school closures in early 2021 was found to be a more negative experience than usual returns to school by over half of children.
- Issues around routine and transitions were the most prevalent challenge experienced around this return to school and was raised by 41.1% of respondents.
- 39% of children had the same opportunities for educational inclusion as pre-pandemic while 19% experienced less opportunities for inclusion. In the latter instance, the majority of parents reported that this was due to school policy.
- The majority of parents reported that rates of verbal protests, rigidity and repetitive behaviours had increased in the past month but that other behaviours had remained steady.

## **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. Since then these measures have continued to fluctuate and change.

### **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 3 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 the gradual phasing out of the COVID-19 restrictions and 2) to compare these findings over time against the effects of the restrictions at Time 1(Summer 2020) and Time 2 (Spring 2021) of this study.

Phase 3 of this study was conducted in Autumn 2021.

## **Methods**

### **Participants**

Parents of children and young people with autism (up to the age of 18 years) were invited to take part in wave 3 of a longitudinal, anonymous, online survey. Demographic information for the participants who took part in Wave 3 were as follows. Sixty six

parents responded in relation to 77 children (age  $M (SD) = 10.35 (3.7)$ ). Of the 66 parents surveyed, 55 provided data separately for one child with a diagnosis of autism, while 11 provided data for two children with a diagnosis. 62 parents in this subset identified as female and 4 identified as male.

There was a low wave 3 response rate from participants of previous rounds; parents responded with regard to 20 children who had previously been part of both rounds 1 and 2, 15 additional children who were part of round 1 previously but not round 2 and 18 children who had previously only been part of Wave 2. Responses for twenty-four new children that only took part only at Wave 3 were recorded also.

**Table 1**

*Number of children with a diagnosis of ASD answered for at Time 3 by each parent*

<b>No. of children</b>	<b>%</b>
1 child	83.4% (55)
2 children	16.6% (11)

## **Measures**

Many of the survey items were similar to Time 1 and Time 2 with questions on topics such as the challenges of the restrictions, behavioural change, skills and abilities. Other questions were asked on predicted and current challenges faced by their child(ren) due to COVID-19 restrictions, the impact of specific 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. There were also questions on the school attendance, attitudes towards school, new Covid-19 related behaviours, Covid-19 supports, routine and

verbal ability. In addition to this, parents completed a measure of behaviour regulation. These were updated to the relevant timeline (Autumn 2021). A number of questions were added on areas such as the long term impact of the pandemic, the relevance of the scales, seeking additional services for anxiety or emotional regulation and whether the child went through major transitions aside from Covid-19 in the past year.

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 invited 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.

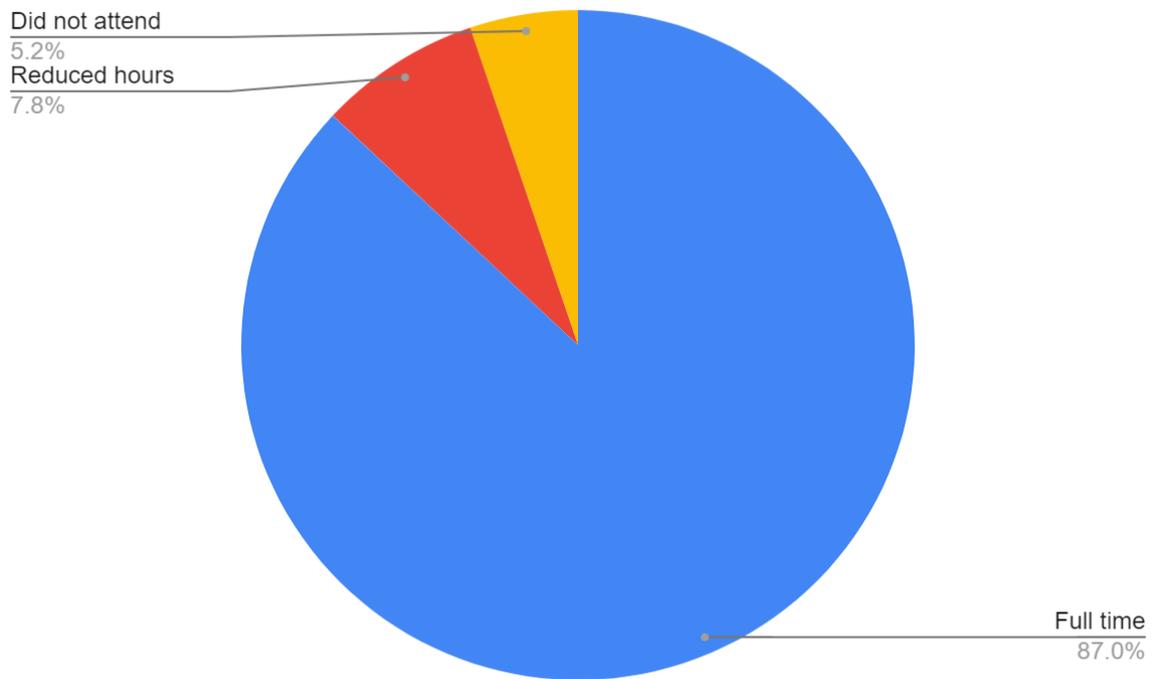
## **Findings**

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**

Schools were closed for in person teaching between the end of December 2020 and Spring 2021. Following the reopening in Spring 2021 (reopening dates were staggered by cohorts

and age groups) 87.01% ( 67 ) of children returned to school full-time, 7.79% (6) children returned on reduced hours and 5.19% (4) 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.

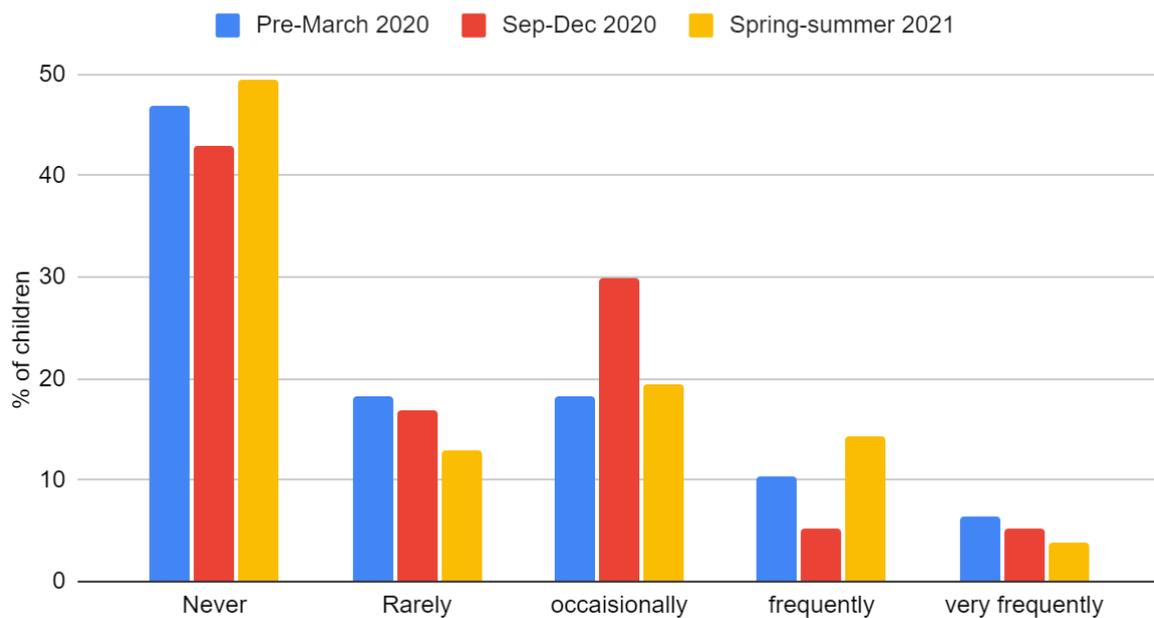


**Figure 1. School attendance after the second period of school closures.**

Parents reported on the frequency of school refusal at three different timepoints pre-March 2020, September to December 2020 and between Spring 2021 and the Summer break. This can be seen in the figure below. Most notably, there was an initial decrease in the reported percentage of children who frequently or very frequently refused to go to school when the time after the first school reopening (Sept-Dec 2020) was compared with pre-COVID. However, following the second school reopening, levels rose again and were higher than

pre-COVID. In

## School Refusal



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

The experience of returning to school in Spring 2021 after the second period of school closures was measured. Participants were asked to rate the experience of returning to school on a 5-point scale “from much more negative” to “much more positive” than in previous years. Of the children who returned to school (N=73) 17.8% (13/73) found this experience to be more or less the same kind of experience as in previous years, while 53.4% (39/73) found it to be a more negative experience and 28.8% (21/73) found it to be a more positive experience.

Parents were asked about any specific challenges that had been experienced around the return to school. Following a content analysis of the answers provided(see Table 2), it was

found that issues around routine and transitions were most prevalent, raised by 41.1% (30/73) participants who returned to school.

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

<b>Challenges</b>	<b>% of children</b>
Routine and transitions	41.1
Anxiety and fear	19.2
Social skills	11

The percentage of children in different types of educational settings remained relatively stable over time (see Table 3). When asked about changes or stability in opportunities for inclusion, parents reported that opportunities stayed the same for 39% (30/77) of children however, they decreased for 19.5% of children. For this cohort (15 children) the majority (14) experienced decreased access because schools kept children in a class “bubble” for public health reasons that did not facilitate inclusion in mainstream classes. In only one case, the parent reported that it was at their own request that their child did not mix with another class for public health reasons

**Table 3**  
*School Setting*

<i>School setting</i>	<i>% of children</i>	
	<i>Pre-covid</i>	<i>Post March 2020</i>

<i>special class or school only</i>	19.48052	29.87013
<i>mainstream mainly</i>	46.75325	44.15584
<i>special class plus inclusion</i>	19.48052	6.493506
<i>don't know</i>	0	2.597403
<i>N/a</i>	14.28571	16.88312

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

Parents were asked if they had observed any changes in their child(ren)'s skills and abilities during the second school closure period in early 2021 and this survey in Autumn 2021. An overall improvement in skills and abilities was reported for 41.6% (32/77) of children. Declines in skills and abilities were reported for 39% (30/77) of children, while no change in abilities and skills was observed in 19.5% (15/77) of children.

Sixty participants gave further details of the changes in skills and abilities noted. A content analysis of the data found that social and communication skills declined in 25% (15/60) children. An increase in anxiety levels was observed in 8.3% (5/60) of children, while 10% (6/60) of children were reported as having increased problems with emotional regulation. Issues also arose with academics and school for 21.7% (13/60) of children. Daily living skills declined for 10% (6/60) of students (See Table 4).

**Table 4**

*Types of skills and abilities that have declined.*

<b>Ability/Skill</b>	<b>% of children</b>
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Social skills	25
Academic skills	21.7
Emotional regulation	10
Daily living skills	10
Anxiety	8.3

While a decline in skills and abilities was most frequently reported, an improvement in abilities and skills was reported for many children. Independence and daily living skills were the most highly reported skills to improve in recent months which were reported by 28.3% (17/60) of children. Improvements in communication and social skills were observed in 15% (9/60) children. Academics improved for 6.7% (4/60) children

**Table 5**  
*Skills and abilities observed that have improved*

<b>Ability/Skill</b>	<b>% of children</b>
Daily living skills	28.3
Social skills and communication	15
Academic skills	6.7

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 children between school reopening in Spring 2021 and the end of the school term in May/June and then again for the period covering the summer holidays, there was a notable difference.

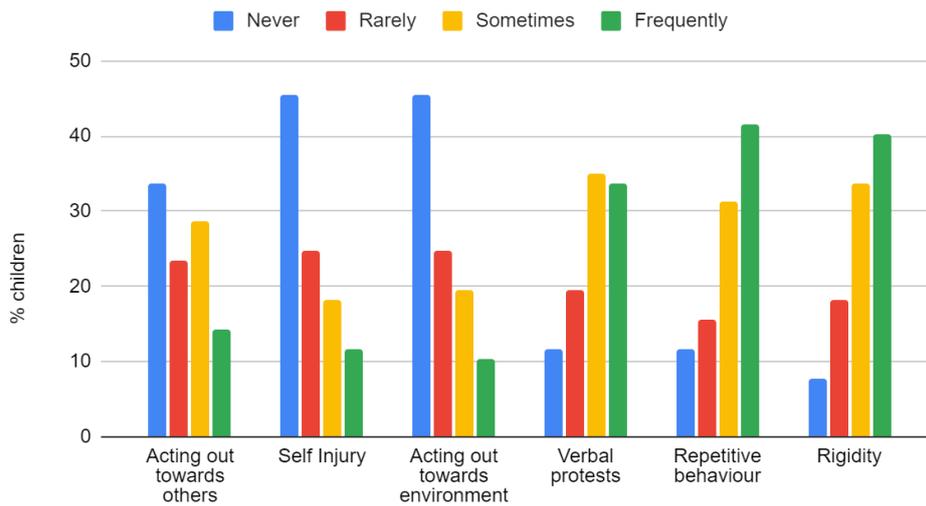
During the School term 30/77 children did not engage in any new covid related behaviours compared to 41/77 during the school holidays. Incidents of each type of new behaviour were lower during the school holidays. Specific details can be seen in Table 6.

**Table 6. Frequency of new COVID related behaviours during school term and during school holidays.**

	During school reopening spring 2021	During school summer holidays
Refusal to leave home	24.7 % (19)	11.75 (9)
fear of death related to Covid-19	26% (20)	14.3% (11)
repetitive questioning	31.2% (24)	19.5% (15)
Excessive hygiene routines	18.2% (14)	10.4% (8)
obsessions with the news	14.3% (11)	6.5% (5)
refusal to allow visitors	16.9% (13)	10.4% (8)

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. The areas where behaviour regulation seemed to prove most difficult frequently were in repetitive behaviour (32/77), rigid behaviours (31/77) and verbal protests (26/77). All data regarding behavioural regulation can be seen in Figure 3.

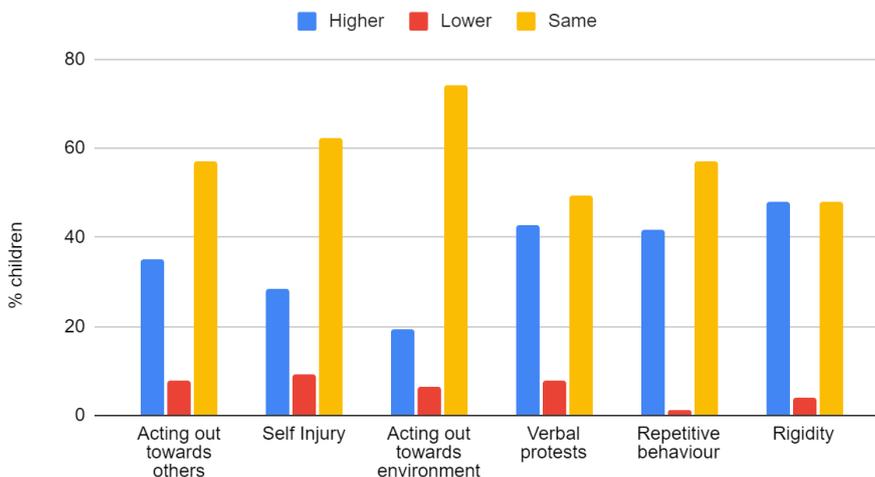
## Behavioural Regulation



**Figure 3. Frequency of difficulties regulating behaviour**

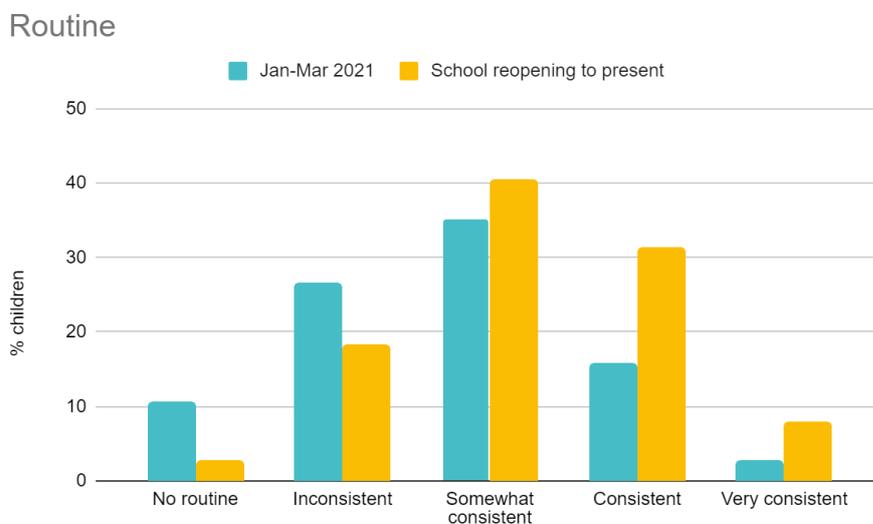
Parents were also asked if occurrences of these behaviours were higher, lower or the same in the past month. The majority of parents reported that rates of many of the behaviours remained the same apart from for rates of verbal protests, rigidity and repetitive behaviours where the majority of parents reported that rates of these behaviours had increased in the past month. This was most marked for verbal protests (see Figure 4 for all data).

## Changes in frequency of behavioural dysregulation



**Figure 4. % change in levels of behavioural dysregulation in the past month**

Autistic people tend to have more problems with transitions and in turn are more reliant on routine. The pandemic caused significant changes to routine for many. We asked parents about routine consistency pre-pandemic and for various time points after that. Their reports can be seen in Figure 5. Of note for the time period covered by the current report, during school closures between January and March 2021, 41/77 had a somewhat consistent routine or better while 36/77 had an inconsistent routine or no routine at all however, at the time of the third survey in Autumn 2021, 61/77 children were reported as having a somewhat consistent routine or better since the return to school in Spring 2021. 16/77 had an inconsistent routine or no routine at all.



**Figure 5.** 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 Friedman test showed that of those who partook in all three time points, there was not a statistically significant change in stress ( $\chi^2(2) = 9.688, p = 0.008$ ) or anxiety scores ( $\chi^2(2) = 4.507, p = 0.105$ ) in individuals between Phase 1, Phase 2 and Phase 3. Median Stress Score rating was 17.5 for phase 1, 14.0 for phase 2 and 12.0 for phase 3. Median Anxiety score was 30.0 for phase 1, 26.0 for phase 2 and 28.0 for phase 3.

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 higher than non-pandemic situations as reported by deSilva and Schalock (reported a mean of 22.93).

## **Conclusion**

Impacts of school closures were reported by parents. Specifically, school refusal and difficulty transitioning back to school were noted. Skills declines were reported less in this wave of the survey than in previous, perhaps due to a less disrupted school term once school resumed in Spring 2021. Opportunities for educational inclusion appear to have remained steady for many children but where there were less opportunities for inclusion parents reported that this was due to school implemented public health measures.

It is apparent that as the pandemic continues, autistic children and their parents continue to experience a considerable level of challenge across various domains. Additional and continued supports as well as continued monitoring are necessary in order to ensure their needs are met.



## References

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