



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

### **Phase 1 Survey, Wave 1 Report**

Sinéad Smyth and Nadine McLaughlin, Dublin City University

#### **Highlights**

- A cohort of parents of children with autism completed an online, longitudinal survey assessing the impacts of COVID-19 restrictions.
- Parents identified a number of common challenges faced by their children as restrictions continue to evolve in the coming months.
- Both improvements and declines in children's abilities and skills were reported by parents, since the introduction of COVID-19 restrictions.
- Increases in some challenging behaviours, compared to the previous month were also reported.

#### **Introduction**

Assessing and addressing the wide ranging, psychosocial impacts of COVID-19 restrictions is of paramount importance. As restrictions have begun to ease in recent weeks, the impacts of these restrictions remain unknown. Furthermore, society now must learn to adapt and cope with the return to daily life, frequently referred to as the "new normal". The T-Res study



This research is funded through a Health Research Board COVID-19 Rapid Response grant.

*These data are correct as of July 2020. Data continues to be collected and findings may change accordingly.*

aims to focus on assessing the impacts of COVID-19 restrictions on children and young people with autism and their families, alongside new and ongoing challenges they may face as restrictions continue to ease. Using the data collected in relation to these challenges, an online resource toolkit will be developed and freely available for parents, children and educators alike, to further support individuals in the immediate and long term future.

The current report is an executive summary of the data regarding challenges, skills and abilities. It is being circulated at this early juncture to inform stakeholders and feed into the development of resources and preparation of materials in advance of the new school year. Future documents will present data on areas such as parental and child wellbeing, future waves of the online survey and results of a consultation process with professionals and experts by experience.

## **Aims**

The aim of Phase 1 of this study was to assess and gain further insights into the immediate and anticipated challenges faced by families, children and young people with autism, as a result of both the COVID-19 restrictions and subsequent easing of restrictions in recent weeks.

## **Method**

### **Participants**

Parents of child(ren) with autism and young people with autism (up to the age of 18 years) were invited to take part in Phase 1 of the study, which consisted of wave 1 of a longitudinal, anonymous, online survey. Participants consisted of N = 107 parents of child(ren) with autism (age  $M = 43.17$ , range 26 -100), who responded with respect to 119 children aged 18 and under. Of the 107 parents surveyed, 11.21% provided data separately for two children

with a diagnosis of autism, while 88.79% provided data for one child with a diagnosis. The majority of participants who took part in the survey identified as female (Female = 93.5%, Male = 4.7%, Other = <1%).

**Measures**

Parents were asked to complete a number of demographic questions and questions related to their (and their child's) experiences, since the introduction of the COVID-19 restrictions and subsequent easing of restrictions in recent weeks. 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 challenging behaviour displayed in the month previous, using Autism-Related Behaviour Scale.

Additional measures were completed in relation to parental stress levels (Parenting Stress Index, deSilva & Schallock, 2012) and their child's level of anxiety using the Anxiety Scale for children with autism spectrum disorder (ASC-ASD) (Rodgers, Wigham, McConachie, Freeman, Honey & Parr, 2016). In instances where participant's child(ren), were aged 8 or above, verbal and consented to take part, they were invited to complete the Anxiety Scale for children (ASC-ASD) to assess their own anxiety levels. In instances where this was not possible, a parent was instructed to complete the anxiety scale on behalf of their child.

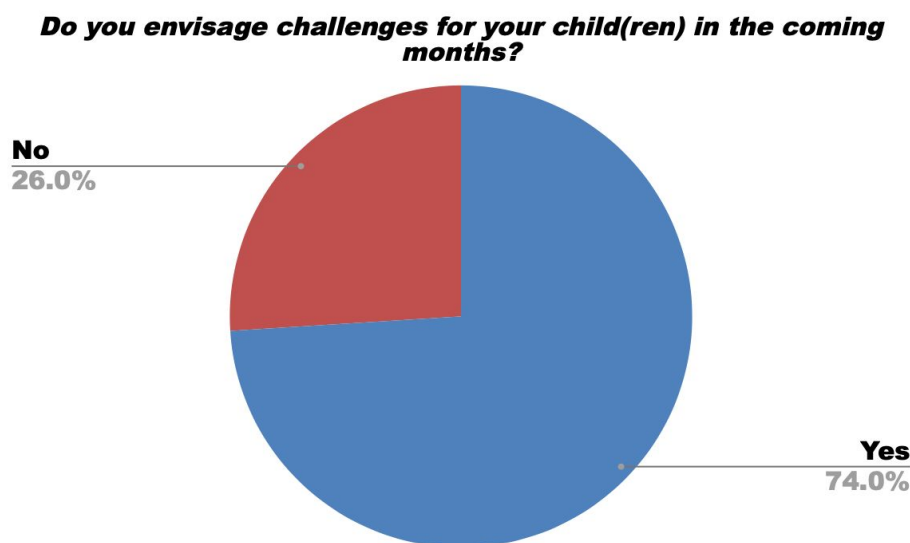
For the purpose of this report, findings on challenges, changes in abilities and skills and challenging behaviour will be presented and discussed. Additional measures assessing parental stress, anxiety levels and other COVID-19 related demographics will be presented at a later stage as part of the longitudinal design of this study.

## Findings

Both quantitative and qualitative methods were used to analyse the data collected through Wave 1 of the online survey. Descriptive and frequency analyses was conducted using SPSS program. Content analysis was used to analyse qualitative data provided by participants in relation to challenges and improvements/decline in skills and abilities.

### Challenges

Parents overwhelmingly reported that 74% of child(ren) would be faced with unique challenges in the coming weeks and months (See Figure 1). To assess the types of challenges parent's envisaged, we conducted content analysis on responses provided and identified a number of commonly reported challenges (See Table 1).



**Figure 1.** The % of children for whom parents anticipate challenges as the COVID-19 restrictions are lifted.

Parents reported that 22.7% of child(ren) may be faced with difficulties in relation to their social skills, typically due to the lack of social interactions experienced by children in recent months. The potential return to school in September was also identified as a challenge for

17% of children in the coming months. Parents also identified challenges in relation to their children leaving the house in general (due to anxiety) (15.9%), particularly in recent weeks as restrictions have begun to ease. Similarly, 15.9% of children have displayed challenges returning to public places (e.g shops, barbers). Specifically in relation to COVID-19 restrictions, a number of parents identified the challenge for their child(ren) in understanding and adhering to the social distancing and public health guidelines/rules, particularly when out in public places (26.13%) (See Table 1). This also included issues with understanding why certain spaces, activities remain closed and conflicting expectations that things have returned to “normal”.

**Table 1. Content analysis of text responses to a question asking about the types of challenges anticipated found the following were the main difficulties expected.**

**Figures reported below are a % of those that anticipated each category of challenge (n = 88).**

<b>Category of challenge</b>	<b>% of children</b>
Social skills difficulties	22.7
Return to school	17
Leaving the house	15.9
Going to public places	15.9
Understanding and adhering to social distancing & public health guidelines	26.13

### **Abilities & Skills**

Parents were asked if they had observed any changes in their child(ren)'s skills and abilities. An overall decline in skills and abilities was reported for 61.3% of children. Improvements in skills and abilities was reported for 29.4% of children, while no change in abilities and skills was observed in 9.2% of children. Content analysis was conducted on the types of declines and improvements most frequently reported by parents. (See Table 2 & 3).

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 34.24% of children in recent months. This included examples such as, decline in "emotional skills", "over reactions, "self regulation...much harder". In keeping with the anticipated challenges identified, parents reported social skills declined for 32.87% of children. Decline in motivation to engage in activities (including school work) was observed in 17.8% of children. Finally, a decline in academic skills, across areas such as mathematics, reading and writing, was observed in 13.69% of children (See Table 2).

**Table 2. Content analysis of text responses to a question asking about the types of skills and abilities observed to have declined. Figures below are a % of those that an overall decline was observed in each category of ability/skill (n = 73).**

<b>Ability/Skill</b>	<b>% of children</b>
Emotional & Self regulation	34.24
Social skills	32.87
Motivation	17.8
Academics	13.69





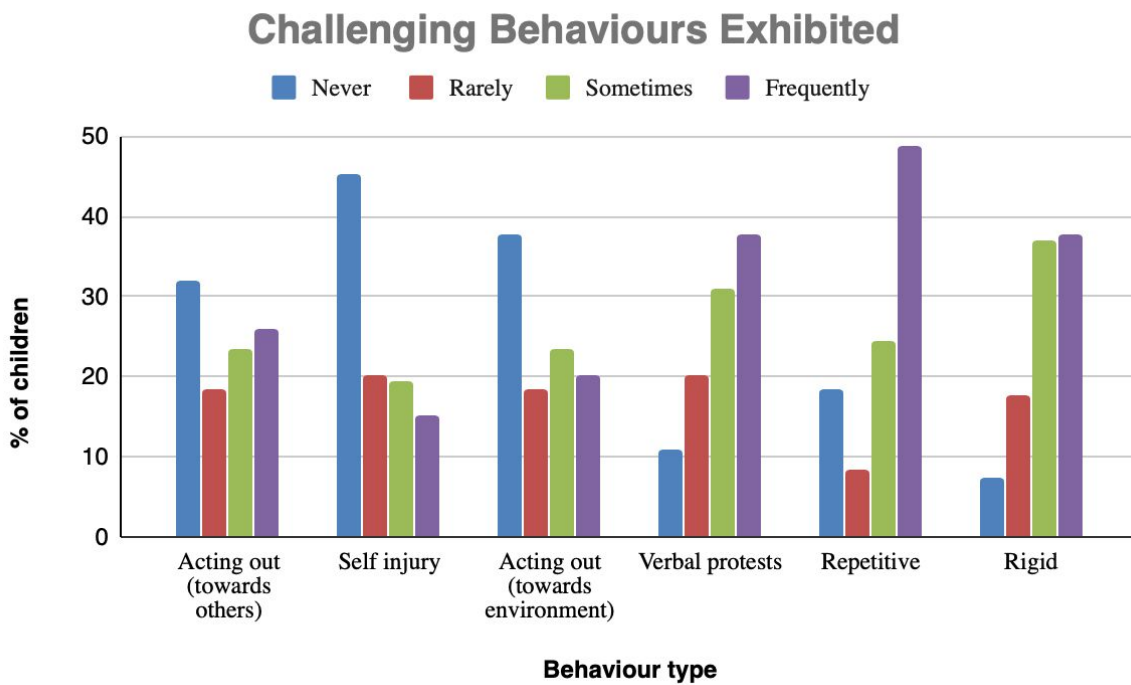
While a decline in skills and abilities was most frequently reported, an improvement in abilities and skills was reported for 29.4% of children. Daily living skills were the most highly reported skills to improve in recent months (28.57% of children). This included abilities to complete tasks such household chores and food preparation. Improvements in communication and academic skills were also equally observed in 20% of children. (See Table 3 below).

**Table 3. Content analysis of text responses to a question asking about the types of skills and abilities observed to have improved. Figures below represent a % of those that overall improvement was observed in each category of ability/skill (n = 35).**

<b>Ability/Skill</b>	<b>% of children</b>
Daily living skills	28.57
Academic skills	20
Communication	20

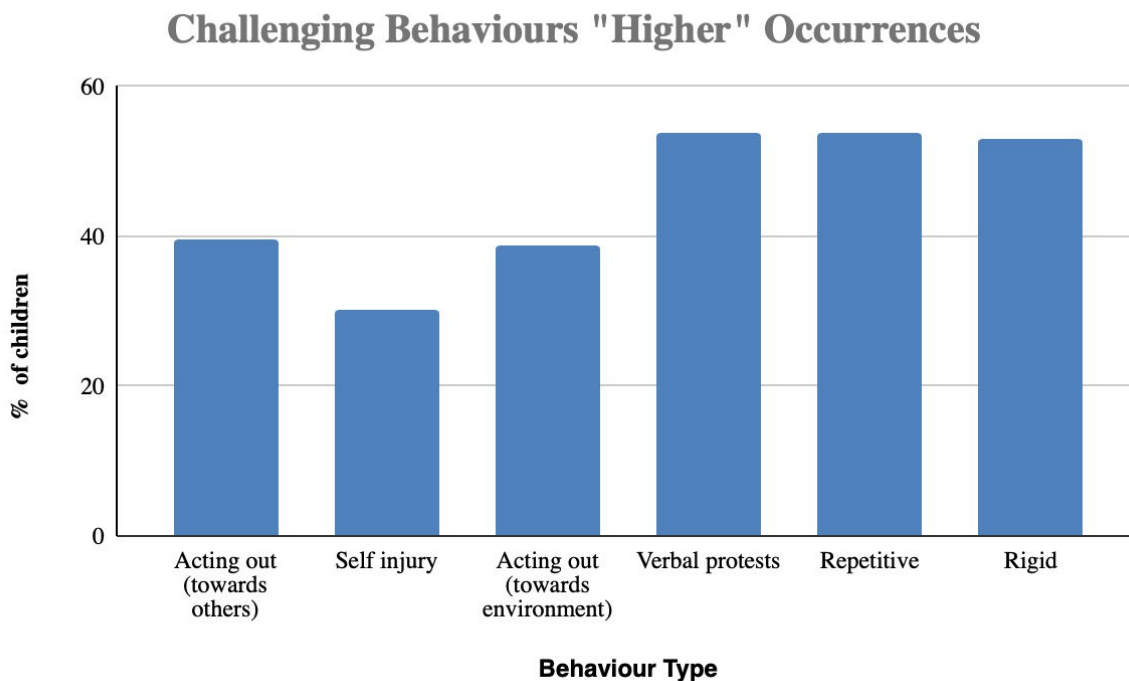
### Challenging Behaviour

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 (48.7% of children), rigid (routine type) behaviours (37.81% of children) and verbal protests (37.81% of children). Acting out (towards others) was also frequently reported for 26.05% of children (See Figure 2 below).



**Figure 2.** The frequency of challenging behaviour exhibited over the previous month.

Parents were also asked if occurrences of these behaviours were higher, lower or the same in the past month. Parents reported that verbal protests and repetitive behaviours were higher in the past month for 53.78% of children each. This was followed by higher instances in rigid behaviours (52.94% of children) and acting out (towards others) (39.49% of children) (See Figure 3 below). Parents reported that 8.4% of children exhibited lower instances of acting out (towards others). Similarly, acting out (towards the environment), displayed lower instances in 7.5% of children.



**Figure 3:** Challenging behaviours reported to have increased in past month

### **Conclusion**

Wave 1 of the longitudinal, online survey aimed to investigate the impacts of COVID-19 restrictions and the subsequent easing of these restrictions, on children with autism and their families. Findings suggest a number of current and anticipated challenges faced by children and their families in the coming months.

As a result of widespread school closures in March 2020, parents are concerned with the challenges associated with returning to school in August/September. Responses suggest heightened anxiety among children, difficulty transitioning and returning to the school routine, as possible challenges faced by children in the coming months. Specifically in relation to the changes posed by COVID-19 and return to daily life, parents identified understanding and adherence to public safety guidelines as a challenge for their children in recent weeks. This included issues relating to adhering to the two metre social distancing rule, wearing masks in public spaces and tolerating queues and wait times at shops.

Relatedly, parents reported difficulties in their children leaving the house generally, due to their confinement to the house in recent months. Difficulties displayed by children also extended to attending public spaces such as shops and barbers, with parents reporting anxiety in children due to issues such as, increased number of people, noise levels and fear of catching the virus.

In addition to these challenges, parents also reported an increase in challenging behaviours, particularly behaviours such as verbal protests, repetitive and rigid (routine type) behaviours. Furthermore, the majority of parents reported an overall decline in their children's skills and

abilities, across a range of areas including emotion regulation, social skills, motivation and academics.

It is clear from the preliminary findings in this longitudinal survey, that children and their parents are experiencing a multitude of unique challenges, as a result of the COVID-19 restrictions and the subsequent easing of these restrictions in recent weeks. It is also noted that these findings reflect children and young people of various age ranges and abilities (e.g. verbal and non-verbal), therefore, indicating a diversity in needs. Taking these factors in combination, it is evident that needs based, freely available resources would be of benefit to families, children and their educators as they continue to navigate through the uncertainty of the coming weeks and months.

References

deSilva, L. M. T., & Schalock, M. (2012). Autism Parenting Stress Index: initial psychometric evidence. *Journal of Autism and Developmental Disorders*, 42(4), 566–574.

<https://doi.org/10.1007/s10803-011-1274->

Rodgers, J., Wigham, S., McConachie, H., Freeston, M., Honey, E., & Parr, J. R. (2016).

Development of the anxiety scale for children with autism spectrum disorder

(ASC-ASD). *Autism Research*, 9(11), 1205-1215.