



Autism Specific Transition Resources (T-Res Study) Report 4

Expert consensus on the resource needs of autistic children and young people during the COVID-19 pandemic.

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Highlights

- A Delphi study aimed to gain consensus on the challenges faced by and resource needs of autistic students and their families since the onset of the Covid-19 pandemic.
- This consisted of two rounds with 24 participants including experts and experts by experience. Round 1 were semi structured interviews while Round 2 was a survey to rate the needs and resources required based on analysis of Round 2 data.
- Of needs which emerged, anxiety, routine and wellbeing ranked most important. The study also provided direction on resource design.

Background

The Covid-19 pandemic has brought with it a profound upheaval to life across the world. Vulnerable groups in society are often the worst affected in crises such as this. In Ireland, school closures and the restriction or cessation of a range of services took place initially in March 2020. Daily routines and social connections were disrupted and the restrictions have continued to change since that time. This study aims to discover the needs of the autistic community and their families since the onset of the Covid-19 pandemic. The study will also aim to attain direction on the most appropriate development of resources for this community. The current study forms part of a larger research project examining the experiences and needs of autistic children and young people with through the pandemic.

Method

The Delphi method involves seeking the opinions of experts in order to achieve agreement on a certain topic or course of action. Earlier rounds should help to inform the design of subsequent rounds. The first round of this study consisted of semi structured interviews with 24 participants. Participants included people with a diagnosis of autism, their parents, educators, therapists and professionals working in the area. The Round 1 interviews were thematically and content analysed. The findings from this round informed the second round where 21 of the original 24 participants ranked the needs and resources according to their perceived importance.

Findings

Round 1

The needs of autistic children were divided into the following themes which emerged during the study, 1) changing routine, 2) Covid-19 specific issues and 3) skills declines. In relation to changing routines, 17 of the 23 participants in the study specifically highlighted this transition back to school as one of their main concerns. Other sub-themes which emerged were access to services The most common theme highlighted in relation to Covid-19 specific issues was the difficulty in understanding and adhering to Covid-19 rules and guidelines. The other subtheme which emerged was anxiety/fear of the virus. With regard to skills declines, participants highlighted regression in skills and abilities, related to emotional regulation, sensory sensitivity and social skills and communication.

Round 2

In Round 2 of the study, the issues and resources outlined in Round 1 were put to the participants again and they were asked to rank each in order of importance. Consensus (over 70% agreement) was achieved in the rankings

of the most important challenges. Participants highlighted anxiety (75.9% participants agreed) and changes to school and routine (75.8%) as the most important areas for resource development. The next most pressing area for resource development was emotional regulation (52.4%).

Consensus was also achieved in rankings of the most important resources for development. Specifically, “wellbeing, including physical, emotional and mental” was ranked in the top three by 81% of participants and “understanding and coping with uncertainty” was ranked by 75.9%. The most effective types of resources highlighted were videos and animations”, which were chosen by 90.5% and “visual supports”, which were chosen by 71.4%. The most popular way to disseminate resources were contact from schools and support groups (90.5%) and recommendations by other users such as teachers, parents, etc. (90.5%).

Conclusion

The Covid-19 pandemic has been a difficult time for large swathes of society, including those not directly affected by the disease. It caused drastic changes to everyday life with mask wearing, social distancing and lockdowns. These transitions have the potential to affect the autistic community more than most and this showed in the results of this study. Despite negative findings for many participants with regression in skills and abilities along with behavioural and other issues for many, a spectrum of effects emerged with some participants improving academic and daily living skills with reduced sensory and other issues. The study has also helped to direct target areas and development of resources which can help to navigate the pandemic and post-pandemic environment. A swift roll out of accessible and useful resources are key to the successful transition of young people and their families to a society which continues to change. The Delphi method is an underutilised tool in investigating the needs of a range of communities and could be used more often and effectively in future research.