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The impact of COVID-19 on education and children's services

The impact on families of children with Special Educational Needs and Disabilities in the UK

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This international collaboration, which involves over 15 countries including the UK, examines the impact of COVID-19 on families of individuals with special educational needs and disabilities (SEND) across the globe. The UK collaborators listed here are all experts on Special Educational Needs and genetic disorders. For more details about this collaboration see www.specialneeds covid.org

Summary:

The impact of the COVID-19 pandemic on the wellbeing of families is likely to be profound and affect those with special needs the most. This submission provides a summary of a recent survey (April-May 2020) in the UK that examined the impact of COVID-19 for families of children with special educational needs and disabilities (SEND) aged 0-18 years old with a focus on 1) the impact of COVID19 around the safety of children with SEND, including how many were hospitalised and directly affected by COVID19, 2) the impact of school closures and support for children with SEND and their families, 3) the immediate and long-term effects of increased anxiety, loss of support and effects of lockdown on both parents and children's wellbeing, 3) lessons learned and concerns about the immediate future as well as future COVID19 events.

Related to the safety of children with SEND:

- As there was no clear message and often conflicting information from the government, most families (73%) self-isolated, and the majority did so before the government told them so, as they were very worried about their child's physical health. However, this worry has shifted now to parents being worried about the impact of social isolation and mental health issues.
- Only 0.5% of children with SEND who were surveyed had tested positive for COVID-19.

Related to Children's mental health and wellbeing:

- Parents are very worried about mental and social wellbeing of children

- Parents are struggling with limited online and face-to-face professional support in how to manage their children's behaviour and mental health at home. These children are at heightened risk of mental health issues than their peers and often cannot verbally express their fear and anxiety. Socialisation and routine are key factors in exacerbating these difficulties and the survey reveals these are the areas children have been most impacted by.
- Managing transitions with professional support is critical for children with SEND. Parents need direct support additional to the child's typically developing peers to manage the transition to the "new normal" that will be evident in schools. Parents report wanting to speak to a range of disciplinary professionals reflecting both health (e.g. paediatrician) and social function/mental health (e.g. psychologists).
- In addition to sudden change of routine, lack of respite for parents and opportunities for children with SEND to exercise daily in a safe environment (as most children do not understand social distancing rules) were the most commonly mentioned issues related to both children and parents' wellbeing.

Related to impact on school closures and support of children with special needs our findings suggest that:

- Only 7% of children with SEND surveyed remained in school during lockdown and the majority of children struggled with the abrupt closing down of schools and lack of routine.
- Respondents worries' about school closures related to the abrupt change of routine as well as lack of routine at home, impact on their child's wellbeing and social relationships, rather than worries related to educational gaps and attainment.
- The lack of support has been particularly a problem for parents who have poor health, special needs themselves or who are single parents.

Related to lessons learned and concerns about the immediate future:

- Allow and prepare for children with SEND to go back to school full-time when schools go back (or part-time if parents feel it will facilitate the transition, their learning and their mental health) as children with SEND are at greater risk for mental health issues and educational gap than their typically developing peers. However, such transitions should be carefully managed and support for parents should be put in place.
- Provide respite for parents and provide alternative provision when schools close for families and children with SEND so that both parents and children with SEND can engage in daily exercise and children can have a routine.
- Provide more online support that is carefully sign-posted, including online counselling appointments for children and families with SEND.
- Ensure parents and children have access to expert advice from educational professionals and medical experts related to how COVID-19 can be explained to these children, what the new social rules entail, and how mental health and behavioural difficulties can be managed.
- Review hospitalisation procedures and provide assurances to parents and children with SEND about what will happen when they or their family members become ill with COVID-19.

Overall background of the participants and their families

A survey was distributed to our contacts and local groups as well as national charities. In total 220 parents and guardians (96% females) from across the UK completed the survey about their child with special educational needs and disabilities (SEND) and their families.¹ More than half of the respondents (58%) who completed the survey had a university degree (see Figure 1). Most respondents were either in full-time (23%) or part-time employment (22%) with 22% being a home-maker or carer (other = 16%) (see Figure 2). Only 19.5% of the respondents lived in urban or city areas, with 56% living in suburban areas and 24.5% living in rural areas. Survey respondents mainly lived across all regions in England (82%) with a minority respondents living in Scotland (15%), Wales (2%) and Northern Ireland (1%).²

The average age of the children with SEND was 10.14 years (SD= 4.095; range age 1 to 18 years old). As can be seen from Figure 3, the children in the survey had a range of special needs including autism (37%), Down Syndrome (30%), ADHD (5%), Intellectual Disability (3%), Williams syndrome (9%)³ and other SEND (17%). Before and during COVID-19, 99% of these children were living at home with 1% living in a supported living arrangement.

The survey itself was distributed via Qualtrics, an online survey tool, and contained a range of open-ended and closed questions over 4 sections. Section A asked questions about the respondent and their child's background, including demographic information and the child's medical background. Section B asked questions about the timing of the events related to COVID-19, including when participants self-isolated and their child's school closed. The questions in Section C focused on the concerns and wellbeing of the participating parent/guardian as well as their child. The final section of the survey asked about the family's and child's coping strategies. The entire survey can be accessed freely: osf.io/5nkq9.

Impact of COVID19 on the families and children with special needs with regards to safety

- 73% of families did self-isolate and the majority of these families (60%) did so before the government advised them to do so, as they were worried about the impact of COVID-19 for their child's health, especially those who had respiratory or heart issues.
- Respondents are currently mainly concerned about the children's health and the impact on their child's mental health and wellbeing, rather than the impact on educational outcomes or their finances (see Figure 4, 5, 6). (e.g., P274: "Our anxieties have changed from worrying about contracting the virus to worrying about how this isolation will affect her - will she be developmentally or socially delayed as a result? I expect she will be, and will spend months or even years catching up".)
- Respondents mentioned that they have been confused about the governments guidelines as it has been unclear who should shield and who should self-isolate like everyone else. Some are currently shielding as they are concerned about their child's health despite not getting a letter to shield. (P13: "I think he should be on the vulnerable list but have heard nothing from Govt . This is extremely worrying").
- 19 children (9%) have been suspected of having COVID-19 and all were tested. Only one child tested positive for COVID-19 and needed hospital treatment but their

¹ The data collection is still ongoing at the time of writing this.

² As we examined the impact of COVID19 for families related to wellbeing and concerns we included all 4 regions, despite their differences in education and support systems as well as COVID19 strategies.

³ Due to the researchers' research expertise there was a large representation of people with Williams syndrome. However, this group often has severe heart and other health issues and thus inclusion of this group gives a good indication of the impact for other people with rare genetic disorders.

situation was not life threatening. All other 18 children tested negative for COVID-19.

Effects of school closure

- Almost 86% of the children with SEND were in full-time education before the COVID19 emergency (See Figure 7), which dropped to just 7% during the COVID-19 situation.
- The schools of 77% of the children closed (including 67% for children who were in special schools) but an additional 16% of parents took their child out of school, even though that school was open:
 - P241: “Took my son out of school a week before they shut, to keep him safe”;
 - P183: “I withdrew my son from school before they closed. GP agreed he was at increased risk, unable to wash hands etc without prompting and often seeks physical reassurance”.)
- The closures of the schools made it really difficult for parents/guardians:
 - P200: “Tommy was originally classed as vulnerable and staying in school - this was then rescinded and this was especially difficult for us.”
 - P62: “I am finding the pressure of working from home, caring for 2 kids with SEND and home-schooling very stressful”)
 - This is especially the case for single-parents, parents who are disabled themselves or when the needs of the child are very severe so that the child actually needs the care of 2 adults: e.g. P100: “[My child] requires 2:1. We can only leave the house when at school. Can't partake in daily exercise or access respite hours. Severe boredom. Diet has suffered so behaviour is poorer.”
- The majority of children had strong negative reactions to the abrupt school closure: including raised anxiety to the change of routine, anger and increase of behaviour issues (See Figure 8):
 - P195: “[My child is] Very upset by change and keeps getting shoes on and school bag every morning, which then leads to a meltdown as we cannot go out.”
 - P194: “He’s very upset and confused asks to go to school every day”). Yet, other children liked being at home as they never liked going to school.

Effects on anxiety, mental health and safety for children with special needs

- 69% of respondents reported that their child with SEND was aware of COVID-19 but only 50% of children would be able to verbally express their fears and anxiety. As such, a substantial number of children were reported to have little understanding of why the schools closed down or why they have to remain indoors and respondents testified that their child with SEND struggles to understand social distancing rules.
- Children who could verbalise had very specific anxieties and concerns, as reported by their parents. These concerns related mostly to what would happen if they themselves or their carer would get ill.
 - P147: “She is afraid she or I will get it. No one to look after her if I’m sick.”
 - P268: “Her being alone in hospital if she catches it.”
- Mental health issues for children with SEND were frequently mentioned by parents and guardians, including references to suicidal ideation.
 - P215: “They [my children] have talked about suicide”
 - P56: “She is so isolated, depressed and withdrawn now.”

- P217: “It has been really hard at times trying to work out my son’s anxieties.”
- These mental health issues have also impacted on the parents and carers, in that some had to give up their jobs to look help their child cope, especially as other services are currently unavailable:
 - P243: “My place of work is still open though I have had to stay at home to look after my daughter as she has been very anxious and crying. It has been difficult to keep her occupied to take her mind off our situation”.
 - P112: When I contacted the school to see if they could put some support in place due to my son needing constant help, routine & school structure I was told there was nothing they could do or help you with”.
 - P111: “The facilities for mental health support and services in the UK were always appalling now they are just none existent”.
- Parents worried about the impact of COVID-19 on their children’s social abilities:
 - P118: “I’m very worried all the social skills that have been learnt have now depleted and all the hard work that has been put in will have to be started again from the beginning”.
 - P245: “I am concerned that he will find it difficult to reintegrate into social situations, especially as all the 'norms' that we have been working hard to teach him will no longer be applicable.”
- Another major concern raised by parents was the fact that most families do not have access to exercise as they need to self-isolate/ should for very long time: has impact on physical and mental health:
 - P161: “Exercise is a problem as we do not go outside much just in garden.”
 - P142: “[I am worried about] Lack of physical exercise and lack of social contact and external stimulation”
 - P112: “I am really struggling with my son at the moment getting him out on a walk daily as where we live there is not really anywhere to go on walks.”

Contingency plan in case of any future national emergency based on our evidence

- Parents/Guardians mentioned that they would like additional support for families of children with SEND. Some respondents are required to work full-time from home without support to look after their child with SEND who requires full-time care, some are single parents without any respite or some children require full time care from 2 adults. Respondents requested that the government puts respite in place for parents/guardians so that they can do exercise themselves/ go for a walk.
- Respondents also questioned how the government is going to prepare for the increased mental health support that will be required due to the fact that children with SEND are having heightened anxiety and behavioural difficulties as a direct result of COVID-19 and school closures. Parents suggested that more online support systems could be set up, including online counselling appointments for children and families with SEND. Currently, a number of charities and professional advisory groups have distributed information and guidelines for families of children with SEND but there is not a clear helpline and information needs to be more sign-posted and cross-sign-posted so that families can be directed to the specific information and support that they need.
- The majority of parents would like to be able to speak to an expert (e.g., a paediatrician/doctor or educational professional who is an expert in their child’s SEND) to discuss the impact of COVID-19 for their child: 24% had personally spoken to a professional about the potential consequences of COVID-19 for their

child with SEND but a further 42% had wanted to speak to an expert yet had not done so. We currently do not know whether this was because no expert was available.

- Respondents are also worried about a clear exit strategy for children with SEND: especially in relation to transition back to school. Our own studies (Van Herwegen et al in prep) have shown that children with SEND's overall wellbeing is significantly affected by transitions and that transitions should be carefully prepared for. Therefore, clear dates and timelines should be provided for returning back to school for children with SEND.
- Respondents also requested that more support from therapists should be made available about how to explain the current situation to children with SEND, including those children who are non-verbal (e.g. a COVID-19 social story). In addition, parents would like to receive more support from professionals about techniques that can be used to manage children's behavioural issues.
- Respondents also suggested that more data should be collected about the impact of COVID-19 for special needs groups so that more SEND specific and child-centred advice can be provided in the future. We are currently surveying more specific groups to contribute to this evidence.

Summary and implications

The evidence suggests that parents of children with SEND have additional concerns and issues and require additional support in order to cope with the impact of COVID-19.

The most concerning impact of COVID-19 for children with SEND relates to their wellbeing, raised anxiety and lack of social connections. For many of these children, there is an earlier onset and higher prevalence of mental health difficulties such as depression and anxiety. This means they are highly vulnerable to a situation like the current where normal routines have been abandoned and they have to socially isolate for a chronic period.

It is unclear yet what the long-term mental health implications will be. It is highly evident that any exit from lockdown will have a further impact for children with SEND, in terms of transitioning to a new normal and the fact that some of the children might not understand the new social norms and will need additional support. These new requirements and adaptations will stretch parents and schools further.

Our data suggest that, should any future lockdowns happen, more support should be made available to parents of children with SEND in terms of 1) explaining the situation to these children, 2) provide additional support for parents in relation to the impact and how to cope, including opportunities for families to talk to experts, and 3) provide respite for parents, especially those who are single parents, key-workers or have children with very severe needs so that parents and families can get daily exercise which will help boost their mental health and wellbeing. In addition, safe opportunities should also be put in place for children with SEND to exercise, especially for those who do not understand social distancing.

Finally, seeing the concerns from children as well as parents about what will happen when their child gets ill, hospitalisation procedures should be reviewed for children with SEND and exceptional hospital procedures or support should be considered. Most children with SEND would not be able to cope with hospitalisations without support from their carer/parents due to increased sensory processing demands, their heightened overall anxiety as well as heightened fear of hospitals, phobias related to blood and fear of dying.

Although the government had announced that vulnerable children could remain to attend school and receive their usual support, many schools closed their doors or parents decided to self-isolate or shield due to the underlying health needs of these children and the fact that the impact of COVID-19 for children with additional health needs was unknown. Our data suggest that only 0.5% of children with SEND surveyed were infected by COVID-19, either because these groups had self-isolated and shielded themselves carefully or because children are less susceptible to COVID-19 infections. More data should be collected about COVID-19 infections in children with SEND in order to help parents make informed decisions should any future epidemics happen.

Figures

Figure 1. Educational qualifications of survey respondents

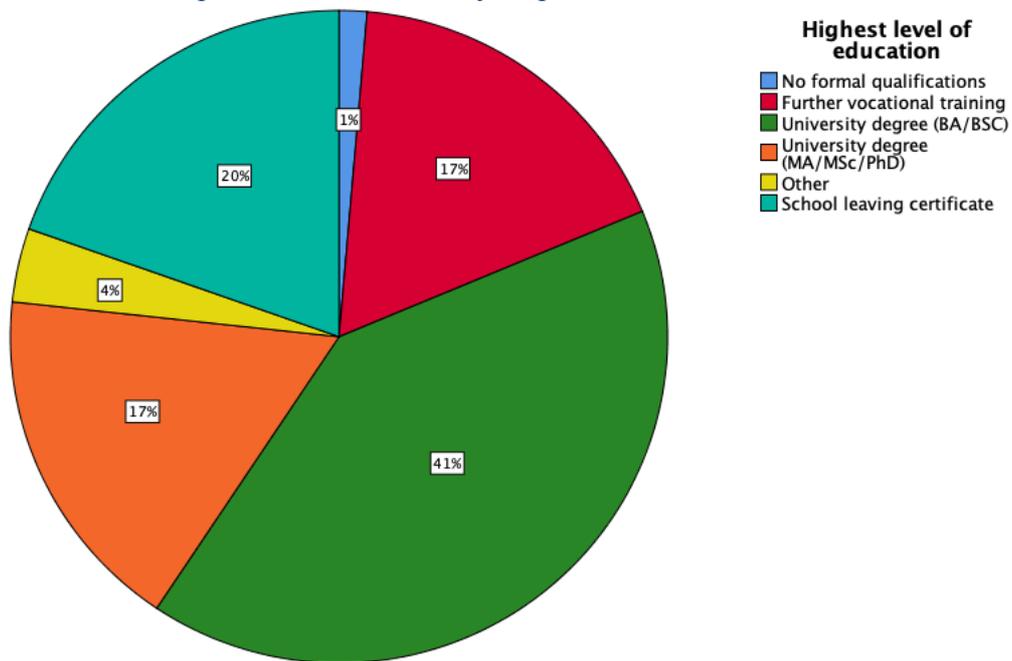


Figure 2: Respondents' employment status before COVID19

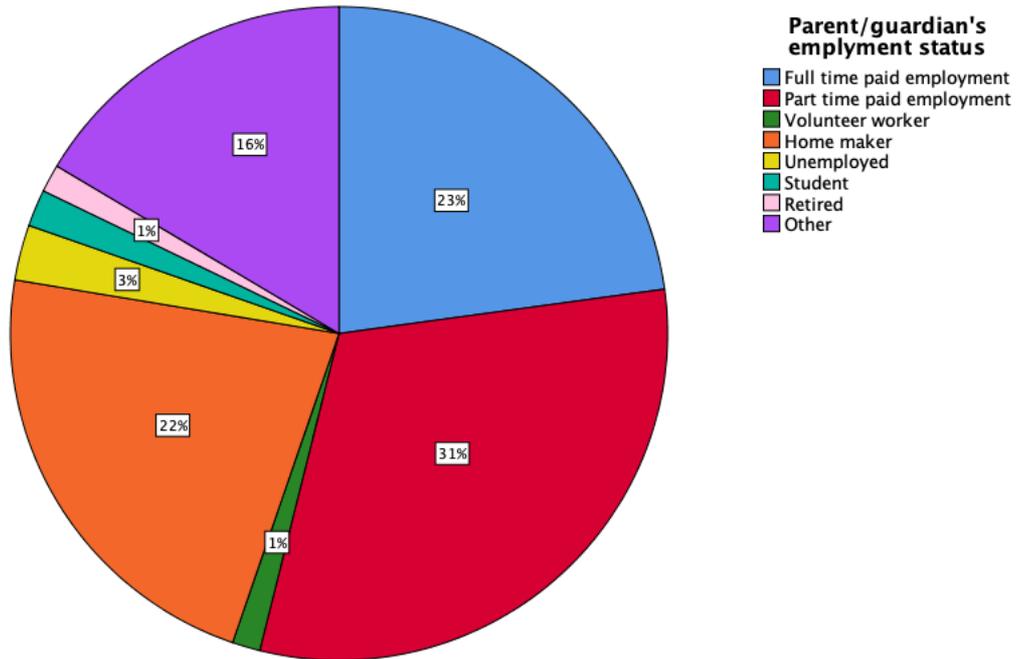


Figure 3: Primary diagnosis of the child's special educational needs and disability

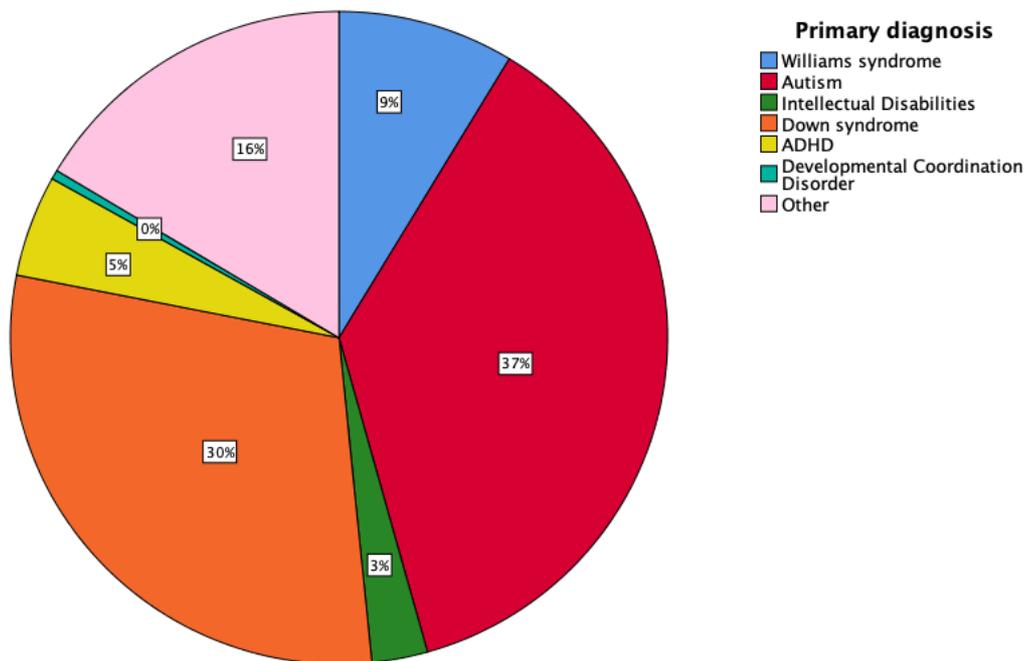


Figure 4: General feeling of concerns by parents/guardians when they first heard about COVID19

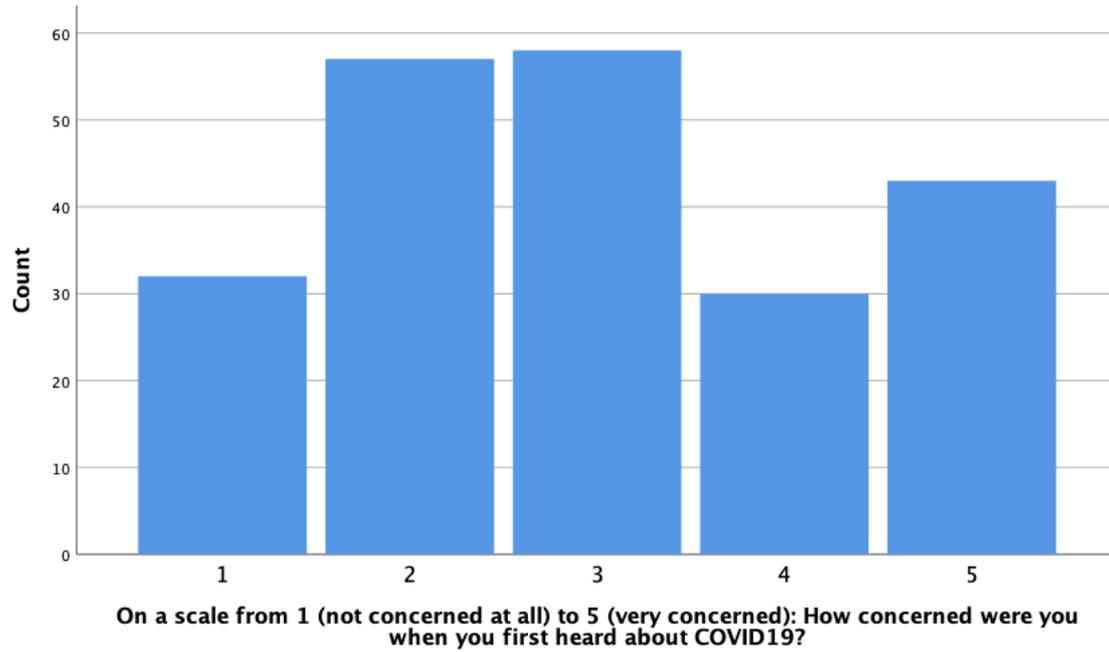


Figure 5: General feeling of concerns by parents/guardians when lockdown started

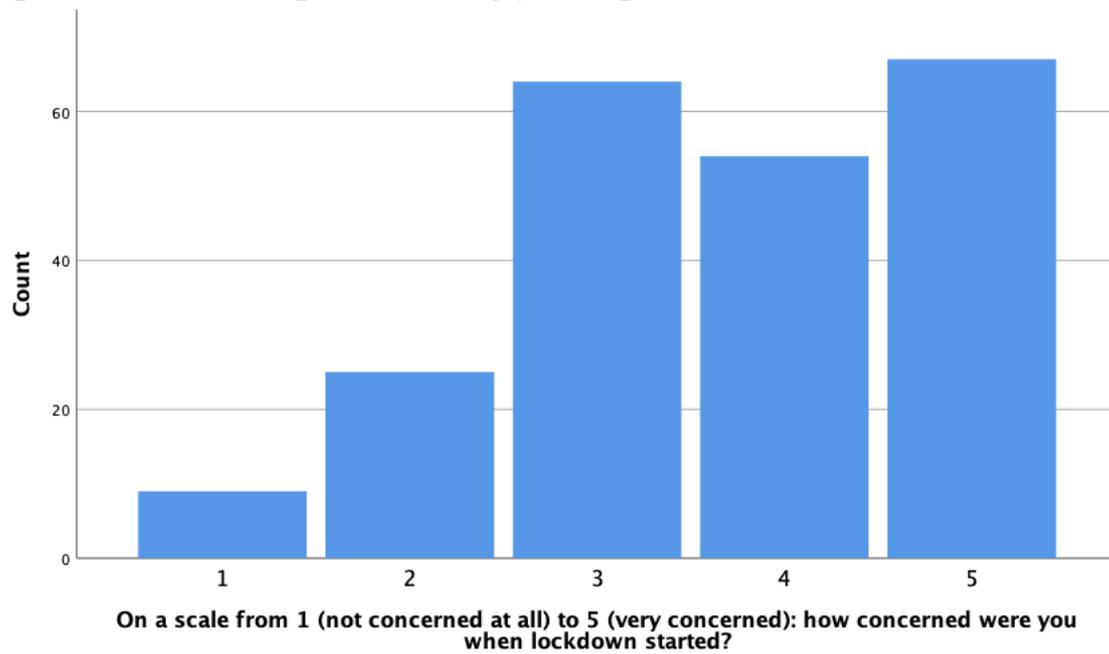


Figure 6: Parental concerns related to COVID19 on a scale from 1 (not concerned at all) to 5 (very concerned).

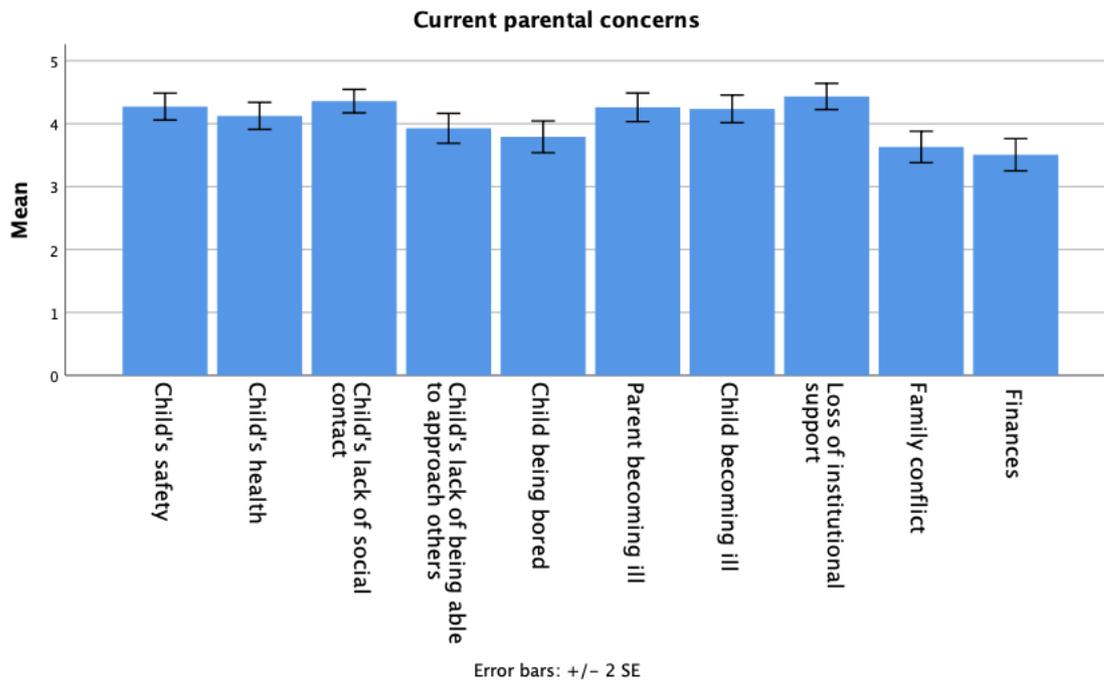


Figure 7: Type of education attended by the child with SEND before COVID19

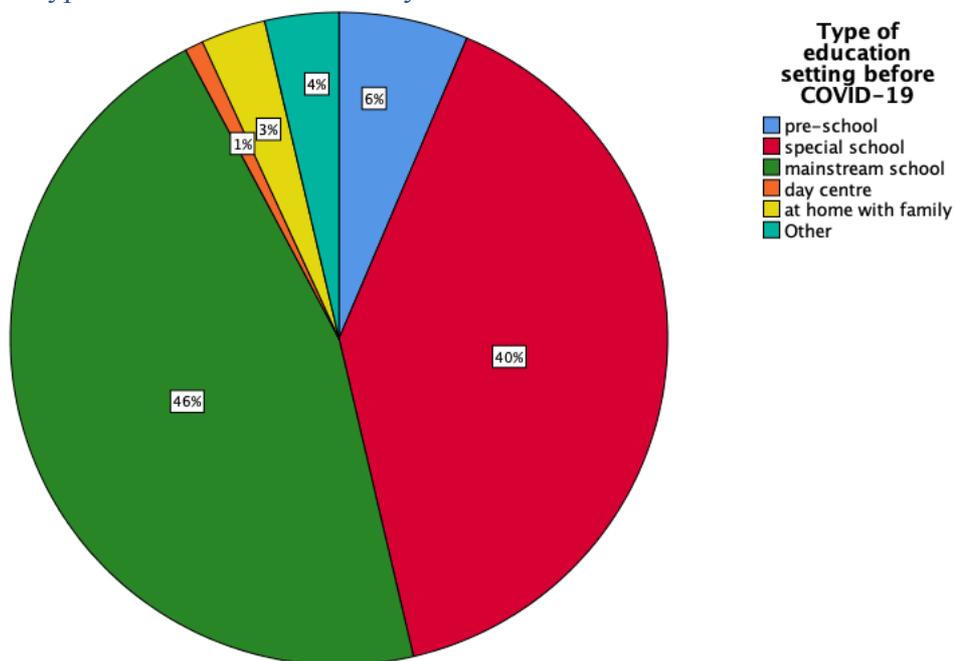
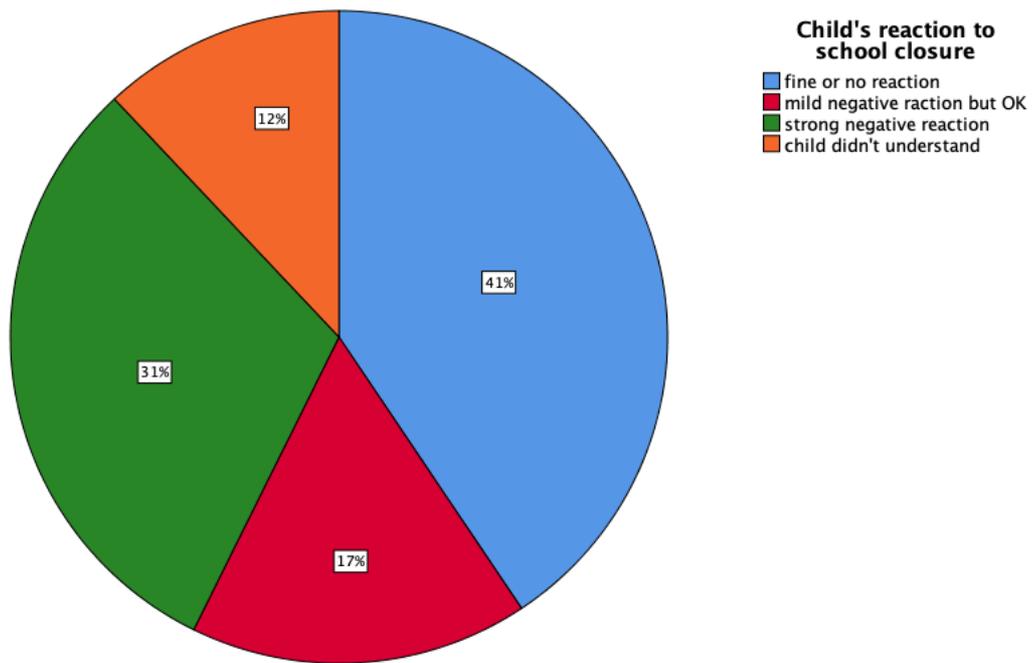


Figure 8: Reaction of the child with SEND to closure of provision/ school



Relevant reading and references

Van Herwegen, J., Dukes, D., & Samson, A. (2020, April 9). *COVID19 Crisis Response Survey for families of Individuals with Special Needs*. Retrieved from osf.io/5nkq9 DOI:10.17605/OSF.IO/5NKQ9

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