



SURREY YOUTH FOCUS

Improving the lives of young people by supporting our members

COVID 19: Listening to Surrey children and young people with Special Educational Needs and Disabilities and their families

Compiled by Jo Cookes

August 2020

This report has been compiled by Surrey Youth Focus in collaboration with:

Family Voice Surrey
The Halow Project

National Autistic Society Surrey Branch
Young Epilepsy

on behalf of the Surrey Safeguarding Children Partnership and Surrey County Council's Children, Families, Lifelong Learning and Culture Commissioning Team. We would like to give huge thanks to the organisations above who have taken the time to listen to our children and young people to find out how they are coping and what their hopes are. We would also obviously give a massive thank you to the children, young people and their families who were willing to be open and talk about their experiences of this pandemic.



Every child is unique, as is their experience... one size does not fit all...



Summary

This report is based on a subset of the data used for the report “COVID-19: Listening to children and young people in Surrey” and has been supplemented by additional feedback from parents supported by the National Autistic Society Surrey Branch.

Sixty-five children, young people with special educational needs and disabilities (SEND) and/or their parents shared their experiences of the pandemic with voluntary organisations working with them to provide support, respite, care, information and advice.

In line with findings from the other two reports in this series, it is clear that one size does not fit all – every child and young person has had a unique experience of the restrictions caused by COVID-19. However, there are some themes that have emerged:

- Being at home
- Free time & access to learning
- The impact of restrictions on existing conditions and emotional wellbeing
- Access to support

As lockdown eases significantly over the coming weeks and life returns to some sense of normality, let’s consider how we can maintain, sustain or change our practice taking into account what we have been told. The summary of findings and points for reflection are outlined below:

- Some children and young people have thrived better under COVID restrictions than during ‘normal’ circumstances.
 - *For reflection:*
 - *What aspects of the restrictions have suited some of our children and young people?*
 - *How can we harness these positives and share the learning with others?*
 - *How can we maintain these positives if there is the need for a local lockdown due to a second wave of COVID?*
 - *How can we ensure we maintain these positives in the longer term?*
 - *What can we learn from this that we can reflect on and consider in our future policy and practice development?*
- Other children and young people have struggled and their conditions have been exacerbated by COVID.
 - *For reflection:*
 - *What aspects of the restrictions have not suited our children and young people?*
 - *How can we improve our practice if there is the need for a local lockdown due to a second wave of COVID?*
 - *What can we learn from this that we can reflect on and consider in our future policy and practice development?*
 - *Do we have the right level of support in place for families who are struggling the effects of COVID?*

- Being at home and strengthening family relationships is an important aspect for children and young people.
 - *Is there anything we can do to enable this to continue?*
 - *How can we balance this for those who need more encouragement to go out and find being in busy social environments difficult?*
 - *If there is a second wave and local lockdown is there a need for allowances to be made for some families with children with SEND that enable relationships with close family and/or key trusted individuals to continue face to face so that these relationships can be maintained rather than risk breakdown?*

- Some children have enjoyed the flexibility of home learning as they can tailor it to their own needs.
 - *For reflection:*
 - *What can we learn from the flexibility that home learning provides?*
 - *What can we take forward and continue particularly for those that are school refusers or struggle with the school environment?*

- Some children have struggled with home learning and parents have voiced concern about transition and the return to school in September.
 - *For reflection:*
 - *If there is a second wave, are there lessons we can learn and practices that we can adapt or encourage that would support home learning for those children who have struggled to engage?*
 - *What can be done to ease the return to school for children and young people who are anxious?*
 - *What support can be given to parents to help them prepare their children for the return to school?*

- Some children and young people have felt isolated and have found it hard to keep in touch with their friends, particularly those who do not have strong friendship groups or find it difficult to communicate and build friendships.
 - *For reflection:*
 - *If there is a second wave, what can we learn from this experience and what can we encourage parents and schools to put in place to enable them to keep in touch with their friends?*
 - *What social provision can be put in place to encourage friendships to flourish, perhaps through other organisations and agencies, not just schools?*

- Some parents have felt isolated and unclear of where they can access advice and support about their children.
 - *Do we have the right provision of services and support in place for these parents?*
 - *How can we improve knowledge across the system to ensure that there is 'no wrong door' and parents can be signposted effectively to support when needed?*
 - *What more can be done to communicate where to find help?*

- For some parents and siblings it has been challenging all being together due to the needs of their child with SEND.
 - *For reflection:*
 - *What have we learnt about different ways of working that might allow families to have some respite if there is a second wave and/or a local lockdown?*
 - *Are there examples of good practice from other areas of the country that we could learn from to ease the pressure on families?*

- Some children and young people have enjoyed doing other activities and hobbies.
 - *For reflection:*
 - *What can we learn from the activities they have been doing that we can use in the way we work with children and young people?*

Background

The existence of COVID 19 in our communities across Surrey has created unprecedented circumstances that the whole population has had to adapt to very quickly. Schools partially closed their doors on 20th March to pupils except for those who were vulnerable or whose parents were key workers and schools for children with SEND were no exception. Our children and young people found themselves at home, learning in a new way, through email, homework apps and virtual communication. They were also limited in being able to go outside and socialise with others. This has continued, although measures have now eased and we are now freer to be in contact with friends, family, and the wider community.

Organisations have rapidly reconfigured services to be able to reach children and young people in different ways and to ensure that we have websites and helplines in place to support vulnerable young people and their families. However, how do we know that in the newly reconfigured landscape of our lives, that we understand what children and young people have faced and had to deal with during this time. What is going on for them? What are their needs? What is going well? What is going badly?

- Imagine a young person with autism who finds it difficult to engage socially in crowded environments. Are they now happier that they don't have to go to school or visit busy shops – the world has fitted in with them rather than them being expected to fit into the world?
- Imagine a child who has anxieties about germs and cleanliness. How have they coped with the presence of COVID-19?
- Imagine a young child who struggles to communicate and socialise. What impact has the isolation had on their ability to engage with others? Have they isolated themselves further into their own world?

This report seeks to understand how the restrictions due to COVID-19 are impacting and will continue to impact our children and young people. Are families with children and young people with SEND finding it more difficult to reach out for help – they “don't want to bother anyone” – it's not as easy when you have to consciously pick up the phone or send an email. Are issues magnified due to the intensity of all working, studying and living under one roof? Is it more difficult for those working with children and young people to watch out and know when things may not be right?

Surrey Youth Focus is working in conjunction with the User Voice and Participation Team on behalf of the Surrey Safeguarding Children Partnership and Surrey County Council's Children, Families, Lifelong Learning and Culture Commissioning Team to gather insight from children and young people themselves. We have asked our colleagues across Surrey who work with children and young people to seek their voices, to listen to how they feel about this situation. This has not been a scientific exercise that has sought a specific representative sample using controlled conditions but rather a piece that seeks insight that can help enrich strategy and a way forward. This report therefore explores the impact of COVID restrictions on families with children with SEND.

Findings

Four organisations from the third sector listened to 65 children, young people with SEND and/or their parents across Surrey during May and June 2020. They were asked about their experiences of lockdown. Seventeen young people were staying at a residential facility and had not returned to their families. We do not know the specific needs of the children and young people that we spoke to but the organisations that they are involved with support learning disabilities, autism, epilepsy, neurological conditions and other special educational needs and disabilities. We do not have a complete set of demographic data for the all children and young people and so this data has been excluded from these findings. The age range was from 3 to 28 years old. This is only a small sample of children and young people and is therefore not representative of the whole of Surrey but the data does provide a rich insight into how these children and young people have fared during the last four months.

Overall, the findings from this listening exercise highlight that children and young people are all individuals with unique experiences of lockdown. This is also overlaid with the medical conditions that these children and young people have which needs to be taken into consideration as this will impact on their experience. There are no definitive findings that are applicable to everyone and this creates a challenge when trying to draw conclusions that can be used to plan and/or adapt service provision. It indicates the need to be openminded and that we cannot predict how lockdown has affected our children and young people with SEND. Those who were thriving may now be struggling and the reverse is also true. Despite this, there are distinct themes that have emerged, and these are summarised below:

- Being at home
- Free time & access to learning
- The impact of restrictions on existing conditions and emotional wellbeing
- Access to support

The following sections provide more detailed insight into each of these themes.

Being at home

More than a third of children and young people with SEND have valued being at home, not having to go out and spending more time with their families. For some children and young people they have felt safe and been able to strengthen their relationships with their family.

"[have liked]...more time with my family and friends and supporting the NHS with clapping"
(unknown age or gender)

"Spending time with everybody at home"
(unknown age or gender)

"she says she is very happy at home and feels safe"
(young woman, 19+ years)

"now he is building a stronger bond with us his family too"
(boy, unknown age)

"We've had time to have some really meaningful chats about life and his future"
(boy, unknown age)

A number of the children and young people who we listened to were living at a residential facility and they missed their family as they weren't able to see them. This group were particularly looking forward to being able to go home and spend time with their family when lockdown restrictions eased.

"[Haven't liked]... not going home to see my family as often as I would like"
(young woman, 16-18 years)

"[Looking forward to]... going home to see my Mum, Dad and older brother"
(young man, 14-15 years)

For some children and young people who find it difficult to build relationships and socialize, they have loved lockdown as they haven't had to go out and be with others. This has meant they are calmer and happier as a result. Of those children, young people and their parents who spoke about what they would like to continue after restrictions had eased nearly half wanted to maintain being at home and /or continue spending more time with family.

"...flourished during lockdown."
(parent of girl, 8-10 years)

"Definitely to stay indoors & [be] at home as much as possible"
(parent of boy, unknown age)

"calmer for not being nagged to go and meet up with his friends"
(parent of young man, 19+ years)

"He'd like to stay at home!"
(parent of boy, unknown age)

"Having me at home all the time..."
(parent of boy, unknown age)

Whilst at home a few children and young people have maintained friendships through online gaming and social media. However, it has been difficult for those who find it challenging to build friendships to maintain them in these circumstances.

Those children and young people who find it easier to be with other people missed their friends when strict lockdown was in place and it has been. But as restrictions have eased it has been possible for socially distanced meet ups which has helped some.

"I'm missing people and Halow"
(unknown age and gender)

"It's a little easier now we can meet people distanced"
(girl, unknown age)

"...has really enjoyed going back recently to Saturday club at a charity."
(parent of girl, 14-15 years)

"Missing my friends so much. I just want to be with them..."
(unknown age and gender)

Being at home has meant that for some children and young people they have felt more isolated than usual. There are a few examples of children who had recently started in a school and therefore had not built strong friendships.

"Isolation. No informal interaction with peers. Can't build on tentative friendships begun before lockdown"
(parent of girl, unknown age)

"... majority of the friends he usually has contact with has not been possible... The disconnect with these groups had been hard & has caused some anxiety..."
(parent of boy, unknown age)

"used to spend 3 days a week with his grandma... they had a very close relationship... when he saw her again [after lockdown] he treated her like he hardly knew her... sad to see close bond broken"
(parent of boy, 3 years)

"Being isolated has had a massive impact"
(parent of girl, unknown age)

"My son has some interaction with friends via Xbox live messaging & during games."
(parent of boy, unknown age)

"he has spent far too much time gaming with his group of friends. He loves this so much but he can get very wound up"
(parent of boy, 8-10 years)

"He has only one friend - also autistic and communication has therefore been a challenge."
(parent of boy, unknown age)

It has been difficult for a few children and young people being at home more due to arguments with family and difficulties in relationships. Siblings of those with SEND have also found it hard as have parents who have tried to manage whole family relationships and support their children's needs.

"A lot of time with family can sometimes be difficult. I don't always get along with my sister"
(unknown age and gender)

"...hard on all of us, especially his poor brother who is controlled by the OCD too"
(parent of boy, 8-10 years)

"It has been hard on his sister as she is not used to being with him constantly... she has spent a lot of time upset"
(parent of boy, 8-10 years)

"myself and my husband are struggling"
(parent of young woman, 16-18 years)

Free time and access to learning

Children and young people have spent their time during the pandemic doing a variety of activities as well as home learning. As would be expected, some children and young people have thrived in having the flexibility to do things at their own pace and spend time doing the activities they like, whilst others have struggled to engage.

For those children and young people who have thrived some have taken up exercise or increased the amount they have been doing.

"Not used to walks but now that they are regular. I now understand why we are doing it."
(unknown age and gender)

"we go out for a daily walk to the river, which is her happy place"
Parent of young woman, 14-15 years)

"She has been outside so much and cycling most evenings so built up stamina (as has Daddy!)."
(parent of girl, 8-10 years)

"He has also motivated himself to do the prerecord of Joe Wicks before 9am"
(parent of boy, unknown age)

As well as walks, children and young people have enjoyed spending time outside playing, helping with gardening and being in open spaces has helped those who struggle with being with other people.

"He loves all the outside bits...he can be freer outside."
(parent of boy, 8-10 years)

"mainly sticking to outdoor large spaces."
(parent of girl, age unknown)

"I've been out in the garden weeding with my mum. I enjoy doing it"
(unknown age and gender)

"Having people over... in the garden so she can escape inside when need be."
(parent of girl, 8-10 years)

Conversely, some children and young people find it difficult to go out and families have struggled to encourage them to be outside.

"...Bit anxious about meeting people so I'm not pressuring him as much to do his daily walks"
(parent of young man, 19+ years)

"We took him to the beach...visibly stressed so we didn't stay long... too many people, the birds were too noisy"
(parent of boy, 8-10 years)

"He hates going out of the house"
(parent of boy, unknown age)

Children and young people have also undertaken activities such as baking, craft, listening to music and reading as well as online gaming. Parents have also taken the opportunity to work on independence and life skills.

"she has enjoyed baking and gradually becoming more independent"
(parent of girl, 14-15 years)

"[doing] things... to build up her self confidence/esteem"
(parent of girl, 10 years)

Some children and young people have found it difficult not being able to continue their routine of activities, work or volunteering.

"he was keen to return to work when asked to...the need to social distance [was] really tricky"
(parent of young man, 19+ years)

"The exercise routines & groups he had have all ceased during this time so this has impacted on his well being."
(parent boy, age unknown)

"our 3 year old likes his routines and was very upset when all of his activities stopped"
(parent of boy, 3 years)

"Unable to do certain activities that I enjoy, such as shopping and other leisure activities in the community."
(boy, 16-18 years)

Given the rules about changes to schooling there has been a range of experiences of children and young people. Some have been able to continue to go to school, others have had to home learn or have a mixture of both being in school and being at home. Schools have responded in different ways in the provision of learning for those at home and this, again, has been a mixed experience for families.

"I am a key worker & my son's school has been very supportive so throughout lockdown he has been going in to school. This has been an anchor for him during these strange times. It has allowed for a semblance of a routine & has the added benefit of additional help, support & reassurance from the staff."
(parent of boy, age unknown)

"We've been very lucky as my son's school sent out a Chromebook to every pupil and morning online Google classroom sessions plus "boarding" social hour at 3pm."
(parent of boy, age unknown)

"her school haven't set very engaging tasks so I've been creative..."
(parent of girl, 8-10 years)

"Not all special needs children have an EHCP, especially younger ones. We asked his preschool if he could continue to attend... they said he could not because of what the law said... it would have been really helpful for him if he had been able to keep attending"
(parent of boy, 3 years)

"I am majorly concerned about her education...having missed so much already and it being very hit and miss with how much her school send her. I've been making random things up for to do... but she doesn't like this"
(parent of girl, 8-10 years)

Many children and young people have appreciated not having to go to school and being able to home learn. Having flexibility to work at different paces has also been a benefit, as has not having to spend time with other children whilst at school.

"He can do things at his pace as we can do it when we like"
(parent of boy, 11 years old)

"All the stress of SATS coming and being at school has gone and he's much more relaxed and calm"
(parent of boy, 11 years old)

"He says it's better as people from school are no longer unkind or rude to him"
(parent of boy, age unknown)

"No school journey means she gets less tired and so has missed fewer lessons... Also less stress from interaction with rowdier fellow students."
(parent of girl, age unknown)

A few children that were listened to were not attending school prior to lockdown due to other issues, and for those, lockdown has exacerbated the challenges they were already experiencing. Others found it difficult to engage in home learning.

"He has engaged in more learning during lockdown...being once step removed and having total control... has helped"
(parent of boy, 10 years old)

"He has thrived without having to go to school or take part in lots of unpredictable social activities."
(parent of boy, 10 years old)

"struggled with lockdown, especially the home schooling side of it"
(parent of girl, age unknown)

"pretty much at full school refusal... in February/March... he hasn't engaged with any school work"
(parent of boy, 8-10 years)

"experiencing problems before lockdown resulting in not being able to go to school... has become severely depressed... lockdown has caused more aggressive behaviour and anxiety"
(parent of girl, 16-18 years)

"Home schooling has been very difficult...he gets very frustrated"
(parent of boy, 8-10 years)

Given that some children and young people have preferred to be at home during lockdown several parents have great concerns about encouraging their children to re-engage with the outside world, to socialise and go back to school.

"I am a bit worried about how I will get her back into the world again"
(parent of young woman, 19+ years)

"I'm worried about him starting secondary school..."
(parent of boy, 11- 13 years)

"We're not even allowed to mention school! I'm bracing myself for September..."
(parent of girl, 8-10 years)

"I have absolutely no idea how I'm going to get him back to school in September – he's adamant he's not going back..."
(parent of boy, 8-10 years)

The impact of restrictions on existing conditions and emotional wellbeing

Concern about the impact of COVID-19 and the associated restrictions on children and young people's mental health and emotional wellbeing is well documented nationally. We have spoken already about children and young people who have thrived during lockdown compared to how they managed before the pandemic and we have touched on the loneliness and isolation felt by some. For others, the circumstances of the pandemic have exacerbated their condition, or they have caused additional concerns. To remind ourselves of these experiences a few quotes are outlined below:

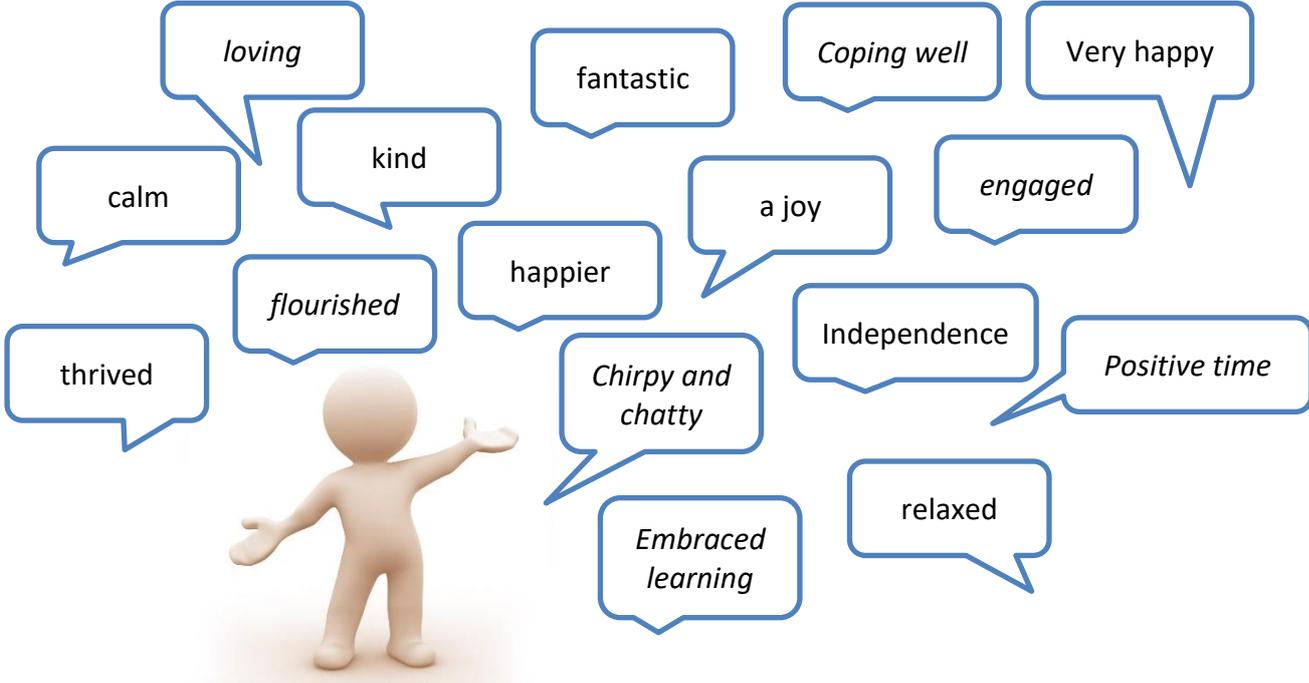
"We are one of the lucky families who haven't seen an increase in distress or violent behaviour"
(parent of boy, 8-10 years)"

"Isolation. No informal interaction with peers... had recently started at new school after nearly 2 years out of school"
(parent of girl, unknown age)

"My son... has LOVED being in lockdown"
(parent of boy, 11-13 years)"

"feeling lonely at home"
(unknown age and gender)

The sample size is small and so this is not representative of all children and young people with SEND but within this sample there has been a range of reactions and behaviours associated with emotional wellbeing and mental health both positive and negative.



For those children and young people who have thrived during lockdown, parents have reported them being calmer and happier. This is particularly the case for those with autism who find it difficult in busy, social environments.

"She is much calmer and happier and generally chirpy and chatty – a joy to have around"
(parent of girl, 10 years)

"She is happy and relaxed"
(parent of girl, 14 years)

"It has been a surprisingly positive time for her"
(parent of girl, 19+ years)

"COVID rules have suited her – no physical contact/ not seeing people/ socially distancing"
(parent of girl, 10 years)

"My anxiety [has been better]"
(young woman, 16-18 years)

A small number of children and young people have found COVID 19 difficult to deal with as it has affected anxieties and conditions they have such as obsessive compulsive disorder (OCD) and fears about hygiene and germs.

"My son has problems relating to anxiety around germs. The current situation is very stressful for him & he is preoccupied with hand washing & whether others are correctly social distancing."
(parent of boy, unknown age)

"He had a random test for COVID-19 and was negative...this has reassured him a bit."
(parent of young man, 19+ years)

"his OCD/anxiety has been much worse... trigger is his twin brother... and now they are together all the time"
(parent of boy, 9 years)

"his hands are red from over washing and he has taken to putting all of his clothes in the wash daily."
(parent of young man, 16-18 years)

"barricaded himself in his room and blocked up the gaps."
(parent of young man, 16-18 years)

"The measures easing & the associated anxieties surrounding it will cause him distress, confusion & worry."
(parent of boy, unknown age)

For other children and young people lockdown has negatively affected their emotional wellbeing and mental health in other ways.

"Then came lockdown and she has gone backwards again but to more of an extreme. She is severely depressed... and her anxiety has become worse too"
(parent of girl, 19+ years)

"She has become severely depressed and has suicidal ideation and is very violent both physically and mentally"
(parent of girl, 16-18 years)

"he already suffers from severe anxiety, however coronavirus has triggered other associated behaviours that we have seen previously during crisis episodes"
(parent of young man, 16-18 years)

"he stopped sleeping properly, became very depressed and didn't want to do anything... he started having regular meltdowns"
(parent of boy, 3 years)

"I am worried about his mental health and his complete lack of contact with the outside world... He has been even more reluctant to engage with humans and has retreated into his room more."
(parent of boy, unknown age)

"a lot of self loathing and talk about being useless and death"
(parent of boy, 13 years)

Access to support

Parents of children and young people with SEND have commented on the level of support they have been able to access during COVID. This is not representative and does not show the whole picture across Surrey but it is important to consider these families' experiences and reflections.

"...school has been very supportive"
(parent of boy, age unknown)

"Worse totally set us all right back do not know how we are going to get back"
(parent of boy, unknown age)

"...school I feel is truly amazing... School are helping immensely"
(parent of boy, unknown age)

"...had just been discharged from CAMHS prior to Lockdown. Being able to check in by phone with someone we have already built a relationship with would be most useful"
(parent of girl, age unknown)

"...has a social worker who we have only heard from once during the whole lockdown, now with a supported employment service... but she [daughter] is being less than co-operative"
(parent of young woman, 19+ years)

"...doesn't have an EHCP so can go below the radar"
(parent of boy, 11-13 years)

"...I was so alarmed... I rang the GP who told me that referrals to CAMHS were not really an option...so privately set up sessions"
(parent of boy, 11-13 years)

"...have a social worker & CAMHS etc but my daughter is reluctant to help herself... All I get told is hang in there... I am truly at a loss"
(parent of young woman, 16-18 years)

Summary of findings and reflection points

- Some children and young people have thrived better under COVID restrictions than during 'normal' circumstances.
 - *For reflection:*
 - *What aspects of the restrictions have suited some of our children and young people?*
 - *How can we harness these positives and share the learning with others?*
 - *How can we maintain these positives if there is the need for a local lockdown due to a second wave of COVID?*
 - *How can we ensure we maintain these positives in the longer term?*
 - *What can we learn from this that we can reflect on and consider in our future policy and practice development?*
- Other children and young people have struggled and their conditions have been exacerbated by COVID.
 - *For reflection:*
 - *What aspects of the restrictions have not suited our children and young people?*
 - *How can we improve our practice if there is the need for a local lockdown due to a second wave of COVID?*
 - *What can we learn from this that we can reflect on and consider in our future policy and practice development?*
 - *Do we have the right level of support in place for families who are struggling the effects of COVID?*
- Being at home and strengthening family relationships is an important aspect for children and young people.
 - *Is there anything we can do to enable this to continue?*
 - *How can we balance this for those who need more encouragement to go out and find being in busy social environments difficult?*
 - *If there is a second wave and local lockdown is there a need for allowances to be made for some families with children with SEND that enable relationships with close family and/or key trusted individuals to continue face to face so that these relationships can be maintained rather than risk breakdown?*
- Some children have enjoyed the flexibility of home learning as they can tailor it to their own needs.
 - *For reflection:*
 - *What can we learn from the flexibility that home learning provides?*
 - *What can take forward and continue particularly for those that are school refusers or struggle with the school environment?*
- Some children have struggled with home learning and parents have voiced concern about transition and the return to school in September.
 - *For reflection:*
 - *If there is a second wave, are there lessons we can learn and practices that we can adapt or encourage that would support home learning for those children who have struggled to engage?*

- *What can be done to ease the return to school for children and young people who are anxious?*
- *What support can be given to parents to help them prepare their children for the return to school?*
- Some children and young people have felt isolated and have found it hard to keep in touch with their friends, particularly those who do not have strong friendship groups or find it difficult to communicate and build friendships.
 - *For reflection:*
 - *If there is a second wave, what can we learn from this experience and what can we encourage parents and schools to put in place to enable them to keep in touch with their friends?*
 - *What social provision can be put in place to encourage friendships to flourish, perhaps through other organisations and agencies, not just schools?*
- Some parents have felt isolated and unclear of where they can access advice and support about their children.
 - *Do we have the right provision of services and support in place for these parents?*
 - *How can we improve knowledge across the system to ensure that there is 'no wrong door' and parents can be signposted effectively to support when needed?*
 - *What more can be done to communicate where to find help?*
- For some parents and siblings it has been challenging all being together due to the needs of their child with SEND.
 - *For reflection:*
 - *What have we learnt about different ways of working that might allow families to have some respite if there is a second wave and/or a local lockdown?*
 - *Are there examples of good practice from other areas of the country that we could learn from to ease the pressure on families?*
- Some children and young people have enjoyed doing other activities and hobbies.
 - *For reflection:*
 - *What can we learn from the activities they have been doing that we can use in the way we work with children and young people with SEND?*

This report provides a rich insight into the lives of families with children with SEND during lockdown. The voice of these children and young people is a snap shot of a unique time. It is not a representative sample and so we cannot draw conclusive findings from them. However, there are themes that would value further exploration and reflection to determine how the system can support these families as effectively as possible. It helps us to understand their perspective so that they can be at the heart of our future planning and decision making. Let's put ourselves in the shoes of others so that we might, as a partnership and a system, use this insight to guide our practice.

Appendix 1: Additional information

Organisations that were involved in the listening exercise and the number of children and young people they spoke with:

Organisation	Number of respondents
The Halow Project	26
Young Epilepsy	17
Family Voice Surrey	6
National Autistic Society Surrey Branch	16
TOTAL	65

The Halow Project is dedicated to creating opportunities and supporting young people aged 16+ with a learning disability so that they are able to live independent, meaningful, fulfilled lives and become more involved in their local community.

Young Epilepsy exists to create a society where children and young people with epilepsy are enabled to thrive and fulfil their potential.

Family Voice Surrey is a Parent Carer Forum, speaking up for the families of children and young people with additional needs in Surrey.

National Autistic Society Surrey Branch is a volunteer led parent to parent support group that helps transform lives, change attitudes and create a society that works for autistic people.