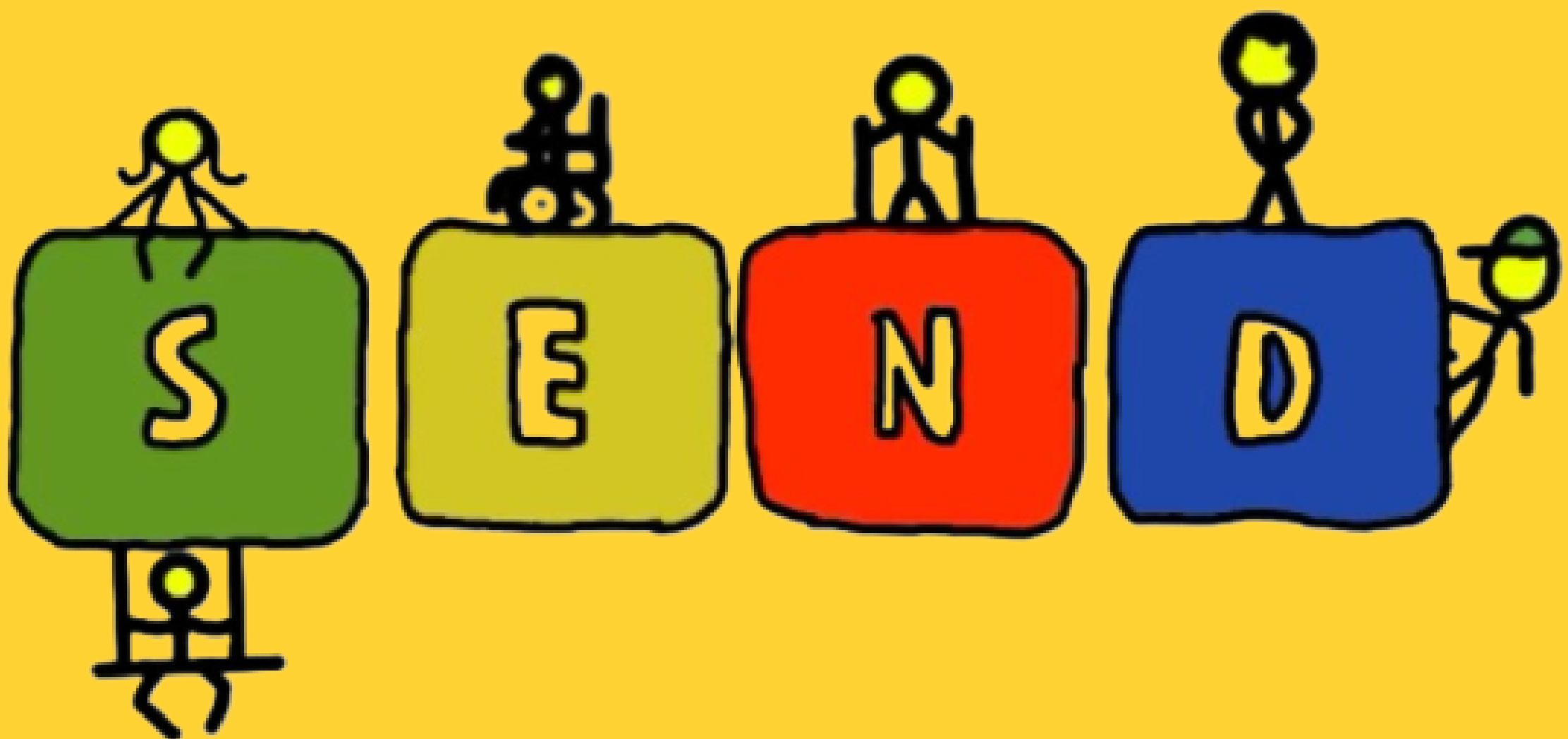


Ask, Listen, Act - working together to inform the provision of Special Educational Need and Disability (SEND) support for children after the COVID-19 pandemic.

The Impact of the COVID-19 Pandemic on the Education, Health and Social Care Provision for Children with Special Educational Needs and Disabilities (SEND): The Ask, Listen, Act Study

Evidence briefing 8: Children with SEND, parent/carers and professionals priority development stakeholder workshops.



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Executive Summary

Background to the Study

In the United Kingdom (UK), the Department for Education and the Department of Health (2015) state that a child has special educational needs or a disability (SEND) if ‘they have a learning difficulty or disability which calls for special educational provision to be made for him or her’ (p. 16). They then expand on this definition by stating that a child has a learning difficulty or disability if he or she ‘has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions’ (p.16). To ensure that each child receives the support they need, some children with SEND have an Education, Health and Care plan (EHC plan) drawn up by their Local Authority; this plan identifies each child’s individual needs and the additional support required to meet those needs.

Before the COVID-19 pandemic, there were already stark inequalities and weaknesses in the provision of services for children with SEND (CQC & Ofsted, 2020; Harris & Davidge, 2019; Byrne et al., 2020; National Autistic Society, 2020; Alghrani & Byrne, 2020). In March 2020, the UK Prime Minister implemented the first national lockdown to slow the spread of the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) and COVID-19. The lockdown involved those who were not key workers staying at home, not mixing with other households, and social distancing when in public. Schools were closed except for the children of keyworkers and vulnerable children. NHS staff were redeployed to respond to COVID-19 related pressures (Special Needs Jungle, 2020), and education, mental health and social care services were rapidly withdrawn (National Autistic Society, 2020). In May 2020, children with EHC plans had their educational rights formally downgraded (Byrne, 2020; Children’s Commissioner, 2020) by the Coronavirus Act.

This study was funded by the National Institute for Health Research’s (NIHR) Policy Research Programme (Recovery, Renewal, Reset: Research to inform policy responses to COVID-19 funding stream) in May 2021. This work aims to examine the perceptions, experiences and lessons learnt in order to scope, understand, and co-develop the policy priorities for reducing inequalities and mitigating the long-term impacts of COVID-19 for children with SEND.

Study Design and Methods

The Ask, Listen, Act study was funded by the National Institute for Health Research’s (NIHR) Policy Research Programme (Recovery, Renewal, Reset: Research to inform policy responses to COVID-19 funding stream) in May 2021. This work aimed to examine the perceptions, experiences and lessons learnt in order to scope, understand, and co-develop the policy priorities for reducing inequalities and mitigating the long-term impacts of COVID-19 for children with SEND.

The research was a rapid cross-sectional multiple phase mixed-methods study. The three phases of the study were;

- Phase 1: a rapid scoping review of the evidence related to children with SEND during the pandemic,
- Phase 2: an online survey and interviews to gain the perspectives of children with SEND, parent/carers and professionals (health, social care, education and local authority),
- Phase 3: stakeholder workshops to co-develop priorities for 'going forward' for children with SEND, parents/carers and professionals to promote recovery and renewal.

This report focuses on the stakeholder workshops (phase 3) and the process of developing the practice and policy priorities. Phase 3 used an adapted Policy-Delphi approach (Turoff 1970) which rapidly 'mapped overlapping priorities from different perspectives and identified mutual priorities across stakeholder groups'.

The workshops with children with SEND and the workshops with parents took place in person and used creative methods and mapping activities. The workshops held with professionals took place via online platforms. Ethical approval was gained through the lead researcher's institutional research ethics committee (UREC Ref: 21/PSY/030 and 21/PSY/024). Participants were recruited using social media and via established working relationships with key SEND organisations and schools across the North West of England. The data were collected between October and December 2021.

Key Findings

20 children with a range of SEND, 11 parent/carers, 38 professionals (health and social care professionals, education professionals and local authority professionals) participated across 8 workshops.

The evidence from the study developed around 5 key areas of priorities for practice and policy and were framed within a child rights-based framework:-

- My right to play, socialise, have fun and be part of my community
- My right to support for my Social, Emotional well-being and Mental Health
- My right to flexibility, choice and support so I can feel safe, belong and learn in school
- My right to health and social care services and therapies in order for me to stay healthy
- My right to support for my parents/carers and my family

Children

Many children with SEND's mental health declined over the lockdown, leaving them feeling sad, lonely and anxious. As such, increased support for children's mental health is paramount as we move out of the pandemic. Additionally, children would like the school environment to make them feel safe and make them want to attend. Those children who continued to access face to face school over lockdowns told us that school was better during these times as it was quieter and there was more 1-2-1 help to do school work. Children would like lessons to be more varied and fun, for example, being able to do more P.E lessons, go swimming and play more games. Outside of school, children would like to have a place to go to participate in activities, play with their friends and make new friends.

Parents/carers

Parents/carers described how exhausting it was to fight for support and navigate the SEND system and would welcome an advocate to help guide them through the process of obtaining support. Safe places where children with SEND can go and be part of the community, socialise and have fun without judgement were described as a 'lifeline' for children and their parents/carers. Parents/carers told us that groups and activities should be local and community-based.

According to parents/carers, children with SEND's anxiety increased over the pandemic. As such, there needs to be more mental health provision for children with SEND to talk about their feelings before reaching crisis point. To be more effective, parents/carers suggested that mental health professionals need to understand SEND and offer types of therapy other than counselling. In terms of education and learning, parents/carers told us that many children with SEND found the transition back to school overwhelming. Parents/carers felt giving children time and space to catch up on social interaction would have been beneficial. Furthermore, parents/carers would like schools to provide their children with more opportunities to pursue special interests, increase their independence and develop life skills, rather than solely focussing on the curriculum. Parents/carers mentioned that they would like mainstream schools to be more inclusive and have more SEND trained staff.

Parents/carers noted that some professionals provided excellent care during the pandemic, going 'above and beyond'. However, most parents/carers told us that health and social care and respite completely stopped. A regular 'check in' phone call from professionals would have been appreciated by parents/carers during this time. Parents/carers indicated that online meetings and phone consultations worked well for some children with SEND but not others. As such, parents/carers suggested that their children with SEND could be given the option of a face to face or online appointment in the future. Parents/carers advised that the wait is too long to get a diagnosis and see a specialist and would like to see additional clinics for easier access to specialists.

Professionals

Professionals stated a need for a graduated response towards mental health support, from lower-level wellbeing support in school to specialists who can support a child in a crisis. Additionally, professionals said that the whole workforce (education, health, social care and Local Authority) needs to be better trained around mental health issues and disability, and the education system needs to be more conducive to children's mental health. Professionals commented that following the pandemic, schools should focus on the wellbeing of children rather than 'catching up' on education and learning. According to professionals, remote learning worked well for a minority of children with SEND and therefore should be kept as an option for these children. Professionals spoke about the value of inclusion and that currently, mainstream schools are not inclusive enough. Professionals mentioned that in their experience, community inclusion is also essential for children with SEND and should be written into EHC Plans.

Professionals noted that parents/carers were exhausted during the pandemic as social care resources completely dried up. The professionals we spoke to would like children with SEND and their families to be asked what support they need and listened to. Professionals reported that they have seen an enormous increase in demand for SEND support, which services cannot meet. As such, professionals suggested that services need to have more funding and resources. Professionals remarked that workforce challenges have been exacerbated, but services cannot recruit new staff as no new staff are coming through the system. As such, professionals advised that there is a need to provide more opportunities to train more health care workers (especially speech and language therapists).

Conclusion

In conclusion, priorities for policy and practice need to consider that children with SEND and their families have struggled due to a lack of SEND provision during the pandemic. Demand for SEND support, particularly mental health support, has increased. Many professionals have gone 'above and beyond' to provide support, but fundamentally, services need more funding and resources to meet the demand. All those who work with children with SEND need more mental health and SEND training. The school environment needs to promote belonging, be more inclusive, and be more conducive to mental health. Parents/carers need to be supported and listened to as experts on their children.

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Introduction

In the United Kingdom (UK), the Department for Education and the Department of Health (2015) stated that a child has a special educational needs or disability (SEND) if 'they have a learning difficulty or disability which calls for special educational provision to be made for him or her' (p. 16). They then expanded on this definition by stating that a child has a learning difficulty or disability if he or she 'has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions' (p.16). To ensure that each child receives the support they need, some children with SEND have an Education, Health and Care plan (EHC plan) drawn up by their Local Authority. The purpose of an EHC plan is 'to meet the special educational needs of the child or young person, to secure the best possible outcomes for them across education, health and social care and, as they get older, prepare them for adulthood' (DfE & DoH, 2015, p.142). This EHC plan identifies each child's individual needs and the additional support required to meet those needs. Currently, 3.3% of children in English schools (or 294,800 children) have an EHC plan because of their disability, while 12.1% of children (or 1,079,000 children) receive additional special educational needs (SEN) support (DfE, 2020).

Children with SEND are some of the most vulnerable children in the education system (Byrne, 2020) and are disproportionately exposed to poverty. Government statistics show that more than twice as many pupils with an EHC plan get free school meals (35%) than pupils without SEND (around 15%) (Skipp, 2021). Children with SEND are also more likely to have a diagnosed mental health condition. For example, nearly a third (35.6%) of children with a mental health condition also have a SEND (compared to 6.1% of children without a SEND), and 71.7% of children with a diagnosed mental health condition also have a physical health condition or a developmental disorder (NHS Digital, 2018). Furthermore, in 2018 children with SEND comprised 45% of all children who had been permanently excluded from all state-funded primary, secondary and special schools (DfE, 2019; Byrne, 2020).

Before the COVID-19 pandemic, there were already stark inequalities and weaknesses in provision for children with SEND (CQC & Ofsted, 2020; Harris & Davidge, 2019; Byrne et al., 2020; National Autistic Society, 2020; Alghrani & Byrne, 2020). Support for children with SEND was described as already diminished, threadbare, and chronically underfunded (O'Hagan & Kingdom, 2020; National Autistic Society, 2021; Boesley & Crane, 2018; Byrne, 2020), with an estimated funding shortfall of £1.5bn (Disabled Children's Partnership, 2018). In 2019 the Disabled Children's Partnership found that only 4% of parents and carers could safely care for their disabled child(ren) with the amount of support they received. On top of this, the framework for the provision of services for children with SEND is 'characterised by confusion, unlawful practices, bureaucratic nightmares, buck-passing, and a lack of accountability, inadequate resources and an overly adversarial process for parents' (Alghrani & Byrne, 2020, p. 2).

In March 2020, the UK Prime Minister implemented the first national lockdown to slow the spread of the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2; COVID-19). The lockdown mandated that all except key workers stayed at home, to not mix with other households, and to socially distance when in public. Schools were closed except for the children of keyworkers and vulnerable children. NHS staff were redeployed to respond to COVID-19 related pressures (Special Needs Jungle, 2020), and education, mental health and social care services were rapidly withdrawn (National Autistic Society, 2020).

In May 2020, children with EHC plans had their educational rights formally downgraded (Byrne, 2020; Children's Commissioner, 2020) by the Coronavirus Act. Typically, the Local Authority has an absolute duty to meet a child's EHC plan by providing health services and special educational support (Alghrani & Byrne, 2020; Children's Commissioner, 2020). However, following the Coronavirus Act, the Local Authority only had to make 'reasonable endeavours' to provide children with EHC plans with the support they need.

Study Overview

Dr Emma Ashworth (Liverpool John Moores University), Prof. Lucy Bray (Edge Hill University), and Prof. Amel Alghrani (University of Liverpool) were funded by the National Institute for Health Research's (NIHR) Policy Research Programme (Recovery, Renewal, Reset: Research to inform policy responses to COVID-19 funding stream) in May 2020. The research was a rapid cross-sectional mixed-methods study to scope, understand, and co-develop the policy priorities for reducing inequalities and mitigating the long-term impacts of COVID-19 for children with SEND.

The research aimed to gather evidence and engage with children with SEND (aged 5-15 years) with or without an EHCP, their parents/carers, and key stakeholders across three phases. There were five objectives to achieve this:

1. To examine the evidence and policy
2. To capture the impact and lessons learnt from various perspectives
3. To explore the experiences of CYP with SEND, parents/caregivers, and stakeholders
4. To understand potential impacts of the COVID-19 pandemic on the long-term development and wellbeing of this generation
5. To work collaboratively with CYP, parents/carers and stakeholders to co-develop priorities for 'going forward' for CYP with SEND to promote recovery and renewal.

The research was a rapid, cross-sectional, multiple phase, mixed-methods study. A Rapid Assessment and Response (RAR) approach to enable rapid insights to be gained and priorities/recommendations identified. The three phases of the study were;

- Phase 1: a rapid scoping review of the evidence related to children with SEND during the pandemic,
- Phase 2: an online survey and interviews to gain the perspectives of children with SEND, parent/carers and professionals (health, social care, education and local authority),
- Phase 3: stakeholder workshops to co-develop priorities for 'going forward' for children with SEND, parents/carers and professionals to promote recovery and renewal.

This report focuses on the collaborative process of developing the priorities throughout all phases of the study and the stakeholder workshops (phase 3). The methods and findings from the phases of the study are reported separately. Ethical approval was gained through the lead researcher's institutional research ethics committee (UREC Ref: 21/PSY/030 and 21/PSY/024).

Methods

The development of the priorities was informed by data collected as part of all three phases of the study.

Participants and Recruitment

Phase 2 - Online surveys - Participants were recruited to take part in the online survey using social media and through the distribution of study information via key organisations working with children with SEND.

Phase 2 - Online interviews - At the end of the online survey, parents/carers and professionals were asked if they would like to participate in an online interview. Participants who registered an interest were contacted via an email with an invitation to participate (for parents/carers this was both for themselves and/or their children). If children wanted to participate, they were offered a 'quick hello' meeting via the online platform to talk about the study, meet the researcher, ask any questions they may have, and to allow the researcher to ascertain their communication needs.

Phase 3 - Stakeholder workshops - Children were recruited to take part in the 3 workshops via two local SEND schools and a national charity. Parents/carers were recruited for 2 workshops through a national charity, and a parent support group. Professionals were recruited for 3 workshops via social media. 20 children with SEND, 11 parent/carers, 38 professionals (health and social care professionals, education professionals and local authority professionals) participated in the workshops.

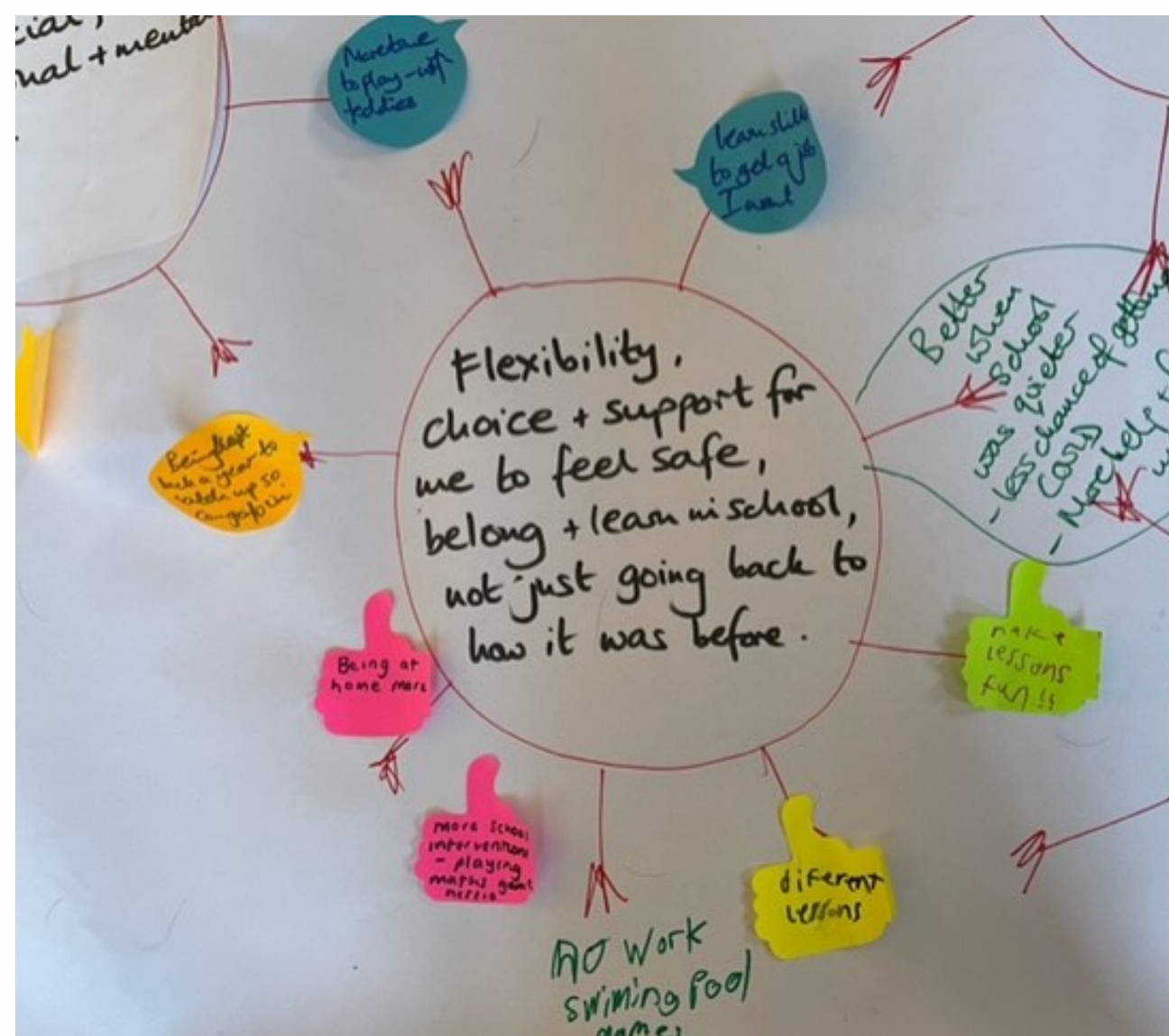
Data Collection

Phase 2 - Online surveys - Separate online surveys were designed with patient and public involvement from children with SEND (the children and young peoples' survey was kept short to try and encourage children with a range of abilities to engage), parents of children with SEND, health and social care professionals, education professionals, and Local Authority staff. Responses were anonymous. At the end of the online surveys parents/carers were asked to identify their top priority for their child over the next year, and professionals were asked to identify their top three priorities for funding and three priorities for policy over the next year. Children with SEND were asked 'if you were in charge of the country, what would you do to help children with special educational needs and disabilities over the next year?' The survey data were collected between June and August 2021.

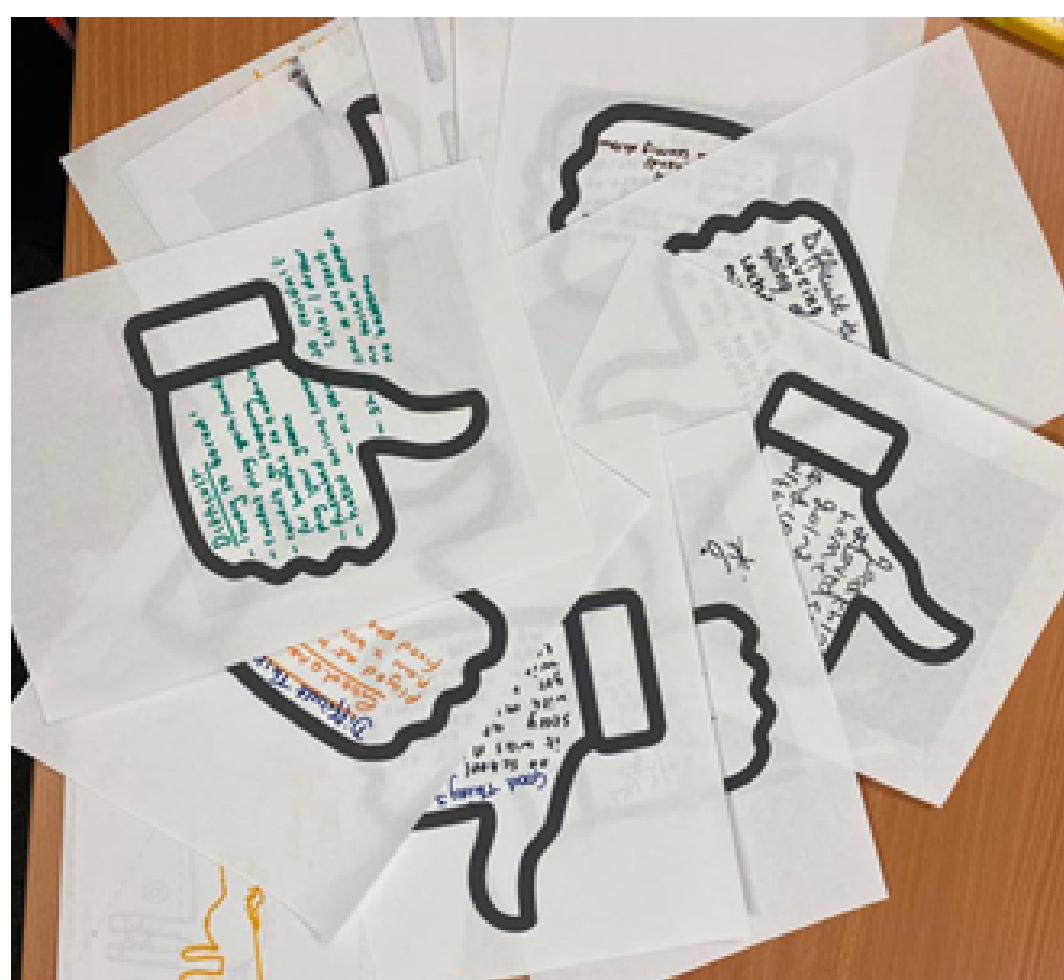
Phase 2 - Online interviews - Data was collected using semi-structured online interviews. Interview schedules were designed with patient and public involvement from children with SEND, parents/carers of children with SEND, and steering group guidance. Separate interview schedules were designed for children, parents/carers, education professionals, health and social care professionals and Local Authority staff. The interview schedule followed a semi-structured format to ensure that certain topics highlighted by the survey were covered, but that participants had the flexibility to lead the interview direction and talk about issues of importance to them. Questions were open-ended, and prompts were used to elicit more detailed responses. Questions for parents/carers, children and professionals covered topics such as the positive and negative impacts of the COVID-19 pandemic on children with SEND, experiences of education, health and social care provision during the pandemic, and the priorities for moving forward out of the pandemic. An activity worksheet was provided to children before the interview so that they knew what to expect and could have a think about the questions beforehand. Questions were tailored for children so that they were appropriate for different ages and abilities. The data were collected between August and September 2021.

Phase 3 - Stakeholder workshops - The workshops aimed to present the key findings from phase 1 and 2 and invite children with SEND, parent/carers and professionals to help identify the priorities which would address or mitigate the impact of the pandemic and associated lockdowns. The five key areas developed from phases 1 and 2 were presented in visual format. The workshops with children with SEND and the workshops with parents took place in person between October and December 2021, and used creative methods and mapping activities. The activities included:-

- Large sheets of paper placed on the wall or floor were used to present the key themes and evidence which had been drawn from the survey data and interviews. Workshop participants were encouraged to draw, write, stick post-it notes or dictate their views of the key areas of priorities.



- Thumbs up and thumbs down templates were used to examine what the key challenges had been during the pandemic and what things had worked well.
- A post box and postcards were used to encourage participants to write or dictate a key message to the Prime Minister about the 'most important' thing which needed to be done for children and young people with SEND now to help recovery from the pandemic.



The workshops held with professionals took place via online platforms. At the professionals' workshops, we presented evidence from phase 1 (scoping review), phase 2 (surveys and interviews), and the 5 key themes. We presented each of the key themes one by one and allowed professionals to give their thoughts on each theme, what each theme might look like in practice, and to discuss anything they thought was missing. We recorded each workshop so we had a record of the discussion.

Data Analysis

This phase of the study used an adapted Policy-Delphi approach (Turoff 1970) which rapidly 'mapped overlapping priorities from different perspectives and identified mutual priorities across stakeholder groups'. We began by taking the phase 2 priority data for each participant group. For parent/carers this was their top priority for their child over the next year. For professionals this was their top three priorities for funding and three priorities for policy over the next year. For children with SEND this involved taking their answers to the question 'if you were in charge of the country, what would you do to help children with special educational needs and disabilities over the next year?' We then took the priorities for each participant group separately, and grouped similar priorities together. We used a tally system to log the number of participants' priorities in each group. Then through further analysis we refined priorities again to create between 4 and 21 top priorities for each participant group. The top priorities from each participant group were presented at two steering group meetings. The discussion with steering group members identified the need to develop an integrated set of priorities. The priorities were also discussed as needing to more clearly reflect the challenges children and young people with SEND, parents and professionals faced as a result of the pandemic against the backdrop of the pre-existing challenges faced by these children. The steering group meetings also identified that the funding and policy priorities identified overlapped and were repetitious and it was decided to merge these priorities to create a comprehensive list of priorities. When merged, we grouped the priorities under 5 key themes. We then presented the 5 overarching themes at each workshop and asked workshop participants for their thoughts.

Findings

Phase 2 - Online surveys

55 children with SEND, 893 parent/carers, 163 health and social care professionals, 100 education professionals and 44 local authority professionals completed the online survey. Respondents were distributed across the UK, children had a broad range of SEND, and a range of multi-disciplinary health and social care and educational professionals took part.

Children and young people with SEND - Children with SEND identified 36 priorities in the survey. These were themed into 4 themes and the child's words were retained in the theme headings.

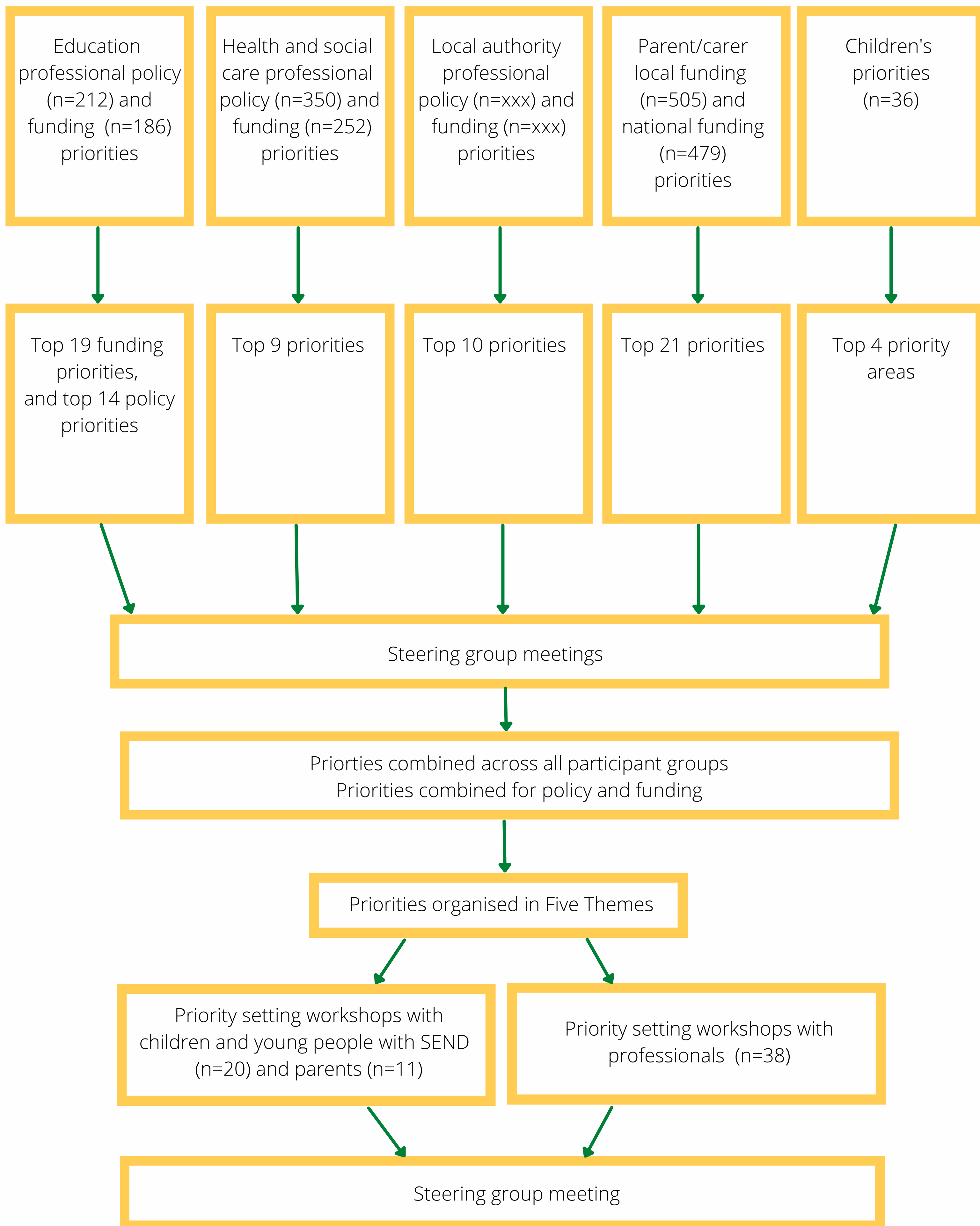
Parents and carers - Parents and carers identified 876 priorities in the survey. These priorities were tallied and collated into 48 main areas. Similar areas were then combined to create the 'top twenty-one' priorities. Parents' words were retained in the phrasing of each priority.

Educational professionals - Education professionals identified 212 policy priorities and 186 funding priorities in the survey. These priorities were then organised and tallied into 49 policy priorities and 54 funding priorities. First, second, and third most frequent priorities were then extracted, based on tallies. This resulted in 14 top policy priorities, and 24 top funding priorities (quite a few had an equal number of tallies). Some funding priorities were similar so these were grouped, resulting in 19 top funding priorities.

Health and social care professionals - Health and social care professionals identified 350 policy priorities from the surveys. These were analysed and refined to 49 policy priorities and then further analysis to group priorities resulted in the 'top ten' themed policy priorities. Health and social care professionals identified 252 funding priorities in the survey. These were refined to reach 53 main areas for funding priorities and further analysis to group and theme the priorities reached the 'top ten' funding priorities.

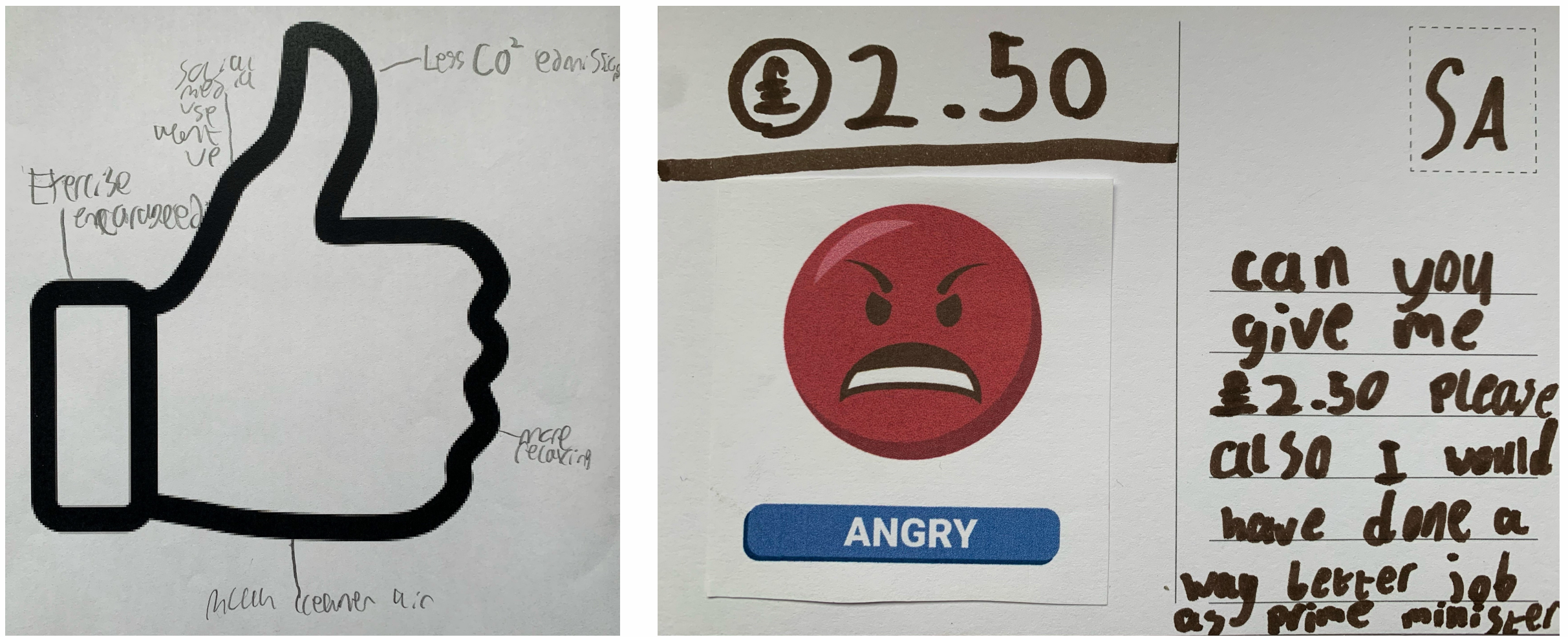
Local authority staff - Of the 44 Local Authority professionals who completed the online survey, 147 policy principles were identified. These were refined and analysed to 10 policy principles and then further analysis to group priorities resulted in the 'top ten' themed principles. LA professionals identified 27 specific funding priorities in the survey, however funding priorities sometimes also seeped into other priorities and some funding priorities were similar. Funding priorities were thus grouped together and refined resulting in 7 funding priorities.

Figure 1: A visual representation of the process of creating priorities for policy and practice



Findings - Perceptions of Children with SEND

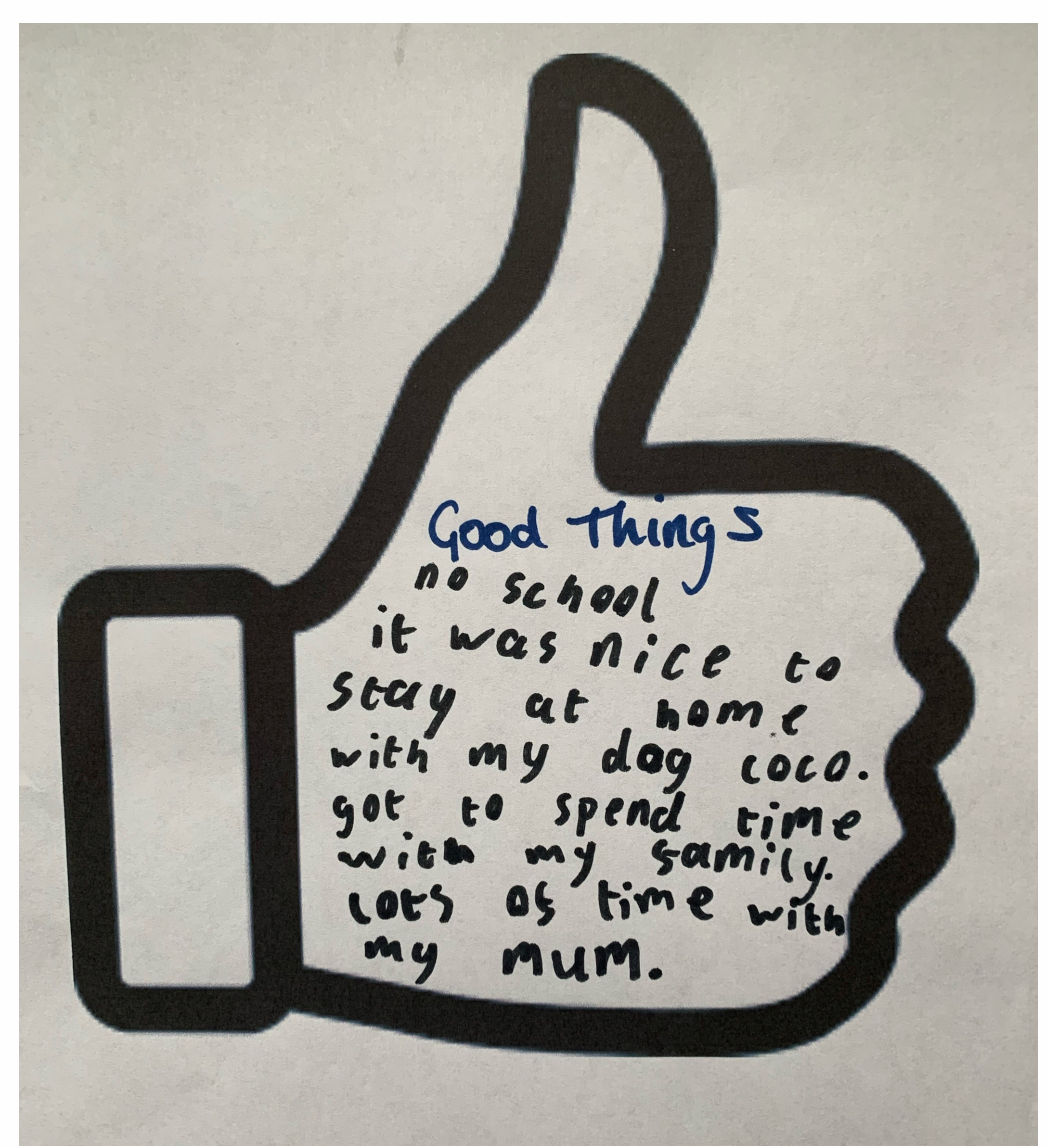
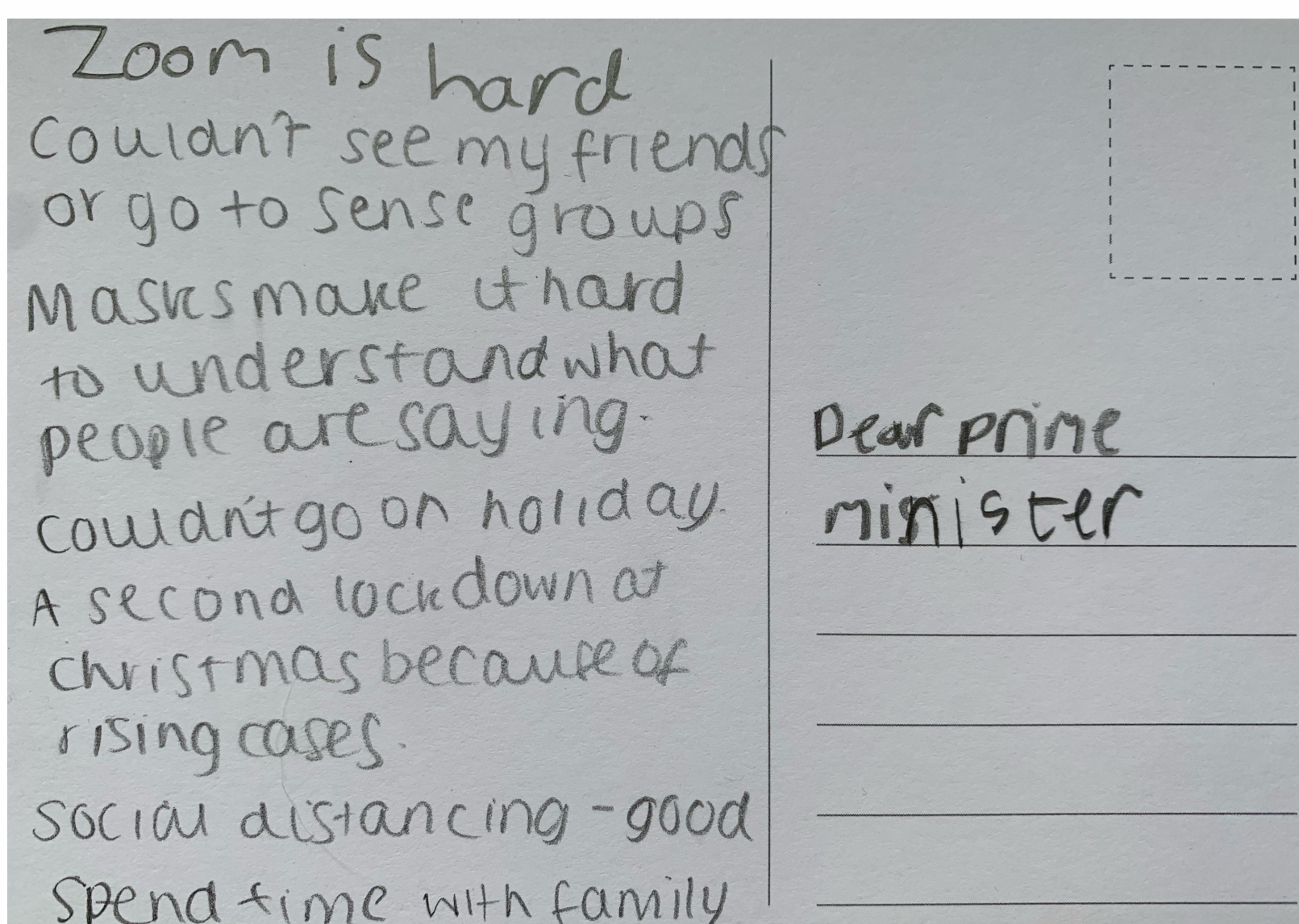
20 children with SEND took part in 3 workshops. Throughout much of the workshop discussions, many of the children told us that they would like everyone to be equal, for there to be no racism, sexism, homophobia or hate speech. Several children we spoke to emphasised their dislike of the current Prime Minister. Children told us that one good thing about the pandemic was that the air was cleaner, and CO2 emissions went down.



My right to play, socialise, have fun and be part of the community

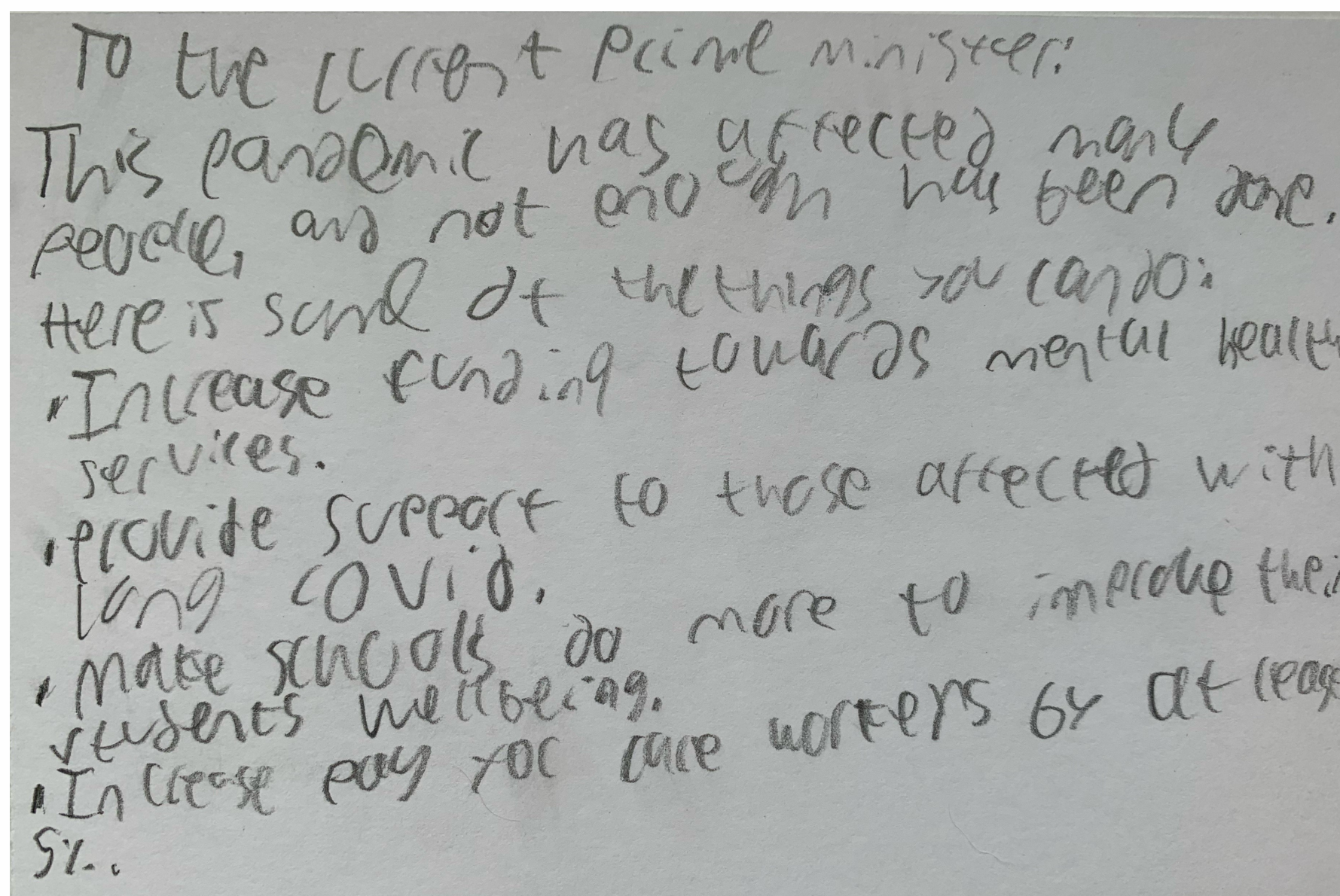
Children shared mixed views about the lockdowns. Some children said they were 'bored', missed their friends, missed activities and disliked not going anywhere, whereas others liked staying at home and not going out. On the whole, children enjoyed spending more time with their family, playing with pets, connecting with their friends online, and playing online games. However, some children would have liked a better internet connection, and others struggled with online communication. Children said they did not like wearing masks, and communication was also hampered by wearing face masks for some children who rely on lip-reading.

Children noted that they would like a fun place to go to where they could play with their friends and make new friends. Ideally, this place would be somewhere they could access practical activities such as cooking and rock climbing. In addition, children would like to spend more time playing games outside and being outside in nature (trees specifically). One child suggested that having a trampoline in the school playground would be a great way to spend more time playing outside.



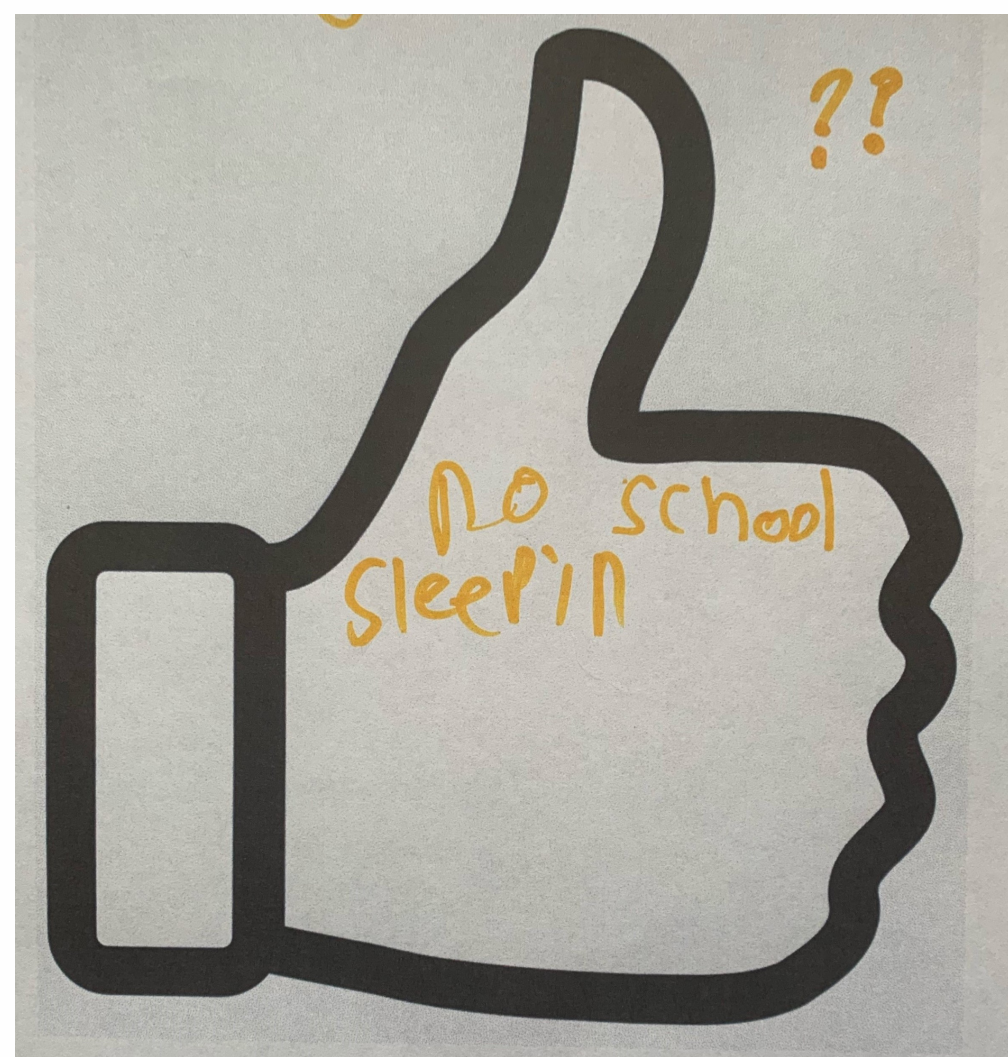
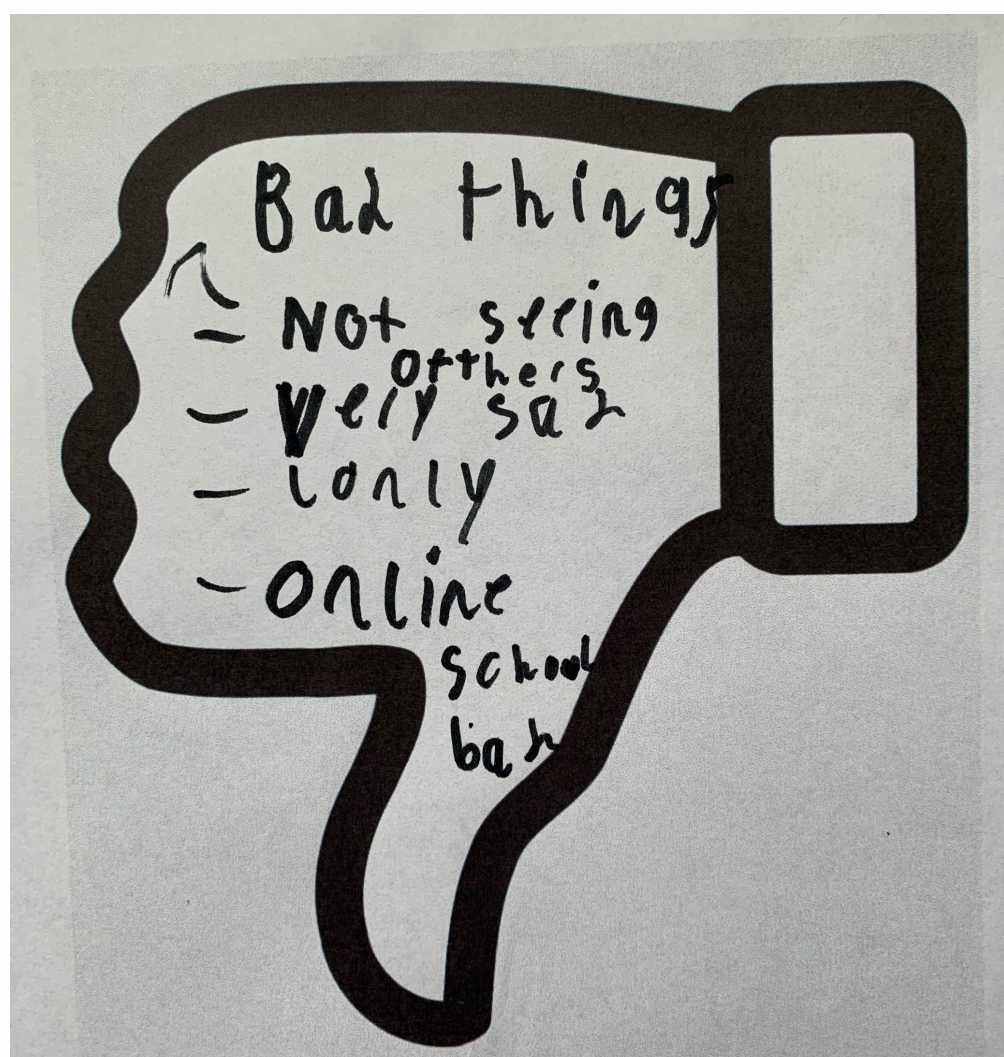
My right to support for my social emotional well-being and mental health

For some children with SEND, lockdown gave them a chance to relax and unwind. However, other children told us that their mental health worsened during the pandemic, leaving them feeling 'very sad', 'lonely', 'anxious', and 'stressed'. To help, children thought that mental health services should have more funding, greater capacity and be provided in schools. One child suggested that a weekly online therapy session for them and their family during lockdowns would have been beneficial. Another child would like mental health services to be more lesbian, gay, bisexual and transgender (LGBT) friendly.



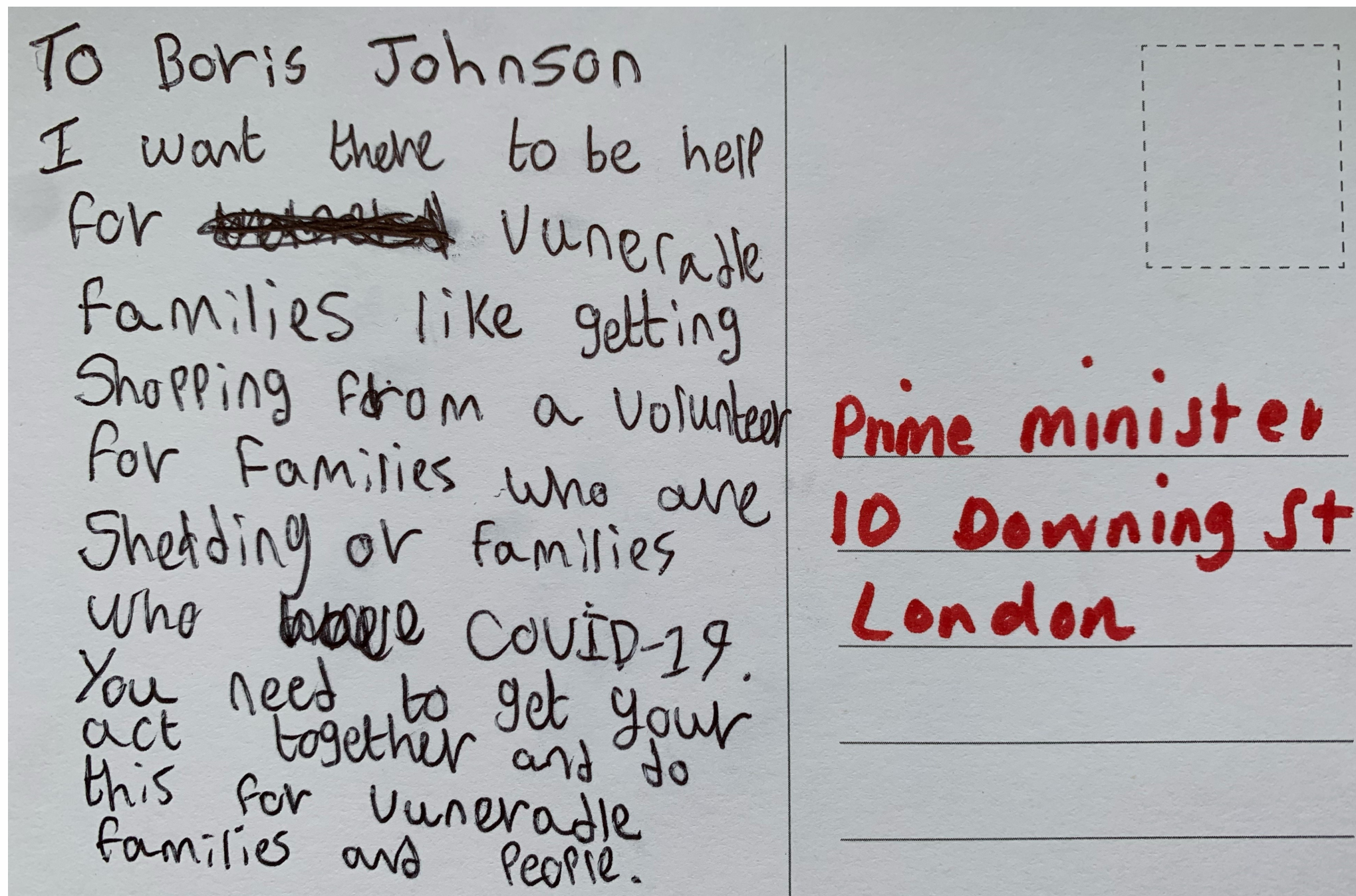
My right to flexibility, choice and support so I can feel safe, belong and learn in school

Some children liked not going to school over lockdown and enjoyed online learning, whereas others really missed school and found remote learning difficult. Several children told us they could not learn online and felt like they had missed out on education. Those children who continued to access face to face school over lockdowns told us that school was better during these times as it was quieter and there was more 1-2-1 help to do school work. Children would like to feel good about going to school and suggested that nice teachers and a safe environment might help them do so. To help them learn in school, children would like lessons to be more varied and fun, such as doing more PE lessons, swimming, and playing more games (e.g. maths games). Learning skills to get a job in the future was important for children. Children reported that they would like more interventions and more special schools.



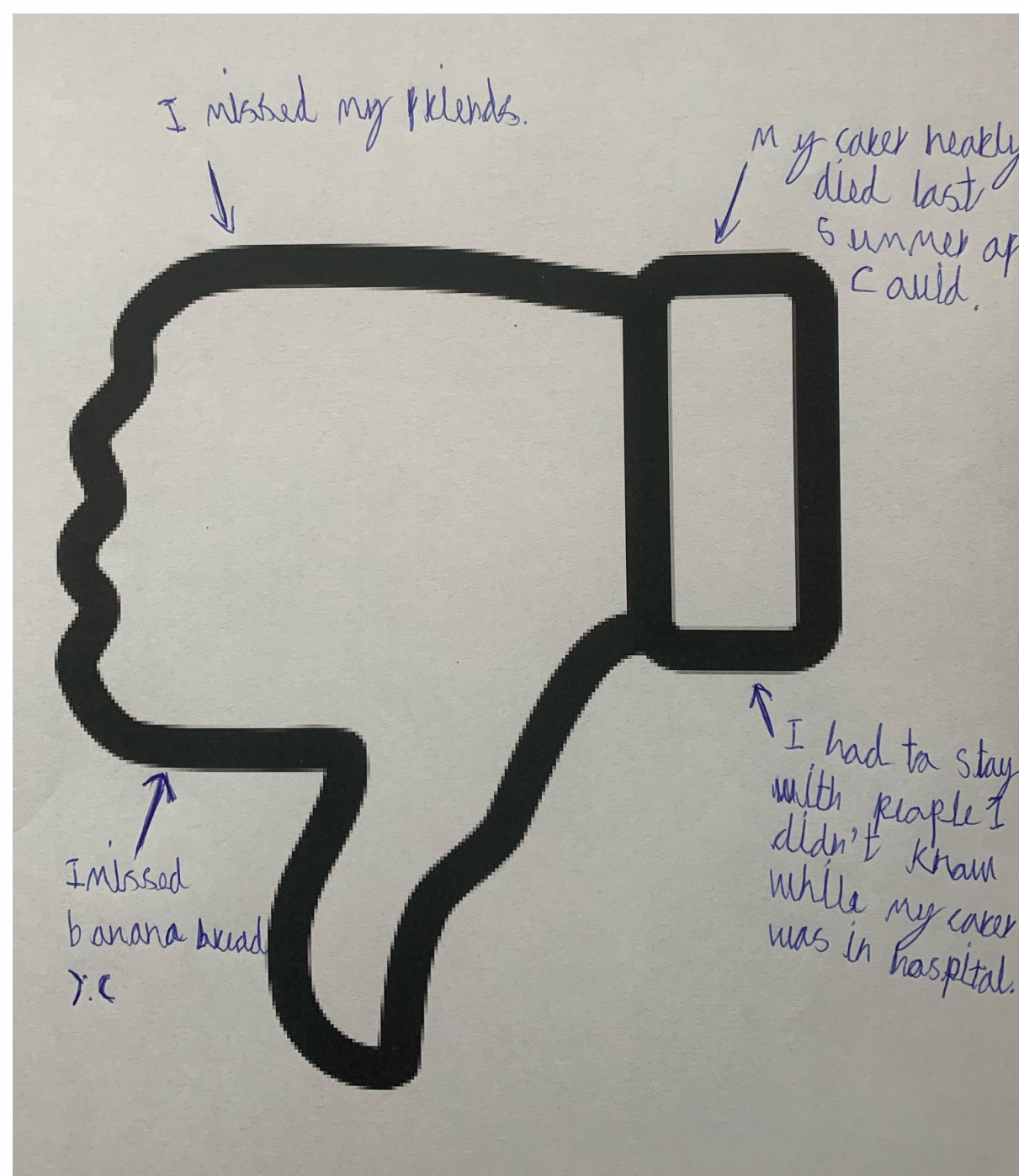
My right to support for my parents/carers and my family

Although most children enjoyed spending more time at home with their family over lockdown, one child told us not having enough time to themselves was difficult. One child suggested that a session for their family to talk about their worries would have helped. Another child whose family was advised to shield from COVID-19 mentioned that a wellbeing phone call and help with their shopping would have been beneficial.



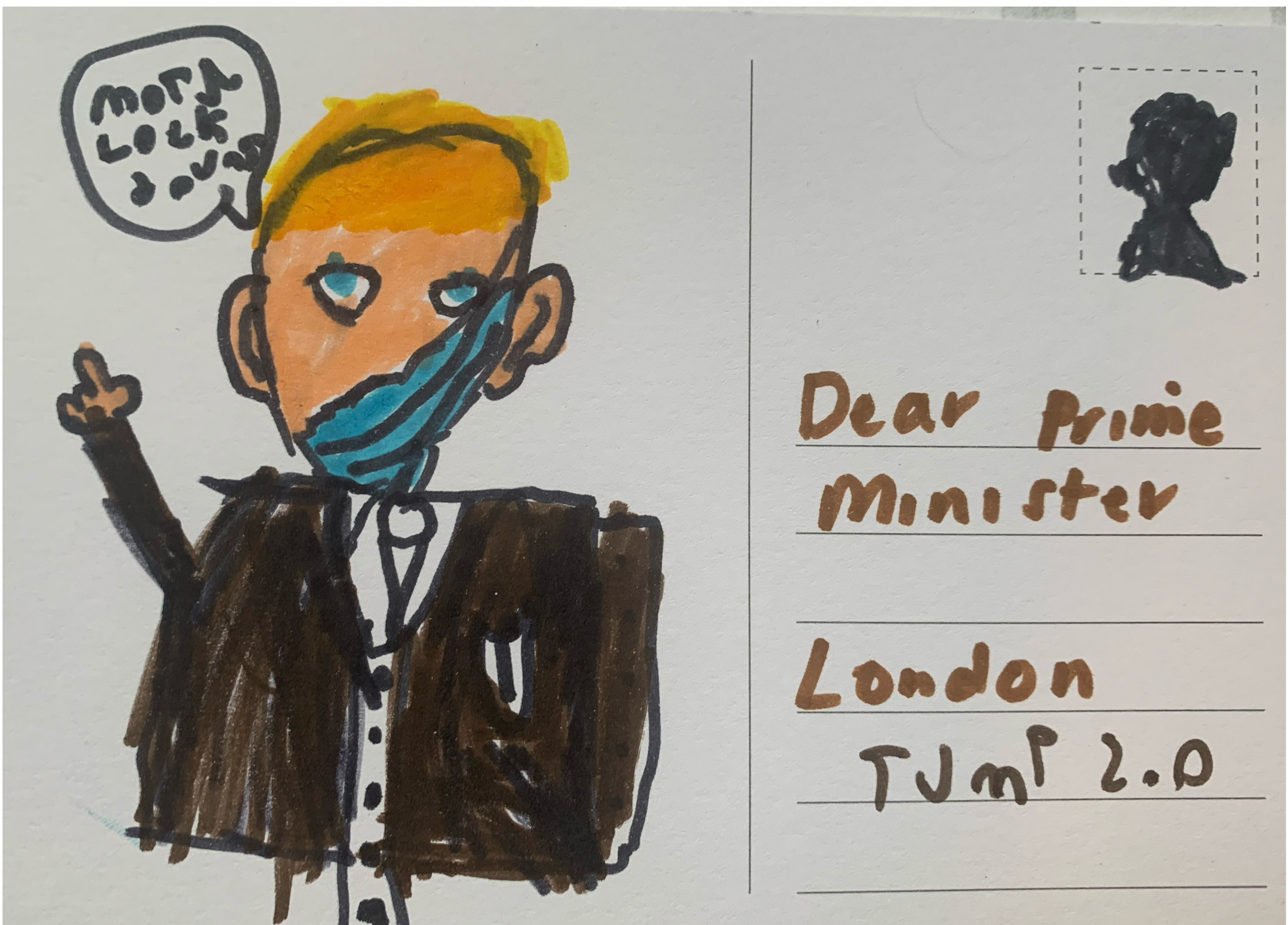
My right to health and social care services and therapies in order for me to stay healthy

Children told us that having no support over lockdown was difficult, and for those advised to shield, shielding without support was particularly hard. Social care was also impacted, with one child having to live with unfamiliar people due to their carer catching COVID-19. One child suggested that they would have liked an NHS key worker to visit them in their home where it is 'nice and private' rather than going elsewhere for appointments.



Conclusion of children's workshops

Many children with SEND reported that their mental health declined over the lockdown, leaving them feeling sad, lonely and anxious. As such, children advised that increased support for their mental health is paramount. Additionally, children would like the school environment to help them feel safe and make them want to attend. Those children who continued to access face to face school over lockdowns told us that school was better during these times as it was quieter and there was more 1-2-1 help to do school work. Children would like lessons to be more varied and fun, for example, doing more PE lessons, going swimming, and playing more games. Outside of school, children would like places to participate in activities, play with their friends and make new friends.



Findings - Perceptions of Parents/Carers of Children with SEND

11 parents/carers took part in 2 workshops. Throughout much of the workshop discussions, parents/carers described how difficult, frustrating and exhausting it was to navigate the SEND system, and an overriding point discussed by many parent/carers was that they would welcome an advocate to help guide them through the process of obtaining support and accessing services. Parents/carers also discussed that when children with SEND receive support, it is often reactive rather than proactive. This reactivity often results in children and families reaching crisis point before receiving the necessary help. Parents/carers discussed and highlighted as a priority how they would like their child to receive assistance in the first instance and be acknowledged as experts on their child rather than having to fight to be heard. Parents/carers spoke of a 'postcode lottery' when trying to access support for their children and said there needs to be equitable access to provision for every child, no matter where they live. Parents/carers reported that they would like support services to be properly funded and regulated so that parents/carers do not have to solely rely on charities. As having a child with SEND impacts the entire family, parents/carers would like provision to take a holistic approach based on a whole family's needs. We asked parents/carers if they thought it would be useful to rank the priorities in order of importance. Parents/carers noted that it would be too difficult to rank one priority as more important than another as they are all of equal importance.

My right to play, socialise, have fun and be part of the community

Parents/carers told us that having safe places where their child could go and be part of the community, socialise and have fun without judgement is essential. When the pandemic hit, activities for children with SEND were cancelled and took a long time to reopen once restrictions eased. As such, parents/carers reported that children with SEND had little opportunity to socialise. Parents/carers emphasised that the activity groups children with SEND attend are more than 'fun', but a lifeline for both them and their children. Over lockdown, face-to-face activities were often replaced by online activities, but parents/carers told us that online activities do not always work well for children with SEND. Parents/carers mentioned that some SEND provision was not always maintained over COVID-19 (e.g., hydrotherapy pools and sensory rooms). According to parents/carers, this provision has deteriorated so much it cannot be used, and there is no budget to reinstate it. Also at real risk of closing following the pandemic are vital activities (such as horse riding) provided by charitable services.

Parents/carers prefer groups and activities to be local and community-based instead of having to travel long distances. Parents/carers would like activities to be facilitated by credible and appropriately trained professionals. Ideally, these sessions would be joint sessions where children are safe and entertained, providing parents/carers time and space to relax and connect. Parents/carers emphasised that activities need to be ongoing rather than stopping just as their children settle into the activity (e.g. not being limited to six sessions). Furthermore, parents/carers would like to see no waiting list for activities. Parents/carers advised that two-year waiting list is too long for activities that build life skills and independence (such as supported trips to the cinema).

Parents/carers recommended that activities need to be inclusive. Parents/carers told us that in their experience, activities are designed with non-disabled children in mind (e.g., soft play areas) and do not cater for physically impaired children. Additionally, parents would like more activities devised for non-verbal children.

My right to support for my social emotional well-being and mental health

Some parents/carers told us that their children's anxiety increased over the pandemic and that there needs to be more mental health provision for children with SEND to talk about their feelings before reaching crisis point. According to parents/carers, children either refused to engage or struggled to engage in online appointments during the pandemic. As such, face-to-face appointments need to be made available. To be more effective, mental health professionals need to understand SEND, and six counselling sessions are not enough for children with SEND as parents/carers stated that it takes them time for children to build trust and open up to professionals. Parents/carers suggested that other types of therapy (activities/walks/music) may be beneficial as children with SEND may feel uncomfortable talking one-on-one with an adult.

Flexibility, choice and support to feel safe, belong and learn in school

Going back to school has been challenging for some children with SEND due to increased mental health issues and high anxiety. Especially hard has been the transition back to school and the return to larger classes which has been overwhelming for some children. Parents/carers mentioned that schools had provided little flexibility in how children transition back to school. Moreover, parents/carers have encountered issues with the transition between schools and spoke about needing new referrals to access services and professionals. Parents/carers observed that some school staff had left their posts during the pandemic and had been replaced by temporary staff. Some parents/carers mentioned that some children found it hard to be taught by unfamiliar staff who were unaware of their needs. Parents/carers reported that communication between school and families has broken down over COVID-19 and has not been reinstated. Previously, parents/carers could go into school to speak to staff, but restrictions prevent them from doing so. Having to use a logbook to communicate was thought to be inadequate from parents/carers point of view. When parents/carers did talk to school staff, they said communication was often impersonal and detached.

Moving forward, parents/carers suggested communication lessons, and giving their children time and space to catch up on social interaction would make school more beneficial. Furthermore, parents/carers would like schools to provide their children with more opportunities to pursue special interests, increase their independence and develop life skills (e.g., vocational options and supported work experience), rather than just focussing on the curriculum. Parents/carers would like mainstream schools to be more inclusive and have more SEND trained staff. One way of doing this would be for mainstream schools to build better links with specialist provision. Parents/carers told us that some adjustments such as continual assessments should be kept, as this was preferable for some children in comparison to exams. Parents/carers would like schools, and EHC Plans to focus on a child's strengths rather than their deficits. Parents/carers felt it was depressing to repeatedly write about their children's 'worst day' when they filled in forms.

My right to support for my parents/carers and my family

Parents/carers told us that when the pandemic hit, all support stopped and they were 'just left to get on with it.' Especially challenging was a lack of respite and face-to-face parent support groups. Instead, some parents/carers resorted to 'car park therapy' outside school. Parents/carers highlighted that everything they learned about navigating the SEND system came from speaking to other parents but warned that parent-run support groups could sometimes do more harm than good. Instead, parents/carers would prefer support groups to be run by credible and trained professionals. Online support worked for some parents/carers but not others as some parents did not have adequate technology or did not like to do video calls. Parents/carers would have appreciated a regular 'check in' phone call to ask how they were. However, one parent felt that phone calls were just a tick box exercise and that nothing could be done if they were not okay. Parents/carers would like mental health support groups for parents/carers and face-to-face sibling support groups for their other children.

Parents/carers would like an advocate on their side to help them navigate the SEND system from pre-diagnosis to post-diagnosis and beyond, as once their child gets a diagnosis, they are often not offered any further support. Parents/carers did not always understand complicated language and confusing processes (for example, there is no guidance on the meaning of an EHC Plan, Early Help Assessment Tool (EHAT) or tribunal). Parents/carers said getting support for their child is like a full-time job (due to the volume of phone calls and forms) and suggested the DLA renewal process be made electronic. One parent told us that a family liaison officer had been helpful, but these do not exist anymore. Parents said that SENDCos are not positioned to help as they do not have the required knowledge. As well as this, parents/carers perceive that they cannot be fully honest with SENDCos (or other professionals) due to fear of being judged (for example, one parent said they would not tell a SENDCo about financial struggles). A final point raised was that services need to recognise generational SEND and then support the parents/carers affected by generation SEND.

My right to health and social care services and therapies in order for me to stay healthy

Parents/carers told us that they struggled to contact health care providers and access equipment during the lockdowns. Face-to-face appointments were cancelled, and when parents/carers tried to call services, they could often only reach an answering machine. Online meetings and phone consultations did not work well for some children with SEND. For example, one family disengaged from online speech and language therapy, calling it a 'disaster'. However, for others, online appointments worked well. As such, it would be helpful if parents/carers and children with SEND could be given the option of a face to face or online appointment in the future. Parents/carers advised that the wait is too long to get a diagnosis as well as to see a specialist, and would like to see additional clinics for easier access to specialists. That said, parents/carers highlighted occasions of excellent care, 'pockets of gold' and instances of professionals going 'above and beyond' during the pandemic. As part of their child's health and social care, parents/carers would also like their children to have more opportunities to engage in physical activity to improve their fitness.



Conclusion of the parent/carer workshops

Parents/carers described how exhausting it was to fight for support and navigate the SEND system and would welcome an advocate to help guide them through the process of obtaining support. Safe places where children with SEND can go and be part of the community, socialise and have fun without judgement are a 'lifeline' for children and their families as long as they are local and community-based.

Parents/carers reported that children with SEND's anxiety increased over the pandemic. As such, there needs to be more mental health provision for children with SEND to talk about their feelings before they reach crisis point. To be more effective, mental health professionals need to understand SEND and offer types of therapy other than counselling. In terms of education and learning, parents/carers reported that many children with SEND found the transition back to school overwhelming. Parents/carers felt giving children time and space to catch up on social interaction would have been beneficial. Furthermore, parents would like schools to provide their children with more opportunities to pursue special interests, increase their independence and develop life skills, rather than solely focussing on the curriculum. Parents/carers would like mainstream schools to be more inclusive and have more SEND trained staff.

Parents/carers noted that some professionals provided excellent care during the pandemic, going 'above and beyond'. However, most parents/carers told us that health and social care and respite completely stopped. A regular 'check in' phone call would have been appreciated by parents/carers during this time. Online meetings and phone consultations worked well for some children but not others. As such, it would be helpful if parents/carers and children could be given the option of a face to face or online appointment in the future. Parents/carers advised that the wait is too long to get a diagnosis and see a specialist and would like to see additional clinics for easier access to specialists.

Findings - Perceptions of Professionals Working with Children with SEND

38 professionals participated in 3 online workshops. Professionals had several overarching suggestions concerning the original priorities. Their main observation was that the points we raised were longstanding issues with the SEND system and were not specific to COVID-19. However, professionals said that it was impossible to separate the impact of COVID-19 from the effects of the SEND system being in crisis. Instead, professionals suggested that there is a need to highlight the issues that have been particularly exacerbated or magnified due to the COVID-19 pandemic. Professionals also noted that the priorities need to be SEND specific rather than relating to all young people.

The refined priorities were organised into priorities for education, health and social care priorities, and local authorities' priorities. Professionals said that when we segregate priorities like this, education, health and social care have individual conversations within their silos. Instead, professionals suggested that a more coordinated, joined-up approach is required. Professionals spoke highly of the multi-agency working the pandemic afforded, and they would like this work to continue. Thus, professionals advised that priorities must be joint rather than having different priorities for education, health and social care, and Local Authorities. Joint priorities would also help reduce duplication across the SEND system and help to maintain a child-centred approach. Professionals noted that we need to be specific about who each priority applies to in order to create accountability. Professionals also mentioned that the word 'improved' is insufficient as it cannot be measured. We asked professionals if they would like to rank the priorities in order of importance. Professionals noted that it would not be helpful to rank the priorities in order as each priority is fundamental and priorities are interlinked. Additionally, there are different stresses in each health care service/Local Authority/place of education, and therefore each health care service/Local Authority/place of education would rate priorities differently.

Professionals from all SEND contexts discussed that services need to have more funding and resources to provide proactive support. Many professionals talked about how they have experienced gaps widening following COVID-19. For example, some of the professionals reported that many parents did not know how to access support from school or from health and social care services during the pandemic. Professionals told us that parents/carers do not see the Local Offer alone as a viable resource. It could be the best Local Offer in the world. Still, parents do not always know how to access what is on the Local Offer and need support to do this.

Professionals told us that they have some very tired staff and have also lost a lot of staff (specifically care agency staff and 1-2-1 staff) due to workload during COVID-19. Recruitment and retention of staff have been incredibly tough. Professionals suggested that they are less likely to leave their posts if they feel valued and listened to.

My right to play, socialise, have fun and be part of the community


Professionals spoke about the value of social activities, play, and having fun for children with SEND's mental and physical health. Professionals observed that during the pandemic, communities came together, which in turn supported inclusion. Professionals would like to harness this community spirit systematically through resources and policy. Professionals also noted that community inclusion is essential for children with SEND in terms of their independence, health, and wellbeing. However, professionals have observed that community inclusion does not always happen naturally for children with SEND due to several barriers. For example, it is harder for children with SEND to make friends locally due to specialist provision being outside of the local community, and it is harder for parents to connect with other school parents due to their children using school transport. Professionals added that community inclusion has to be developed consciously through writing community inclusion into EHC Plans and asking schools to promote activities for children with SEND in the local community. One professional suggested using current pots of money to create inclusive centres within 15 minutes from any house where children with SEND and their parents/carers could attend. Another professional recommended that community inclusion for children with SEND be improved by making reasonable adjustments to existing spaces and places, such as putting stickers on the windows of all shops and cafes that are SEND friendly. Children with SEND can then be signposted to these places instead of creating more specialist provision. Professionals expressed the need for local, inclusive holiday activities with 1-2-1 support for children with SEND to attend.

My right to support for my social emotional well-being and mental health

Professionals noted that children with SEND's mental health declined during the pandemic due to not being able to go out and not getting enough support. Specifically, professionals said that CAMHS support was diabolical for children with SEND due to staff working from home.

Professionals suggested that all of the workforce (education, health, social care and Local Authority) need to be better trained around mental health issues. According to the professionals we spoke to, the education system does not support any young person's mental health, including those with SEND. Professionals suggested that teachers, teaching assistants and headteachers need to be trained in creating an environment conducive to mental health. Another suggestion was that special schools could support mainstream schools with training around mental health. A third suggestion was that a job role for a professional to help children with SEND gain a sense of belonging and build friendships could be created.

Professionals mentioned a need for a graduated response towards mental health support, from lower-level wellbeing support in school to specialists who can support a child in a crisis. Good signposting, a sound triage system, and provision whilst young people are waiting for CAMHS support were said to work well. Professionals commented that standards are needed, such as an immediate appointment when a child is in crisis and no more than a 2-week wait otherwise. Professionals thought that teaching emotional literacy and helping children with SEND understand and manage their feelings rather than medicalising feelings was vital. Interventions also need to be tailored to each child, as some children may benefit more from a lower level intervention than seeing a CAMHS practitioner.



Professionals said that more training needs to be provided to upskill mental health professionals so they are disability confident, and full assessments need to be undertaken to prevent diagnostic overshadowing. Diagnostic overshadowing is when symptoms are assumed to be attributed to a disability or psychiatric condition rather than fully exploring a person's symptoms. Particularly in children with SEND, there might be physical causes for exacerbations of poor mental health or vice versa (for example, constipation might cause anxiety and anxiety might cause constipation). One professional noted that mental solutions do not always work when the issue stems from a physical condition.

My right to flexibility, choice and support so I can feel safe, belong and learn in school

Professionals observed that in their experience children with SEND who did not go to school during lockdown did not receive as much support as they would have usually received in school. Children lost their teaching assistants, found working at home very difficult, and lost structure and routine. On top of this, many children with SEND have had difficulties going back to school, received no transition back to school, and reasonable adjustments were not made. An original priority identified from the surveys was for children with SEND to 'catch up' on missed education and learning. Professionals saw the term 'catch up' as potentially problematic and suggested that a better term would be for children with SEND to be supported to achieve their full potential.

An original priority identified from the surveys was to increase the number of places available in specialist provision. However, professionals questioned whether the real issue is the lack of inclusivity in mainstream schools rather than the sufficiency of places in specialist provision. Professionals spoke about the value of inclusion and that currently, mainstream schools are not inclusive enough. Professionals said that inclusion needs to be rewarded by the inspection system rather than assessing schools on performance criteria. Professionals thought that training and expertise would follow if OFSTED criteria were changed. Professionals mentioned that some other countries do not need special schools because all schools are inclusive.

Professionals reported that they felt more children are presenting with SEND following the pandemic and that this may be due to decreased access to learning during the lockdowns and the circumstances leading to children's development being delayed. Professionals suggested that schools should be allowed to focus on the wellbeing of children with SEND rather than narrower academic performance criteria.

Professionals pointed out that parents/carers are home educating more because they feel that sending their child to an unsuitable school placement is not a viable alternative. Schools should consider providing the option of an online offer for young people who benefit from home learning, such as children with pain and fatigue, children who cannot cope with school, and children who thrived by not having to go to school.

My right to support for my parents/carers and my family

Professionals noticed that the issues that affected families the most during the pandemic were poverty, deprivation, loss of jobs, no free school meals, and higher bills due to more time spent at home. Parents/carers were exhausted as social care resources (such as short breaks, respite and children's homes) completely dried up. Single parents especially struggled without a support network of carers and respite. Parents could not afford to do the activities they would have usually done with their children pre-pandemic. Professionals found that parents were most appreciative of activity vouchers for their children. Professionals spoke about the need to support families of children with SEND to do 'ordinary' things in 'ordinary' settings in the community (such as accessible activities in parks rather than institutionalised care through direct payments) as they thought that providing families with short breaks segregates children with SEND further. When children struggled to go back to school because no reasonable adjustments had been made, professionals observed that parents/carers were 'hit again with the stick'. Professionals noted that many parents/carers had been 'stressed' but had no support to take care of their own mental health. One professional suggested that children's centres could have a mental health practitioner available to support parents. Professionals queried whether Local Authorities understand what it has been like for children with SEND and their families and spoke about the need to ask children with SEND and their families what they need and listen to them, rather than being driven by waiting lists and performance indicators. One professional spoke about increased innovation during the pandemic, saying the 'ideas just flew' once bureaucracy and pressure to meet targets were lifted.

My right to health and social care services and therapies in order for me to stay healthy

Professionals have seen a huge increase in referrals for SEND support from parents/carers. One professional spoke about a massive increase in the waiting list for occupational therapy as more parents/carers have requested house adaptations to help keep children with autism safe after realising their home was not suitable during the lockdowns. This professional suggested the need for a more effective, holistic solution such as an autism family support worker, rather than the adaptation of homes. Professionals also noted that parents/carers are also requesting SEND support following homeschooling after noticing the gap between the level of the work sent home for their child and the level of work their child could do.

Professionals have also seen increased referrals for SEND support from school settings. COVID-19 has affected some children's development, and professionals have recently noticed that children have started school with profound communication needs after minimal interaction during the lockdowns. Professionals have also noticed that children have regressed physically due to lost time on their physical development. Professionals said it is hard to unpick whether these needs are SEND or COVID-19 recovery needs. One professional suggested that SEND may have to be redefined following the pandemic to encompass COVID-19 recovery needs. In contrast, another professional said that redefining SEND to include COVID-19 recovery needs may cause the SEND system to implode due to additional pressure on services. Professionals told us that their services already could not meet the increase in demand for provision due to COVID-19 even when they are turning down 50% of requests. Services are struggling to recruit new staff as no new staff are coming through the system. There is a need to provide more opportunities to train more health care workers (especially Education Psychologists and speech and language therapists). Furthermore, professionals said that early intervention work is the responsibility of education and the Local Authority, rather than just healthcare.



Conclusion from professionals

Professionals noted a need for a graduated response towards mental health support, from lower-level wellbeing support in school to specialists who can support a child in a crisis. Additionally, the whole workforce (education, health, social care and Local Authority) needs to be better trained around mental health issues and disability, and the education system needs to be more conducive to children's mental health. Following the pandemic, schools should focus on the wellbeing of children rather than 'catching up' on education and learning. The option of an online offer should be kept for children who benefit from home learning. Professionals spoke about the value of inclusion and that currently, mainstream schools are not inclusive enough. Furthermore, community inclusion is essential for children with SEND and should be written into EHC Plans.

Professionals noted that parents/carers were exhausted during the pandemic as social care resources completely dried up. Children with SEND and their families should be asked what they need and listened to. Professionals have seen an enormous increase in demand for SEND support, which services cannot meet. As such, services need to have more funding and resources. Workforce challenges have been exacerbated, but services cannot recruit new staff as no new staff are coming through the system. There is a need to provide more opportunities to train more health care workers (especially Education Psychologists and speech and language therapists).

Priorities for Practice and Policy

The workshops led to the development of more tightly focussed priorities applicable across all services which are focussed around 5 key areas, framed by a children's rights-based approach:

- My right to play, socialise, have fun and be part of my community
- My right to support for my Social, Emotional well-being and Mental Health
- My right to flexibility, choice and support so I can feel safe, belong and learn in school
- My right to health and social care services and therapies in order for me to stay healthy
- My right to support for my parents/carers and my family

The detailed priorities according to these 5 areas are available in a separate document available on:- <https://www.ljmu.ac.uk/~media/files/ljmu/research/centres-and-institutes/rcbb/priorities.pdf?la=en>

Conclusion

In conclusion, priorities for policy and practice need to consider that children with SEND and their families have struggled due to a lack of support during the pandemic. Demand for SEND support, particularly mental health support, has increased. Many professionals have gone 'above and beyond' to provide support, but fundamentally, services need more funding and resources to meet the demand. All those who work with children with SEND need more mental health and SEND training. The school environment needs to be more inclusive, conducive to mental health and promote a sense of belonging. Parents/carers need to be supported and listened to as experts on their children.

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