

# Scottish Covid – 19 Inquiry

## Opening Statement

By

Core Participant – Families of Children with Additional Support Needs

### Introduction

1. The Core Participant Group, Families of Children with Additional Support Needs, comprises 7 individuals and two charities, Children’s Health Scotland and the National Autistic Society, Scotland.
2. Of the individuals, all have provided statements to their legal representatives and all but one wish to give oral evidence to the Inquiry, if called. Each individual story is different but there are broad themes that can be taken from each experience. The common themes are that whilst prior to the pandemic the needs of the respective children were not necessarily being fully met due to limited or restricted services in the field of children’s mental health, most of the children were coping with life and in some cases flourishing. Without exception our members reported that the Scottish Government’s strategic response to the pandemic had a direct, adverse impact on their child’s life. While all had a measure of sympathy for the decision to impose a lock down in March 2020, all considered that the Scottish’s Government’s subsequent strategic responses to the pandemic failed to consider their demographic with significant long-term consequences for their children.
3. This core participant comprises individuals of extra-ordinary resilience who are raising non neuro typical children, many of whom have co-morbidities. For these children the prolonged closure of schools, the withdrawal of already limited essential services

and what seemed like constantly changing rules caused and continues to cause significant disruption to their lives.

4. In relation to the two charities who are members of this group while their evidence is in part anecdotal their overview of their members' struggles because of the Scottish Government's strategic response to the Covid 19 pandemic echoes and therefore reinforces the experiences narrated by the individual members of the group.

### **Overview of the Evidence of Individual Members of the Group**

5. One of the individual members of the group told us it was her opinion the Scottish Government 's strategic response to pandemic caused her previously happy child to attempt to take his own life five times. The child is currently 12 years of age. He first attempted to take his own life in November 2021 when he was 10.
6. This member's evidence is that prior to the pandemic she and her husband struggled to get a diagnosis of autism for her child which she considered was in part due to services not taking her concerns seriously and poor and inconsistent service provision. Once there was a diagnosis of autism the child was diagnosed as having ADHD and during the pandemic as having anxiety. The member says that prior to the pandemic while there were challenges for her child educationally due to resources issues, he managed academically albeit he was behind his peers. The member had had to fight to get an education plan put in place, again citing a reluctance of the part of professionals to listen to and acknowledge the concerns of she and her husband.
7. All that said, the member describes the child pre-pandemic, while having a diagnosis of autism, ADHD and being anxious, as a generally happy boy who was coping with life. She stressed he needed routines and coped when routines and structure were in place. She explained that her child enjoyed out of school activities and had three regular hobbies that he engaged in with joy and enthusiasm. All in all, despite less-

than-ideal services and support the member says that prior to the pandemic and the Scottish Government's strategic response thereto, her child was doing well in the sense that he enjoyed life despite his diagnoses and the challenges those brought to his day-to-day life. She says she and her husband were generally able to meet his needs and were satisfied that they were doing so.

8. Following the pandemic, the member reported that her child's health and wellbeing progressively declined. He struggled to cope with the first national lockdown as his routines and the necessary structure that enabled him to manage life ended abruptly. The child's extra curriculum activities ended abruptly too. We were told that as the child is a rule follower and very literal thinking the over simplistic messaging was problematic. The child's anxiety increased, and he believed that if a person caught covid they would die or end up in hospital hooked up on machines as was being reported daily. The constant news stories which were often reported in a sensational and dramatic manner over numerous outlets became a source of anxiety. The child became obsessed with following the myriad of rules which became a bigger issue over time as the rules kept changing. The child worried that his grandparents, two of whom were key workers, would get Covid and die as Covid was reported as a disease with a very high mortality rate in most infections. The child withdrew from family life; he withdrew from his parents and when restrictions eased, from wider family such as his grandparents. The child spent increasingly lengthier periods in his room. When school started, he struggled with the mask mandate and the constant changes to the rules.
9. The member said she was aware her child's anxiety had increased exponentially at the start of the pandemic. She sought assistance from services. As the child was already under CAHMS due to his diagnosis of ADHD he was offered a six-week session of talking therapies on a remote platform. The member reports that the child struggled to engage with remote therapy sessions as he could not see body language and pick up on non-verbal cues via a screen. The child tended to cope in social interactions by observing non-verbal cues and body language, which he had learned to do. These learned responses helped him understand the whole context of his interactions with others. We were told that during the therapy sessions the child would pick his fingers

until they bled but the counsellor was unaware of this because she couldn't see his hands on the screen. The child was able to give the counsellor the responses he considered she sought and her inability to fully assess him in person likely impacted her approach to his care. The member says the child continues to pick his fingers and now wears gloves to stop him picking his fingers.

10. The child's first suicide attempt was not treated appropriately and, in the member's view, was dismissed with inadequate treatment from CAMHS. It was only after the child's third attempt on his life that he was referred to a psychiatrist. The member considers that prior to the pandemic CAHMS was an underfunded and under-resourced organisation but believes that it used the pandemic as a means of not seeing children face to face. This member feels that had her son been seen face to face by CAHMS when his anxiety levels first increased it would have allowed a more pro-active approach to his treatment to have been taken as the full extent of the child's presentation was not fully assessed during the remote therapy sessions.

11. This witness raises many broader concerns about the Government's attitude to children with mental health concerns which go beyond the strategic response to the pandemic. However, she is also adamant that in responding to the pandemic the Government response was heavily focussed on the economy and on maintaining only a few essential services. This member considers that the heavy focus on the clinically vulnerable to the impacts of Covid 19 meant that the Government's strategic response to the pandemic failed to consider the impacts of the virus and the response to the pandemic on other vulnerable members of society. She is of the view that while the strategic response to the pandemic may have saved clinically vulnerable members of society it has caused the loss of many more members of society who are or were vulnerable in other ways. This, she claims, requires to be factored into an assessment of the Scottish Government's strategic response to the pandemic.

12. Other individual members have recounted similar experiences to the individual members whose experience has been set out. They speak of the devastating impact

of services being withdrawn, schools being closed and when opened operating in new and unusual ways, the difficulties of home schooling and their struggles to motivate their non neuro typical children. Most if not, all consider that the Government's strategic response to the pandemic was too heavily focussed on the clinically vulnerable and not on children, especially vulnerable children. Most feel their child's development was adversely impacted by the strategic response to the pandemic and some consider the damage to their child caused by the impacts of the Scottish Government's strategic response to the pandemic will be lifelong.

13. The stories of the individual members of the group are often harrowing. There can be additional challenges raising a child with additional support needs. Prior to the pandemic members' experiences were worsened by inadequate provision of services and under-resourcing and underfunding of other services, including schools. However, the members and their children were generally managing as life was structured and organised. The closure of schools, the withdrawal of what services there were and the frequent introduction of new rules, which were often changed or abandoned after a short period, brought an end to the largely structured and organised society that provided a constant and essential backdrop to the lives of our members and their children. The failure of many services, such as CAMHS, to try to return to pre pandemic service as quickly as possible, exacerbated matters. It seems to our individual members that their children did not feature in the Scottish Government's strategic response to the pandemic and the consequences of that are ongoing for them their children.

### **Overview of the Evidence of the Organisations/Charity Members of the Group**

14. The two organisations who are members of the group have each provided a detailed statement setting out the experiences of those they support. Children's Health Scotland is a leading health charity in Scotland. It is the only charity in Scotland dedicated to informing, promoting, and campaigning on the healthcare needs and rights of all children and young people. The National Autistic Society Scotland (NAS

Scotland) is part of the UK's leading charity for people affected by autism. It offers a range of services and support including supported living, befriending, social groups, advice and information, local branches, outreach, and training/consultancy. Part of its services include statutory functions. Those services apply to adults only. Accordingly, so far as this core participant is concerned, the evidence from NAS Scotland refers only to its charitable function which provides support to, among others, children, and young people.

15. Children's Health Scotland is small charity. Prior to the pandemic the employees worked in their individual locations and made little use of technology in furthering the aims of the organisation. When the first lockdown happened the organisation did what it could by telephoning members. Many of the young people to whom Children's Health Scotland offers support have physical health limitations and disabilities. Therefore, the Charity's members were more concerned about the effect of the pandemic on their health than many young people of a similar age.

16. Over time Children's Health Scotland moved meetings and engagement with others to Teams and Zoom. The organisation engaged the services of a tech company which helped them build an online platform. While this was not the same as in person meetings the representative, we spoke to considered that her organisation managed to provide confidential and secure support to its members during the pandemic in this way.

17. The representative with whom we spoke opined that health ought not be defined as being an absence of illness but as holistic wellbeing. The representative said that after the pandemic there was a focus on the fact that the response to it had isolated the elderly but there were limited investigations into the response to the pandemic on children and the young. She reports that the closure of respite and day centres during the pandemic had an impact on the overall health and wellbeing of many young people and their families. She considers that the redeployment of resources because

of the pandemic to, for example, vaccine centres resulted in those resources being withdrawn from services for children and young people, although that is anecdotal evidence only. The representative considers that many NHS services for children were slow to re-open after lockdowns for reasons that are not clear to her.

18. The representative believes that in terms of the decisions that the government made, their effect on children has been “horrendous”. She observes that even during the world wars the schools remained opened and so the magnitude of the decision to close the schools cannot be underestimated. Children’s Health Scotland is aware that more children remain off school with anxiety and more children are not attending school than at any other point in time according to the Charity’s records. The representative does not think that is coincidental that more children are refusing to attend school than ever before and believes it be linked directly to the Scottish Government’s strategic response to the pandemic. The representative states that her organisation has recorded a massive increase in childhood anxiety which she believes is a huge barrier for children engaging with education.

19. The representative from Children’s Health Scotland can offer a unique perspective on effect on children with additional support needs and their families of the Scottish Government’s strategic response to the Covid 19 pandemic. Her evidence echoes that of the individual members but her insight into the effect on children of the decisions of the Government in response to the pandemic has been gleaned from hearing numerous stories directly from vulnerable children and their families about how the decisions made in response to the pandemic affected them.

20. At least one child of almost every member of the core participant group, Children of Families with Additional Support Needs, has a child with an autism diagnosis. Their individual narratives about the effect of the Government’s strategic response to the pandemic on their children and family were echoed by what we were told by the

representatives of NAS Scotland about the effect of the strategic response to the pandemic on their young members.

21. NAS Scotland told us, among other things, about their concerns in relation to the oversimplistic messaging which not only raised anxiety levels for many non neuro typical people, but which failed to address many important issues for non-neurotypical members, such as exemptions from mandatory mask wearing. While it was understood by NAS Scotland that the desire was for a “pure” message it was felt this desire overlooked that the fact that many people who are neuro diverse were left unsure of what they could and do not do and, crucially, left without key information that would have helped them navigate their own response to the pandemic and the measures imposed in response. NAS Scotland told us that while they attempted to keep their website updated with changes to the rules that became increasingly challenging when the rules started to change on an almost daily basis.

## **Conclusion**

22. The experience of each member of the core participant group, Families of Children with Additional Support Needs, as result of the Scottish Government’s strategic response to the Covid 19 pandemic is unique. However, all individual stories are linked by common themes which highlight that a more nuanced and balanced strategic response to the Covid 19 pandemic which considered, and which made provision for the families of children with additional support needs ought to have been possible. The two charity members of the core participant group, Children with Additional Support Needs, reinforce the common themes in each individual story thereby reinforcing that a more nuanced and balanced strategic response to the Covid 19 pandemic and one which made provision for the families of children with additional support needs ought to have been possible.



