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# **The impact of COVID-19 on children with additional support needs and disabilities in Scotland**

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# **The impact of COVID-19 on children with additional support needs and disabilities in Scotland**

Recently, as a result of international treaties and domestic legislation, children's rights have moved to centre stage. In Scotland, under the terms of the Education (Scotland) Act 2016, those with additional support needs and disabilities (ASND) enjoy enhanced and legally enforceable rights, described by the Scottish Government as the most progressive children's rights regime in Europe. This paper assesses the extent to which children's rights have been prioritised in the midst of the global public health crisis associated with Covid-19. Evidence is drawn from a qualitative study of the experiences of sixteen families including a child with ASND during June and July 2020. We conclude that, particularly in the early days of the lockdown, scant regard was paid to the rights of children with ASND as education and care services were suddenly withdrawn. Existing inequalities were exacerbated, such as unequal access to IT, varying levels of direct support from teachers and differences in family cultural and economic resources. Families also reported some positive experiences, such as enjoying more time together and a release from school-generated stress. Diverse experiences of returning to school are also reported. The paper concludes by arguing that the hiatus in educational provision is likely to have a negative impact on the educational progress and general wellbeing of children with ASND, which will take determined efforts to rectify in the future.

Keywords: child rights; disability rights; quarantine school; pandemic education, Scotland

## **Introduction**

Scotland has long prided itself on its inclusive and egalitarian educational system, although there has often been a gap between government rhetoric and grassroots reality, with persistent social inequality in educational attainment (OECD, 2007). In relation to children with additional support needs and disabilities (ASND), there has been a somewhat paternalistic focus on identifying and meeting children's needs rather than securing children's rights (Tisdall, 2015a; b). In addition, the rights of parents have

tended to outweigh those of children (Riddell & Weedon, 2016). Recently, however, the discourse has shifted, with a much greater focus on children's independent rights (Riddell et al., 2019). Change has been driven in part by international treaties such as the United Nations Convention on the Rights of the Child (UNCRC) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). This shifting discourse is evident in the Education (Scotland) Act 2016, which sets out the clearly defined and legally enforceable rights of participation and redress owed to children and young people with ASND. Furthermore, the programme for government, announced in September 2020, committed the Scottish Government to the incorporation of the UNCRC into domestic legislation. Overall, all policy and legislation affecting children is designed with a view to making Scotland:

...the best place to grow up and bring up children. This ambition requires a positive culture towards children. One where children are welcomed and nurtured. One where we are all alert to their needs and look out for them. Where children are listened to, where their views are heard and their rights protected. They should be respected as people in their own right, with rights to a life that allows them to fulfil their potential (Scottish Government, 2017, para 7)

In this paper, we examine the extent to which this commitment to the children's rights agenda is reflected in the Government's response to the Covid-19 pandemic, when emergency legislation (The Coronavirus Act 2020) provided the underpinning for the closure of Scottish schools for almost five months between March and August 2020. During this time, as discussed further below, local authorities' duty to ensure the provision of extra support to children with ASND was suspended and children were no longer able to exercise their newly acquired rights of participation and redress.

This paper begins with a summary of the emergency measures introduced by the Scottish Government in March 2020, along with an assessment of their implications for the rights of children with ASND, drawing on findings of a Children’s Rights Impact Assessment (CRIA) commissioned by the Children & Young People’s Commissioner for Scotland in June 2020 (Observatory of Children’s Human Rights Scotland and Children & Young People’s Commissioner Scotland, 2020). This is followed by an overview of the emerging research literature documenting the impact of school closure on children and their families, with a particular focus on those with ASND.

Subsequently, the paper reports on findings of a qualitative study examining the experiences of sixteen families of children with ASND between June and July 2020.

The broad questions addressed are the following:

1. What emergency educational measures were introduced by the Scottish Government at the outbreak of the Covid-19 pandemic and how did these impact on the rights of children with ASND?
2. What provisions were made for education and care during the period of school closure and how were these experienced by children with ASND and their families?
3. What do families need from care and education services following the return to school in August 2020?
4. What are the future implications for the safeguarding of children’s human rights during national emergencies?

### **Emergency education measures and implications for children’s human rights**

The Children’s Rights Impact Assessment, referred to above, summarised the specific measures taken by the Scottish Government across a range of policy domains and

considered their implications for children's human rights. Appendix 8 of the main report addressed the impact of education measures on children and young people with ASND and their families, and key points are summarised below. Following the passage of the Coronavirus Act 2020, schools in the four UK nations were closed for an indefinite period of time to help reduce the virus transmission rate, effectively suspending many children's access to education. In Scotland, local authorities were required to support in-home learning and provide education and childcare for children of key workers and vulnerable children. There was no clear definition of which children should be counted as vulnerable (Scottish Government, 2020), and whether the category was intended to include all or only some of the group of children identified as having ASND, who now make up more than a third of the Scottish school population (Riddell, 2021 forthcoming). Despite the stipulation that hub schools should remain open, only 1% of all children attended these schools, of which the majority were children of key workers rather than those with ASND (Scottish Children's Services Coalition, 2020). Low uptake was attributed to practical problems such as lack of transport and a sense that families wished to avoid the stigma of having their children labelled as vulnerable. Local authorities' normal duties to assess and meet the needs of children with ASND were suspended, as long as failure to comply with these duties could be attributed to the Covid-19 pandemic. Implicitly, the duty on parents to ensure that their child receives an education was suspended. Simultaneously, local authorities were given additional time to deal with school placing requests, many of which pertain to children with ASND. Changes to placing request regulations meant that many disagreements about school placements could not be resolved for many months after the commencement of the academic year, and parents were obliged to agree to the school suggested by the local authority or keep their child at home until after their appeal was heard. The First-tier

Tribunal for Scotland Health and Education Chamber deals with ASND appeals, but changes to tribunal regulations meant that only time-critical cases proceeded, with no face to face hearings and minimal involvement by children and young people. Tribunal hearings were generally dealt with by conference call or by a judge without the input of other members.

These emergency measures, which were introduced rapidly and with little or no consultation with children and young people, were initially justified in human rights terms to protect public health (Nolan, 2020), and could be interpreted to have been decisions taken in the ‘best interests’ of the child (UNCRC, Article 3). However, as is clear from the evidence presented below, the measures had serious implications for the realisation of children’s rights as set out in the United Nations Convention on the Rights of the Child (UNCRC) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). For example, Article 12 of the UNCRC guarantees that all children capable of forming their own views have the right to express their views freely in all matters affecting them, and that due weight will be given to these views in accordance with the age and maturity of the child. The UN Committee General Comment No.12 (2009) explains: ‘Respect for right of the child to be heard within education is fundamental to the realization of the right to education’ (UN Committee 2009, Para: 105). Since there was a lack of consultation with children and young people prior to the introduction of these measures, this right was clearly not respected. Furthermore, Article 28 of the UNCRC guarantees the child’s right to education and Article 29 states that the education provided must be directed to the development of the child’s personality, talents and mental and physical abilities to their fullest potential.

The United Nations Convention on the Rights of Persons with Disabilities underpins the importance of inclusive education. Article 24 of the UNCRPD requires

states to ensure ‘an inclusive education’, reinforcing the fundamental right to be educated in an inclusive environment with reasonable adjustments to ensure full participation. This interacts with Article 7 of the UNCRPD, which states that disabled children and young people should have access to primary and secondary education ‘on an equal basis with others in the communities in which they live’. This conceptualisation accords with the Scottish Government’s presumption of mainstreaming, a principle underpinned by the Standards in Scotland’s Schools (etc.) Act 2000, which ensures that the vast majority (99%) of children with ASND are educated in mainstream schools alongside their peers. The on-line delivery of education during the pandemic meant that local authorities were unable to ensure equal educational access, since children’s home environments reflect wider social inequalities. Local authorities were also unable to control educational quality or to ensure that reasonable adjustments, including auxiliary aids and services, were available, with negative implications children and parents with ASND, including those for whom English is an additional language, those with particular communication needs and those with learning difficulties.

It was also impossible for local authorities to ensure that ‘vulnerable’ children attended a hub school, since the category of vulnerable child was undefined, no data were available and the label was resisted by parents who regarded it as stigmatising (Reay, 2020). Moving beyond education, Article 31 of the UNCRC guarantees the child’s right to rest, leisure, play, cultural life and the arts, which again was difficult to ensure during the first wave of the pandemic due to the closure of playgrounds and the injunction on everyone to stay at home.

To summarise, the CRIA commissioned by the Children and Young People’s Commissioner highlighted the potentially serious consequences of the emergency



measures for children's human rights across a range of policy domains including education, highlighting risks for particular groups including children with ASND. In the following section, we summarise findings emerging from the academic literature on the impact of these changes.

### **The impact of the emergency measures: Findings from the emerging literature**

Research findings on the impact of school closures underline the serious consequences for children's educational progress and the resulting exacerbation of existing social inequalities (Reay, 2020; Green, 2020; Major & Machin, 2020). In a review of evidence for the Sutton Trust, Montacute (2020) notes the importance of the home learning environment for children's educational development and the difficulties faced by parents living in areas of social deprivation due to financial pressures and overcrowded housing. A report by the Scottish Commission for People with Learning Disabilities (SCLD) (2020) highlights the negative impact of social isolation, economic disadvantage and withdrawal of normal support.

Cullinane and Montacute (2020) note the way in which on-line learning has exposed the digital divide between more and less socially advantaged groups, reflected in differential ownership of digital devices, varying internet access and school-level differences in digital competence. A survey conducted by Teacher Tapp reported that, compared with pupils attending state schools, independent school pupils were twice as likely to access to on-line lessons every day (Montacute, 2020). Within the state sector, children attending schools in areas of social deprivation were less likely to receive on-line lessons delivered in real time compared with their peers attending schools in more socially advantaged areas.

Concerns are also raised about the impact of school closure on future school attendance. A Nuffield Trust funded survey (Sharp et al, 2020) shows that English head teachers in more socially deprived neighbourhoods believe that parental fear of the virus will depress school attendance following the reopening of schools. By way of contrast, head teachers in less deprived areas believe that normal patterns of attendance will resume because parents are better informed about the relatively low risks of the Covid-19 to children.

While recently published studies highlight the amplification of educational inequalities arising from school closure, there has been little research on the specific experiences of children and young people with ASND and their families. The research reported below addresses this gap by exploring the lived experiences of children with ASND and their families during the pandemic.

### **Research methods**

In this section, we report findings of a qualitative study based on sixteen case studies of families including a child with ASND. Parents were contacted via a voluntary organisation focusing on policy development for the inclusion of disabled children and were requested to participate in the study. Initial contact was via the group's closed Facebook page (a primary means of connection for the group), with permission from their leaders/administrators. Sixteen parents, all mothers, agreed to participate and were invited to choose their preferred interview medium. Fourteen opted to communicate via e-mail and two were interviewed on-line. It was not possible to interview children themselves because of the combination of Covid-19 restrictions and the additional support requirements of many of the children. In order to hear the children's views, face to face interviews in familiar settings would have been most appropriate, with communication support available for those who needed it. Non-essential face to face

work was illegal during lockdown, and other methods to fulfil the children's right to be heard (Article 12, UNCRC) would have favoured those without ASND, which is counter to the purpose of this research.

| Participant | SIMD decile | Household  | Ethnicity                  | Shielding? | Employment<br>(WFH = working from home; PT = part-time; FT = full-time) |   | Schooling                                      |  |
|-------------|-------------|--|----------------------------|------------|---|---|--|--|
|             |             |  |                            |            | Before  | During lockdown                         | Before   | During lockdown  |
| Annie       | 1           | Andrew (14, ASND), Ava (16, ASND)                      | White Norwegian / Scottish | One adult  | Student / employed PT   |   | Mainstream secondary                           | Home   |
| Beth        | 10          | Husband, Brooke (16), Brianne (14, ASND) and Brody (8) | White Scottish             | No         | Both employed   | Both employed. Husband WFH              | Brooke and Brody: Mainstream; Brianne: special | Brooke: home; Brianne: 2 days in school hub; Brody: 3 days in school hub |
| Caroline    | 2           | Husband, Connor (11, ASND) and Cara (4)                | Black Zimbabwean           | No         | Caroline: employed PT; husband: employed FT                             |   | Mainstream / nursery                           | Home   |
| Dot         | 9           | Husband, Danny (8, ASND) and Derrick (10)              | White                      | No         | Employed: Dot: PT; husband: FT  | Dot: furlough<br>Husband: WFH/furlough; | Derrick: Mainstream primary; Danny: Special    | Home   |
| Emma        | 8           | Husband, Elias (10, ASND), Ethan (18, ASND)            | White Scottish             | No         | Unpaid carer  |   | Home educated                                  | Home   |
| Helen       | 7           | Husband, Hayley (11), Harrison (8, ASND)               | White Scottish             | No         | Helen: not employed; husband: employed                                  | WFH                                     | Mainstream primary                             | Home   |

|           |    |   |                |       |  |  |   |      |
|-----------|----|---|----------------|-------|--|--|---|------|
| Julia     | 9  | Husband, Jessica (18) and Jo (16, ASND)             | White British  | No    | Husband: self-employed; Julia: carer/volunteer; Jessica: student | WFH (no substantial difference to normal)                | Jo: Special   | Home |
| Katherine | 9  | Partner, Kiara (17, ASN)                            | White Scottish | No    | Katherine employed, partner unemployed since January             | WFH  | Special   | Home |
| Louise    | 8  | Husband, Luke (18) and Layla (young adult)          | White British  | Luke  | Louise: self-employed; husband: employed                         | Louise unable to work due to caring; husband WFH         | Special   | Home |
| Michelle  | 6  | Husband, children Mia (8), Micah (6, ASND), Mae (4) | White British  | Micah | Michelle: employed PT; husband employed FT                       | Michelle: WFH then furloughed; husband: employed FT, WFH | Mia: state primary; Micah: special unit within mainstream primary; Mae: state & private nursery | Home |
| Miriam    | 6  | Molly (16, ASND) and Mitchell (14, ASND)            | White          | No    |  | Unable to work during lockdown                           | Both children in mainstream with ASND support   | Home |
| Nicola    | 10 | Husband, Noah (16), Nate (13, ASND)                 | White Scottish | No    | Nicola: employed PT; husband: employed FT, WFH                   | Nicola: carers' leave; husband: employed FT, WFH         | Noah: secondary, Nate: special  | Home |

|          |   |   |                |        |  |  |  |      |
|----------|---|---|----------------|--------|--|--|--|------|
| Rachel   | 8 | Ruari (14), Rose (11, ASND)                                   | White British  | Rose   | Self-employed                                      | Self-employed with some work moved online                            | Rose: mainstream primary; Ruari: mainstream secondary  | Home |
| Samantha | 6 | Husband, Sally (9) and Stuart (4, ASND)                       | White Scottish | Stuart | Samantha: self-employed and WFH, husband: employed | Both WFH   | Sally: mainstream primary; Stuart: mainstream nursery. | Home |
| Sarah    | 5 | Husband, Simon (11, ASND), Silas (8, ASND) and Sam (6, ASND). | White Scottish | No     | Sarah self-employed, her husband employed          | Sarah did not work throughout lockdown; her husband is a key worker. | Combination of mainstream and ASND provision           | Home |
| Tanya    | 7 | Husband, Tom (11, ASND) and Theo (5)                          | White Scottish | No     | Tanya: employed; husband: carer.                   | Tanya: key worker; husband: carer.                                   | Liam: mainstream; Joseph: special                      | Home |

### Table 1: Participant profiles

The families included 35 children, 24 of whom had ASND. Eight of the children with ASND were educated in special schools or units and a further two were home-educated. In the UK, individuals were classified as in need of shielding if they had specific vulnerability to Covid-19, such as a long term health condition. Of the sixteen families, four were shielding a child and one had a shielding adult. Adults in at least two families reported that they contracted Covid-19 during lockdown. Further demographic information is detailed in Table 1.

The families were spread across thirteen of Scotland's thirty two local authorities. The Scottish Index of Multiple Deprivation (SIMD) was used as an indicator of the relative affluence of the neighbourhoods in which the families lived. To rank neighbourhoods in terms of social deprivation, SIMD uses a range of indicators, such as housing quality, access to services, level of education and employment rate, with 1 being the most deprived and 10 being the least deprived. The majority of families lived in more socially advantaged neighbourhoods (mean: 7.0, median and mode: 8).

Three of the families were single parent households headed by the mother. Most mothers were either unpaid carers or self-employed, and only two were in full-time employment. Among the fathers, by way of contrast, only one was an unpaid carer and the majority were in full time employment. Three families contained critical workers, a

government designation of employment deemed to make a significant contribution to the national effort against COVID-19<sup>1</sup>.

The three questions that participants were asked to reflect upon were the following:

- (1) **Education:** what has been supplied for children to continue with their education during lockdown, and how well does that meet children's needs?
- (2) **Care:** how have physical and emotional care needs been met during lockdown?
- (3) **Planning:** what concerns and needs do families have relating to schools reopening?

Responses were collated and analysed according to these themes. All responses were read multiple times to extract key subjects. These were then used to develop charts quantifying the subject's mention across the dataset, and quotes were extracted exemplifying experiences. Throughout the analysis, great care was taken to respect the intended meaning of interviewees. All names have been changed and identifiable details removed. To avoid decontextualising responses, family background was taken into account in interpreting the data.

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<sup>1</sup> These areas included health and social care; education and childcare; key public services; local and national government; food and other necessary goods; public safety and national security; transport; utilities, commercial and financial services.



## **Key findings from the qualitative study**

### ***Education***

#### *Learning resources and digital access*

Education during lockdown was largely delivered by time asynchronous digital means. Schools provided students with access to online systems for communication, such as Microsoft Teams, Google Classroom, Seesaw, Class Dojo and other apps. Some families found that they needed to purchase or borrow more devices to enable each of their children to access the work. Internet access was critical, and families in rural areas were at a substantial disadvantage due to poor coverage.

Beyond devices and internet connection, families found it challenging navigating the online systems which had been hastily set up and typically supplied without any training. Secondary education is delivered by different subject teachers who often used the platforms differently.

Parents in the study described the challenge of accessing, then effectively translating, the work for multiple children to meet their individual learning needs.

I ended up converting most of it the morning of each day into physical resources - again I was fortunate to have lots of cubes, pens, drawing paper. (Sarah, mother of three boys, SIMD 5)

Some websites were free but some materials signposted by the school required subscription payments so we just googled and found our own free materials instead. I actually spent most of my time in an IT support role instead of directly instructing them on anything! (Helen, mother Harrison and Hayley, SIMD 7).

Half of the participants in the study found that they needed to create educational opportunities for their children, buying books, finding materials online, and adapting worksheets from school. Families with a wide age range needed to find ways of

occupying all their children simultaneously, since there was no alternative childcare.

This required foresight, creativity and an ability to adapt the materials provided:.

Often I have ended up getting all three children doing Micah's activities because they are a lot more fun than Mia's. (Michelle, mother of Mia, Micah and Mae, SIMD 6)

I tried to do a combination of work and play to challenge both Sally and Stuart but also that would allow them to work together. (Samantha, mother of Sally and Stuart, SIMD 6)

Almost all families referred to the need for an established routine.

The sudden proliferation of resources nationally and internationally to support education and recreation during the pandemic was overwhelming for many families. So many opportunities were being offered, often for free, but the requirement to filter and plan usually fell to parents. Combining the requirement to be online for school materials and then also online for social and recreational reasons contributed to exhaustion.

Additionally some disabled children were excluded:

[There were] wonderful things being offered for other and especially younger kids, Maths with Carol Vorderman, PE with Joe. There are so few resources out there for kids like Brianne. Especially ones that are free. (Beth, mother of Brooke, Brianne and Brody, SIMD 10)

School shared lots of tweets but most were irrelevant to my son's needs. This completely overwhelmed me in the beginning. My mental health took a dive. (Dot, mother of two boys, SIMD 9)

For other families, suddenly having access to free resources was illuminating and significant. Families requesting support for children struggling with full time school attendance have often been told that online learning is impossible. Some months before the pandemic, Emma was forced to deregister her disabled and chronically ill children

from school. As a result, they were unable to access the online curriculum provided during lockdown, since their GLOW login (Scottish schools online platform) had been deactivated. Another parent saw this as evidence of ableism, since online learning, previously deemed ‘impossible’ for disabled children, was now implemented on a vast scale:

My overall view, that it is clear due to Covid-19, is that the Government is able to change society in a way that suits all, so our request for a fairer and equal society can clearly be done. It is about willingness. Keeping people safe and alive has been the ultimate narrative in lockdown. (Annie, mother of Ava and Andrew, SIMD 1)

### *Support*

Parents in the study reported a mixed picture of support from schools during this period. Some were disappointed by the apparent lack of knowledge of their child, shown through the inappropriate work provided. They were aware of contrasting responses, particularly when they had children at different schools.

I’m extremely bitter at the level of support Nate’s school has supplied and have said to them that in a time of crisis, they have firmly sat in their educational sandbox.... I could see other schools reaching out to their community and delivering activity packs, having online assemblies ... Our school couldn’t do that. (Nicola, mother of Noah and Nate, SIMD 10)

They honestly didn’t have a clue how to support us or what Luke could be given to do at home. Considering he has been at the school for 13 years, it was appalling, and finally we knew just how little they do for him there. (Louise, mother of Luke, SIMD 8)

Most families found they were able to contact their schools when necessary, however many were surprised that their children’s teachers were not actively contacting them. For example, Miriam was upset that her son with ASND was not managing his

work but the school did not offer support and relied on her to contact them. In contrast, her daughter was receiving a phone call every fortnight to ‘see if she is struggling with anything and if so they try work with her to try sort it out as best as they can’.

Another family knew that local schools were providing specialist equipment, such as visual timetables and ‘now and next’ boards (visual depictions of current task and what will follow, used to aid communication and motivation), while receiving nothing physical from their own school. Dot felt that her child with ASND would benefit from a home routine which was similar to that followed by the school, but the lack of communication made this impossible. Towards the end of lockdown, the school invested in an app (Seesaw) for home/school communication and sharing of learning:

School and the teachers look after our children but nobody invests in the parents, no one takes the time to teach ASN parents what tools, skills and strategies they can use to educate at home (if they wish). It made me feel useless, uneducated, low-skilled and completely guilty because I didn’t know how to ‘teach’ my ASN son. (Dot, mother of two boys, SIMD 9)

A few parents related that their children would have benefitted from some more direct contact with the school, and some schools increased their contact towards the end of term, offering live chat sessions, or transition materials for those entering P1 and S1. Some young people were reluctant to enter live, online sessions after months of not seeing their friends, however some were buoyed by the connection. One parent felt that her autistic teenager is much less likely to have problems returning to school after the summer having ‘met’ some teachers in online face to face sessions.

Some families experienced a higher degree of responsive communication. One family was supported throughout by their child’s ASN Outreach Worker, who provided appropriate resources and tasks for learning and entertainment. Some schools were

enabling weekly calls for children to hear their teachers and report back on work or ask questions. Families experiencing this found it to be highly beneficial:

The help from school, regular phone calls from teacher and headteacher explaining to kids why school was closed and why work had to be done at home, made it easier for them to understand and help to settle. (Caroline, mother of Connor and Cara, SIMD 2)

One child's teacher set up weekly calls with the entire class. Her mother reported, 'there was a real effort to provide appropriate work and also to incorporate activities that the class would have been doing such as camp week, sports week and transition events'.

### *Impact of lockdown on education*

Parents' assessment of the impact of these months of home learning was extremely mixed. For those with older children especially, the concern about missed learning and missed exams was widely expressed. Older children were also often reported to be struggling with anxiety, and for some their usual mental health support was hard to access. For others, the lack of the routine itself had a dramatic impact on their children, including their ability to socialise, to sleep, and even to eat.

Some families saw the opportunity to experience home education as a positive thing. One parent reflected that they now believed they would be able to home educate if this was ever necessary to achieve the best outcome for their autistic child. Another described the improvement that they have seen in their non-verbal child's speech development.

### *Health, wellbeing and care*

This section describes the impact of lockdown on caring roles and responsibilities,

which are essential to families who have often invested much time and energy to achieve appropriate support for their disabled child. During lockdown, personal assistants and other carers were still allowed to work, however, due to the greater risk of serious illness for those with underlying health conditions, many families suspended the support of in home care.

### *Impact on children's physical health*

Physical care was carried out almost wholly by family members during lockdown.

Looking at it purely in numbers of hours, with 168 hours in a week, previously if Rose was at school and we had staff covering all of the hours in her care package, Rose would have support for up to 66 hours, around 40% of her week. Currently she is getting help for 6 hours, just under 4% of her week. (Rachel, mother of Ruari and Rose, SIMD 8)

Many disabled people employ personal assistants in order to help them achieve their goals without relying solely on their family members. During the Covid-19 pandemic, families were often advised to avoid all outside contact, so that the provision of care became the responsibility of parents and, in many cases, siblings. There are many implications of this for families, including a loss of autonomy for the disabled person, altering of roles and relationships to enable care to be provided (such as in the case of young carers), and a loss of respite for primary carers.

Individuals in the 'shielding' category, indicating that their health condition or disability put them at higher risk of severe illness from coronavirus, were advised to stay inside their homes and to avoid contact with members of their household. In the case of children with ASND, this type of social distancing is impossible, so entire families quarantined. In some cases, families decided to continue to pay their personal assistants, but not allow them to come to the house. Other parents had a few carefully

chosen carers still involved. One young person's main personal assistant effectively isolated in order to continue to carry out his caring role without compromising the health of the young person.

Siblings were impacted by the need for their parents to carry out more physical and emotional care.

My eldest daughter (8) has voiced the fear that I don't love her as much as Micah, because I 'choose' to spend time with him instead of her. This has been heart-breaking for all of us, and we have not found a solution that meets everyone's emotional needs at all times. (Michelle, mother of Mia, Micah and Mae, SIMD 6)

My 16 year old has obviously struggled with the situation. He wants us to sit in the garden and have cocktails like his peers' parents do. I want to get ready for bed at 8pm. As ever he's had to entertain himself as we just don't have the energy to. (Nicola, mother of Noah and Nate, SIMD 10)

I'm completely overwhelmed with meeting Rose's care needs. I'm unable to give Ruari (aged 14) the attention he needs because I'm constantly looking after Rose. (Rachel, mother of Ruari and Rose, SIMD 8)

Siblings also became more involved in the caring roles, enabling family life to be manageable. In most cases in this study, siblings were also of school age.

Sally was not doing much manual handling before lock down but she now carries [her brother] with ease and can get him into and out of all of his different pieces of equipment. (Samantha, mother of Sally and Stuart, SIMD 6)

### *Impact on children's mental health*

The impact of the pandemic on the mental health of children and young people has been a prominent concern across national boundaries, and across demographics. Courses are being promoted to train teaching staff in mental health support, and local authorities are presenting their 'trauma-informed' and 'relationship-based' visions for rebuilding

individual and community mental health following lockdown. The abruptness of school closure, with little or no transition for children and young people, was reported as a cause of anxiety for children with ASND.

Requirements of school work, missing peers, missing other activities, and confusion about the situation all contributed to poorer mental health for most families in the study. Concerns about the virus itself impacted the mental health of many of the children. Concerns that they – or their parents – would get ill and die were present early in lockdown for a few families, gradually receding when they saw people recover from coronavirus, or their parents managing to go to the shops without becoming unwell.

The impact of poor mental health on individual's ability to look after their physical health was observed in the study. Four families noticed that their children's ability to eat was negatively impacted due to anxiety. For one teen, this was in the form of overeating and avoiding exercise, while for other young people, their eating substantially reduced.

Families reported the challenge of maintaining sufficient exercise for their children. Eleven parents mentioned exercise in their reflections about their children's needs. Some managed to ensure regular exercise, for example by daily dog walks. Others expressed concern that their children were refusing to go outside due to fear of catching the virus or breaking the rules.

Exercise was rationed by government advice (not law) to one trip out per day. Prior to lockdown children in Scotland often exercised multiple times per day: walking to school and back, playing and doing PE at school, spending time at clubs and parks. During the early weeks of lockdown this was reduced to one form of exercise per day, and only with their households. Recognition of the impact of restricting movement so dramatically on individuals with ASND led to additional guidance that included the pre-



existence of certain conditions as a 'reasonable excuse' for being out. Children's right to play (UNCRC Article 31) was significantly undermined by these restrictions.

Some families noticed that the removal of the school-related stress made some children happier and more eager to learn. For example, children experiencing separation anxiety ordinarily have tended to thrive at home. One family reported that their children enjoyed the freedom to work at their own pace without having to engage in group work.

### ***Emerging from lockdown***

This study was completed as some lockdown measures were beginning to ease in Scotland. This allowed participants to reflect on quarantine school, as well as on how schooling might be for next year for their families. In general, there was a sense that the experience of school closure had a profound impact on the entire family:

The impact of our three boys not being able to attend school on a daily basis has impacted on every aspect of our family's emotional, physical and mental wellbeing. (Sarah, mother of three boys, SIMD 5)

The Scottish Government initially announced that the return to school would consist of 'blended learning', with part of the week spent in school and part at home. Subsequently, after parental objections, it was agreed that all children would go back full time from mid-August. These shifting arrangements were disorientating for some children with ASND:

The news of a 14 hr week has been welcomed and now it's back to full-time education, this back and forward approach has upset my son and he now does not wish to go back to school at all. (Annie, mother of Ava and Andrew, SIMD 1)

Parents commented positively on bonding with their children during lockdown, but also of a renewed awareness of the essential contribution made by school to children's development:

I have learned so much about how my boys learn during this time.... A school day truly depletes them but I realise I couldn't cope long term if I didn't have my break from them which school provides. (Sarah, mother of three boys, SIMD 5)

Anxieties were also expressed in relation to children who had missed a significant part of their education and were shortly passing into a much more uncertain world:

I could weep with rage and frustration when I think of how her opportunities for independence will fall off a cliff when she leaves school next year, unlike other school leavers who start a new chapter. (Katherine, mother of Kiara, SIMD 9)

## **Conclusion**

To summarise, the qualitative study reported above suggests that school closure had profound effects on children with ASND and their families. When the emergency measures were introduced, children's rights experts argued that they were justifiable to protect public health and, in line with Article 3 of the UNCRC, might be interpreted as decisions taken in the best interests of the child. However, as noted by Nolan (2020), serious questions remained about the extent to which the government took adequate steps to safeguard the interests of the most vulnerable groups, including those with ASND and those from socially disadvantaged backgrounds.

Scientific evidence indicates that, particularly for children living with social deprivation, the risks to health and wellbeing of staying at home in these circumstances outweigh the risks of returning to school (Scottish Government, 2020; Ferguson et al., 2020). Overall, it is clear that children have suffered considerably as a result of school

closure, with the burden falling disproportionately on those with ASND, especially those experiencing additional social disadvantages.

Study participants illuminate the challenges of facilitating education at home without notice or training. Many parents noted the additional work required on behalf of their disabled children, from requesting work, to providing 1:1 support, to creating structures within the home to suit each child. Disabled children's right to be included on the same terms as others in their community (Article 7 UNCRPD), was not always upheld, as demonstrated by the difficulties reported here. The limitations of digital education were also powerfully illustrated during the pandemic, underlining Zhao's acknowledgement that on-line learning, while offering opportunities for some students, is unlikely to work for large groups of children (Zhao, 2020). Indeed, the reliance on digital learning in isolated home environments positioned children as atomised individuals cut off from face to face contact with teachers and other pupils. This appears to be at variance with the principles of inclusive education, which seeks to reduce differences by supporting individuals through the creation of supportive communities and through the provision of additional educational aids and services. Further work is needed to consider how the principles of inclusive education may be preserved during national emergencies involving school closures.

Children were unduly impacted by lockdown, had no collective voice and as individuals were denied involvement in key decisions such as school placement, contrary to the central principle of Article 12, UNCRC. Were concerns for the nation's health and healthcare systems sufficient to justify this? Scotland's commitment to incorporate the UNCRC into domestic law must surely now include scrutiny of the systems which allow emergency legislation to be passed to 'protect', without concurrently ensuring that children's rights to participate are also upheld.

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