Witness Name: Nuala Toman, Rhian Davies and Kamran Mallick

Statement No.: 1

Exhibits: 118

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UK COVID-19 INQUIRY

WITNESS STATEMENT OF NUALA TOMAN, RHIAN DAVIES AND KAMRAN MALLICK. ON BEHALF OF DISABLED PEOPLE'S ORGANISATIONS

We will say as follows: -

- We make this statement on behalf of the following Disabled People's Organisations ('DPO'):
 - Disability Action Northern Ireland ('DANI') Nuala Toman, Head of Innovation and Impact
 - Disability Wales/Anabledd Cymru ('Disability Wales') Rhian Davies, Chief
 Executive
 - Disability Rights UK ('DR UK') Kamran Mallick, Chief Executive Officer
- 2. This statement is made in response to the Rule 9 Request for Evidence, dated 25 April 2025, for Module 8 of the Covid-19 Public Inquiry which is examining the impact of the Covid-19 pandemic on children and young people in England, Wales, Scotland and Northern Ireland. We make this statement on the basis of our own knowledge or belief. Where something is outside our own knowledge, we have referred to the source. If it would be of assistance, we are willing to give oral evidence to the Inquiry in Module 8 to expand upon the matters set out in this statement or address any other issues arising.
- 3. Each of our organisations meet the United Nations definition of a DPO as set out at General Comment No.7 (2018) paragraph 11, as they are majority led, directed, governed and staffed by Disabled people. The DPO are distinct from disability charities

¹ The DPO use the term 'Disabled people' to mean people facing disabling social barriers due to their impairments or conditions regardless of their age. This includes physical impairments, mental health conditions, hearing difficulties, d/Deafness (including those that use BSL as their first language), visual impairments, learning difficulties and neurodiversity.

that represent Disabled people, however well, rather than enabling us to represent ourselves.

- 4. Each DPO provides a variety of different support services to Disabled people including Disabled children and young people throughout the UK. These services can include: advocacy, employment support services, digital connectivity, transport, community integration, information and advice, and mental health and wellbeing services. In addition to these services, the DPO also raise awareness, campaign and work with government departments on key issues impacting Disabled people in society with the goal of improving legislation, policies and practices. Our vision is a society which is inclusive and adapts to meet the needs of Disabled people rather than one that expects them to fit in and we aim to achieve that by ensuring Disabled people are actively consulted and involved as decision makers on the decisions that affect us. In the case of Disabled children that consultation should not only include them but also their respective adult guardians.
- 5. In this statement we have used the terminology 'children and young people with learning disabilities' to ensure consistency with the terminology used in a number of academic reports and studies exhibited. Similarly, we have also used the term 'Special Educational Needs and/or Disabilities' ('SEND') for consistency with reports and legislation. However, the DPO note that both these terms are incompatible with the social model of disability given that the word 'disabilities' is used in place of 'impairments' rather than as it should be, namely, to denote disabling barriers.
- 6. The following are views and experiences gathered by all three DPO through our contact with Disabled people, other DPO and government departments across the UK. For example, to gather these views, DANI conducted surveys and gathered evidence in relation to Disabled children and their parental carers before producing their report, 'The impact of Covid-19 on Disabled people in Northern Ireland' which raised key concerns in the middle of the pandemic [DPO/001 INQ000142172]. DR UK's Disabled Students helpline operated throughout the pandemic, and they also held discussions with the parents of Disabled children and young people when preparing their 'We Belong' report which called on the Government to provide families with Disabled children with a key worker/advocate to coordinate support services [DPO/002 INQ000511434/10]. Disability Wales worked with the Welsh Government to produce the 'Locked Out' report which considered the impact of the Covid-19 pandemic on Disabled people [DPO/003 INQ000353434].

- 7. We have also referred to reports that have been drawn to the DPO's attention through our work in this sector which we think are relevant to the scope for Module 8 and will be of assistance to the Inquiry. To supplement these reports, we have provided a number of case studies which highlight the personal experiences behind some of the issues and statistics discussed. As these individuals were and often remain children and young people, we have, where appropriate, anonymised their accounts.
- 8. In preparing this statement, each DPO has conducted a search of our records, however, this has brought up a large number of documents and communications. It is also the case that some DPO have seen a transition of personnel since the relevant period. We hope to have exhibited the key documents, however, if other relevant documents come to our attention at a later date, we will provide them to the Inquiry.
- 9. There are a number of challenges in collating data on the number of Disabled children and young people across the UK. For example, statistics are often based on small sample sizes and can rely on parents and guardians reporting a child's disability status on their behalf. To account for these challenges, statisticians such as the Family Resources Survey, use averages over a period of years to arrive at figures. Between 2020 to 2023, the average number of Disabled children and young people aged under 25 was 2.4 million, on average this amounted to 12.3% of all individuals in that age group across the UK [DPO/004 INQ000643641].
- 10. It is also important to note at the outset that the number of Disabled children and the systems in place to provide education, social care, and health services to meet their needs are different in each of the UK nations. These differences are as a result of education, health and social care being devolved matters. In this statement we have sought to identify common issues but also, where appropriate, highlight specific issues in each nation relevant to the headings below.

Education

Pre-pandemic position

11. Before considering the impact of the pandemic, it is first necessary to consider the system of support for Disabled children and young people and the shortcomings that existed prior to the pandemic. As a broad approximation, in England over 1.6 million

children have special education needs amounting to 18.4% of all pupils [DPO/005 INQ000643642], these figures are 52,152 and 11.2% in Wales² [DPO/006 INQ000643643], 241,639 and 34% in Scotland³ [DPO/007 INQ000643644/9], and 62,650 and 18.4% in Northern Ireland [DPO/008 INQ000643645/20]. The fluctuation in these numbers is a result not only of different demographics in each nation but also different legislation, guidance and procedures for identifying and supporting children and young people with special educational needs. For the sake of clarity and to adopt the terminology used by the Inquiry, all children and young people across the UK that meet these broadly equivalent definitions are referred to as children with Special Educational Needs and/or Disabilities ('SEND') in this statement. Despite the differences, a common theme that pervaded all of the systems before the pandemic was their inability to provide sufficient support for the Disabled children and young people who relied upon them.

- 12. In 2009, an inquiry led by Brian Lamb into the SEN system in England found that, "As the system stands it often creates 'warrior parents' at odds with the school and feeling they have to fight for what should be their children's by right; conflict in place of trust." [DPO/009 INQ000643646/2] This in turn led to Ofsted's SEN and disability review in 2010, which found similar concerns of parents having to fight for the rights of their children. The report noted that it was not enough for pupils to have a statement of special educational needs (the precursor to Education Health and Care Plans) because having one did not mean that pupils' needs were being met.
- 13. Although the Children and Families Act 2014 placed new duties on local services in relation to children with SEND, this did not result in significant improvements to the system by the start of the Covid-19 pandemic [DPO/010 INQ000621278]. Several inquiries and reviews have reported on significant failings in the SEN system, both in identifying children with SEND and then providing support. It is the DPO's experience that this was the situation that existed on the eve of the pandemic. The system still required warrior parents, children and young people themselves to fight for the support they were entitled to receive.
- 14. The 2014 Act provided, amongst other things, for Education Health and Care Plans ('EHC plans'). A child or young person should be issued an EHC plan where the special

² Note this figure only includes those in government maintained schools and incorporates the Welsh Government's categories of both children with Additional Learning Needs and children with Special Educational Needs

³ Note this figure represents those with Additional Learning Support Needs

educational provision they require is more than can be reasonably provided from within the normally available resources of a mainstream school. Where a child has an EHC plan, this will specify, amongst other things, the special educational provision they require to meet their needs. This can specify, for example, that particular teaching strategies will be used, that they will receive support from a teaching assistant, that they will receive specialist therapies such as speech and language therapy and/or occupational therapy, or they will attend social skills groups etc. Under the 2014 Act, a local authority who maintains a child's EHC plan has an obligation to secure the special educational provision specified in that child's plan. In this way, EHC plans are the mechanism through which Disabled children and young people with special educational secure support, where there needs cannot be met from within the normal resources of a mainstream school.

- 15. In January 2020 there were 294,800 pupils with an EHC plan in England representing 3.3% of all pupils. There were a further 1,079,000 pupils with SEN support without an EHC plan, representing 12.1% of all pupils [DPO/011 INQ000643653]. Although it is understood that not all children with SEN would require an EHC plan, the DPO are nonetheless concerned that the large numbers of children with SEN supported but not provided with an EHC plan were a result of the issues highlighted in reports set out below.
- 16. The Local Government & Social Care Ombudsman's report 'Not going to plan?' published in October 2019 found serious failings by local authorities in relation to EHC plans. The Ombudsman had received 45% more complaints concerning EHC plans in 2018-19 than 2016-17. Shockingly, nearly 9 out of 10 complaints were upheld, which was described as "exceptional and unprecedented in our work", as in other areas the uphold rate was under 60%. The complaints painted "a picture of a system beset with serious problems" including severe delays, poor planning and anticipation of needs, poor communication, and inadequate partnership working between education, health and social services. It was "not uncommon to hear the SEND process described as a battleground".
- 17. The report also detailed upheld complaints where the council did not react to a request for an EHC assessment or introduced unnecessary additional requirements before an assessment was triggered, a form of 'gatekeeping' of access to support. Even when those assessments took place, there were failures to obtain all the necessary specialist advice, for example advice from an educational psychologist, a failure to cooperate with

health and social care services, and failures to involve young people themselves. These failures could result in poor quality EHC plans. the whole process for the request of an EHC plan assessment to the issuing of a final plan should take a maximum of 20 weeks. That is a statutory limit, however, the report noted there were regularly delays of over a year and in some cases up to 90 weeks. During this time, children and young people could be left without the special educational provision they needed. There were also instances of severe delays in the annual review of EHC plans. Annual reviews are a statutory requirement and are essential to ensure that a child or young person's plan remains up to date. Again, without timely reviews, a child can be left without the support they need [DPO/012 INQ000643648].

- The DPO are aware that the House of Commons Education Committee also published a report on SEND in October 2019 [DPO/013 INQ000643649] as did the Committee of Public Accounts in April 2020 [DPO/014 INQ000643650].
- 19. Faced with these failures in the support system, it was often necessary for parents and young people to 'fight' for the right support by appealing to the First-tier Tribunal (Special Educational Needs and Disability). Amongst other things, it is possible to appeal where a local authority refuses to carry out an EHC assessment or to issue a plan, or where the content of the EHC plan is disputed, for example, where there is a disagreement about how much support is required to meet a child's needs. In September 2018 August 2019, of more than 2,500 appeals to the First-tier Tribunal (SEND), over 90% were determined in favour of the appellant [DPO/015 INQ000643651].
- 20. Unfortunately, even once an EHC plan is secured that specifies the support a child is entitled to, that does not mean the battle is over. In 2020 the Council for Disabled Children carried out a survey of nine leading claimant SEND law firms and organisations. They found that between March 2019 March 2020 around 370 pre-action letters had been sent to local authorities challenging their failure to secure provision for a child in accordance with their EHC plan, or in respect of other EHC-plan related failings (such as breach of statutory time limits). In over 95% of cases where a pre-action letter was sent, the local authority agreed to take the actions sought either in full (91%) or part (5%). However, during the same period, the firms and organisations reported that thousands of parents had approached them for support who could not be assisted, because of a lack of capacity or funding [DPO/016 INQ000643652].

- 21. The pre-pandemic position in Northern Ireland was captured by a report published by the Northern Ireland Commissioner for Children and Young People in March 2020, which sadly portrayed a similar situation. In a survey conducted as part of that report, only 1 in 8 respondents felt that there were adequate facilities and services to meet the needs of all children and young people with SEND and less than 1 in 5 believed that the SEND process was child-centred. Respondents highlighted that children were waiting long periods for their learning to be assessed and to receive the support that they needed and that this was having a negative impact on their academic progress. An Educational Psychologist also noted the social and emotional development challenges faced by children who had seen their statutory assessment delayed [DPO/017 INQ000641959].
- 22. The reports above demonstrate that even before the pandemic, many children and young people with SEND were not receiving the support they needed and were entitled to, and the SEND system was under considerable strain. The Local Government & Social Care Ombudsman concluded that his 2019 investigations suggested "a system in crisis".

Impact of government decision making during the pandemic on education

23. It is the experience of the DPO, through our engagement with Disabled families, and young people, that the four UK nations were simply not prepared for the decision to close schools in March 2020. We are therefore not surprised that both the former Prime Minister and former Minister for Education have already provided evidence to the Inquiry to that effect.⁴ The DPO are concerned that there was no adequate pre-pandemic plan should schools be required to close for a significant period of time and this resulted in decisions being rushed without appropriate equality impact assessments and consultation taking place. It was not unforeseeable that a national crisis would require the closure of schools and yet the overwhelming experiences we have heard are of a disjointed system in each nation. This resulted in approaches, guidance and materials provided differing from local authority to local authority and, in many cases, from school to school.

Guidance

24. The experience of one of the trustees of DR UK who has a Disabled son, was that the

Williamson Witness Statement [M2/INQ000268013/10] and Johnson [M2/T32/168/20-169/24]

guidance around education was a 'minefield'. Although the guidance was particularly difficult to navigate in the early months of the pandemic, these difficulties persisted throughout. Government briefings would only talk about children in general and not specifically Disabled or even 'vulnerable' children. Even communications around decisions later in the pandemic brought challenges. For example, when it came to school returns in England, the Government mandated school returns before under 12s could receive a vaccine, meaning the parents of those who were clinically vulnerable and under 12 faced a difficult choice of whether to return their child to school. The lack of clarity in respect of Disabled children led to different areas taking different approaches and only increased the stress on parents and children in an already challenging period.

25. In Northern Ireland the National Children's Bureau described how schools developed their own approach to communication with parents, with some sending regular emails, others telephoning parents and others using platforms such as Zoom to provide updates. Although these were appreciated when they happened, other parents described that communications were limited or non-existent [DPO/018 INQ000643655].

'Vulnerable children'

- 26. One key aspect of the decision to close schools that the DPO are keen to understand and examine the full rationale behind, was the definition of 'vulnerable children' who were allowed to continue to attend school. Of particular concern is that, in England, this category did not include the almost 1.1 million children who received SEND support but did not have an EHC plan [DPO/010 INQ000621278]. As noted above, there were well documented deficiencies with the EHC plan system. Therefore, the Government should have been aware that this was unlikely to be a suitable definition to use. It did not account for the individuals who were eligible for EHC plans but were facing delays in assessment or finalisation of a plan. Nor did it account for individuals who had been inappropriately rejected by a system that was often putting the onus on parents to challenge decisions.
- 27. In Northern Ireland, 'vulnerable children' encompassed students with statements of special educational needs, which roughly appear to be the equivalent to EHC plans in England [DPO/019 INQ000643656]. There were concerns that special schools were often too quick to close across the country often before mainstream schools [DPO/020 INQ000643657]. This would mean that even if Disabled children were eligible to attend

- schools, they would often need to go to a different school, if one could be found, where they would not receive the educational support they required.
- 28. The DPO were also troubled by the fact that even those who had EHC plans and were therefore entitled to attend school were, in large part, not doing so. One study found that only 6% of children with EHC plans attended school on average from the start of the first lockdown to the end of May 2020 [DPO/021 INQ000231345/8]. One reason for this low figure is likely that schools were failing to involve parents in risk assessments or even conduct them at all. Schools were asked to conduct risk assessments with parents to determine whether it was safer for a child with an EHC plan to be at school or at home but 75% of parents in one survey said those risk assessments did not take place or they were not aware if one had happened. A further 9% said that where the assessment had taken place they were not fully involved [DPO/022 INQ000643659/8].
- 29. In general, whether or not affected by the definition of 'vulnerable children', Ofsted and CQC inspections confirmed that children and young people with SEND were less likely to attend their schools and colleges compared to their peers. A Family Fund survey in 2021 revealed that only 3 in 10 Disabled children attended school between March 2020 and the end of the school year. By January 2021 that figure had only increased to 4 in 10 [DPO/023 INQ000618444/21]. In Scotland, it was reported that only 1% of all children attended the 'hub schools' which remained open and the majority of those attendees were children of key workers rather than those with Additional Support Needs and/or Disabilities ('ASND') [DPO/024 INQ000643661/6].
- 30. The decisions around the closure of schools ought to have also considered the need to continue to provide accessible school transport to those who were permitted to attend school. In Northern Ireland, the Children's Law Centre ('CLC') successfully brought judicial review proceedings on behalf of two Disabled children. One of the children was unable to attend specialist education placements in person for all but one day of nursery and the entirety of the P1 and P2 academic years. CLC successfully argued that prolonged and disproportionate Covid-19 restrictions on school transport for reasons related to disability were unjustifiable and unlawful. The Education Authority accepted that they had breached the children's rights in both cases, as there was an interference with their access to education on the basis of their medical condition, contrary to Article 14 (prohibition of discrimination) in connection with Article 2 of Protocol 1 (right to education) of the European Convention of Human Rights [DPO/025 INQ000483305].

31. The importance of correctly defining the category of children who should continue to attend school during a crisis and then supporting them to do so, is emphasised by the numerous negative impacts of not attending school on a child and their family. From an educational perspective, a study by University College London found that being absent for eight days would move a pupil one place down in a ranking of 100 pupils by achievement [DPO/026 INQ000588297]. Absence from school also impacts children and young people's social development and emotional and mental wellbeing. It ought to have been foreseeable that many of the impacts of being unable to attend school would have been disproportionately felt by Disabled children and young people. Of course, there would have been situations where it was not in the child's best interests to attend school in-person but in light of the effect it could have on their education, such situations needed to be identified carefully.

Inaccessible materials

- 32. Many Disabled children and young people were disproportionately impacted by school closures because of the inaccessibility of materials and resources that were provided to students to continue their education at home. In some cases, no materials were provided to Disabled pupils at all. Again, a lack of guidance and joined up approach inevitably resulted in different schools taking different approaches to this issue and, as is sadly common, it was Disabled children and young people who fell through the cracks. Parents of children with SEND have described to the DPO how often generic materials were universally sent out to all students with no tailoring for a child's individual learning requirements. Instead, it was left to parents, many of whom were already managing jobs and increased caring responsibilities, to not only take on teaching roles but to try to adapt materials to meet their children's needs.
- 33. A survey conducted by the Alliance for Inclusive Education ('ALLFIE') in April 2020, found that over 8 in 10 parents were expected to home school their Disabled children but over half of parents had not received any support from either the local authority or school to help with home schooling. A further third of parents said they had received some support but it was not sufficient [DPO/027 INQ000643664]. These results aligned with a survey conducted by the Special Educational Needs Jungle in July 2020 which found that fewer than one in four parents of children with SEND said that the schoolwork sent home had been tailored to their children's needs [DPO/022 INQ000643659]. One academic article by Shakespeare et al, described how the failure to provide accessible

- and appropriate learning materials to children with SEND was a result of Disabled people being "an afterthought in the response to COVID-19." [DPO/028 INQ000361827]
- 34. Relying on parental carers to home school children also increased the influence of socioeconomic factors on a child's education. For example, if a child lives in a home where
 all parental carers are in full-time employment they are less likely to receive one-to-one
 support. Further, those from lower income families are less likely to have access to digital
 devices and internet services to complete online learning. Sadly, poverty rates have
 been on average 11% higher for families with a Disabled member compared to nondisabled families across the past two decades [DPO/023 INQ000618444/44] and on the
 eve of the pandemic, nearly half of all individuals living in poverty in the UK were either
 disabled or lived with a Disabled person [DPO/029 INQ000509880]. This disadvantage
 was exacerbated by parental carers having to give up working hours due to caring
 responsibilities [DPO/030 INQ000224594/2]. Even when there were schemes in place
 to provide digital devices, organisations such as the Equality and Human Rights
 Commission ('EHRC') were concerned that their eligibility criteria were too narrow
 [DPO/031 INQ000185286].
- 35. Examples of the accessible learning materials that should have been provided include visual materials for autistic children, materials in braille for children with severe visual impairments, or audio versions of content for d/Deaf children. If these are not provided, they are either not possible to create in a home environment or are very expensive to do so, requiring for example, specific technical software or printers and laminators. Again, this highlights the role socio-economic factors play in a child's education when there is not adequate provision for their needs from the state. At the very least adapting materials requires considerable time and also expertise. For example, it is common for children with an EHC Plan to have specified in their plan the ways in which the curriculum should be differentiated and individualised to meet their particular cognitive and learning needs. Some children's EHC Plans also specify that they need support from educational professionals with specialist training, or access to specialised educational resources or programmes, recognising the expertise required to provide the right support. The additional challenges of home schooling faced by families with Disabled children understandably contributed to stress and impacted family relationships.

Attending school

36. Even for children who were able to continue attending schools, there was often a

reduction in the special educational services provided. This was caused by reduced staffing numbers meaning a child may not be assisted by their usual trained teachers and assistants or may not receive the small group or one-to-one support which they require. The impact of easements in legal duties owed to children with SEND is discussed further below. Further, as previously discussed, there were reports in Northern Ireland of special schools and Further Education Colleges being quick to close and or operating on reduced hours. Some mainstream schools only offered supervision, not actual teaching [DPO/018 INQ000643655/8]. Simply attending schools did not necessarily mean that a child's needs were being met. For some children, attending school without the support they need means they are being provided with only a limited opportunity to learn. This can even be counterproductive, causing distress and damaging self-esteem. In some instances, children with SEND without adequate support experience school-based trauma with a knock-on effect for their future ability to access education. The DPO are concerned that decisions about school closure and re-opening were taken too reactively without proper consultation and consideration of the needs of Disabled children and young people, including the diversity of those needs.

- 37. The imposition of infection prevention and control measures also had a larger impact on Disabled children and young people compared to their peers. For example, many children with SEND require one-to-one support to help them access learning and regulate behaviours and may require close contact. Other Disabled students, such as autistic children, are more likely to touch and come into contact with different surfaces and were unable to independently employ the personal hygiene measures, including social distancing, advised during the pandemic [DPO/032 INQ000643669/18-19]. This left parents with the difficult decision on whether to send their children back to school to support their educational needs knowing the added health risks that such a decision brought. Those risks were not just for the child themselves but the whole family unit back home and the difficult decisions were exacerbated by a real lack of guidance, information and support for families in weighing the competing risks.
- 38. Even when families took a decision about what was in a Disabled child's best interests, they were not always supported. The DPO are aware of instances of parents of Disabled children deciding to keep children home, either before schools formally closed, or after they reopened, and being threatened with non-attendance action. At the other end of the spectrum, the DPO are aware of cases where families wanted their Disabled child to attend school and they were permitted to do so under government policy at the time, but this was not facilitated because of a school's risk assessment, which was not shared.

- 39. Requirements around PPE, not only presented challenges for schools in sourcing adequate supplies before they could admit students but also affected the learning experience itself. Some Disabled children rely on lip reading or facial expressions to help understand communications and face masks presented a barrier for them. Particularly in mainstream schools, if a teacher was trying to cater for the needs of a number of pupils there could be occasions where they had to choose between the educational support needs of a Disabled child and the health risks. This could lead to situations where the Disabled child felt stigmatised or their parents felt they would be unable to attend school at all. Other Disabled children and young people with complex health needs required support from staff with enhanced and fit-tested PPE and delays in access to such PPE meant delays in children returning to school.
- 40. Regardless of whether children with SEND attended school, the pandemic brought disruption to routine. Many children with SEND, particularly autistic children, find routine and consistency helpful to their learning. The constant changing of environments, teachers and materials during the pandemic had a negative impact not only on their education but also on their behavioural and social development [DPO/023 INQ000618444/21]. Indeed, for some children, unexpected changes in routine can lead to significant dysregulation and distress, sometimes resulting in behaviour that challenges. The Challenging Behaviour Foundation, a charity that specifically focusses on the needs of children, young people and adults with learning disabilities whose behaviour challenges, described how families were reporting that visiting restrictions, including blanket restrictions, on residential schools and supported living services had a significantly negative impact on their relative's wellbeing. Young people with severe learning disabilities found it difficult to understand why their families were not visiting. There was limited government guidance on these issues leading to different providers taking different approaches on how to balance the human rights of someone with severe learning disabilities whose behaviour challenges with public health measures. Sadly, many families felt that it took their relative reaching a crisis point or a safeguarding alert being raised before best interest meetings were held and decisions about family contact were considered [DPO/033 INQ000651203/8]].5

⁵ See in particular the case study of 'Craig' provided in the Challenging Behaviour Foundation's December 2021 Information Sheet [DPO/033] INQ000651203/8 for an example of these issues at a personal level.

- 41. The negative impact of all this disruption was aggravated by the suspension or reduction in emotional and behavioural support services, and other specialist therapies, which are often provided through schools, during the pandemic. Schools go beyond merely providing education, they play a vital role in supporting families with children with SEND, as well as supporting referrals to further social and health care services. We will discuss the impact on health and social care services more below.
- 42. When schools re-opened, which predominantly happened in September 2020, many parents felt that 'catch-up' measures were insufficient as education and support was still being affected by the issues with infection prevention and control measures, staff shortages and pre-existing issues with the SEND system as described at paragraphs 11-22 above. This issue had been pre-warned by a number of organisations, including Special Needs Jungle, in a letter to the Parliamentary Under Secretary of State for Children and Families, on 29 May 2020 [DPO/034 INQ000643670]. That letter raised concerns that decision making around the return of schools in September was overlooking how the needs of children with SEND would be met. The signatories stressed that the plan for school returns needed to "focus on promoting wellbeing, securing missing therapies and individual planning for all pupils with SEND" and that the review of SEND needed to "come out of cold storage" because "nothing short of an overarching re-design of many aspects of the system is enough to address the gross inequalities in educational entitlement faced by many children and young people with SEND." Sadly, it was the DPO's experience that these concerns were not addressed and little catch-up support was provided to children with SEND. They were again disproportionately disadvantaged; trying to recover from the impact of the pandemic and lost educational opportunities without the additional support they needed to do so.
- 43. As to pupil progression and grades, the solution commonly adopted by schools, and education boards more widely, was to provide grades and approve progression based on teacher predictions from earlier in the year. Although these were appreciated as a measure to ensure students did not lose out on qualifications, they did not compensate for the lack of underlying learning, as predictions had been made after only part of a course had been taught. Students were expected to progress to the next stage without that learning. This was not just limited to knowledge of specific topics but also included the development of writing, communication, logistics and all other foundational skills. As noted by the EHRC in their letter to Secretary of State for Education on 21 May 2020, the use of predicted grades, if not correctly implemented, also risked deepening existing inequalities for children such as those with SEND who had been disadvantaged prior to

the pandemic [DPO/031 INQ000185286]. Instead, of following this advice, the UK Government initially applied an algorithm to teacher's predicted grades which disproportionately downgraded the grades of children from low socio-economic backgrounds who in turn were more likely to be Disabled [DPO/035] INQ000651204 [].

44. Some families also found that when schools re-opened, they refused to provide the same levels of support. For example, for children and young people with learning disabilities whose behaviour challenges, the disruption caused by initial school closures and then lockdown had negatively impacted their wellbeing. When they had started to adapt this new routine, they were returned to school causing further disruption and an increase in behaviour that challenges. Some schools, who had previously supported children refused to do so when schools re-opened saying they were now 'too challenging to support'. This could consequently lead to other measures being taken for example medication could be started or increased and there remain concerns around the overmedication of people with learning disabilities [DPO/036 INQ000651205]].

EHC plans

- 45. As the name suggests, EHC plans are not only concerned with a child's education, but also health and social care. We will explain below the impact of the pandemic on the provision of health and social care services. As to education, EHC needs assessments, the issuing and reviewing of EHC plans, and the delivery of special educational provision specified in EHC plans were all profoundly impacted by the pandemic. There were even longer delays in EHC plans being issued and reviewed, resulting in delays in identifying the provision a child needed. Even when a plan was in place, individuals did not receive the support they were entitled to.
- 46. In England, 72% of respondents to the Disabled Children's Partnership survey said that their child's EHC plan or SEN Support had been negatively affected by the Covid-19 pandemic. This could be for a number of reasons, such as necessary equipment not being available at home, the reductions in staffing, and the loss of specialist therapies (such as speech and language therapy and occupational therapy). A further 66% of respondents said that they were experiencing delays to the EHC plan assessment process and 43% noted that annual reviews had been delayed or put on hold. Despite the legal deadline for an EHC plan assessment being 20 weeks, 27% of families reported that they had been waiting for more than 6 months [DPO/023 INQ000618444/23].

- 47. The situation was not substantively different in the other UK nations. The Northern Ireland National Children's Bureau reported in June 2021 that prior to the pandemic there had been delays in identifying and providing support to children with SEND and these issues were only exacerbated by the pandemic. In particular, the DPO are aware that educational psychology assessments were paused resulting in long waiting lists. Advice from an educational psychologist is a legally required component of an EHC needs assessment and must be obtained before an EHC plan can be issued.6 Respondents to the National Children's Bureau also highlighted the negative impact of school closures on their children who normally received therapies whilst others stated that it felt like Covid was being used as an excuse by some agencies not to provide services for Disabled children or to limit what was on offer. A practitioner in a voluntary sector organisation which supports children with SEND told the National Children's Bureau, "a statement [of SEN] gives a child an enforceable right to very specific education support that's set out in that statement. And that's not happening for those children who do have very specialist provision set out for them, whether that may be classroom assistants or behaviour support or particularly literacy programmes. Things like that that are actually in their statements that would normally be happening, they are not happening for those children who are in school at the minute. Their statements are just not being implemented at all." [DPO/018 INQ000643655/10, 18, 47] The DPO are aware that the Northern Ireland National Audit Office published an Impact Review of Special Educational Needs in September 2020 [DPO/037 INQ000643671].
- 48. The DPO are particularly concerned that the sudden reduction in support for children with SEND experienced during the pandemic was facilitated and encouraged by easements to core statutory duties. The Coronavirus Act 2020 came into force on 25 March 2020 and enabled the Secretary of State for Education to give notices disapplying or modifying specified statutory duties, including section 42 of the Children and Families Act 2014. Section 42 is the duty requiring local authorities to secure the provision specified in children and young people's EHC plans. For example, where a child's EHC plan states that they require 1 hour of direct speech and language therapy every fortnight, section 42 means that the local authority that maintains their EHC plan "must" secure it for them. The courts have long recognised that this duty is "absolute" and not merely a "best endeavours obligation". Notices issued under the Coronavirus Act 2020

⁶ Reg 6(1)(d) of The Special Educational Needs and Disability Regulations 2014.

⁷ R (N) v North Tyneside Borough Council [2010] EWCA Civ 135, in respect of the predecessor to section 42 Children and Families Act 2014; R (BA) v Nottingham County Council [2021] EWHC 1348 (Admin).

modified this duty so that it was treated as discharged if the local had used "reasonable endeavours" to secure special educational provision. Alternative wording proposed during the legislative process, that local authorities be required to "take all practical steps" to secure special educational provision, was not adopted.

- 49. The Secretary of State for Education issued three notices under the Coronavirus Act for the months of May, June and July 2020, downgrading the section 42 from an absolute duty to one of 'reasonable endeavours'. Similarly, the Special Educational Needs and Disability (Coronavirus)(Amendment) Regulations 2020 came into force on 1 May 2020 and relaxed various time limits for completion of EHC assessments and finalisation of plans, as specified in the Special Educational Needs and Disability Regulations 2014. Where a statutory time limit could not be met because of a reason relating to the incidence or transmission of Covid-19, action should instead be taken as soon as "reasonably practicable." These latter provisions only lapsed on 25 September 2020 approximately one month after children had returned to school for the autumn term [DPO/038] INQ000651206 [/4-5].
- 50. Similar easements were enacted in Northern Ireland and Scotland but not in Wales [DPO/039 INQ000607933/47]. In Northern Ireland the Department of Education reduced the duty on Health and Social Care Trusts regarding the SEN framework to "best endeavours" from 2 April 2020, earlier than in England. In Scotland, directions under the Coronavirus Act 2020 excused local authorities from certain responsibilities for children with Additional Support Needs including duties to make adequate and efficient provision for additional support as well as to meet specific time limits around assessments and placing requests [DPO/040 INQ000643673/8].
- 51. DANI, have had contact with the Children's Law Centre, a charity that works to protect the rights of all children living in Northern Ireland, particularly those who are most disadvantaged including Disabled children and those with special educational needs. The CLC worked throughout the pandemic to support children and their families by providing free advice through their CHALKY phone service. Where appropriate, CLC also assisted children in protecting their rights to education and support by challenging decisions including through legal proceedings where necessary. The CLC therefore have a deep understanding of how the legal support for children with special educational

⁸ Regulation 5 Special Educational Needs and Disability (Coronavirus)(Amendment) Regulations 2020

⁹ The Temporary Modification of Education Duties (No.2) Notice (Northern Ireland) 2020

- needs changed during the pandemic and what impact this had in practice. They have helpfully set this out in a briefing paper which we exhibit at [DPO/041 INQ000651207].
- 52. We would highlight a couple of points from that briefing paper; the first is that it was the CLC's experience that although only certain specified duties were 'eased', public authorities often took this as a general opportunity to reduce rights to assessments, services and support even if a statutory easement did not specifically apply. In a time of disruption when need was greater, statutory easements sent a worrying signal that it was ok to reduce support for some of the most disadvantaged children. The pervasiveness of this message is emphasised by the CLC noting that the replacement duty of 'best endeavours' was arguably a high standard and, indeed, is higher than 'reasonable endeavours' used in England. If fully applied, it would appear to require public authorities and schools to do everything that could possibly be done to meet the needs of Disabled children. However, due to the underlying message of easements, in practice this duty was not sufficiently adhered to or monitored.
- 53. The DPO understand that schools and local authorities faced challenges in adapting to the pandemic, but we are concerned that the application of these easements signalled that it was acceptable to simply stop providing for the needs of Disabled children and young people. As set out above, the system was already struggling pre-pandemic. Even when statutory duties were in force, local authorities were routinely failing to secure special educational provision, and to carry out assessments, issue and review EHC plans within the time limits. Despite this context, instead of seeking to protect children and young people with SEND and their families, who relied on these duties to secure essential support, the respective governments introduced easements which allowed the previously failing protections to be reduced further.
- 54. The EHRC wrote to the UK Secretary of State for Education on 21 May 2020 to notify him that "many children with special educational needs and disabilities (SEND) are now at home without the support they need to access education. This situation is likely to deteriorate following modification of the duties of local authorities and health bodies to secure provision for children with Education, Health and Care Plans." [DPO/031 INQ000185286] The same letter called for effective oversight of the 'reasonable endeavours' being used and ring-fencing part of the funding to local authorities to be specifically applied to support the needs of children with SEND. A group of organisations, including the Special Needs Jungle and The Children's Trust, wrote another letter to the Permanent Under Secretary of State for Children and Families just

over a week later. That letter raised concerns that parents were reporting some local authorities to be making "little or no attempt to engage with them to agree what provision in their child's Education, Health and Care Plan will continue to be made and how and when this will happen" and called for no further amendments to assessment timelines to prevent children and young people who were waiting for a plan from suffering any further disadvantage [DPO/034 INQ000643670].

- 55. Disability Rights UK issued a statement on 1 June 2020 after the Secretary of State for Education issued a further notice to extend the downgrading of duties: "The modifications extension document released over the weekend says in essence, if it's too hard to make the necessary adaptations for children as per their EHC Plans, Local Authorities don't need to bother. The government has, at the drop of a hat, further extended the time disabled families have to endure being in a precarious position by shoving the legal rights of children with SEND to vital adaptations down the list of priorities." [DPO/042 INQ000643675]
- 56. Unsurprisingly, the issues in relation to education identified above, led to a series of criticisms of how children with SEND were considered and treated during the pandemic across the UK. The National Children's Bureau Northern Ireland described how families with Disabled children or those with SEND were the 'forgotten ones' when it came to devising the response to the pandemic [DPO/018 INQ000643655/10]. Scottish academics, Couper-Kenney and Riddell concluded that "scant regard was paid to the rights of children with ASND as education and care services were suddenly withdrawn." [DPO/024 INQ000643661/3]
- 57. To demonstrate the impact at a personal level and to show that the issues set out above existed throughout the UK, I have provided a couple of individual case studies that the DPO are aware of through our members and close associates. DANI have worked closely with Andrew Hamilton, the founder of Just Include, who has previously shared his experiences of the impact of the pandemic in an informal review held by the All-Party Group on Disability. Just Include is a disability non-profit organisation which aims to educate and empower Disabled people to advocate for themselves by creating resources, delivering workshops and engaging with policymakers on key issues facing Disabled people such as legislative protections for accessibility and inclusion in the digital world [DPO/043 INQ000643674].

- 58. When the pandemic hit, Andrew was in secondary education preparing for his GCSEs. When the country went into lockdown and schools were closed, his educational support arrangements fell apart overnight. He was told to continue his learning at home but that meant he no longer had the support of his full-time teaching assistant and the teaching materials that were provided were not modified to his needs. Instead, Andrew had to try to access this material by himself with some support from his parents, who although were either furloughed or working from home, were not trained in providing the necessary specialist support. Their primary role was to be parents to Andrew, not his teaching assistant.
- 59. Andrew was sent many of his teaching materials digitally, but these were inaccessible. Although he was provided with an iPad and laptop to access the curriculum, the elearning software used by schools was not compatible with Andrew's assistive technology and instead this software disabled his assistive technology when he tried to use it. Andrew had numerous meetings raising this issue and ended up spending more time testing different options that did not work than actually completing his coursework. Eventually, Andrew ended up using his own laptop which was compatible with his assistive technology from home, however, this was only possible because Andrew had access to his own personal technology, a privilege that many Disabled young people do not have. It should not have been left to children and young people to both raise and find solutions for such basic accessibility requirements.
- 60. Moving teaching online should have been an opportunity to build in greater accessibility. Sadly, the common (and incorrect) assumption of education boards was that making teaching documents digital would in itself address most accessibility issues. This failed to take into account digital accessibility requirements, for example, ensuring that webpages or documents are compatible with screen readers. The failure of the education system to ensure the digital accessibility of e-learning programmes, and their compatibility with assistive technology, frustratingly persisted and was still unresolved when Andrew left education in May 2024. This demonstrated a lack of urgency to fix issues which disadvantage Disabled young people with SEN and impact their educational opportunities.
- 61. When schools did re-open many of the infection prevention and control measures and guidance was not suitably adapted for Disabled children. For example, Andrew was exempt from wearing PPE, he was not able to tell whether he was 2 metres apart from others and the various social distancing barriers created environmental hazards for him.

Andrew was particularly keen to follow infection prevention guidance as he was considered clinically higher risk, but he was unable to do so because the guidance and environment had not been adapted to his needs. That left him at a particular disadvantage: he needed to go back to school because of the inaccessibility of online learning but also faced higher medical risks and potentially being stigmatised should he return to school. Neither option had been reasonably planned and adapted to meet his needs.

- 62. DR UK are also aware of a Disabled young person, Y, who is a wheelchair user and was at a residential special needs college at the start of the pandemic. He was attending this school, which was far from his family home, on a residential basis because his local school had informed him that they would not be able to meet his needs. Y described how the decision to close schools came suddenly with little opportunity for his school to prepare. Although they were able to remain open for day students, they could not maintain residential placements. Y had to go home and was unable to attend school (even though it was open for day students) because of its distance from his family home. Once at home, Y was not provided with the educational support he needed or tailored materials. He was told not to worry if he was unable to access the materials, because the GCSE's he was studying for at the time would be based on predictions. Although Y was grateful to receive the qualifications based on his previous work, he missed out on learning the topics and skills that others did. Even after Y enrolled in college the problems persisted as his dictation software would not interact with the online resources the college was using, meaning that Y needed someone to type for him, greatly reducing his independence.
- 63. Y's experiences highlight how failures in the system that prevented individuals from accessing the support they needed in their local area before the pandemic had serious consequences during the pandemic itself. Those consequences were not limited to education but also impacted Y's access to the health care needed to manage his condition. Y was registered with a GP close to his residential school who then wished to discharge him when Y moved back home. As Y requires regular prescriptions to manage his condition and GPs in his local area were not taking on new referrals, Y's mother had to argue to convince his GP not to discharge him so that he could continue to access his medication. Thankfully this was eventually accepted but it required Y and his mother to fight for his rights rather than medical practitioners proactively considering and providing for his health needs. We will speak further on the impact of the pandemic on

access to health care below, but this shows how many of these issues are interlinked for individuals.

- 64. In respect of the easement of EHC plan duties, the DPO are aware of a Disabled young person, Amber, who was in her final year of a mainstream secondary school with an EHC plan in place when the pandemic hit. Although there were issues with her EHC plan, Amber and her mother, Deanne, had decided it was easier to try to work with it rather than challenge it. Amber was planning to go to college the following autumn, which was a big step in her education, and had been working hard to be prepared for the transition. In mid-March 2020, due to Amber's health condition, her mother decided it was safest for Amber to complete her learning at home. There was very little guidance to support parents in making this decision and initially Amber's school threatened her with letters stating they would take non-attendance measures before agreeing that it was appropriate for Amber to remain at home to manage her increased health risks. Once Amber was at home, and even after schools were closed, she was simply provided with large textbooks to learn from despite her EHC plan specifying that information needed to be broken down into accessible sections. This material was not tailored for Amber's needs and it was left to her mother to try to adapt it.
- It was always accepted by Amber and her mother that there were some aspects of her EHC plan that could not be provided at home; for example, 1-1 support in lessons and additional support from a teaching assistant when necessary. However, Amber and her mother believed that many aspects of the plan not being delivered to Amber could have been delivered. Further, there were no contingency arrangements or alternatives offered in relation to the special educational provision that could not be delivered. Those parts of the plan were crucial to ensure she did not lose the skills she had already developed and was ready to transition to college. For example, Amber was not provided with access to a laptop and basic skills training and the opportunity to record longer pieces of written work by alternative means. This was provision specified in her EHC Plan which - if modifications were not in force - she would have had an absolute legal entitlement to. Similarly, visual memory exercises and digital games-based spelling and reading programmes were not facilitated. Amber also did not receive tailored advice from Occupational Therapists and Physiotherapists on how programmes could be reasonably implemented at home; all she received was an envelope of papers in the post that set out standard exercises. These were not tailored to Amber nor capable of being completed in her house. As with education materials, it was left to Amber's mother to find alternative ways of securing physical and movement therapy.

- 66. Under the easements to the 2014 Act, the local authority was only required to use 'reasonable endeavours' to meet Amber's EHC plan, however, it was unclear what this meant in practice and Amber and her mother were concerned that the reduced duty had instead been taken as an opportunity to cut her support. Local authorities should have secured all special educational provision in an EHC plan apart from that which it was impossible to deliver to a child's home during the pandemic. Parents understood that the pandemic would bring changes to EHC plans and some aspects may be impossible to deliver but in Amber's, and many other cases, the local authority unnecessarily cut provision.
- 67. Amber and her mother were also concerned about the impact of the changes to the timescales for complying with the EHC annual review process. Amber was in a 'phase transfer' year and her annual review of her EHC plan should have been completed by 31 March 2020 to allow sufficient time to prepare for the next phase of her education. The regulation changes which came into force in May 2020 which relaxed timescales should not have affected children and young people in a phase transfer year, as local authorities ought to have completed reviews for these children already. However, this was not the reality on the ground. Amber's review was delayed and she only received an amended draft plan a month later which, although appreciated, still did not address all of her needs. Amber and her mother were anxious that should they not be able to agree this plan with the local authority they would need to appeal to the First-tier Tribunal and, even if that was successful, the local authority would still not have to comply with the normal strict time limits on complying with Tribunal orders until after 25 September 2020 which would be far too late for Amber in terms of her starting college. Thankfully Amber's amended EHC plan was agreed, but the delays and changes to regulations caused unnecessary anxiety that Amber would not have the support in place to prepare for the next phase of her life and education, putting her at a significant disadvantage.
- 68. Sadly, it is Amber's experience that many of the issues with EHC plans have not improved since the pandemic. After Amber left college no one turned up to complete her annual review and she was floating around the system with an EHC plan but not one thing was being provided through it. Support for individuals transitioning out of education was already poor prior to the pandemic but appears to have worsened. Amber's mother, who also heard about the experiences of other children, young people and their families through her involvement in her local Parent Carer Forum, believes that relaxations to

- duties during the pandemic created an attitude where what is now considered acceptable is worse.
- 69. In relation to the challenges in accessing all support under an EHC plan, the DPO are also aware of a young boy, Liam, who has been diagnosed with Down's Syndrome with associated learning difficulties and was 11 years old in 2020. Liam best communicates non-verbally but this has in no way held him back from forming proper connections and friendships with his peers. He also has low muscle tone meaning that he regularly uses a standing frame and wheelchair. Liam's medical needs are complex and he requires a high level of adult support, however, despite facing medical challenges in the past, including before the pandemic, he has always bounced back. He had an EHC plan dating from 2019 and he attended a community special school at the start of the pandemic.
- 70. When the first lockdown took place, Liam was entitled to attend school (following a risk assessment) as he had an EHC plan in place and his father was a key worker. Despite this, Liam's school required him to be homeschooled by his mother. Liam's mother explained that despite her best-efforts, Liam really struggled to engage with remote education. The family did not have the same levels of tools and equipment to allow him to fully engage, for example, they did not have the switches or an eye gaze to allow Liam to make choices and meet his Speech and Language Therapy ('SALT') needs. Although Liam's mother innovatively adapted the educational and therapeutic programmes that were provided through videos sent home by Liam's school, this was not always possible, for example, because Liam did not have access to outdoor play equipment. Liam's mother was also limited by the fact that she was supporting him on her own and could not complete his rebound therapy and physiotherapy which required at least a second trained person. Even after fighting to have equipment delivered to Liam's home, such as a standing frame, this would often require two people to safely help Liam use the equipment. Due to these challenges, Liam's parents pushed for him to be able to attend school whenever possible so that he could receive face-to-face instruction, which he responded well to, and access a much fuller education.
- 71. In June 2020, Liam's parents wrote to his school asking what plans were in place to allow Liam to attend school again the following month. The response they received was that the school was unable to facilitate Liam's return, a decision apparently based on their risk assessment that he was a student with a complex medical condition. Liam's parents did not receive a copy of that risk assessment nor was any further detail provided

to justify the decision. In September, Liam's parents received two letters from his school; one welcoming students back to school for September but the other explaining that, based on guidance, they were unable to put in place the necessary environment and operational safety measures to safeguard Liam, his peers and staff due to his medical needs. Liam's parents continued to correspond with his school, the local authority and local NHS Trust regarding this decision and this eventually led to Liam being allowed to attend a different special school run by the same provider, albeit this latter school was primarily aimed at younger students. They provided Liam with a timetable to return to school but this contained reduced hours and omitted some of the key provision to meet his educational needs under his EHC plan, for example, there was no rebound therapy or timetabled provision for social interaction. It is important to remember the context that Liam had found himself in, he had been removed from the school he had attended for over 9 years, leaving friends and trusted teachers behind and in his new surroundings he was not scheduled to have activities with other children which he greatly enjoyed.

72. In addition, it was the experience of Liam's parents that his schooling was impacted by strict infection prevention and control measures adopted by his school which went beyond government guidance. There were long delays in getting all the staff that would support Liam, fit-tested for enhanced PPE as required by the school's policy and even after this had taken place, there were days when Liam was unable to attend school because there were no fit-tested members of staff available. In general, throughout their correspondence with the school over attendance and the safety measures required, Liam's parents were frustrated that there was a lack of understanding of what his medical needs actually entailed and consequently how they could be balanced with his educational and social needs. Despite Liam's hospital team confirming in November 2020 that it was appropriate for him to attend school, it was sadly only after a legal challenge was pursued in 2021 that Liam's school improved his access to his entitlements under his EHC plan. In particular, until legal action, Liam had been kept in a room completely separate from all his peers, which was not necessary as an infection prevention and control measure. This meant for almost 7 months, Liam was segregated from other children. Parents should not have had to resort to legal action to see their children included alongside their peers and their needs met.

Higher Education settings

73. Less than a quarter of respondents to a Disabled Students UK survey conducted during the pandemic felt that they received the support they required during the pandemic. For

those who were shielding, that figure was reduced to less than one in seven [DPO/044 INQ000591922/17-18]. These figures show that the systems put in place by decision makers, including governments and higher education institutions themselves failed to meet the needs of Disabled young people.

- 74. One of the major changes that occurred during the pandemic in higher education settings was that teaching moved online. Although this brought benefits for many Disabled young people, for others it brought challenges and some individuals became Disabled under the social model of disability requiring reasonable adjustments when previously they had not. To illustrate this point, over 45% of respondents to the Disabled Students survey felt that online learning was more accessible than on-campus learning, however, a sizeable number (30%) felt it was less accessible.
- 75. Starting with the benefits, online learning can overcome the physical barriers that many Disabled students face. It reduces barriers faced in securing accessible transport and navigating the built environment. Accessible and assistive technology can be built into teaching software or utilised to access digital materials. Lecture recordings could be accessed at a time and pace that worked for Disabled people, which reduced barriers for Disabled people who experience chronic pain or fatigue. It was, however, frustrating that as with the other beneficial changes brought about by the pandemic, for example work from home policies, these changes were only implemented when they were suddenly required by non-disabled people despite DPO requesting them for years.
- 76. The adoption of technology, however, is only beneficial for Disabled people if their needs are considered, the technology is designed (or adapted) with these needs in mind, and training is provided. For example, lecture recordings allowed Disabled people to better manage their conditions by giving them greater independence, but the Disability Rights UK student helpline still received a high volume of calls where universities were delivering live online lectures rather than recordings. Disabled young people aged 16-24 are also less likely to be internet users [DPO/045 INQ000509869] and Disabled people generally are less likely to have digital skills [DPO/046 INQ000620518]. When learning and socialising moved online Disabled young people were starting from a disadvantaged position, underlining the necessity to provide training and resources that disappointingly, in the main, never arrived.
- 77. These issues would have been addressed through direct consultation with Disabled students and their representative organisations. In the Disabled Students UK survey,

only 8% of respondents agreed that their university had prioritised making their courses accessible for Disabled students during the pandemic and only 5% said their universities had proactively consulted Disabled students on how to make sure teaching methods were accessible to them [DPO/044 INQ000591922/19]. By asking students how their needs could be met during the pandemic, workable solutions and adjustments could have been found. Instead, many universities and colleges simply felt that moving learning online would automatically make it accessible. Not only did this fail to account for individual needs and circumstances of students, it also relied on staff to be sufficiently trained and capable of using a variety of technologies to deliver their teaching digitally [DPO/047 INQ000591921/13 §7]. In many cases staff had not received prior training and were not equipped to make this sudden change. This resulted in significant variation in the suitability of resources, including between different classes in the same college. Even where individual staff tried to make new digital materials more accessible to Disabled students, they were not given the time, resources or software to do so.

- 78. This failure to consult Disabled students was not limited to the start of the pandemic but continued throughout. Over 45% of respondents to the Disability Students UK survey who reported accessibility issues said they still had not been addressed one year into the pandemic [DPO/044 INQ000591922]. This is disappointing not only because the lack of reasonable adjustments restricts an individual's ability to participate and learn but also because the administrative and often financial burden of asking for adjustments falls on the individual [DPO/048 INQ000643680/7]. This highlights that, as in all previous stages of education, the systems in higher education relied on individuals and family members to advocate for their rights. The reliance on 'warrior parents' identified by the Lamb Inquiry in 2009, not only persisted in 2020, but also included 'warrior students'. The DPO were not alone in calling for greater consultation, with the Higher Education Commission recommending in October 2020 that higher education providers undertake reviews of Disabled students' access to teaching and learning with Disabled Student representatives [DPO/048 INQ000643680/8-9].
- 79. In 2021, a report commissioned by the Thomas Pocklington Trust into blind and partially sighted student accessibility in further education colleges shockingly found that 8 out of every 10 further education colleges in the UK do not provide accessibility information which is useful for users or meets legal requirements. The report described how many further education college application processes were also not set up to respond to requests from blind and partially sighted students, presenting a barrier for such individuals in accessing further education [DPO/049 INQ000643681/3-4 & 22].

- 80. As well as a failure of consultation, there was also a failure to adequately consider the needs of Disabled students when taking decisions. Higher Education providers must comply with the Public Sector Equality Duty, which requires them to have due regard to the need to eliminate discrimination and advance equality of opportunity for Disabled students. That includes having regard to the need to remove or minimise disadvantages suffered by Disabled students, and to the need to take steps to meet Disabled students' needs that are different from the needs of non-disabled students. One study of 104 Higher Education providers in the period of March-June 2020 found that only 2 had conducted equality impact assessments about the changes to online teaching and only 16% provided new advice regarding remote teaching for Disabled students. The study's authors concluded that "Disabled students' needs appear forgotten" [DPO/050 INQ000651208 /1].
- 81. This failure to conduct equality impact assessments undoubtedly contributed to the application of blanket policies that disproportionately affected Disabled students, without proper regard to their needs. For example, there were reports of universities employing a 'no mask, no entry' policy after classes restarted and failing to provide an exemption for Disabled students who could not wear face masks on medical grounds. Many universities also provided a standard extension to exam timings and coursework deadlines to account for the impact of the pandemic but these were universally applied and no account was taken of the extra time Disabled students may have previously been entitled to [DPO/047 INQ000591921/7 §3].

Health

Physical health

82. As the Covid-19 pandemic was primarily a health pandemic, it was vital that the UK governments provided clear, accessible and prompt information on how to manage the health risks and adhere to non-pharmaceutical interventions. However, over half of the respondents to a Disabled Children's Partnership survey said that government information on Covid-19 was not clear and consistent, and over two thirds said that the information was not relevant to the needs of families with Disabled children [DPO/051 INQ000347077/7]. The DPO have already provided evidence that information about the pandemic provided by national governments was not provided in accessible formats such as braille, easy read and British Sign Language ('BSL'). For example, early UK

Government briefings did not have a BSL interpreter. These failures were replicated at local level and not only signalled a lack of respect and understanding but also caused unnecessary worry as parents and children could see that there was a life-threatening virus but could not access the information on what steps they should be taking to protect themselves.

- 83. In health care settings, services should have been, but often were not, implementing the NHS Accessible Information Standard [DPO/052 INQ000510569]. Although limited in scope to health settings, the NHS Accessible Information Standard Implementation Guidance sets out many good practices that should be applied when engaging with Disabled people, including children and young people, in the consultation, communication and roll-out of all types of policies. Failure to provide clear information not only increased the risk of transmission and direct consequences of contracting the virus but also led to confusion around lockdown measures which greatly impacted Disabled children and young people.
- 84. The Inquiry has already heard evidence from the Children's Commissioner for England, Anne Longfield, that Disabled children and young people "suffered disproportionately due to the lockdowns and other high-level government decisions, which often amplified existing inequalities." 10 Part of this disproportionate impact was caused by Disabled children being more likely to be in poorer socio-economic households and therefore more likely to spend lockdown in poorer quality housing with less space. In their report 'The Longest Lockdown', the Disabled Children's Partnership highlighted that 64% of parents reported that reduction in activity levels had affected their child's health [DPO/053 INQ000643684/7].
- 85. Disabled children and young people were also more likely to be clinically vulnerable to the Covid-19 virus itself. Although the risks of Covid-19 hospital admission and death among children in general were small, the risks for children and young people with learning disabilities were much higher. A study in 2021 found that adults and children with learning disabilities had a 5-fold higher risk of Covid-19 related hospital admission and an 8-fold higher risk of Covid-19 related death compared to people their age without learning disabilities [DPO/054 INQ000643685]. Public Health England research into Covid-19 death rates up to June 2020 uncovered an even starker picture. In every age group the death rates of people with learning disabilities were substantially higher than

¹⁰ Anne Longfield Module 2 Statement [INQ000273750/5 §10]

for the general population. However, for people aged 18 to 34 with learning disabilities the death rate was 30 times higher than the general population in the same age group IDPO/055 INQ000089700/39].

- 86. Despite these known risks, as DPO have previously explained in evidence to the Inquiry, 11 individuals with learning disabilities were originally omitted from the draft vaccine priority groups and when they were added to the priority list, it was only those who were recorded as having a severe and profound learning disability. It then took considerable campaigning and lobbying to encourage governments to, in practice, broaden that eligibility. How a child's learning disability was recorded on GP records was inconsistent and also had a knock-on effect for whether their parent or unpaid carer could access the vaccine as a prioritised carer.
- 87. These issues with the vaccine prioritisation list were a disappointing repetition of the delay in the addition of individuals with Down's Syndrome to the definition of Clinically Extremely Vulnerable ('CEV'). As early as 16 March 2020, individuals with a learning disability were identified as being at an increased risk by the UK CMO [DPO/056 INQ000048143] then throughout the summer and early autumn of 2020 increasing data highlighted the risks for those with learning disabilities, eventually leading to the UK Clinical Review Panel recommending on 30 September 2020 that individuals with Down's Syndrome should be added to the definition of CEV. However, it took a further month before individuals with Down's Syndrome were finally added on 2 November 2020. 12
- 88. Returning to the experiences of Liam, his family have also described the challenges they faced in accessing antivirals for him when he contracted Covid-19 in January 2022. Liam's mother explained how phone calls with 111 and the local children's ward did not result in action being taken and eventually they had to rely on a consultant who knew Liam well and was suitably empowered to deliver antivirals quickly within the relevant timeframe. Liam was fortunate to have these connections, but in a time of high stress and when timing matters, families should not be dependent on 'who they know' and there should be suitable systems in place to provide the treatment they require. Liam's family were also deeply concerned throughout the pandemic that Liam may not be chosen for ventilation, due to his complex medical needs, if his reaction to Covid-19 was life

¹¹ Mallick [M4/INQ000474256/7 §§22-31]

¹² See Module 2 DPO Closing Submissions 15 January 2024, pp19-21 §§30-31

threatening. This was a concern shared by many families as decisions, such as inappropriate DNACPR notices, suggested that medical professionals did not appreciate and understand the quality of life individuals like Liam had and their right to treatment even in a crisis situation.

- 89. As well as the direct harm to health caused by the virus, there was also the indirect impact caused by the reprioritisation and reduction in health care services. For Disabled children and young people, this impact was far broader and often led to a deterioration in pre-existing conditions and late diagnoses. Disabled children and young people who rely on consistent health care services to manage their conditions, often require a multidisciplinary team to address complex needs. In attempting to improve the capacity of the NHS, Trusts reviewed the necessity of services by distinct categories, for example, by particular disease groups. This worryingly resulted in many disability specific health services being closed or reduced during the lockdowns as they were considered 'nonessential', despite the sometimes very serious consequences of this for Disabled children and young people. This led to a reduction in appointments and consequently prescriptions and treatment for many Disabled children and young people. Even when appointments did take place, they were often conducted over the phone or by video call and, especially for children who need greater relationships of trust to explain symptoms, these formats presented barriers to accessing health care. In Northern Ireland, it was reported that children with impairments and pre-existing and life-limiting conditions faced the most disruption to access to health care [DPO/057 INQ000498623/43].
- 90. The reduction in health care services was not the only factor that caused concerns around whether sufficient diagnoses and treatment were being provided for Disabled children and young people. The fear of contracting the virus also led many to avoid using health care services even when they were available. Although the general reduction in visits to emergency departments during the pandemic could to some extent be seen as a positive, as pre-pandemic visits may in some instances have been unnecessary, the DPO are concerned that the number of children presenting to paediatric emergency departments had decreased by more than 30% in March 2020 [DPO/023 INQ000618444]. We are concerned that this figure was in part caused by parents, children and young people choosing not to seek emergency treatment in appropriate circumstances, due to a fear of contracting the virus at hospital.
- 91. In this section it is also important to note the anxiety and worry caused by the inappropriate use of Do Not Attempt Cardiopulmonary Resuscitation ('DNACPR')

notices and the Clinical Frailty Scale. The DPO have provided substantial evidence on these issues in previous Modules. 13 The fact DNACPR notices were incorrectly applied caused distress to both the individual, their family and also the wider public when the issue was reported in the media. This created considerable fear and anxiety as to what would happen if a Disabled child or young person had to access health care. For younger people, who are already more likely to suffer from anxiety, these types of reports could be particularly troubling and impact how they chose to access healthcare. There was particular concern for young people with learning disabilities as the notices appeared to be disproportionately applied to them [DPO/058 INQ000643689]. Such individuals ought to have been reassured that their voices would be heard during the pandemic. Instead, the application of DNACPR notices without consultation made them feel ignored and that their lives were a burden for society and that medical services did not consider it worthwhile to keep them alive. The Care Quality Commission report into DNACPRs recommended that "People must always be at the centre of their care, including advance care planning and DNACPR decisions." [DPO/059 INQ000235492] That approach ought to have been obvious to all medical professionals from the outset of the pandemic.

92. For many Disabled children and young people, schools support their education and their health by providing or hosting therapy services and specialist interventions, including occupational therapy, physiotherapy, speech and language therapy, and emotional wellbeing and mental health support (including support from Emotional Literacy Support Assistants with specialist training). Many schools can provide shared equipment to aid movement, assist with a child's physical development and relieve pain. Schools may also have sensory rooms with specialist equipment, or other equipment, that can be accessed by students to assist them in regulating their sensory systems and to support their wellbeing. Such equipment can often be impractical or impossible to assemble within a family home or is simply not provided. The school day itself also facilitates movement throughout the day which can contribute to physical therapy and also to sensory regulation. When home becomes the setting for education, that movement is limited and socio-economic differences become a determining factor in what physical therapy an individual can receive. Although services have a statutory duty to provide equipment for Disabled children as needs are identified, yet research by Newlife in 2021 found that 68% of families said their child did not have the equipment they needed [DPO/023 INQ000618444/28].

 $^{^{13}}$ See Davies [M6/INQ000520201/23 $\S 68$], Mallick [M6/INQ000520998/40 $\S \S 120$ -125] and Sansome [M6/INQ000520343/35 $\S \S 114$ -116]

- 93. It was not only that necessary equipment was unavailable. A large number of therapists were redeployed during the pandemic due to a reprioritisation of healthcare services. Again, this contributed to a reduction in the provision of therapy to Disabled children. During the first lockdown the Disabled Children's Partnership conducted a survey of Disabled children who had previously accessed therapy through their school. 85% of respondents said they were unable to use physical therapy or physiotherapy, 84% said they were unable to use speech and language therapy and 81% said they were unable to use occupational therapy [DPO/023 INQ000618444/27].
- 94. The impact this reduction in therapy services had on Disabled children and young people should not be underestimated. Without these services a child's development is not only delayed but can decline. Indeed, DPO are aware from a conversation with an organisation working with young children with complex needs that for some, the lack of necessary equipment and therapy during early years means there are now children who cannot walk, where pre-pandemic they would have been expected to attain this milestone after receiving the necessary support. The impact of the reduction of therapies was not only detrimental to physical health, but also to Disabled children and young people's confidence, social skills and mental health. It is disappointing that many of these therapy services have yet to return to pre-pandemic levels.
- 95. Returning to the experiences of Y as set out at paragraphs 62-63 above, another issue that was interlinked with the requirement for him to return home was that he had accessed physiotherapy and movement therapy to manage his condition through his residential school and they had adapted these programmes and equipment to meet his needs. He could no longer continue these programmes when he returned home because he did not have the same space, routine and equipment. For a long period, Y was unable to do anything and he went backwards in terms of his physical ability and his muscles started collapsing, hugely decreasing his movement and independence.
- 96. Y described how the response he received in trying to get support was incredibly poor. He was desperately asking local services to provide support because if his physical ability is not maintained for a period of time, he will lose this ability in the long-term. At first Y relied on a local physiotherapist who assessed his condition with an Occupational Therapist 'as a favour'. However, their opinion was that Y's condition was not as bad as some of the elderly people they worked with so he was not considered a priority. They

simply suggested Y needed to get out more without considering that he was shielding at the time.

- 97. Y was finally able to receive some support through a local consultant who he has known for a long time and who referred him to a separate physio team. Y's ability to access this essential support was as a result of connections he already had and the proactive efforts he made to fight for support. There did not seem to be an overall contingency plan for children and young people who could no longer access therapy. Even with the connections Y had, the support he received was delayed and not as effective, meaning his physical ability greatly declined during the pandemic. Despite now recovering for 2 years, he has yet to get back to his pre pandemic levels of strength and movement.
- 98. In another case study described above of Amber's mother was heavily involved in her local Parent Carers Forum ('PCF'). Through that forum she contacted other families in similar situations to check they were receiving the support they required. The PCF heard how children with behavioural needs were often struggling the most as a result of reduced therapies, resulting in an increase in behavioural challenges. They also heard of families being provided digital resources, but they did not have access to digital devices to use them, such as laptops. Through the PCF they were able to apply for grants and distribute funding to these families to purchase digital devices or fund very practical solutions, for example, trampolines in gardens for physical and/or sensory support. This was a welcome source of support for many families, particularly when local authorities could be restrictive over what direct payments provided by social care could be spent on. In general, the PCF heard of families being exhausted from trying to meet therapy needs, alongside providing homeschooling and tailoring materials (as discussed above), while at the same time there was greatly reduced, if any, access to respite and short break centres.

Mental health

99. In response to the Disabled Children's Partnership's survey 'The Loneliest Lockdown', over 9 out 10 of parents indicated that their child was socially isolated and over 7 in 10 reported that their child was often unhappy, downhearted or tearful [DPO/060 INQ000643691/2-3]. Social isolation and loneliness were nothing new for Disabled children and young people, however, the pandemic compounded these issues. Even before the pandemic, children with SEND were more likely to experience isolation due to a lack of accessible communications, stigma and difficulties accessing social

- opportunities. This could often lead to anxiety around social interactions and low self-esteem. Lockdowns and school closures often only exacerbated these issues as they further reduced the opportunities for these children to engage with friends and the limited mechanisms to do so, such as virtual schooling, were often not adapted to their needs.
- 100. The reduction of therapies discussed at paragraphs 92-94 above not only impacted the physical health of Disabled children and young people but also their mental health. However, what was perhaps just as detrimental was the closure of social clubs and youth work that provide numerous benefits to Disabled Children and Young People. For example, DANI have worked with Mencap NI who support people, including children and young people, with learning disabilities in Northern Ireland. They explained how lockdown measures drastically impacted the youth work programmes they provided. Suddenly those programmes lost all in-person contact and engagement with the young people they were serving. Mencap NI's teams, with very little guidance had to quickly reconfigure those services to make them available online and allow Disabled children and young people to maintain and continue to build social relationships at a time when this was not happening in schools and social clubs. Although adaptations and compromises were found, it was not a replacement for in-person engagement, particularly because children with learning disabilities can struggle to socially interact using digital devices, as it can be harder to read social cues and the software layout can be overwhelming.
- 101. It was also often left to organisations, such as Mencap NI, to facilitate alternatives for Disabled children and young people. This included applying for grants to provide digital devices to individuals to continue interactions with friends, family and youth work. Even if digital devices could be provided, there remained issues when families did not have fast access to the internet. To help get people online and continue contact, the learning disability charity would regularly have phone call check ins.
- 102. Overall, Mencap NI described how practitioners had to be very adaptable to support children whilst trying to keep changes minimal so as not to overwhelm them. They did this with little government support or guidance. Even after the pandemic started to ease, there were challenges reintegrating children into social activities as they had lost confidence and understandably found it hard to express feelings about what had happened during the pandemic. Great care still needs to be taken when asking questions and working with children and young people to recover from trauma caused by the pandemic. Mencap NI are not aware of any national programme to help children

- and young people with learning disabilities recover mentally from the pandemic. They often find it is up to staff at support organisations to identify the support needs of specific children and notify the local education authority rather than the other way around.
- 103. The DPO are aware of reports indicating that some adolescents and children with special educational needs experienced an improvement in emotional difficulties whilst their peers saw a significant deterioration. For some children and young people, they experienced a reduction in anxiety in no longer having to try to access school and other settings, often in circumstances where they were not adequately supported. However, the picture is nuanced. For example, one report which found a reduction in emotional difficulties amongst children with SEN published in June 2020 did not specifically consider feelings of loneliness and isolation [DPO/061 INQ000643692]. Further, the findings of this report were not reflected in a Family Fund survey conducted later in the pandemic in February 2021, which found that 91% of families with a Disabled child or young person had reported the pandemic had negatively impacted their child's behaviour and emotions, up from 72% in March 2020. 87% of families in February 2021 also reported that their Disabled child's mental health had been negatively impacted [DPO/062 INQ000588307/17]. The Challenging Behaviour Foundation, which looked specifically at families with individuals with learning disabilities, reported that families were twice as likely to report negative impacts to mental health and well-being than positive [DPO/063 INQ000643694/6 §2.1].
- 104. It is also worth reflecting that, even for those children who saw a reduction in anxiety when they could stay at home, this could reflect a lack of adequate support prior to the pandemic which impacted their ability to access environments outside the home. Post-pandemic, these children and young people faced the challenges of re-engaging with the outside world and often experienced heightened anxiety and, in some cases, Emotionally Based School Avoidance ('EBSA'), that is, reduced or non-school attendance driven by emotional distress. EBSA has profound long-term consequences for children and young people, resulting in lost education, fewer friendships, increased likelihood of experiencing mental health problems, and poorer employment prospects. One article, published in 2024, describes an upward post-pandemic trend in EBSA, and how the pandemic created a "perfect storm" by amplifying known risk factors for EBSA while simultaneously reducing access to support services [DPO/064 INQ000643695].
- 105. As has been a common theme throughout this statement, the impact on an individual's mental health was tightly linked to socio-economic factors. For children and young

people living in larger houses with more space, more equipment or with more technology that allowed them to communicate with friends, family and support services, the impact on mental health could be mitigated. For those who had a parent guardian who was not reliant on full-time employment, they could actually experience an improvement in mental health as they could have more contact, support and often greater control over their routine [DPO/063 INQ000643694/6 §2.1]. However, relying on already overburdened but supportive parents is not a solution to the mental health challenges of the pandemic. The adverse mental health impacts of the pandemic have been most sustained for children living in families with lower incomes and higher parental stress [DPO/064 INQ000643695/2].

- 106. The nature of an individual's impairment and/or condition could also affect how the pandemic impacted their mental health. A study in Northern Ireland found that children with a physical impairment were at a much higher risk of developing a mental health condition compared to their non-disabled peers [DPO/057 INQ000498623/42]. The impact was also not limited to the young person or child but could affect the whole family unit. Four in five families reported that the pandemic had negatively affected a sibling's mental health and the average mental wellbeing score of parent carers significantly reduced between March 2020 and February 2021 [DPO/062 INQ000588307/19-20]. One respondent to the Greater Manchester Disabled People's Panel's survey described how "I have a disability, plus my son has autism, and with his school closed, I have been having to care for him 24 /7 and meet his support needs at home while his dad works, which has taken a huge physical toll on my physical and mental health. I think it has been overlooked that there are people with multiple disabilities and caring responsibilities in the same family coping without school childcare and support." [DPO/065 INQ000643696/22]
- 107. Both the immediate negative mental health impact of the pandemic and its persistence were contributed to by the reduction in mental health support services. Without sufficient access to these services individuals were unable to address issues at the time and then develop suitable recovery techniques going forwards. The Family Fund survey found that, as with therapy services generally, there was a significant reduction in the support provided by Child and Adolescent Mental Health Services ('CAMHS') during the pandemic. Just over half of respondents said they were no longer receiving any support from CAMHS by February 2021 [DPO/062 INQ000588307/4-5].

- 108. The surveys we have quoted above, clearly indicate that despite this reduction in services there was no reduction in need which instead increased substantially. There is worrying data showing that the number of referrals reduced during lockdowns but would then return at a higher than routine rate when lockdowns ended. Not only did the pandemic inhibit the provision of mental health support it also reduced identification of children and young people as eligible to receive this support in the first place [DPO/023 INQ000618444/41]. The Challenging Behaviour foundation have noted how digital communication made it harder to monitor wellbeing and behaviour particularly as individuals with learning disabilities and autistic people may not feel comfortable or able to act naturally when communicating online and therefore monitoring could rely too heavily on a relative or carer's account [DPO/063 INQ000643694/6 §2.1].
- 109. For the many Disabled children and young people who did experience a deterioration in their mental health, the DPO are concerned this impact will be long-lasting and affect children into adulthood. This is because loneliness and depression can affect a child's confidence and self-esteem which can be slow to rebuild and perpetuate mental health challenges throughout life. It is also noted that young adults, aged 18 to 24, were one of the highest risk population groups for mental health challenges and, in particular, research suggested that youth unemployment has long-term 'scarring' effects on mental health [DPO/066 INQ000643697/13].
- 110. Disabled young people have faced historic and notable barriers to accessing employment including a lack of support to transition from education to the workplace. For example, Access to Work is only available for those who either already have employment or are about to start a new job. Individuals can find themselves excluded from employment because they need support to get a job, but that support is not available until they have one. The pandemic only exacerbated these challenges. It was reported that Disabled young people were more likely to be affected by job losses [DPO/067 INQ000620483/21]. The DPO are also aware of individuals who have 'fallen through the gaps', having lost critical support under the regime applicable to children and young people during the pandemic, which would have helped them prepare for transition into work. Post-pandemic they are no longer eligible for this support because they have 'aged out', but they are simultaneously unable to secure a job and therefore qualify for Access to Work.
- 111. Finally, when considering the impact of the pandemic and, in particular, nonpharmaceutical interventions such as lockdown, an intersectional perspective is

required. I provide two examples here. Disabled children and young people with other protected characteristics, such as being LGBTQ+, faced additional disadvantages that could further negatively affect all aspects of their lives including their mental health. In particular, there is emergent research suggesting a link between gender dysphoria and autism, albeit further research is needed [DPO/068 INQ000643699]. During the pandemic, trans or non-binary Disabled students who faced discrimination at home were in some instances unable to return to their families during lockdowns. When searching for alternative accommodation and financial support, many financial grants were also dependent on how much parents earned with little consideration for children who were not in contact with their parents. For Disabled young women lockdown could bring the benefit of avoiding sexual harassment, which disproportionately impacts Disabled women [DPO/069 INQ000643700]. However, there was then very little support when lockdowns suddenly ended for those who had been sheltered from harassment and, particularly, young women who may be experiencing this for the first time post-pandemic.

Access to and Engagement with Social Care Services

- 112. The starting point for the DPO when considering the impact of the Covid-19 pandemic on access to social care services is the Coronavirus Act 2020. That is because, as with the easements relating to a child's education provision discussed at paragraph 48-55 above, the Act completely changed the landscape of how the social care needs of Disabled children and young people were to be assessed and what they would be entitled to receive. Those rights were downgraded in a time when need was greatest.
- 113. The easements brought in under the Coronavirus Act 2020 removed the requirements on Local Authorities to comply with a number of duties relevant to young people transitioning to adult care and support services. In this respect, local authorities no longer had to comply with the duties in sections 58 and 59 of the Care Act 2014 to carry out an assessment to determine if a person was likely to have continuing needs for care and support after the age of 18 and thus be eligible for adult social care support. ¹⁴ Nor were local authorities required to comply with their duties in sections 2A(2)-(4) and (6) of the Chronically Sick and Disabled Persons Act 1970 and sections 17ZH(2)-(4) and

¹⁴ "Adult" for the purposes of the Care Act 2014 is a person aged 18 or over: see sections 2(8), 80(1) Care Act 2014.

- (6) of the Children's Act 1989, which ensure continuity of children's social care provision during transition to adult services. ¹⁵
- 114. For those young people who were already 18 during the pandemic, they were impacted by the easements to the adult social care regime, including as to assessments, reviews and indeed the downgrading of the core duty under section 18 of the Care Act 2014 to meet a person's eligible needs for care and support. This was replaced by a duty to meet needs if the local authority considered it necessary to do so for the purpose of avoiding a breach of that person's Convention rights, such as articles 3 and 8 of the ECHR.
- 115. Although the DPO understand that only 8 Local Authorities in England officially stated that they invoked Care Act easements, our experience was that care services were reduced across the country regardless of whether they had officially been invoked. This was likely in part because of the message the possibility of easements sent to local authorities; that in a time of crisis it was acceptable to reduce support for those reliant on care services. The possibility of easements also sent a message directly to Disabled young people; that their rights to care were less important, and the services that allowed them to live independent lives were simply a burden that could be cut during a pandemic. For all Disabled people, this not only created anxiety and worry but also actively impacted our physical health and independence. This anxiety was particularly acute for those on the cusp of transitioning to adult services at the age of 18. Even before the pandemic, this process was often fraught and there was often a sharp reduction in services on entry into the adult regime; this was even worse during the pandemic.
- 116. The reduction in care services, whether directly caused by Care Act easements or not, impacted entire families and not only Disabled children and young people. The Left in Lockdown survey of 4000 families in May 2020 reported that all support had stopped since the start of lockdown for over three quarters of respondents. The cessation of these, often essential, services meant it was up to untrained parents and siblings to take on all caring responsibilities. This could involve carrying out procedures, such as using hoists when helping with washing, without the required number of individuals or using inappropriate techniques. Parents responding to the Left in Lockdown report spoke of their "extreme exhaustion, stress and sleepless nights." [DPO/051 INQ000347077/4]

¹⁵ See section 15 and Schedule 12 Coronavirus Act 2020.

- 117. Carers UK reported an increase of 4.5 million new unpaid carers due to the pandemic by October 2020. The impact on them was not only the physical and mental impact brought about by the increase in hours spent caring for friends and family, but also financial. 2.8 million carers were juggling work and care with 9% of carers having to give up paid employment altogether and a further 11% having to reduce their hours [DPO/070 INQ000239445]. Such a financial impact would have had consequences for Disabled children and young people within families, perpetuating the socio-economic issues discussed throughout this statement. 17% of parents taking part in the Disabled Children's Partnership survey said they had relied on food banks during the first year of the pandemic [DPO/023 INQ000618444/45].
- 118. As well as taking on these new caring responsibilities, unpaid carers also experienced the closure of respite and day care centres, meaning they were providing longer periods of care with no breaks. Such respite opportunities are not simply a luxury but are essential even outside of a pandemic, they enable carers to provide high quality care by affording them opportunities to recover and their closure was especially impactful considering the cessation occurred at the same time as school closures so that many carers had no break at all. This could impact both sides of the caring relationship and the DPO have heard how young people felt guilty and sorry that their parents had to care for them with no respite. The Disabled Children's Partnership found that, of families previously accessing respite services, 85% of those previously accessing residential stays no longer could, that figure stood at 80% for short breaks away from home, 74% for short breaks within the home, and 70% for overnight short breaks [DPO/023 INQ000618444/31]. The DPO, through our members, heard that the closure of such services was often sudden with little opportunity for consultation on what alternative measures could have been adopted to continue to provide children, young people and their carers with much needed respite.
- 119. Many families with Disabled children and young people use personal assistants to manage caring duties. Such personal assistants come into family homes and meet the care needs of children so that parent guardians and the child themselves can maintain greater levels of independence. This can be particularly important for young people, who understandably do not wish sometimes intimate support needs to be met by their parents. As with other aspects of social care, access to personal assistants reduced during the pandemic with reports by January 2021 noting that almost half of families previously accessing a personal assistant no longer could. Further, over half of families receiving domiciliary support of some sort no longer could [DPO/023]

INQ000618444/30]. Again, this left parent guardians with very limited support to manage the care needs of their children.

- 120. Direct payments are a budget provided by local authorities to families and individuals to cover some or all of the costs of their care. Such direct payments allow families and Disabled young people to have greater autonomy in managing care needs in a way that suits them. The DPO have spoken in previous Modules about the challenges recipients of direct payments faced during the pandemic. 16 For this Module, it is necessary to reiterate the importance of enabling the flexible use of direct payments to meet care needs. DR UK's helpline received accounts of local authorities rigidly enforcing what specific services and equipment direct payments could be used for, despite these services and equipment not being available or suitable during the pandemic. This issue was not only limited to direct payments. The DPO have heard that local authorities could also be restrictive over how grants for early help services, previously provided to charities and DPO to distribute, could be used. In general, there was increased flexibility, however, this often took considerable time to secure and practices were highly inconsistent across the country. The DPO consider the failure to ensure quick and consistent flexible practices in the use of direct payments was a significant missed opportunity, which prevented steps being taken to continue meeting the needs of Disabled children and young people during the pandemic, or at least to mitigate the impact of the pandemic on them so far as possible.
- 121. An example of the benefits of the flexible use of direct payments and grants was when DR UK's advisers were able to advise callers that they could seek agreement from their local authority to use the 'socialising element' of their direct payments to purchase digital devices such as tablets and laptops when other opportunities for social contact were not possible. These devices were a vital lifeline to aid social contact for those who were otherwise isolated. DR UK also had contact with West of England Centre for Inclusive Living ('WECIL'), who worked with a young individual with mosaic Down's Syndrome. When he was no longer able to access a personal assistant, he innovatively chose to use his payments to buy technology that allowed him to meet his social needs through online communications. He continues to have his social needs met through that technology and as a result he no longer requires the same number of care hours as before the pandemic and has consequently agreed to reduce his direct payments. This

¹⁶ See Davies [M6/INQ000520201/10 §26], Mallick [M6/INQ000520998/10 §§29-39], Sansome [M6/INQ000520343/20 §§64], and Nafeh [M6/INQ000587595]

is an important example of a Disabled person knowing how to use their direct payments in a cost-efficient manner to manage their own care.

Identifying and monitoring safeguarding risks

- 122. The DPO are concerned that the reduction in care services, school closures and staff absences led to a situation where safeguarding risks were not efficiently identified and acted upon. It has long been reported that Disabled children and young people are at an increased risk of being abused compared to their peers and, worryingly, even outside of a pandemic, professionals can have difficulty identifying safeguarding concerns for Disabled children [DPO/071 INQ000643702]. During the pandemic, children and young people were spending more time at home or in care settings with fewer services, teachers and care workers monitoring their wellbeing. For some children, lockdown measures essentially meant their residential placements became *de facto* 'closed settings', with all the attendant safeguarding risks this can entail when there is limited oversight. The DPO are keen to understand what steps were taken to ensure the safety of Disabled children and young people during the pandemic.
- 123. The safeguarding challenges were not assisted by confusion caused by the use of the word 'vulnerable' during the pandemic to refer to clinical risk of contracting the virus when previously it had been used to refer to protection needs [DPO/072 INQ000643703]. The reduction in staff may also have contributed to reports of inappropriate restraints of autistic children and children with learning disabilities [DPO/073 INQ000651209 /6-7]. Physical and chemical restraints may also have been used on children at home by medical practitioners who felt they had no other option due to limited capacity. Such techniques would be used during episodes of behaviour that challenges (which might be self-injurious or risk harm to others) which was caused by distress when routines were disrupted and families were deprived of necessary support and respite. The potentially long-lasting mental impact of such restraint must not be underestimated as it can trigger memories of past trauma, lead to frustration and challenging behaviour and considerably damage therapeutic relationships [DPO/074 INQ000643704].

Shielding

124. Many of the issues described above were heightened for shielding Disabled children and young people or for those who shared a household with someone who was

shielding. Children who were classed as clinically extremely vulnerable were required to shield and usually unable to attend school. This is despite the fact that 78% of families who took part in the Disabled Children's Partnership's parent panel and who had a child shielding reported that their child had an EHC plan and a further 4% reported they were in the process of applying for one. Sadly, but unsurprisingly only 14% of those with an EHC plan reported receiving all of the provision in the plan. 21% reported they were not getting any of the specified provision at all [DPO/023 INQ000618444/28-29].

- 125. As with non-shielding Disabled children and young people, being unable to attend school affected shielding individuals' access to therapies but for the latter group the impact was amplified. The Disabled Children's Partnership's parents panel found that shielding families had reduced access to all types of support previously provided via educational placements apart from occupational therapy (which was comparable) when compared to families not shielding. The percentage of respondents accessing hydrotherapy (10%), play therapy (16%) and talking therapies (19%) remained at particularly low levels of pre-pandemic access even into Lockdown 3 [DPO/023 INQ000618444/28-29].
- 126. Although legitimately aimed at addressing health risks, the shielding guidance restricted access to all aspects of life for those it applied to and the DPO are concerned that there were insufficient measures to mitigate that impact. Shielding led to increased levels of isolation and when coupled with the challenges Disabled children and young people faced in accessing technology, this likely led to increased levels of loneliness. Managing such health risks also brought stress and anxiety, further contributing to poor mental health and challenging behaviour [DPO/060 INQ000643691/6]. There was also a lack of guidance for children and young people with increased health risks, whether shielding or not, whose parent guardians were key workers and therefore exposing themselves to the risks that their children were trying to shield from. In some instances, individuals were shielding within the family home, so that they were not only isolated from the outside world, but isolated from their family in order to manage the risk to their health.

Criminal Justice System

127. Recent evidence estimates that 70-90% of children in the justice system have some form of SEND [DPO/075 INQ000643705/3]. This huge over-representation existed prior to the pandemic and figures for 2019/2020 show that 80% of children in England that had been cautioned for any offence had been recorded as having SEND [DPO/076 INQ000643706]. Put simply the Criminal Justice System that entered the pandemic was

drastically failing to meet the needs of Disabled children and young people. The DPO are also deeply concerned that issues with the way children with SEND were, and continue to be, policed results in a disproportionate number entering the criminal justice system in the first place. Once they enter the system it presents barriers around understanding, communication and decision making without the adequate support for Disabled children and young people to fully participate.

- 128. Starting with policing, the DPO are concerned that there was, and remains, a lack of training around SEND within police forces and, consequently, needs are not being identified and catered for when communicating and using force on children and young people. The role of intersectionality in this context must also be considered with research indicating that children from Black Caribbean and Mixed White backgrounds are significantly over-represented among children with identified social, emotional and mental health needs [DPO/075 INQ000643705/9] and in 2019 it was found that Black children were over four times more likely than White children to be arrested [DPO/077 INQ000643707/6].
- 129. For Disabled children and young people in the criminal justice system, the DPO are concerned that, as with education and social care, the reprioritisation of resources and a lack of capacity to manage pandemic arrangements such as infection, prevention and control measures led to a reduction in the access of detainees to entitlements such as education and recreation. Dr Bateman's report 'The State of Youth Justice' published in 2020 found that the impact of the pandemic included that "Education has been severely restricted. An inspection of three YOIs confirmed that in two of them, children's educational activities were limited to worksheets in their cells" and that "The STC [Secure Training Centres] rules have also been amended to reduce the minimum amount of time a child must be out of their room in each 24-hour period from 14 hours to just 1.5 hours." [DPO/078 INQ000643708/118-119] Clearly, Disabled children and young people, who are more likely to have educational needs and require physical therapy to manage conditions, would be disproportionately impacted by these measures.
- 130. Research completed by the Howard League for Penal Reform and the Independent Provider of Special Educational Advice in 2022 highlights the dire state of support for Disabled young people in the criminal justice system. They found that the special educational needs of children in custody, including learning difficulties, speech language and communication difficulties, and social emotional and mental health problems, are

"often mislabelled, unrecognised and unmet". Further, many children in custody who need an EHC plan do not have them, or if they do, they are poor quality and the support specified in them is often not provided. Despite this, young people and their parents in custody rarely have access to the legal means of challenging these failings. The law and practice around education in custody for children, including those with SEN, is not equivalent to that in the community [DPO/079 INQ000643709].

Access to and use of the internet, social media and online resources

- 131. We have set out at paragraphs 74-76 above, how the provision of education often moved online and the impact that had on Disabled children and young people. Although there were government programmes to provide devices, grants often only went as far as to purchase the devices themselves. This did not resolve difficulties faced by Disabled families in terms of internet connectivity and digital literacy. Nor did it ensure provision of necessary adaptations, whether that be the provision of protective covers that may be required for the safe use of technology by Disabled children and to prevent damage, assistive technology such as specialist software or hardware (such as 'switches'), or even training in the use of accessibility features that are increasingly incorporated into standard software and platforms.
- 132. Outside of school, socialising also became digital with clubs and general friendship interactions moving online. Although this was better than nothing, it was not the same as in-person interaction. Children with learning disabilities can take longer to adapt to interacting digitally and the different social skills it requires, if they are able to access digital interactions at all. There was also a high degree of multi-tasking required with online conferencing and education, requiring multiple facilities to be used such as video, audio, digital whiteboard, chat functions and polls. This could be overwhelming for some Disabled children and young people and contribute to stress that was only enhanced by the number of different platforms that needed to be used. As above, barriers such as the accessibility of design, support within the household and connectivity challenges were often not considered [DPO/080 INQ000643710]. Families who are digitally disadvantaged find themselves in a vicious cycle of stress due to the consequent detrimental impact on education and socialising. Instead of the general position that technology was always beneficial, there needed to be greater realisation that, for Disabled children and young people, it brought both opportunities and difficulties.

133. The DPO are also concerned that certain Disabled children and young people face an increased vulnerability to online harms compared with their peers and this was amplified due to the additional time spent online during the pandemic. At a time when young people were making new connections through online gaming and social media, neurodivergent children might struggle to determine what is appropriate to share publicly and consequently leave themselves more susceptible to cyberbullying, exploitation and other forms of online abuse [DPO/081 INQ000643711]. Parents often had to manage these risks with little support from schools and authorities and instead appreciated the support of charities such as the National Society for the Prevention of Cruelty to Children ('NSPCC') to fill the gap [DPO/082 INQ000643712].

Interactions with National Governments and Local Authorities

- 134. DPO across the four UK nations sought to engage with government and local authorities at all levels throughout the pandemic on the issues set out above. The most common experience of DPO was that the process was challenging, with limited opportunities to raise concerns through forums and direct engagement. Even when those opportunities did arise it primarily felt like they were tick-box exercises, rather than vehicles for DPO to genuinely co-design and help shape policy. In England, DR UK often felt the need to try to influence policy by raising awareness publicly, for example, in July 2020 they highlighted that during the pandemic "the majority of families were left to cope along with the health, care and educational needs of their Disabled children." They emphasised the negative mental and physical impact this had had on Disabled children and their families and how the removal of rights in relation to delivering EHC plans had only made the situation worse. DR UK called on education, care and health bodies to dramatically improve their services to disabled children and work with families to shape personalised plans in advance of schools returning in September [DPO/083 INQ000643713].
- on the eve of the pandemic, when they called for families with Disabled people to be allowed to self-determine whether to start home schooling their child [DPO/084 INQ000238504]. This was not a call for all Disabled children to be sent home but rather asking that families should be able to make the decision themselves based on the health risks within their families. It would appear obvious that government should provide guidance to help families make that decision. As evidenced by the case study of Amber, parents and children can determine the health and learning needs of their children and, with guidance, are capable of making best interest decisions. Allowing families to self-

determine would have prevented schools from withholding teaching materials from those who decided it was in the best interests of their child to be homeschooled, and to avoid attendance action being taken (as was threatened in the case of Amber). DR UK did not receive a response to their letter until 9 April 2020, and although by that point the majority of schools had closed, it did not acknowledge the impact of the pandemic on Disabled children [DPO/085 INQ000238515].

- assignatory to a letter sent to the UK Government on 23 March 2020 expressing concerns over the Coronavirus Bill [DPO/086 INQ000238526] and stating that previous protections relating to Disabled children must be maintained. The response we received set out in detail Government's approach to 'vulnerable children' and EHC plans but it did not say anything we did not already know and did not allay our concerns [DPO/087 INQ000643717]. The guidance referred to confirmed that 'vulnerable children' included those with EHC plans but did not refer to what provision was being made for children with SEN but no EHC plan [DPO/088 INQ000497932]. We are not aware of any specific guidance at that time on what provision should be made for this large cohort of children with SEN. The guidance for parents and carers [DPO/089 INQ000643719] and schools [DPO/090 INQ000643720] again did not state what should be provided if a child with SEN did not have an EHC plan. The response we received went on to explain the easements to EHC plan duties, the issues of which I have set out above at paragraphs 45-56.
- 137. On 3 April 2020, DR UK asked that Directors of Social Care establish regular, responsive and speedy ways of engaging with DPO in their areas to ensure Disabled people, including Disabled children and young people, received the best possible support [DPO/091 INQ000643721]. DR UK shared this letter on our website so others could also provide it to their local director. DR UK received a response from ADASS which was disappointingly brief [DPO/092 INQ000643722].
- 138. Also in April 2020, DR UK published an open letter on our website to the UK Government and NHS England asking for equal treatment of Disabled people, equal value of our lives and to be consulted on treatment decisions [DPO/093 INQ000643723]. We were concerned that the rights of Disabled people under legislation, including the Convention on the Rights of the Child were not always being upheld. We received responses to this letter from NHS England on 5 April 2020 [DPO/094 INQ000238493] and the BMA on 15 April 2020 [DPO/095 INQ000238495], endorsing the principles set out in our original letter.

- 139. During the second wave of the pandemic, DR UK wrote to the Secretary of State for Health, Matt Hancock MP, on 22 October 2020 [DPO/096 INQ000238519] and again on 5 November 2020 [DPO/097 INQ000238520] calling for further guidance and support for those who were shielding. That second letter specifically asked for guidance on the decision to ask the children of shielders to attend school. The DPO have not been able to locate a response to those letters from our records and are not aware that one was provided at the time.
- 140. In terms of forums that involved the DPO, in England, the Regional Stakeholder Network's main focus was on the DWP Green Paper and the National Disability strategy with little opportunity to discuss the challenges caused by the pandemic to education, health and social care support for Disabled children and young people. The DPO Forum ought to have been a more suitable vehicle for engagement with DPO and indeed at the meeting on 27 August 2020, there was a specific discussion on how to ensure public services support the transition to adulthood for Disabled young people [DPO/098 INQ000238513]. At the DPO forum meeting it was highlighted that there should be greater cooperation between children and adult social services, there should be more support to transition into employment as the Access to Work scheme was failing to meet needs, and more flexibility in how funding could be used.
- 141. Ultimately, however, the DPO Forum was a short-lived government initiative which was disbanded even before Terms of Reference could be agreed [DPO/099 INQ000238516]. Towards the end of 2020 and into 2021 meetings were cancelled by the Government often at short notice and there was a gap of approximately 18 months between November 2020 and May 2022 when the DPO forum did not meet with Government. The meetings that did occur were unstructured and seemed to be vehicles for government updates as opposed to a forum for meaningful engagement. They did not seem worth the resources required to prepare for and attend them. The Government did not offer any resources to DPOs to facilitate their engagement, even though they should have been aware of all the demands on DPOs which increased considerably during the pandemic.
- 142. In Northern Ireland, it was DANI's experience that there was very limited consultation with DPO on policies affecting Disabled children and young people. This led DANI to write to the Minister for Health [DPO/100 INQ000396827], Deputy First Minister and First Minister [DPO/101 INQ000396828] and Paula Bradley MLA [DPO/102 INQ000396829]

in November 2021 calling on the Executive to "establish without delay, a mechanism to consult with and actively engage with Disabled people (including Disabled children) in planning and delivering its response to COVID-19 in line with Article 4 of the UNCRPD (General Obligations)." Following those letters, sadly, a meeting with Paula Bradley MLA was cancelled at short notice [DPO/103 INQ000396837], Minister Swann concluded that a meeting at that juncture would not be helpful [DPO/104 INQ000396838]¹⁷, and although the First Minister and deputy First Minister accepted DANI's request for a meeting [DPO/105 INQ000396849] it did not proceed due to the resignation of the First Minister. Although Michelle O'Neill visited DANI on 13 April 2022 and engaged with DANI on the impact of Covid-19 this was not an Executive Meeting as Michelle O'Neill was not in a Ministerial position at the time. The Inquiry has now heard from the former First Minister and former deputy First Minister who both accepted that engagement with organisations like DANI ought to have been more structured. ¹⁸

- 143. There were, however, examples where engagement was improved, for example, Disability Wales worked with the Welsh Government to highlight how the rights of Children and young people had been impacted by the pandemic in their report 'Locked Out'. Although measuring the impact of the pandemic on Disabled people's education was beyond the scope of the report, it recommended that the Welsh Government ringfence part of the Government's pandemic grant to local authorities to ensure children with Special Educational Needs who stay at home receive appropriate and essential equipment, training materials and social care. The report also called on Digital Communities Wales, in partnership with DPOs, to urgently develop an education and skills programme specifically tailored to Disabled people to address ongoing digital exclusion. The report went on to consider the socio-economic factors that disproportionately affect Disabled children [DPO/003 INQ000353434/12 & 51-56]. Although the DPO welcomed this improved level of engagement, the findings of the report, which was published in July 2021, indicate that not enough was done prior to the pandemic or during its first year, to address the issues that came to be identified.
- 144. Another example where engagement was improved at a local level was the Greater Manchester Disabled People's Panel ('GMDPP'). The GMDPP was created in 2019 as an initiative between DPO and the Greater Manchester Mayor, Andy Burnham. It is convened by the Greater Manchester Coalition of Disabled People ('GMCDP') and in

¹⁷ See [M2C/T9/192/9-194/12] where Minister Swann accepted on reflection that such a meeting at that time would have been helpful.

¹⁸ See [M2C/T11/151/5-15] and [M2C/T10/196/12-199/14]

2020 was made up of 13 member DPO. The principles of the GMDPP are publicly available in an accord with the Greater Manchester Mayor and Combined Authority [DPO/106 INQ000643736]. During the pandemic, members of the panel regularly attended meetings of the Greater Manchester Humanitarian Assistance Group which allowed them to be kept up to date on local pandemic response policies. The GMDPP also conducted a survey on the lived experiences of Disabled people during the pandemic. 11% of respondents were aged 18-24 and others were parents of children and young people. The survey results found concerns children were not getting access to CAMHS and that EHC plans were not being delivered. The resulting report called for urgent prioritisation of funding for mental health support and a fully supported inclusive education system [DPO/065 INQ000643696/§§13.5 & 13.12]. Through the GMDPP's connections it was able to present the results of the survey to the Mayor, council leaders, MPs and other leading stakeholders across Greater Manchester in June 2020 [DPO/107 INQ000643737]. The work of the GMDPP and the issues highlighted by the survey also encouraged the creation of a Greater Manchester Inequalities Board which held its initial meetings in 2021 and is attended by GMDPP members.

- 145. The GMDPP also completed annual reports setting out their work and recommendations for policymakers going forwards. The 2020-2021 Annual Report made a series of recommendations relevant to this statement, including that local authorities measure how children with EHC plans have been supported during the pandemic and publish any action plans implemented to address identified gaps [DPO/108 INQ000643738/39]. The report also noted that young people turning 18 and not having access to children's mental health services "seems to be a particularly acute problem post-pandemic, especially for young autistic people." [DPO/108 INQ000643738/30]
- 146. The GMDPP, is an example of what greater engagement and consultation with Disabled people and DPO should look like. It is, however, limited by its geographical area. The DPO call for similar panels to be set up throughout the UK to co-produce local policy. Although it is vitally important that this style of consultation takes place at a local level, it also needs to be replicated with national governments as many decisions, particularly in relation to non-pharmaceutical interventions and school closures, are taken at a national level and it is important that the voices of Disabled people are heard and considered before such decisions are made.

Compliance with human rights conventions

- 147. As we have sought to set out above, the impact on the pandemic on Disabled children and young people was shocking. However, we have tried to explain that it was not only the direct impact of the pandemic. It was also the impact of decision-making that sought to mitigate the pandemic's impact for the general population but failed to meet the needs of Disabled children and young people, and in many instances, even to consider their needs. In many cases, that failure breached Disabled children and young people's rights under international conventions. Two such conventions are of particular importance. First, the United Nations Convention on the Rights of the Child ('UNCRC') [DPO/109 INQ000176156]. The legal status of the UNCRC differs in the four nations. For example, in England, the UNCRC is not directly incorporated into domestic law, but is reflected in some statutory provisions and case law. In Scotland, the UNCRC was incorporated by domestic legislation in 2024. Second, the United Nations Convention on the Rights of Persons with Disabilities ('UNCRPD') [DPO/110 INQ000279959] to which the UK is a signatory state but which has not been directly incorporated into domestic law. In addition to these conventions, the UN Secretary General also published a policy brief 'A Disability-Inclusive Response to COVID-19' in May 2020 which Disabled children and young people were least likely to benefit from distance learning solutions and called on Education actors to take measures to ensure continuity of their learning [DPO/111 INQ000279962/6 & 14]
- 148. The inability to provide adapted education materials and teaching, as described at paragraph 33 above, meant that Disabled children did not enjoy the rights in the UNCRC without discrimination of any kind irrespective of the child's impairment pursuant to Article 2. The reduction in therapies and support services, described at paragraphs 93-94 above, also meant that Disabled children did not enjoy a full and decent life in conditions which ensured dignity, promoted self-reliance and facilitated their active participation in the community pursuant to Article 23. Access to play and recreational activities is a fundamental right under Article 31 of the UNCRC, yet, as has been discussed throughout this statement, it was disproportionately denied to Disabled children during the pandemic. Lockdown restrictions resulted in the widespread closure of accessible play areas, youth groups, and respite schemes, with many never fully reinstated. There were reports that mainstream online youth services were not inclusive or accessible, particularly for children with sensory needs, non-verbal communication or limited access to devices [DPO/112 INQ000651212]. Social isolation deepened during the pandemic due to restrictions and barriers to accessibility, reinforcing the need

for inclusive community and play services as part of pandemic resilience planning. The DPO consider that government measures to uphold the right to play were either insufficient or not introduced at all.

- 149. The DPO would also seriously question whether the impact and responses set out above, amounted to taking "all necessary measures" to ensure the protection and safety of Disabled children and young people pursuant to Article 11 of the UNCRPD. I have also explained that many decisions, such as the closure of respite services, were taken without close consultation and active involvement with Disabled children and young people and their respective organisations. As these decisions clearly affected those individuals, the failure to consult was a failure to meet Article 4(3) UNCRPD. The impact of easements both in respect of EHC plans and aspects of the social care framework call into question whether the best interests of the child was the primary consideration pursuant to Article 7(2) UNCRPD. These decisions led to children being excluded from education, communities and friendship groups, resulting in a breach of Article 19 UNCRPD. The challenges Disabled children faced in accessing education, and the easements in respect of statutory duties to secure special educational provision, was a breach and derogation of the duty under Article 24 UNCRPD.
- 150. When DANI and the European Commission for Northern Ireland conducted a survey in late 2021 on the progress made to implement the UNCRPD, 59% of respondents believed that Disabled children's rights were unprotected and 57% indicated that they do not think Disabled children are able to fully take part in education [DPO/113 INQ000396796/7]. Similarly, in Scotland, Inclusion Scotland's report 'Rights at Risk' painted a shameful picture when considering how the pandemic had impacted children's rights under Article 7 and Article 24 of the UNCPRD. It noted the poor situation prior to the pandemic had been made considerably worse and this would have long-term impacts on the mental health and education attainment of Disabled children and young people if corrective action was not taken urgently [DPO/114 INQ000142277/9 §3.2]. A number of DPO also contributed to the UNCRPD Civil Society Shadow Report in March 2022 which highlighted how support services stopped or reduced during the pandemic were slow to return, consequently impacting on Article 7 rights [DPO/115 INQ000279965/16]. An Alternative report from Civil Society was also published in August 2023 to assist the Inquiry concerning the UK carried out by the Committee on the Rights of Disabled People under article 6 of the Optional Protocol to the UNCRPD. That report

¹⁹ See also §66 of General Comment No. 6 on Equality and Non-Discrimination 26 April 2018

also set out the impact of the Covid-19 pandemic on Disabled people including children and young people [DPO/116 INQ000509859/80-85]

Lessons learned/recommendations

- 151. The lessons that must be learned in this Module may have the greatest legacy, as the impact of any future pandemic on the youngest members of our society necessarily have long term implications for the future. We must implement those changes now so they can be embedded and ensure we are better prepared for the next pandemic. The Covid-19 pandemic was a clarifying lens that brought into sharp focus the inequalities that already existed and remain. Without urgent change, Disabled children and young people will not be in a better situation when the next pandemic arrives. Indeed, in many respects, the DPO are concerned that matters have deteriorated since prior to the Covid-19 pandemic, leaving Disabled children and young people in a worse position.
- Make the SEND system work for all Disabled children and young people The DPO are calling for improvements to the SEND and equivalent systems across the four nations. We agree with IPSEA that the law is not necessarily the problem and current systems have the potential to work better for children and young with SEND but only if they are fully implemented. There needs to be greater accountability with zero-tolerance approach to local authorities that fail in their duties to Disabled children and young people. Instead, the respective Departments of Education must fund local authorities to implement the SEND system properly and deliver the support children and young people are entitled to within that system. SEN support for children who do not require an EHC plan must be made statutory, funding for this ring-fenced, and sufficient training provided to ensure mainstream schools are truly inclusive. This should create a system where schools and local authorities proactively consult families on how to meet their needs, comply with their existing duties, and families no longer have to fight for their rights. The DPO are aware that IPSEA provided written evidence to the Parliamentary Inquiry on 'Solving the SEND crisis' on 12 March 2025 [DPO/117 INQ000643742].
- 153. Prevent the future use of easements to educational, health and care support duties Legal easements that meant that children with EHC plans no longer had an absolute entitlement to the support set out in their plans should not be reintroduced in any future pandemic. This particular recommendation was also made by the Children's Commissioner in their 'Childhood in the time of 'Covid' report [DPO/21]

- INQ000643742/29-30]. Similarly, easements to the Care Act which also affected support for individuals under 25 must not be introduced in times when need is greatest.
- 154. Broader approach to children entitled to attend school during a lockdown In general, a broader approach should be taken when considering what children should be entitled to attend school during periods of lockdown. In particular, for children in England, those in receipt of SEN support who do not have an EHC plan should also be entitled to attend school, if appropriate for them, alongside those with EHC plans. Alongside this, young people and families should be provided appropriate guidance to make tailored best interests decisions about whether a child or young person should attend school.
- 155. Protect the provision of community youth work and respite services These services are not only essential in providing unpaid carers with respite and support but also enable physical, social and emotional development of Disabled children and young people who attend.
- 156. Ensure the provision of therapy services during a pandemic The provision of these services is essential not only for Disabled children and young people to manage their conditions but also to continue their development. When access to such therapies is rapidly reduced it has the potential to have a deleterious impact on physical and mental health. In some cases, the disadvantage caused can take years to recover from if at all. If services cannot be provided in the home, then alternatives must be provided through consultation with children and their families.
- 157. Improve the accessibility of digital resources The pandemic did bring opportunities for greater accessibility. For example, the increased use of digital resources should have brought greater accessibility opportunities, as materials could have been provided in accessible formats and could have been compatible with assistive technology. However, as the experiences of Andrew Hamilton show, for that to be a possible, such resources must be designed with Disabled children and young people to ensure they are accessible. The challenges individuals faced in accessing digital services are all the more frustrating considering that regulations were introduced in 2018 to improve digital accessibility and the All-Party Parliamentary Group for Assistive Technology and Policy Connect published a report in 2018 on Accessible Virtual Learning Environments. Chapter 4 provided a 'how-to' guide on implementation to make digital education accessible to all [DPO/118 INQ000643743].

158. Improve consultation with parents, Disabled people and DPO – The pandemic brought about unprecedented challenges requiring unprecedented action. Disabled children and young people and their parents understood that. What they did not understand and actively reject is why those actions were taken without their engagement. Disabled people, parents, DPO are all valuable engagement partners, capable of providing significant expertise, sharing personal experiences and accounts of impact at local level, disseminating accessible information quickly amongst our members and finding practical solutions to problems. We must not be excluded from decisions that so evidently affect us, and we call on Governments to recognise and utilise our value when implementing measures that ensure we are prepared for the next pandemic.

Nuala Toman - Statement of Truth

I believe that the facts stated in this witness statement are true. I understand that proceedings may be brought against anyone who makes, or causes to be made, a false statement in a document verified by a statement of truth without an honest belief of its truth.



Rhian Davies - Statement of Truth

I believe that the facts stated in this witness statement are true. I understand that proceedings may be brought against anyone who makes, or causes to be made, a false statement in a document verified by a statement of truth without an honest belief of its truth.



Kamran Mallick - Statement of Truth

I believe that the facts stated in this witness statement are true. I understand that proceedings may be brought against anyone who makes, or causes to be made, a false statement in a document verified by a statement of truth without an honest belief of its truth.

