Policy and Practice Note



Long COVID and children's rights

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Abstract

This policy note calls for the recognition of long COVID as a children's rights issue in the UK. While children have been affected by school closures and lockdown restrictions throughout the pandemic, the relatively low rates of COVID-related hospitalizations and deaths among children have led to their de-prioritization in efforts to reduce the spread of the SARS-CoV-2 virus. Yet infection rates are extremely high among children in the UK, particularly secondary school students, and early studies suggest that many are not recovering for up to a year after infection. Prolonged illness following infection, 'long COVID', has implications for children's rights to education, health, and a private and family life, among others. By extension, children have a right to have their best interests taken into consideration in policy-making processes relating to long COVID. The policy note thus argues that we must recognize the significance of long COVID in children and, upon this basis, call upon the State to address its human rights implications.

Keywords: children; COVID-19; education; healthcare; international law; policy

1. Introduction

This policy note calls for the recognition of long COVID as a children's rights issue in the United Kingdom.¹ Media reports and political rhetoric throughout the pandemic have focused on hospitalizations and deaths resulting from COVID-19 infection. These metrics can lead officials and the public to underestimate the significance of COVID infection in children, among whom deaths are relatively low. Yet COVID-19 is spreading rapidly among children in the UK, particularly secondary school students, and it appears that many children continue to experience symptoms of ill health long after SARS-CoV-2 infection itself has cleared.

This policy note advances three arguments, First, long COVID is likely to affect many children who are infected with SARS-CoV-2. It is a potentially severe, long-term illness that ought to be taken seriously, even though infection itself rarely results in severe illness or death in children. Second, long COVID has many implications for children's rights; these should be recognized by public authorities, and they should form the basis of robust policy responses. This note focuses on children's right to the highest attainable standard of health, emphasizing the State's obligations to provide preventive, curative, and rehabilitative healthcare services to address long COVID. But the note also acknowledges the need to place children's right to health within its broader context. Long COVID has implications

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¹ For the purposes of this article, "children" are as all persons under the age of 18. This definition is in accordance with the UN Convention on the Rights of the Child, Article 1

for children's enjoyment of various rights, including the rights to education and to a private and family life. Protecting children's health is, therefore, key to the fulfilment of many of their human rights. Third, viewing long COVID from a children's rights perspective allows us to recognize the ways in which it intersects with other forms of disadvantage. Public authorities are required, under international and domestic law, to implement policy responses to long COVID that promote equality of opportunity for socioeconomically disadvantaged children, children with disabilities, and children who belong to marginalized communities. The concluding remarks reflect upon the prospects of the recognition of long COVID as a children's rights issue. I situate the call for recognition of long COVID as a children's rights issue within two broader struggles: (i) to ensure respect for international instruments—including the UN Convention on the Rights of the Child (UNCRC)—in the context of a backlash against human rights in the UK; and (ii) to disavow 'childism' in policy responses to COVID.

2. What is long COVID?

According to the UK's National Institute for Health and Care Excellence (NICE), 'long COVID' refers to the persistence of signs and symptoms consistent with COVID-19 infection for over four weeks (NICE 2020: 7). Long COVID typically develops three months from the onset of SARS-CoV-2 infection and lasts for at least two months (WHO 2021). The most common symptoms include fatigue, shortness of breath, chest pain or tightness, memory and concentration issues referred to as 'brain fog', insomnia, heart palpitations, dizziness, pins and needles, joint pain, depression, and anxiety (National Health Service (NHS) 2021). As these signs and symptoms may be the result of any number of health issues, medical practitioners are advised that they should only treat a patient's condition as long COVID in the absence of an alternative diagnosis (NICE 2020: 7).

Long COVID is a relatively new condition with a limited evidence base. NICE only established a clinical case definition—the first step towards systematic research and treatment of a medical condition—in October 2020, with the WHO issuing its definition a year later in October 2021. Although research is in its early stages, it is widely accepted that long COVID is a potentially severe medical condition that affects many persons previously infected with COVID-19. A 2021 study conducted by scholars at University College London tracked long COVID symptoms in 3,762 participants who previously had confirmed or suspected SARS-CoV-2 infection (Davis et al. 2021). Of the study's participants, 45.2 per cent required a reduced work schedule and 22.3 per cent were not working due to their health (Davis et al. 2021: 32). Respondents who still had symptoms more than six months after infection experienced an average of 14 different symptoms of long COVID in the seventh month after infection. 77.2 per cent experienced fatigue at that time, 72.2 per cent experienced post-exertional malaise, and 55.4 per cent experienced cognitive dysfunction. The researchers concluded that long COVID patients suffer 'significant disability', with most failing to recover by seven months post-infection (Davis et al. 2021: 2). Long COVID now affects a significant proportion of the UK population. Data released by the Office for National Statistics (ONS) in June 2022 indicates that almost two million people in the UK are currently suffering from long COVID, 826,000 of whom were infected over one year ago (ONS 2022). Of the people currently suffering from long COVID, only 92,000 were hospitalized while infected, an indication that a person may be affected by long COVID even if they did not suffer severe or life-threatening illness immediately following their infection.

NHS England launched its response to long COVID in October 2020, when it announced a 'five-part package of measures' to enable the NHS to treat long COVID patients. This package includes the commissioning of long COVID guidance from NICE; the launch of an online service called 'Your Covid Recovery' to support the rehabilitation of long COVID patients; £10 million in local funding for the launch of dedicated long COVID clinics providing physical, cognitive, and psychological services; funding for a research project

involving 10,000 long COVID patients; and the establishment of a new NHS England Long Covid Taskforce (NHS 2020). Yet most studies and policy responses to date have focused on long COVID in adults. It is, therefore, crucial to recognize that long COVID is potentially widespread among children and has significant implications for their human rights.

3. Long COVID in children

UK policy responses to COVID have taken conflicting approaches to children. On the one hand, children have been approached as 'vectors' of COVID-19 transmission, driving cases and deaths in the community. Children were banned from many supermarkets and other essential stores during the lockdowns, and schools across the UK were closed for lengthy periods. On the other hand, children are not themselves seen as vulnerable to severe illness and death resulting from COVID-19 infection. Indeed, COVID-related deaths have been high in the UK throughout the pandemic, but they have remained very low among children. There were, for example, no COVID-related deaths of children under the age of 15 in the week ending 3 June 2022, the most recent week for which statistics were available at the time of writing (ONS 2022a). The relatively low rates of hospitalization and death in children have led to their de-prioritization in preventive and curative efforts relating to COVID. 'Test and trace' programmes were abandoned in schools in late 2021, with persons under 18 years and 6 months no longer required to self-isolate if they were a close contact of a person who tested positive for COVID-19. Public health restrictions were then eliminated in each of the UK nations in 2022, with this shift to a 'new normal' seeing the end of the requirement that COVID-positive school students isolate for ten days. This change in policy might have led to a decrease in the number of COVID-related student absences from school, but it will equally have caused an increase in children's risk of exposure to the virus and, by extension, the risk of long COVID. While policies designed to slow the spread of the virus in schools have quickly been repealed, the vaccination of children has progressed much more slowly. Vaccination appointments for children aged 5 to 11—the youngest age group currently being offered the vaccine—only became available in the 2022 Easter break (NHS 2022).

COVID-19 is, nevertheless, a significant issue affecting the health of children in the UK. In late 2021, secondary school students were testing positive for COVID-19 at higher rates than members of any other age group in the UK, and infection rates remain high in this age group (ONS 2022a). This has had significant knock-on effects for children's education. According to the ONS, more than 3 per cent of all students (around 250,000) in state-funded schools were absent from school for COVID-related reasons for one or more days in October 2021 (ONS 2022b). While rates of COVID-related school absence have not been recorded since the end of isolation requirements, high rates of COVID-19 infection among children have had significant short- and long-term implications for children's health. In the four-week period ending 1 May 2022, it was reported that 115,000 children aged 2 to 16 in the UK were experiencing long COVID symptoms, with 26,000 still living with symptoms more than 12 months after infection. 5 per cent of secondary school students and 2 per cent of primary school students reported that long COVID was affecting their daily lives (ONS 2022).

While it is known that many children are living with long-term symptoms, it is not yet clear what *percentage* of those initially infected with SARS-CoV-2 develop long COVID. Early studies suggested that up to 51 per cent of children who are infected with SARS-CoV-2 may develop long COVID (Wise 2021). A larger and more recent study, the 2021 'CLoCk Study', found that the figure is lower, the researchers estimating that 14 per cent of children infected with SARS-CoV-2 still have symptoms 15 weeks later (Stephenson et al. 2021). Yet from a human rights perspective, discussions of the statistical prevalence of long COVID in children are something of a distraction. Children are rights-bearers as *individuals*, and their capacity to exercise their human rights is affected by long COVID regardless

of whether 14 per cent or 51 per cent of those infected develop the condition. Of course, the number of people affected by a condition might inform the level of investment of public health resources. But the discipline of human rights allows us to recognize the State's duty to assist and support all children suffering from long COVID, however many there are.

4. Long COVID and children's right to health

The pandemic has already had far-reaching effects on children's capacity to exercise their human rights, many of which have been documented in the academic literature (Peleg et al. 2021). Children have become more likely to witness domestic violence and to become victims of domestic violence (Driscoll et al. 2021). Education has been disrupted because of school closures, and as noted above, because of widespread infections among children. Children living in split families have, at times, been prevented from moving between parents in joint custodial arrangements, disrupting their familial relations (Peleg et al. 2021: 255). Also, many children will have lost family members or have been exposed to the prospect of such a loss for the first time in their lives. Such ordeals are likely to have serious developmental, psychological, and emotional impacts, all of which are particularly difficult to detect and treat in the context of the pandemic. The physical, cognitive, and psychological issues potentially resulting from long COVID further endanger children's capacity to enjoy various human rights.

There is, therefore, an urgent need to recognize this condition's implications for children's rights and to develop robust policy responses on this basis. The analysis presented below focuses on the 1989 UN Convention on the Rights of the Child (UNCRC), ratified by the UK in 1991. It should be noted that the application of this Convention varies across the nations, with the Children and Young Persons (Wales) Measure 2011, the Children and Young People (Scotland) Act 2014, and the Rights of the Child (Incorporation)(Scotland) Bill—once it becomes law—demanding greater compliance with the UNCRC by public officials in Wales and Scotland than required in UK law more broadly. The Convention is, however, a reflection of the children's rights standards that the UK has undertaken, and has an international obligation, to meet.

Long COVID most clearly affects children's right to the highest attainable standard of health, recognized in Article 24 of the UNCRC. According to the Committee on the Rights of the Child (CRC), which oversees the UNCRC's implementation by States, the right to health is inclusive and far-reaching (CRC 2013a: 2), encompassing several elements that are relevant to the issue at hand. First, the right to health entails the right to access community-based, preventive healthcare (CRC 2013a: 8; UNCRC: Art 24(2)(f)). Preventive healthcare programmes implemented by States should 'address the main challenges facing children within the community and the country as a whole' (CRC 2013a: 8). Preventive healthcare thus includes behavioural and structural interventions to address communicable diseases. Preventive efforts for children are currently limited in the UK. In fact, according to commentators, the UK Government's informal policy is to allow the development of 'herd immunity' through the mass infection of children (Alwan 2021; Pagel 2021). Such a policy is, of course, at odds with a children's rights-based approach to long COVID, as the only way of preventing long COVID is preventing SARS-CoV-2 infection in the first place.

Implementing preventive measures will, of course, involve a rights-balancing act. Certain measures, like school closures, have already had a devastating impact on children's right to education, and their unlikely reintroduction would affect the opportunities available to children throughout their adolescent and adult lives (Kahambing 2021). But a range of measures short of school closures could effectively protect many children: use of facial coverings indoors; social distancing; ventilation of crowded spaces; and promotion of good hygiene. These measures would have a measurable impact on infection rates among children while allowing the continuation of education and social interaction, both

of which are key to children's development. It is also vital to reinstate healthcare interventions designed to break chains of transmission between children. Though disruptive and challenging in settings like schools, contact tracing and isolation—of COVID-positive persons, their close contacts, or both—are key to protecting children from exposure to SARS-CoV-2.

Yet while infection prevention and control measures are likely to reduce infection rates, it is unrealistic to expect such measures to stop infections altogether. Thus, the number of children affected by long COVID will continue to rise, further engaging the State's duty to ensure the availability of treatment and rehabilitation. Indeed, children's right to health entails the right to access facilities for the treatment of illness and rehabilitation of health. Primary healthcare—the treatment provided to individuals by GPs, dentists, opticians, and other professionals who form the first point of contact between individuals and the healthcare system—'must be available in sufficient quantity and quality' and be physically and financially accessible to all (CRC 2013a: 4). The treatment provided for long COVID—be it medication, physical rehabilitation, psychological treatment, or otherwise—should also be 'medically appropriate and of good quality', informed by the best available evidence and rigorous scientific investigation (Committee on Economic, Social and Cultural Rights (CESCR) 2000: para 12(d)). Thus, the State is required to establish healthcare services that are suitable for the treatment of long COVID in children and to facilitate research into the issue. While some data on the prevalence of long COVID in children is already available, there is limited knowledge of how the condition manifests in-and affects-them. Such knowledge gaps must therefore be filled to facilitate the proper functioning of healthcare services.

Yet long COVID has implications beyond children's right to health and the way in which it is fulfilled by the State. As a condition that lasts months and possibly over a year, long COVID can have detrimental effects on children's enjoyment of various rights, both presently and throughout their adult lives. Alwan writes:

A proportion of children are not recovering after [SARS-CoV-2] infection, and the higher the community infection rate, the higher the number of children experiencing longer term effects. Long COVID does not only affect children's physical health, but also disrupts their education, causes social isolation, and may lead to declining mental health (Alwan 2021).

Researching and addressing long COVID in children should, therefore, be seen as crucial to the fulfilment of children's rights more generally. The disruption caused by long COVID may have lasting effects on a child's education and cognitive development, impairing their capacity to exercise their right to education. Meanwhile, the social isolation and poor mental health potentially resulting from long COVID may also reduce children's capacity to exercise various other rights. For example, Article 27 of the UNCRC recognizes children's right to live in conditions adequate for their physical, mental, spiritual, moral, and social development. The right to a private and family life—recognized in Article 8 of the European Convention on Human Rights (ECHR) includes the right to 'establish and develop relationships with other human beings' (Von Hannover v Germany 2012 [ECHR] 228: § 95). Both provisions presuppose the importance of autonomy, familial relationships, and human interaction for personal development—all factors that are likely to be impaired by long COVID. The State must, of course, refrain from deliberately interfering with these rights. But it must also take steps to fulfil them, creating the conditions necessary for their exercise through the implementation of appropriate policies. To implement a policy of allowing long COVID to affect large numbers of children—particularly with knowledge of its potential severity—would be to abandon this duty to create the conditions necessary for children's enjoyment of their human rights.

5. Equalities and non-discrimination

Studies have found that certain groups of children are more likely to suffer severe illness resulting from COVID-19. These include socioeconomically disadvantaged children, children from minority ethnic backgrounds, and children with pre-existing conditions such as obesity, cancer, kidney disease, mental disabilities, and immune disorders (Murdoch Children's Research Institute 2021: 2). Yet, as noted above, research into long COVID and children remains limited. It is not known whether children with co-morbidities are more likely to suffer from long COVID, nor whether children with co-morbidities suffer more severe symptoms. Furthermore, data on long COVID in children in the UK is not disaggregated by factors such as socioeconomics or ethnic background, making it difficult to understand whether children from disadvantaged groups are disproportionately affected by long COVID at present.

Nevertheless, it is known that the COVID-19 pandemic has disproportionately affected disadvantaged and vulnerable children. UNICEF reports that the pandemic has most severely impacted children who are reliant upon health and social care services, charitable organizations, and the volunteer sector, which have all weakened during the pandemic. According to UNICEF, the consequences of the depletion of such services have been compounded by school closures, which threaten to widen the 'attainment gap', the difference in academic achievement between children who suffer disadvantage and those who do not (UNICEF 2020). A December 2021 report published by the National Health Science Alliance focused on the pandemic's impacts in the north of England, where children are significantly more likely to live in poverty than in the rest of England (27 per cent compared to 20 per cent). The report showed that children in the north of England missed more schooling, suffered greater loss of access to childcare and residential care, and experienced more loneliness than children elsewhere in the country (NHSA 2021). From a human rights perspective, it is vital that we now seek to understand how long COVID affects vulnerable and disadvantaged children, whose education, access to health and social care, and living conditions have already suffered as a result of the pandemic.

The State's response to long COVID in children must be rooted in the principles of non-discrimination and equal opportunity. This will require, first, investment in research into how long COVID impacts already vulnerable children, whose life opportunities are affected by chronic illness, disability, socioeconomic disadvantage, marginalization, experiences of discrimination, or difficulties accessing healthcare. Second, healthcare services and facilities developed to treat long COVID in children must be made accessible to the most vulnerable young members of society, meeting their specific needs. In fact, both international human rights law and UK domestic law require that public authorities directly address discrimination and promote equality of opportunity through their work (CESCR 2000: para 43(a); Equality Act 2010: pt 11). For example, those providing paediatric care for long COVID should be given the training, resources, and infrastructure needed to treat children with mental disabilities, developmental disorders, psychological conditions such as anxiety disorder, or difficulties accessing healthcare in a language they understand, all of which may reduce a child's ability to identify and communicate symptoms of long COVID.

Finally, as scientific understanding of the condition develops, it will be important to consider whether children living with long COVID should be considered as persons with disabilities for the purposes of equality and non-discrimination laws. As noted in section 2, studies have found that long COVID causes ongoing and significant disability, and trade unions and medical associations in the UK are currently calling for the condition to be recognized as a disability under the UK's non-discrimination legislation (Trade Unions Congress 2021; Pharmacists' Defence Association 2021). Long COVID cannot be recognized as a disability unless it is shown that the condition has caused, or is likely to cause, lifelong impairment or significant impairment for at least twelve months (Equality Act 2010: sch 1). But if indeed long COVID is recognized as a disability, the legal effects will

be significant. For example, the Equality Act 2010 prohibits direct and indirect discrimination against persons with protected characteristics, including children with disabilities. Its scope of application extends to schools, universities, and employers. Such actors—who are constantly and directly in contact with children—must refrain from discriminating against persons with disabilities, and they must also make reasonable adjustments to meet their needs (Equality Act 2010: sch 8, 13). This includes, for example, physical arrangements in classrooms and tailored approaches to student assessment.

6. Conclusion

One might, of course, argue that there are disciplines other than human rights that are more relevant to the State's response to long COVID. From a medical perspective, long COVID is a condition that appears to cause mild-to-moderate symptoms in children and one from which most recover. This analysis might form the basis for a relatively limited response to the issue of long COVID in children, and one that is narrowly focused on symptomatic relief. From an economic and policy-making perspective, long COVID does not appear to be particularly widespread in children, and, unlike other health conditions that may affect children, it does not cause severe or life-threatening illness. This, too, might justify the allocation of minimal resources to the issue or even lend credence to a 'wait and watch' approach, in which no decisions on the State's response to long COVID in children are made until the development of a reliable evidence base on the condition.

But neither of these perspectives provide for a satisfactory response to the fact that thousands of children are already living with long COVID and many more are at risk. This is where the discipline of human rights is particularly helpful; it highlights the need and obligation to take immediate steps to research, understand, treat, and attempt to prevent long COVID in children. Ultimately, the core of the Convention on the Rights of the Child is the Article 3 requirement that courts, administrative bodies, legislative bodies, and welfare institutions base all decisions concerning an individual child, a group of children, or children in general upon the child's best interests. The concept of the child's best interests entails the child's *substantive* right to have their interests taken into account and a *procedural* obligation to undertake a best interests evaluation in decision-making processes. As the CRC has noted:

Whenever a decision is to be made that will affect a specific child, an identified group of children or children in general, the decision-making process must include an evaluation of the possible impact (positive or negative) of the decision on the child or children concerned. Assessing and determining the best interests of the child require procedural guarantees. (CRC 2013b: para 6(c)).

Whether it is the result of a formal decision-making process or the absence of any such process, a policy of allowing SARS-CoV-2 to spread among children—and thus taking the risk that they will be affected by long COVID—is incompatible with this best interests principle. As noted above, academic studies and ONS statistics show that children can be, and are, affected by long COVID. There is clear evidence that long COVID is a potentially severe, multi-symptomatic, and long-lasting condition that can affect physical health, mental health, cognition, and interpersonal relationships. Any decision-making process centred on the child's best interests will take these potential effects of long COVID into account, thus recognizing the need to prevent and treat the condition.

While it is important for long COVID to be recognized as a children's rights issue in the UK, such recognition can only be meaningful in the context of broader respect for the relevant international frameworks. Recent years have seen a significant backlash against international human rights law and institutions in the UK. This pattern of backlash is

beyond the scope of the present paper, but it is important to note that there exists clear resistance to the integration of instruments like the UNCRC into domestic law- and policy-making processes. For example, the UK's Attorney General recently referred to the Supreme Court new Scottish legislation that incorporates the UNCRC into Scottish law, arguing that the Scottish government had, in implementing this legislation, acted beyond its devolved authority (Reference by the Attorney General and the Advocate General for Scotland [2021] UKSC 42). And, when recently faced with a question relating to a child's rights, the Family Division of the High Court made the following remarks on the CRC's General Comments, which provide further detail on the Convention's application and implementation by States:

The General Comments vary between commentary, exhortation and application of the text. We do not set them out. Whatever their value in interpreting the UNCRC and in particular the concept of the 'best interests' of the child, they are not part of the UNCRC, nor a guide to the interpretation of the ECHR. Nor do any deal with the issue we have to resolve (London Borough of Barnet v AG & Others [2021] EWHC 1253 (Fam): [77]).

These views of the UNCRC and its application represent a systematic, institutional tendency to read international human rights law away from the UK's domestic legal system. They pose a challenge for researchers and practitioners advocating for greater respect for children's rights in the context of the pandemic.

These challenges are compounded by what some refer to as 'childism' in the context of COVID-19 (Adami and Dineen 2021; Alwan 2021). Childism is a form of discrimination against children based upon the idea that they are merely 'appendices to their families' and their interests are secondary to those of adults (Adami and Dineen 2021: 366). Such a view of children has led to widespread violations of their rights during the pandemic and is, according to Alwan, exemplified in the current policy of allowing SARS-CoV-2 to spread in UK schools without infection prevention measures (Alwan 2021). This approach is in stark contrast with the prolonged closure of schools earlier in the pandemic, which was based on the view that children were 'vectors of transmission' of the virus, responsible for its spread within the unvaccinated adult population (Adami and Dineen 2021: 362). Children have, in other words, been treated as means to prevent COVID-related illness and death in the adult population—not as individuals who are themselves worthy, or in need of, protection.

Where children's rights have been discussed in the context of the pandemic, rhetoric has often revolved around their rights as human 'becomings' (Campbell et al. 2021): as individuals whose rights will only be affected as they grow into adults in a world still experiencing the pandemic's longer-term consequences. It is, of course, vital to consider the pandemic's long-term impacts on the world and its inhabitants. But a UNCRC-focused discussion around long COVID allows us to balance such considerations with due regard for children's present circumstances. It enables us to discuss long COVID as a condition currently affecting thousands of children, limiting their ability to exercise their rights to health, education, and a private and family life, and engaging their right to have their interests taken into consideration in policy decisions regarding the condition. A UNCRC-based approach also enables scholars and practitioners to call upon the State to respect its international human rights obligations vis-à-vis children, implementing infection prevention measures, providing treatment and rehabilitation, and—as relevant—requiring educators and employers to meet the needs of children suffering from long COVID.

Conflict of Interest

None declared.

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