Returning to school: children and young people living with chronic illness
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Introduction
The reopening of schools is an integral part of our gradual recovery from the social and economic lockdown implemented as part of the measures to contain the COVID-19 pandemic. Reopening schools after a closure is a major challenge. Stephania Giannini, the UNESCO Assistant Director-General, in mid-May 2020 said:

When and how to reopen schools is one of the toughest and most sensitive decisions on political agendas today. Is it safe to reopen schools or is there a risk of reigniting infections? What are the consequences to children’s mental health and to the social development of young children? Are students engaged in remote learning actually learning? And when the time comes, how will schools ensure students return and help learners who have fallen behind during school closures? (Giannini et al., 2020)

In 2014, 23% of young people in England between 11 and 15 years of age reported that they had a long-term illness, disability or medical condition (Hagell and Shah, 2019). It is understandable that a high level of concern should exist about the return of children and young people (CYP) living with chronic illnesses such as asthma, diabetes, juvenile arthritis or mental health problems. The use of the word “vulnerable” in policy documents (Department for Education, 2020) to describe a diverse group of CYP is perhaps unhelpful in this regard. Nevertheless, the return of these CYP to school is very desirable, on the one hand, because prevention and treatment services for chronic illnesses have been severely disrupted since the COVID-19 pandemic began (Elbarbary et al., 2020; Lynn et al., 2020; WHO, 2020a) and to halt the decline in learning (Haecck and Lefebvre, 2020) and socialization (Orben et al., 2020) because of the isolation linked to lockdown on the other hand.

At the time of writing, not all countries have reopened their schools and, for those that have, different strategies have been adopted (Jourdan et al., 2020). There is a real need to consider the issue of CYP living with chronic illness in policies that are formulated and to base these policies on robust data. Learning from evidence published in peer-reviewed literature, from the experience of other countries and from professionals in practice can inform this challenging process. In this article, we explore the available evidence and offer strategies for the return to school of CYP living with chronic illness.

Attending school is best for children and young people, especially those living with chronic illness
Both socialization and learning are key components of educational success and that is why physical attendance at schools is the best situation for the health and well-being of all CYP (Viner et al., 2020). Getting children into school and keeping them there for as long as possible as young people improves their health outcomes (Patton et al., 2016). Educational
attainment improves future life prospects. Supervised physical activity prevents future illness and promotes overall health (Chen et al., 2020). Peer contact is vital for healthy development of the body and brain (Orben et al., 2020). Frank conversations with trusted adults outside the home can bring a new perspective to the pandemic and our ongoing co-existence with the virus. This is true for all CYP, including those with chronic illness and we must support their return to schools. In the context of the present pandemic, three situations arise among CYP living with chronic illness.

Firstly, for a significant minority, it is not yet possible to return to school. In England, a child or young person can be formally “shielded” by the National Health Service (Public Health England, 2020). The UK Royal College of Paediatrics and Child Health (2020) issued shielding guidance in April 2020; for CYP, significantly immune-suppressed by disease and/or therapy, the advice given was not to leave the house except for occasional exercise. Updated UK Royal College of Paediatrics and Child Health guidance from July 2020, benefitting from the increasing knowledge of COVID infection in CYP, is significantly less restrictive. Other commentators agree that some CYP receiving treatment affecting the immune system may remain isolated for now (Goldman, 2020), but this is a diverse group and others in the paediatric medicine community are concerned that “blanket assumption” of increased risk might mean long-term “educational and social harm” for this group (Munro and Faust, 2020), as the data we have do not bear out these concerns for all individuals. There will be challenges for families with siblings who are eligible to return; this will need careful discussion with medical staff and may entail social distancing within the household for those who are going to work or school. The UK resource “Germ Defence” [i], for example, has guidance for protecting other people in your household at risk, including social distancing by rearranging room layouts, avoidance of shared household items with a person at risk and enhanced cleaning.

The second situation concerns the child or young person with well-controlled conditions such as asthma or diabetes. It is widely accepted that COVID-19 infection produces milder symptoms and fewer critical episodes for CYP than for older adults (Silva et al., 2020) and that CYP living with asthma are less likely to experience severe COVID-19 infection than adults with respiratory disease. In some countries, where schools have already reopened, students with asthma have coped very well with the return – possibly better than other students, as they are tuned into changes in their respiratory health. These students with good control should return to school.

The third situation relates to CYP with poorly controlled illness. Obesity and chronic hyperglycaemia might be linked to more serious effects from COVID-19 infection (Silva et al., 2020), affecting CYP living with undiagnosed or poorly controlled Type 1 diabetes. The daily school routine can help many families to adhere to medication (Abrams and Szeffler, 2020), which is vital for optimum control. Circumstances, however, will differ; some students will benefit from the return and others will need to remain at home. To make a sensible decision, the collaboration of teachers, health-care professionals and CYP is requested. In the USA, for example, the Centers for Disease Control and Prevention (2020) recommends an exchange with parents of CYP with chronic conditions and refers to specific management plans. CYP with chronic illness in extended lockdown are at risk of a lack of educational and therapeutic input (Société Française de Pédiatrie, 2020) and – for a small but significant group – of abuse, physical or otherwise (WHO, 2020b; UN, 2020). Professionals in the field report that “some families of children and young people with complex healthcare needs have found that school closures ease the pressure on their daily lives” and predict that a significant number may favour home schooling rather than return [1]. The child or young person may not have a say in this decision, so they would have less access to school-based support services. It would also devalue the creativity and commitment that many schools have invested in inclusive teaching practices. That is why, for those for whom it is medically possible, creating the conditions for a full or partial return to school is a priority.
Importance of a positive and responsible inter-sectoral approach

The key to a successful return for CYP with chronic illness is effective inter-sectoral working. A plan for each CYP – representing a partnership between the student, their family, medical staff and teachers – should address concerns, increase confidence and mitigate shortcomings in the current system (Webster and Blatchford, 2019). Some students will already have a comprehensive management plan initiated by hospital staff overseeing their treatment – examples include Education, Health and plans in England [ii], Projet d’accueil Individualisé in France [iii] and Student Health Support Plan in Australia [iv]. Others managed mostly in primary care might wish to consult medical staff to talk through their level of control and ways in which they can stay safe at school, including an Individual Health Plan [v]. It would also be good to see an increase in the deployment of health professionals into schools, with strong school nurse input (Nicholson, 2014). Teachers, students and parents will benefit from rapid access to trusted advice. A personalised approach will be needed, but the default position must be to encourage a sensible return to school life.

It is important to acknowledge previous barriers to developing inter-sectoral collaboration. For example, the UK Royal College of Nursing (2018) reported on the significant decline in school nurses and an emerging trend of reductions in the health visiting workforce and included three recommendations addressed to the government, local authorities and Health Education England. These were to reverse cuts in public health spending, to gather data about the children’s public health workforce and to secure specialist education and training for the children’s public health workforce. The pandemic has provided an opportunity to reflect again on these trends and a strong case can be made by school nurses to have more input into schools. Relevant activities include:

- continue to assess the data available, integrate it into prior knowledge about infection control, capitalize on emergency preparedness planning, advocate for equitable distribution of services, access evidence-based resources, plan for interventions in the schools, and constantly evaluate outcomes to improve approaches. (McDonald, 2020)

It is also apparent that there is a disconnect in the language and culture of health and education professionals – we need to nurture a common context and discourse to optimize joint working. Other tensions in the relationship between medical teams and school teams can relate to power issues and difficulty knowing who is responsible for communicating matters about the student to whom – and the parent may take on an intermediary role (Jackson, 2013). Murphy et al. (2018), as recently and prophetically as 2018, reflected from their inter-sectoral school-based prevention work in Wales that “Investment in and the linking of resources develops the capacity for key social agents to take advantage of disruption points in the re-orientated system, and engagement activities develop the network to facilitate new social interactions and opportunities for trans-disciplinary activities”. This pandemic provides an unprecedented “disruption point” in the system that might offer new opportunities for collaboration. Knowledge exchange is also key to this process and should be encouraged.

Exploring the opportunities of digital technologies: telemedicine and blended learning

Our inter-sectoral efforts must not forget the educational, health and social needs of CYP who will be shielded from public life for many months to come. There is a clear need for a change of paradigm. The COVID-19 crisis has shown the on/off vision of schooling or not schooling is no longer relevant. Ongoing flexible learning platform development will help CYP with poorly controlled or complex chronic illness to reduce their educational disadvantage. Some teaching and learning research groups have been discussing the contribution of digital technologies to the education of students with a chronic illness for some time. Jones and McDougall (2010) concluded during the Link ‘n’ Learn project in Melbourne, Australia, that blended learning would work best when truly listening to what the student wants and what they think they can
accomplish and when teachers are supported to properly engage with the remote learning option. This latter point has now been thrown into sharp focus for all students during the pandemic, which means that more teachers will be developing their skills in the near future.

Rapid recent advances in telemedicine also offer these students a way to avoid long journeys and more missed school days (Barney et al., 2020). This could potentially lead to more frequent short check-ins with their medical team to get quick guidance, but there will still need to be a good referral system for physical examinations or symptom exacerbation problems (North, 2020). Caution will be needed when students go back to school and parents return to work, to ensure that the child or young person is still present and heard in the remote consultation. We may assume that young people welcome home-based care, but research about home treatment services pre-dating the pandemic showed that some young people and families still expressed a preference for in-person hospital care (Hazen et al., 2008).

Conclusion

The COVID-19 crisis has highlighted the challenges of getting ALL CYP into school. It made it possible to verify on a large scale that hybrid-learning modalities could develop and, without a doubt, be beneficial to CYP living with chronic illnesses. It is up to us to make good use of what we learn from the COVID-19 crisis for the benefits of all students, especially those who need school the most to succeed. Most CYP with well-controlled conditions will be able to return and families should be encouraged to support them to do this.

There is no opposition between distance learning and face-to-face learning. Hybrid schooling and medical care arrangements offer a good balance that can be adapted to each CYP, with the caveat that the impact of deprivation must always be considered in terms of cramped housing, access to technology, etc. and that the system is shaped by the child or young person's individual needs and preferences. We have an opportunity to better meet the holistic health and educational needs of CYP living with chronic illness – with a positive and responsible inter-sectoral approach and we can grasp it.

[i]  www.germdefence.org/someoneElseHighRisk1.html
[iii] www.service-public.fr/particuliers/vosdroits/F21392

Acknowledgement

The authors would like to thank Dr Gill Turner, Northumbria Healthcare NHS Foundation Trust, UK; Dr Gail Dovey-Pearce, Northumbria Healthcare NHS Foundation Trust, UK; Dr Marie Hauerslev, Chair of NCD Child and Dept of Pediatrics, Herlev Hospital, Copenhagen, Denmark; and MinChien Tsai of Fu jen University, Taipei, Taiwan.

Funding statement: The UNESCO Chair Global Health and Education Research Group (NJG and DJ) is supported by two non-profit organizations Mutuelle Générale de l’Education Nationale and group Vyv (mutual benefit insurance companies) regulated by the French Mutual Society Code. JMcD is supported by Versus Arthritis Centre for Epidemiology (UK grant No: 21755) and the NIHR Manchester Biomedical Research Centre.

Declaration of interest: JMcD has received speaker’s fees from Sanofi Genzyme and Biomarin; consultancy fees from Pfizer and support to attend conferences from Abbvie.

Keywords: Young people, Children, Chronic illness, School health, COVID-19 pandemic, Intersectoral working
Note

1. Personal communication by email – Dr Gill Turner, 13 May 2020 and affirmed by Dr Gail Dovey-Pearce, 15 May 2020.

References


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