

Senedd Cymru
Y Pwyllgor Plant, Pobl Ifanc ac Addysg

Welsh Parliament
Children, Young People and Education Committee

Ymchwiliad i effaith argyfwng Covid-19 ar
blant a phobl ifanc yng Nghymru

Inquiry into the impact of the Covid-19 outbreak on
children and young people in Wales

COV - 19
Ymateb gan: Y Gymdeithas Syndrom Down

COV - 19
Response from: Down's Syndrome Association

Response to Welsh Government Children and Young Peoples' Education Committee Consultation "*How the outbreak of COVID-19 is affecting all aspects of life for children and young people (including students in further and higher education)*"

Background

We would firstly acknowledge that Welsh Government and Westminster colleagues are dealing with significant pressures. These are truly unprecedented times. We understand decisions have had to be made swiftly (in response to the emerging pandemic). Guidance to schools and the public had to be issued quickly, in the absence of usual consultation processes. We therefore welcome this opportunity to submit details of how the current COVID-19 pandemic (and the closure of education settings, in particular) is affecting the children and young people with Down's syndrome (and their families) that we support.

As suggested, this submission has been assembled quickly. We would be happy to provide additional information, or enter into further discussion on any of these points, if that would be helpful.

Families' Concern

In terms of reactions from families to news that education settings were closing, many families were already extremely anxious. Many individuals with Down's syndrome have underlying health conditions (cardiac and respiratory conditions and sometimes issues with immunity). A number of families had already taken the decision to withdraw their children from school or college in the week or so before they officially closed. This was not a decision that was easy for any of them. Additionally, a proportion of families of children and young people with Down's syndrome will be similarly anxious about whether it is safe for their children to return to school or college, when these settings eventually reopen.

Children and young people with Down's syndrome could be within a group of pupils/students considered 'vulnerable'. This is because of the likelihood

of them having a statement and multi-professional involvement (including a social worker). The term 'vulnerable' is perhaps ill advised and maybe a better term could be thought of? Many young people and their families may not identify as such.

A minority of children and young people with Down's syndrome have received letters from the NHS informing them that they should 'shield', meaning attendance at school or college would not be possible in the period ahead, anyway. This has raised a number of employment rights / welfare benefits calls to our helpline, since some parents who are keyworkers (and eligible for school placements for their child to continue) have had to negotiate with their employer if they need to be at home to support a child that is shielding,

It is our experience that few children with Down's syndrome have continued to attend their education placements, even if local protocols would allow. This is due to families' concerns about the health risks of their son or daughter mixing with other people.

We have seen a significant increase in calls and emails to our helpline over recent weeks. Around 60% of the calls we received were health related, with the majority being connected to Coronavirus questions.

The amount of information we have had to process is vast and changes quickly. We have been introduced to new vocabulary and concepts that are unfamiliar to us. The people that children with a learning disability usually look to for advice, support and reassurance (relatives and support staff) are also understandably worried and stressed.

Depending on individuals' living situation (e.g. supported living), some young adults have been kept apart from their loved-ones, as social-distancing measures prevent face-to-face contact in the usual way. This is a particularly distressing situation for these families.

Health Inequalities

Many families of children and young people with Down's syndrome feel extremely anxious about possible inequalities in access to healthcare for their loved-one. At the beginning of this pandemic there were significant concerns that demand for NHS critical care beds (and ventilators, in particular), may exceed capacity. NICE guidance issued in the in the middle of March 2020 suggested that health professionals should make decisions on assigning patients to a critical bed according to a *Clinical Frailty Score*. This was immediately recognised by The Down's Syndrome Association (and others) as treating individuals with a learning disability less favourably. We wrote to the Health Minister seeking clarification, which was duly issued.

The Clinical Frailty Score should *not* be used for individuals with a learning disability nor children. This has gone some way to reassure families, however, some considerable residual anxiety still exists.

Families have also been concerned about some individuals with underlying health conditions being written to by their GP suggesting that they complete *DNACR* notifications or complete *Advance Care Directives* in anticipation of them becoming seriously unwell with COVID-19. These letters were later withdrawn and GP practices who sent them criticised by many authorities (including the Royal College of General Practitioners and the Department of Health), however, by then, great distress had been caused. The recipients of these letters were generally adults, however families of children with Down's syndrome have been understandably worried by the messages these communications send to disabled people of all ages.

In the early stages of the pandemic, guidance issued by NHS, indicated that family members would not be able to accompany someone into hospital if they were thought to be infected with COVID-19. In late March, a very tragic case was reported of a 13-year-old boy, who died in a critical care setting in England, without family support. This guidance was revised to state that children could be accompanied and visited by a family member whilst in hospital. This has gone some way to address a policy that lacked compassion, however significant anxiety was caused to families, who were aware of the initial guidance and were very concerned by it.

Children and young people with Down's syndrome may find it harder to communicate symptoms and so need greater vigilance to assess whether they have become infected (especially in the early stages of the virus) or if they are becoming more unwell and in need of medical intervention

The Downs Syndrome Medical Interest Group (DSMIG), with whom we work closely, issued a statement in April 2020, recording their concern that some families of children with Down's syndrome may delay seeking medical help for health issues **unrelated** to COVID-19. This was for fear that, either the NHS was too busy, or that by going to hospital or their GP they may expose their child to risks of contracting the virus

<https://www.dsmig.org.uk/growing-concerns-regarding-late-presentation-for-medical-help-for-non-covid-related-illness/> This trend has been reported on widely for the general population, too.

We are now aware of a number of people with Down's syndrome who have developed coronavirus and very sadly a number of these individuals have died (to our knowledge all of these have been adults, not children). In addition, we are able to report that a number of people with Down's syndrome have now thankfully recovered and have been discharged from

hospital following critical care treatment (and this has included a number of children with Down's syndrome). It is important for us to record that families have overwhelmingly reported health care of the highest possible standards. Families report receiving care that was compassionate and unstinting. We have purposefully shared these good news stories to try to encourage families to feel confident that NHS clinicians will do their utmost to provide lifesaving interventions. It is regrettable that the initial policy guidance seemed to be ambiguous and cause understandable levels of anxiety to many family carers. We are continuing to monitor the situation very closely and are working with Down Syndrome International in sharing a global perspective, especially from cases in Italy and Spain, who encountered the pandemic a number of weeks before the UK.

Mental Wellbeing

Like many charities who support families of children and young people with additional needs, we are particularly concerned about the detrimental impact of COVID-19 on the mental wellbeing and emotional health of children and young people with Down's syndrome. Feelings of isolation might be most keenly felt by children with additional needs, since their other regular activities (after school clubs, sports, drama and other youth activities) will also have paused.

Families and schools often work very hard to facilitate friendship groups and support social inclusion of a child or young person with Down's syndrome in a mainstream setting. It is hoped that these developing social connections will survive during this period of absence, but many are quite fragile.

It is likely that children and young people with Down's syndrome find virtual means of communication more challenging than most and so, whereas some children cope very well with Zoom calls, and phone chats with friends, others may not.

We are in the process of developing some new online resources aimed at supporting the mental wellbeing of young people and adults with Down's syndrome. These will be launched shortly on our website and publicised in our closed Facebook groups and other social media outlets.

Attendance at Hub Schools

Where schools have remained open to cater for children of keyworkers and vulnerable children, these tend to be *hub schools* for a wider area. It is therefore unlikely that the school will be the child's usual school and it is unlikely that the staff supporting a pupil would be their familiar teachers and support staff. For this reason, many parents of eligible children with Down's syndrome have deemed this unsuitable for their child (due to

concerns that the staff would be unable to confidently meet the needs of their child) and have declined this offer.

It is the experience of many people with a learning disability that a focus on routine and predictability is helpful. Many young people with Down's syndrome love being at school and usual school holiday periods can be a stressful interruption to this routine. The extended school and college closures (coming so abruptly) did not allow families to undertake any preparation with their child and as things stand, there is no way of telling their child how long the current situation will continue. This is stressful for all young people, but especially so for those who have a learning disability, for whom familiarity is reassuring.

Resources for Home Learning

In the days that followed the closure of education settings, The Down's Syndrome Association began to collate information and resources that could help families supporting their child at home. Our webpage is updated daily, with new resources added. This is available to view here <https://www.downs-syndrome.org.uk/coronavirus-covid-19/>.

We have some concerns about how much tailored advice or differentiation of materials to support home schooling has been put into resources that schools are sharing with the families of their pupils. Generic resources are unlikely to be accessible for someone with Down's syndrome. Continued contact with named teaching assistants has not been widely facilitated and there is concern that these relationships, which have, in many cases, been built up over a number of years, are at risk of being dismantled during this prolonged period apart.

As for all children and young people, there is concern about inequality of access to certain basic facilities at home. Not all families have broadband connections, computers or even quiet spaces for children to focus on activities. Some families have access to safe outside spaces, while others will not. We are not 'all in the same boat'.

Some parents will feel empowered to use skills they have to support their children's learning at home, whilst others will feel overwhelmed. This is clearly not a situation unique to families of children and young people with Down's syndrome, but the added stress of trying to meet the support needs of their child with Down's syndrome within a family setting of maybe two or three siblings (who will need different approaches to being occupied) is an additional pressure.

Training for Teachers and Support Staff

The Down's Syndrome Association has a long established record of providing training for schools and education staff. These twilight sessions or

INSET training days have all been paused and we are concerned that there is now a vacuum in terms of continuing professional development for education staff. Many teachers and support staff are working from home and perhaps looking for opportunities to update their knowledge and skills, however, this does not seem to be coordinated in any way. With some thought, ZOOM or other online training sessions could be facilitated and The Down's Syndrome Association is prepared to respond to these requests.

Individuals' Understanding of New Ways of Living

We are aware that many individuals with a learning disability find the concept of social distancing difficult to understand. They may need additional visual supports and prompting. Some people with Down's syndrome may have greater difficulty in remembering this and concepts of distance may be less robust than in other people.

We have developed our own easy-read resource <https://www.downs-syndrome.org.uk/download-package/social-distancing-easy-read/?highlight=distancing> to help address this important area. In looking ahead to when schools and colleges may return, this issue needs to be given careful consideration.

When Schools Reopen

A minority of pupils with Down's syndrome, especially younger children, maybe reliant on teaching assistant support with certain aspects of personal care. Not all children starting school will be independent in using the toilet and for some this support may continue throughout their time at school. This poses a question of how easily social-distancing could be implemented in that sort of scenario and also what consideration might need to be given to appropriate Personal Protective Equipment (PPE) for relevant staff.

If the return to school or college was to be staged (some reports have suggested that schools might operate with a 50% attendance, with children attending on alternate days), we would question how this would affect children with additional learning needs. As previously stated, routine and consistency are very helpful strategies to support learning. Children with Down's syndrome benefit from additional opportunities to practice and consolidate learning. A halved weekly attendance could be significantly detrimental to this.

Reviews and Management of Provision

Pupils / students with Down's syndrome will be in receipt of a Statement of Additional Learning Needs. Whilst it has been advised that annual reviews

will continue (via virtual meetings) these are less satisfactory than face-to-face meetings.

We are aware that some health professionals, who would be submitting reports to inform these reviews, have been redeployed within NHS settings and so are unlikely to be able to submit their reports at this time. Their ability to carry out up to date assessments has also been affected.

Clearly, there will be a cohort of children and young people who will be i) due to start school this year ii) transition from primary to secondary school iii) undertake a 14+ Annual Review meeting and iv) leave school and transition to FE or employment. It is concerning as to how the essential preparatory work behind these important transitions will be undertaken. Will usual timescales change or will key transition dates stay broadly the same?

We are aware that some young people with Down's syndrome attending residential college this year (where funding packages have been agreed with their local authority) have been informed that no agreement exists for funding of their remaining time at college to be carried over and so essentially their college year has been curtailed by at least a third of a year (ending in March and not July). This means they are missing-out on provision because of the coronavirus situation.

For many children and young people with Down's syndrome, provision of certain therapies (especially speech and language therapy), is delivered within a school setting. These important visits are therefore not happening. It would be helpful to have clarification on how these services may reorganise themselves in the medium term. This is to ensure that children do not regress. Advice needs to be given to families about appropriate strategies to support their child's speech, language and communication during this interim period.

Approaches to Inclusion Post COVID-19

Finally, we have concerns that, where families have fought hard for a placement with a mainstream school, these 'unprecedented times', along with certain easements outlined within the Coronavirus Bill 2020, might give scope for local authorities (or individual schools) to outline reasons as to why a child's placement cannot continue. Issues around social distancing, temporary classroom reorganisation and redirection of resources could be wielded as justification for a child moving from a mainstream school to a specialist placement. This would be very unwelcome. Guards against this need to be put in place. Whilst we obviously have no evidence to support this fear at this stage, we will be monitoring the situation closely.

Welsh Government colleagues will be aware of the current timescales for implementing statutory reform for ALN across Wales. We are now supposedly moving towards the final stages of children and young people moving across to IDPs. This legislative reform has taken nearly 12 years to come to fruition (from the initial *Statementing or Something Better* consultation). It would be extremely regrettable if these reforms, which now see Wales significantly behind England in the reform schedule, were delayed again. We are hopeful that the focus on reform can be maintained, even though schools and colleges might not currently be open.