

Insights into the impact of COVID-19 on children and young people with Special Educational Needs and Disabilities in Northern Ireland

Summary Interim Report

March 2021



Introduction

It is widely noted that COVID-19 has had different impacts on different parts of the population across Northern Ireland. Much of the local research conducted with children and young people on its impact has focussed on facts and figures and has been quite generic. Some research into the impacts on children and young people has concentrated on the impact on education, usually from their parents' perspective¹. While, there has been some specific research on the experiences of families with children with Special Educational Needs and Disabilities (SEND), all of this too has been focussed on the facts and figures at a specific point in time. As such, while it provided useful headlines, it told us nothing in-depth about the experiences of these families and how the impact of the pandemic on them is changing. This research fills this gap as it presents an in-depth look at the impacts of COVID-19 on the lives of families of children with SEND, giving them a voice to tell their story and share their experiences, over a six-month period of time.

This research has adopted a partnership approach with the Council for Disabled Children, Mencap, SENAC (Special Educational Needs Advice Centre) and Specialisterne. The partner organisations have:

- advised on the design of the research;
- provided some context to the research team interviews regarding specific disabilities/SENs and the current situation in Northern Ireland;
- supported access to families and professionals;
- ensured that the research is accessible to those participating and
- fed into and supported the research outputs and their dissemination.

The research comes at a time when there has been increased scrutiny and criticism of the SEN system in Northern Ireland, e.g. from the Northern Ireland Assembly Public Accounts Committee on The Impact Review of Special Educational Needs (the report from which was published on 25 February 2021); from the Northern Ireland Audit Office Review of Special Educational Needs in Northern Ireland (published on 29 September 2020); from the Northern Ireland Commissioner for Children and Young People in October 2020; in evidence provided to the Northern Ireland Assembly Committee for Education (Minutes of Proceedings, 21 October and 18 November 2020) and at the All Party Group on People with Learning Disabilities in June 2020. A Review of the SEN system has been underway since 2016, following the passing of the SEND Act (although this has been disrupted due to the suspension of the Northern Ireland Assembly and the pandemic). In September 2020, the Department of Education initiated a public consultation on certain aspects of the SEND Act which is currently ongoing.

1 O'Connor-Bones et al, 2020; Walsh et al, 2020

Research participants

In total, 31 in-depth interviews and 2 focus groups were held with participants from across Northern Ireland between late October and mid December 2020. Therefore, they were largely related to the first few months of the pandemic and lockdown restrictions and other measures, from March to mid December 2020.

The breakdown of participants is as follows¹:

- 35 young people aged 15–25 years;
- 16 parents whose children were aged 5–21 years;
- Between the young people and parents, a variety of disabilities (i.e. physical, learning, sensory, psychological, other and SEN) and severity of disability (i.e. mild, moderate, severe/profound) were represented;
- 9 practitioners representing organisations from the voluntary and community sectors working with families whose children are aged from birth to 25 years (some of whom were specialists in specific areas such as SEN, autism, sensory disabilities, learning disabilities, physical disabilities and complex disabilities) and;
- 3 teachers – one from a mainstream primary school and two from a special school.

The topics that the research explored were:

¹ It was not possible to include the views of HSC practitioners due to the process required by HSC Trusts to grant ethical approval to participate, which was outside the timescale of the research.

- How families and practitioners saw the practical changes the pandemic is imposing on children and young people;
- What implications they saw this as having for different aspects of children and young people's wellbeing and development;
- How families adapted to these changes in the environment and how their needs are impacted;
- How families were supported by services and wider civil society, including what worked well, what did not work so well and how services could be improved and;
- What families' and practitioners' priorities and lessons were for recovery from the impact of COVID-19.

The remainder of this interim report covers the key findings under the following themes:

- COVID-19 creating a double disadvantage for children and young people with SEND
- The impact on mental health and wellbeing
- The impact on learning and development
- Support from other agencies
- The impact on family life
- Participants' priorities for the near future and
- Next steps for phase two of the research



Key findings

COVID-19: creating a double disadvantage for children and young people with SEND

Children and young people with SEND are already isolated and at a disadvantage in several different ways, such as educationally, developmentally and socially. Parents of children with SEND and professionals who support them often feel they have to battle for each and every support that is offered. This already-poor situation has been exacerbated by COVID-19 and the measures taken to contain it:

"That has been my experience all along. Unless I go and roar and shout, nothing is done [about appropriate educational support for her child] ... I have to fight all the time" (Parent).

"There's always a shortage of [sports and social] things for young people with learning difficulties to do and activities and things like that" (Parent).

"Well there's always a battle, there's always a fight and we've been fighting from the first child we had with learning difficulties, who would have been in her thirties now and sadly she died. So, we've been fighting this battle endlessly for whichever child it was...and I think it's going to be even harder now... So, we are just going to have to keep battling even more [for access to adequate support from education and social services]" (Foster carer).

A recurring message from both parents and practitioners was that children with SEND were the 'forgotten ones' when the measures to combat the spread of COVID-19 were implemented:

"Children with special needs have just been forgotten about with this COVID" (Parent).

"They felt very left behind... (they were)

the words I heard on every phone call. We are forgotten about. We are left behind" (Practitioner).

The impact on mental health and wellbeing

Both the physical and mental health and wellbeing of young people and parents were impacted by the pandemic and the lockdown measures introduced to combat it. One parent contracted COVID-19 and another reported a child getting it. Both parents and young people highlighted the stress and anxiety of dealing with the fear of contracting the virus itself and the impacts of lockdown.

"I was terrified of [my daughter] getting it, because at that stage we didn't know how COVID would impact her with her disabilities, because she has a lot of respiratory issues" (Parent).

"At the start...I felt so uncomfortable and nervous on the bus. Felt very dirty and like I could catch it. I just didn't feel comfortable" (Young Person).

"...the other fear was myself getting it and not being able to care for [my daughter]" (Parent).

Parents also feared that, in the event of their child being hospitalised with COVID-19, they may not be prioritised if resources such as ventilators were in short supply.

"When the NICE guidelines came out at the start, that was really upsetting for parents because... there was a lot of panic with those families where they felt that, if their child needed a ventilator, were they going to get it?... So, that became a real fear for people" (Practitioner).

"...we were made aware that... the learning disabled were in the same category as the over eighties, and if necessary they would be pulled off a ventilator to give

it to somebody else. So, you are talking a seventeen-year old and twenty-one-year-old essentially not getting treatment because they had a learning disability... that angered me" (Parent).

For parents, school closures removed one of the few respite opportunities they have to recharge their batteries, attend to the needs of other family members and their own needs. Many parents stated that they felt they were at breaking point during the first period of school closures in spring and summer 2020:

"...he just lay on the floor and started screaming... having frequent meltdowns, his behaviour changed...So that actually resulted in me going off on sick leave with stress... it felt like I was getting burned out..." (Parent).

"...it was very claustrophobic. The behaviours just went through the roof...it became very extreme and emotional, very emotional...it was just me and the children. There was no let up at all... there was times you were just banging your head against a wall because...There's no let-up" (Parent).

The impact on learning and development

School and college closures had a profound, largely negative effect on children and young people with SEND, not only due to the loss of learning but also the loss of routine, access to therapies, specialised equipment such as sensory equipment and social opportunities with peers.

"From an educational point of view, it is not good for any child, but children with learning disabilities, you may as well take a year plus off them. They had all that time from March right through to September and they had absolutely nothing and no education.... (My daughter) has gone back to tech this year and she has regressed so much. She has regressed years. We are talking back down to stuff that...primary school kids would be doing. She was

always achieving and she is right down. I think educationally it has had a massive impact" (Parent).

"...the big thing I noticed with (my son was) his speech... and that's the big thing with special school. There are all the therapists on site. And then that was cut straight away" (Parent).

"...I could see the children who came to me whose parents had done absolutely no work with them at all during lockdown. And you could see that they had dipped massively...The majority of the children seemed to have gone down" (Teacher).

However, the lockdown measures did have some positive impacts in terms of education for some children: those who find attending school stressful felt more at ease being at home, without having to adhere to strict schedules; those who find social situations with peers difficult were relieved of having to do this and; older young people reported having more time to concentrate on their studies, as extra-curricular activities were cancelled or postponed.

"...whereas we really liked routine with the school work, we also had that freedom of doing it when it suited, to a degree. So, lockdown to me probably was a welcome relief compared to the year I'd had with the school prior to it" (Parent).

"... at the beginning of the year I was contemplating taking a break from uni and coming back to it at a time when my mental health was better...And because that pressure was taken away I could, you know, power away at it [university work]. My dissertation was ready a week before it was actually due... So, it really helped take the pressure off the academic side of things" (Young Person).

Support from other agencies

At the same time that schools were closed (from March 2020), other respite facilities were also closed and only opened up in a very limited

way when lockdown measures lifted in the summer. Social care services and other statutory supports were, parents perceived, also reduced or non-existent at this time. Some parents felt that the only support they received came from voluntary and community organisations, which were very agile and able to respond quickly to the changing situation to meet families' needs:

"I think the respite units should have been recognised as an essential service, just as much as the hospitals were... Did they really need to close down?" (Parent).

"He [son] has a disability social worker... We have heard nothing from them..." (Parent).

"Accessing support from social services is a battle... [and with] COVID ... [there's been] ...further disengagement...from the services that are meant to be there to support you" (Parent).

The impact on family life

Whole families were affected by the lockdown measures, not just the children with SEND.

"Because she was very angry and cross, she was taking a lot of anger out on her brother. He is only one and a half...and he got really afraid of her. And he couldn't understand. He was trying to comfort her and she was lashing out at him... she took a lot of her anger out on him. We couldn't leave them in the same room. She would have grabbed his hair and dragged him to the floor... He got a wee bit afraid of her... And it was very hard seeing her hurt him... But she would have pushed him down the stairs and she dragged him by the hair to the ground and kicked him" (Parent).

Older siblings living at home frequently assumed the role of informal carer to help support parents, often while trying to study too.

"...there's been a huge impact on siblings... And the more lockdown went on, the worse it got. They were trying to do school work..., maybe trying to prepare

for exams, but having to do a huge amount of care help in the home as well..." (Practitioner, voluntary and community sector).

There were, however, some positive aspects to lockdown, such as more family time for joint activities or hobbies and less pressure from external demands on families' time.

"We did loads of things, like we baked and walked to the shop through the fields and we were out on our bikes and we went for walks...We did an awful lot... Things that you don't have time to do, sometimes, in the normal day to day stuff...we camped outside...So, initially for those twelve weeks, I would have said the whole lockdown thing was quite positive" (Parent).

Participants' priorities for the near future

Priorities identified by the participants for the short term, in meeting the needs of children and young people with SEND as the pandemic continued, included the following:

Clear and consistent communication from government:

Practitioners called for clear and consistent communication from government to teachers and other service providers and, in turn, from service providers to parents, which would reduce the potential for confusion, reassure professionals as well as parents and create realistic expectations for both service providers and service users:

"...communication is vital in all of this, to be open and honest and have good communication...what was lacking at the beginning of this whole thing back in March, is that the communication was all through the media and it was scary, it was frightening... there wasn't reassuring communication from the Education Authority or from the Department of Education asking what the school needed. We were left to find our own way in the

dark. And it just wasn't good enough..." (Teacher)

Keep educational and respite facilities open:

The closure of schools, colleges and respite facilities has had a profound impact on young people and their families. Parents and some young people felt that keeping such facilities open should be a priority because disabled children are already disadvantaged and closing such facilities further compounds this disadvantage, making it even more difficult for both the young people and their parents:

"...keep techs and schools open... people with learning disabilities have the right to be educated... I don't want to lose my education" (Young person).

"My concern would be that the schools close again and then everything closes. His whole world shrinks again" (Parent).

Speed up the SEN system, so as to better meet the needs of children:

The current review of Special Educational Needs provides an ideal opportunity to improve several aspects of the system, including speeding up the assessment procedure and having more timely access to appropriate support so that the educational needs of children and young people are more effectively met.

"Well there's so much wrong with the current SEN system that that has to be addressed bit by bit. I think what's needed at the minute is the assessment for the children. They need to have access to the assessments they need in terms of their education. And then access to resources and specialist services. And that needs to be done much quicker than it is happening at the minute" (Practitioner, voluntary and community sector).

See education holistically:

Some practitioners and parents called for education to be seen, not just as an area for academic learning, but also for it to have more

of a focus on the emotional wellbeing of children and parents, with more resources provided to support the development and maintenance of positive emotional health:

"I do think that there probably would be an opportunity, a gap there that we could tap into, some more emotional support for the children. And actually, for their parents" (Teacher).

"I would like to see them focus on children's mental health a bit better at the minute... and... I would like to see them just not pressurise children as much at the minute to be up to the standard that they believe they should be at, because they have missed out on so much of their education" (Parent).

Enhance mental health provision:

Other respondents felt that there is an immediate need to prepare for a perceived likely increased need for mental health services as a result of COVID-19 and therefore, there is a need to invest in these to increase provision in the shorter term as well as in the longer term:

"I think the mental health impact of COVID is, and is going to be, huge. So, I think just to have more supports available for young people is what's needed" (Practitioner, voluntary and community sector).

"I think the government needs to recognise that the mental health of people during COVID and coming out of COVID, again is going to be far worse than what COVID actually did" (Parent).

Have more coherence across government to meet the needs of disabled people:

Some participants called for much more coherence from government, both in terms of the response to COVID-19 and in relation to meeting the needs of disabled people. This means coherence across policy development, service provision and communication with disabled people and their families, so that there can be a much more joined-up approach within and between different areas (e.g. health,

education etc.) to meeting all of their needs:

"More higher-level government (decision making) and ceasing f**king around with stuff, would certainly be much appreciated" (Young person).

"...we have written to the Health Minister to ask for a detailed plan around the restoration of key services. I feel that's really important for us all, collectively, but for the people we support to have some certainty around that. And we would also really welcome a more consistent approach in policy terms around the

guidance" (Practitioner, voluntary and community sector).

"I think some government department or somebody needs to be taking control of people with disabilities...(an) overarching person or body that would have government influence" (Parent).

"I just want them to look at the services and get their act together. It is very, very important that they get that message. You can't pull what little services that are there for people." (Parent).

Next steps – phase two of the research

NCB is currently conducting the second set of interviews. This involves returning to the same young people, parents/carers and practitioners, tracking and understanding their journeys through the second and third waves of the pandemic, exploring the impact of the more recent measures taken, as well as the potential for optimism now that the vaccination programme is underway.

The findings from all interviews will be reported in a full report later in 2021 which will include detailed case studies documenting individual families' journeys, lessons learned and how we might, as a society, build back better from this experience.



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The National Children's Bureau brings people and organisations together to drive change in society and deliver a better childhood for the UK. We interrogate policy, uncover evidence and develop better ways of supporting children and families.

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