Understanding Life in Lockdown for Autistic Young People

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Acknowledgements

1.0   Introduction

Children and young people with disabilities have clearly stipulated rights under the United Nations Convention on the Rights of the Child (UNCRC) (1989) and the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (2006). These include substantive rights such as the right to education, to health services, and to play, rest and leisure. Children with disabilities also have the right not to be discriminated against; to express their views in decision-making processes and for their views to be given due weight; as well as for their best interests to be a primary consideration when decisions are being made that affect them. In addition, they have the right to appropriate support to enable them to achieve their fullest possible individual development and to be provided with disability and age-appropriate support in expressing their views.

The onslaught of coronavirus has exacerbated the inequalities that children with disabilities experience and made it all the more challenging for countries to ensure that the rights of children are effectively realised. The Committee on the Rights of the Child (2020) has expressed grave concern at the effect of the pandemic on children and young people, particularly those who are marginalised. It has called on governments to consider the health, social, educational, economic and recreational impacts of the pandemic on the rights of the child and for restrictions to be imposed only when necessary, be proportionate and kept to an absolute minimum. Additionally, while acknowledging that the COVID-19 pandemic may have a significant and adverse impact on the availability of financial resources, the Committee has called on countries to ensure that responses to the pandemic, including restrictions and decisions on allocation of resources, reflect the principle of the best interests of the child.

The pandemic has implications for the extent to which children, including children with disabilities, are able to enjoy their right to education and to play, rest and leisure. The Committee on the Rights of the Child (2020) has called on governments to ensure that online learning does not exacerbate existing inequalities or replace student-teacher interaction. It acknowledges that while online learning is a creative alternative to classroom learning, it poses challenges for children who have limited or no access to technology or the Internet or do not have adequate parental support. Alternative solutions should be available for such children to benefit from the guidance and support provided by teachers. Finally, the Committee has emphasised that governments should explore alternative and creative solutions for children to enjoy their rights to rest, leisure, recreation and cultural and artistic activities including supervised outdoor activities at least once a day which respect physical distance protocols and other hygiene standards, and child-friendly cultural and artistic activities on TV, radio and online.

While there is a growing body of work that is examining the impact of the pandemic on children and their rights, there has been limited research that has specifically explored the impacts and experiences of children and young people with disabilities. This gap is all the more evident in the context of autistic children and young people despite anecdotal evidence suggesting that autistic children are no longer be able to access critical statutory and targeted support. This, combined with changes to 'normal' routines, profound uncertainty, a transition to online learning via home-schooling and restricted movement, can be especially distressing for autistic young people and some may find it difficult to express this. The primary focus of this small study was on the experiences and impacts of COVID-19 on autistic young people in post-primary education settings.

2.0   Research Methods

The project gathered qualitative data from 9 autistic young people using a child-rights based approach (Lundy and McEvoy 2012). The project was guided by a group of 4 autistic young advisors from across Northern Ireland aged between 11-15 years of age.

In collaboration with the young advisors, the researchers refined the project aims, developed the research method and developed the questions that would be used to visually capture their peers' experiences of their human rights during the pandemic, including during lockdown. The young advisors also played a key role in data interpretation, identifying the key themes that emerged from the data and the recommendations that should follow. When this project began, Northern Ireland was in a state of lockdown and the young people involved were engaged in home schooling. Towards the end of the project the restrictions began to ease.

Data was collected using Photovoice, a participatory arts-based method (Wang and Burris 1997). Existing research suggests that Photovoice is a particularly useful and rich method for accessing the perspectives of autistic young people (O'Hagan 2020, Teti et al 2016), requiring only a basic knowledge of photography and aligning itself with the widespread adolescent use of smartphone photographic technology. The research team designed a short guide to the project questions and things for the participants to consider when taking photographs including examples from the young advisors. Participants were asked to document the realities of their life under lockdown using their smartphones and to send their photographs to the research team via email or WhatsApp along with a short description of their reason for taking the photographs. Follow up individual interviews were conducted with each participant to confirm and clarify the meaning of each photograph. The questions used in the follow up interviews were designed in collaboration with the young advisors.

In total 9 participants took part in the study; 3 girls and 6 boys. While post-primary aged participants were sought from all school sectors, the final participant group profile reflected post-primary mainstream education in Northern Ireland. Participants were recruited through an email-drop to the Autism Advisory and Intervention Service (AAIS) and various SENCO networks across Northern Ireland. A poster advertising the research project was widely shared through the online platforms of Facebook and twitter. Young people and their parents who expressed interest were provided with accessible information sheets and consent forms and all participants who returned completed forms were included in the research.

Ethical approval for the study was received from the School of Social Sciences, Education and Social Work Ethics Committee in May 2020.

3.0   Main Findings

The findings are divided into two sub-sections. The first set of themes relate to the challenges that young people experienced since the emergence of the pandemic and lockdown; the second set of themes relate to the coping strategies and supports that young people identified as being helpful.

3.1   Challenges

The first part of this report depicts the challenges faced by the participants during their time in lockdown. These are divided into three sub-sections: isolation and space; uncertainty and the pressures of home-schooling.

3.1.1 Isolation and space

Young people told us that they felt very isolated during lockdown and that this led to what they experienced as a 'sombre' and 'depressed' mood. For the young people in this study the isolation manifested itself in the amount of time they now spent alone, often in their bedrooms. One girl presented herself as feeling very small in the face of something that was overwhelming and effectively 'taking over' her social life and leaving her feeling alone. Eimhear compared the coronavirus to a seagull 'because I sometimes feel like lockdown is eating up all my social life' (Photo 1).

Another participant shared how he felt 'sluggish' during lockdown and struggled to keep himself occupied in the absence of his daily school routine. In the picture below he shared with us his new hobby – collecting snails in the garden 'as a way to keep myself occupied during lockdown.' The object of the picture had a deeper meaning for him however; representing 'how I've been feeling during lockdown. At times it can feel a bit sluggish, nothing much changes and usually I'm okay with that but it's starting to get a bit monotonous.' (Photo 2)

This was reinforced by Stephen who noted 'I have been sleeping lots through lockdown as there isn't as much to do. I like to lie in and I've probably gotten a bit lazy'. (Photo 3)

Others spoke of being isolated from their friends. This could occur even when they had tried to keep in touch with friends and classmates. Ellen described how 'Everytime I've tried to facetime or meet up with my friends, they've all said No. They're all going out with each other and whenever I ask to join they say no' (Photo 4)
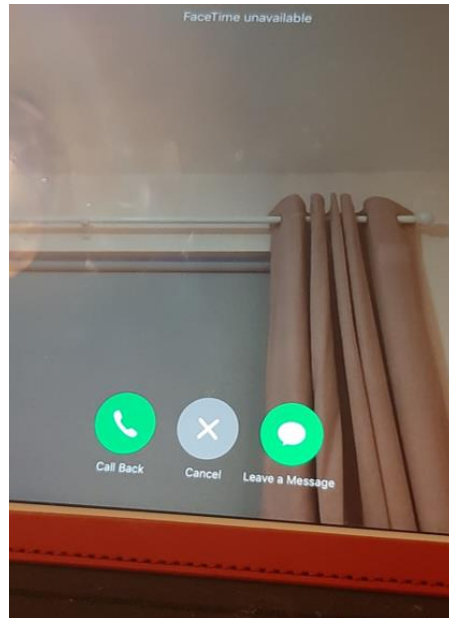
Some participants were more successful than others at keeping in contact with friends as Jarlath depicts in Photo 5 but Stephen in a similar photo describes this as "being social without having to be social."

Spending all of the time at home during lockdown and school closures heightened already existing stress and anxiety for some of the young people. Young people in the study were perhaps not used to spending so much time with family and siblings in restricted spaces and so felt that having their own space was a necessity. It was not necessarily something they wanted to do but was deemed to be necessary in

order to keep bubbling anxiety under control. Ellen for example, shared a picture of her bedroom, telling us 'I'm usually in my room all day. I know if I come downstairs to socialise with everybody I would get stressed. Sometimes my stress and anxiety take over and it makes me say things I don't mean'. (Photo 6)

As lockdown restrictions eased, some young people were able to go out and participate in sporting activities. What should have been an enjoyable activity caused anxiety when adults did not appear to take social distancing measures seriously. Sam shared a picture of a gravestone with a disused mask beside it. Sam explained the reasoning behind the picture – 'The technology that we were using was very stressful but it just didn't compare to the stress of catching Covid-19 was causing me and that Mummy could potentially die. There were situations when I was going to Gaelic even the coaches were standing shoulder to shoulder. I was so annoyed as I had gone there in confidence thinking social distancing like a sort of lockdown. I found it very difficult at times. The gravestone represents the danger of not being careful.' (Photo 7)

3.1.2 Uncertainty

Many of the young people referred to the uncertainty caused by the pandemic and noted that subsequently finding a way to construct some kind of 'certainty' became important as a way of coping with lockdown. Like all young people, the participants in this study were worried about what was going to happen and how long the pandemic was going to last. Darach used a picture of the sea to tell us how he felt about the current situation. He said 'The beach goes out a bit so you can't really see what's at the end, this is like my current situation and the world's current situation, we don't know what's at the end and we don't know what's coming for us and what's coming for me. I don't really know what's at the end of the road. It's uncertain.' (Photo 8)

Some in the study tried to regain control of this uncertainty by taking on new hobbies (see below) or implementing a new routine. In the picture below we can see a visual representation of this routine from going for a run in the morning, having breakfast, doing schoolwork, playing camogie, reading in the afternoon followed by dinner, some television and bedtime. This was important for Patricia since 'When we had school at the start, I found it quite hard. I needed routine and I needed structure. I needed to know. I'm not the sort of person who can do school one day at 9am and then 4pm the next day. I need things to be the same and predictable. These are all the objects of my routine,' (Photo 9)

3.1.3 Pressures of Home-Schooling

Young people who took part in the project consistently referred to the pressures and stresses associated with the move to home-schooling. The need to engage with new educational platforms across multiple subjects could be overwhelming at times. Sam for example shared a picture of books and pens covering each other and told us 'It's as if you are covered by all the books, like they're traps. I was finding it very difficult with all the work coming in. All the writing and reading coming in was overwhelming and there was no clarity' (Photo 10)
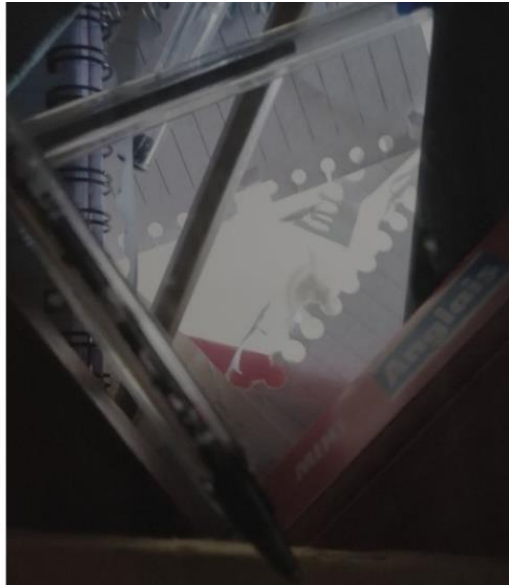
Jarlath used his photograph to demonstrate just how much homework was part of his life during lockdown. (Photo 11)
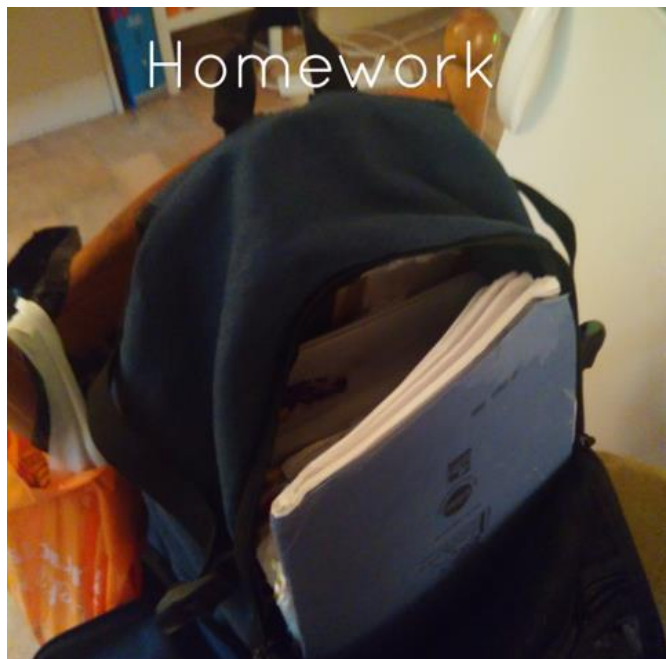
This feeling of not quite knowing what to prioritise or what to focus on what shared by another young person. Sam also took a picture of tangled leads to demonstrate the 'messiness' and frustration with trying to make sense of online learning. Sam said 'I felt like my hand was tied by having to check all these different tasks on different platforms, some projects on MyMaths, some on google classroom, some as notifications, some as assignments. You don't know where to find work and teachers expected you to remember exactly what would happen and to check at different

times. It actually would take so much time to look for your work [that] you wouldn't have very much time left to do it in the end' (Photo 12)

For some participants, certain subjects were easier than others. Subjects that were traditionally experienced as stressful became even more stressful in an online environment. Ellen shared a picture of google classroom alongside a notebook: 'That's google classroom and these are some of my classes but my book is closed because I'm trying to represent that I've been finding work really stressful and I haven't been able to do it. I've been able to do the stuff that I find easy but I find maths and science really stressful' (Photo 13), this was something also confirmed by James who stated that not having his learning support teacher made it impossible for him to do Maths at home due to his dyscalculia.

3.2 Coping Strategies

The second part of this report focuses on the coping strategies that young people found helpful during lockdown and in adapting to a 'new normal'. These are divided into three sub-sections: relationships, hobbies and the importance of being outdoors.

3.2.1 Relationships

Families were usually the first point of contact for young people in the study. Young people shared their anxieties with parents who were able to provide reassurance and help the young people navigate the challenges that arose. Patricia for example shared a picture of a large teddy bear and a small teddy bear, representing her and her mother chatting over a cup of tea. She said 'I chat with my Mum on a day to day basis. She knows what would make me anxious most of the time, she can almost predict when I'm going to be anxious. If I'm worried about something, I can just talk to her about it and she can help me. My mum can calm me down, give me a hug, get the weighted blanket or go on the swings.' (Photo 14).

Relationships with extended family members were also important – grandparents and cousins provided participants with happy memories they could tap into although also sadness due to not being able to see each other during lockdown. Ellen shared a picture of a drawing she had done of her cousin, encouraged by her grandfather: 'Whenever I see this picture I remember about my baby cousin and how I was always happy holding him. I hope I get to see him soon. My Granda is an artist and he helps me with tips. I'm still working on this and it's better now than before. (Photo 15)

Pets were perceived as a central part of family lives and a key source of comfort and companionship during what was an isolating time. A number of the young people in the study shared pictures of their dogs. Stephen introduced us to his dog, Lennie: 'Lennie has helped me through lockdown. It's hard not being able to see my friends but I have been able to take Lennie for a walk everyday'. (Photo 16)

Ellen's family welcomed a new puppy during lockdown. This appeared to be a conscious decision: 'This is my new puppy Beano, He helps me with my stress but sometimes he puts stress on me. He's been a good addition since lockdown'. (Photo 17)

Other young people found it helpful to talk to professionals. This emerged as an important source of constant support during lockdown. However, the now virtual nature of this support brought its own challenges and made it more difficult to engage with. Patricia explained that her therapist 'phones me every week or every two weeks. Talking… is problem solving. It's more than just conversation. If I have a problem or am worried about something I talk to her and come up with the solution. But on the phone you can't see her reaction. You can only hear it, normally I would have a bit of time to catch up with her but it's harder to talk on the phone than in person. The phone calls are shorter than normal appointments so you can't go into as much detail' (Photo 18)

3.2.2 Hobbies

The majority of young people in the study had drawn on existing hobbies or developed new hobbies as a coping strategy during lockdown. This provided a source of distraction, routine and instilled a sense of calmness. Hobbies ranged from exercise and music to learning new skills and rediscovering existing ones. Stephen, for example, had taken up mountain biking: 'I like to get out of the house and do something myself everyday. I cycle around the Mary Peters track and am respectful of other people's boundaries. I didn't really do this before lockdown'. (Photo 19)

Some young people found solace in nature and used the lockdown as an opportunity to grow plants and vegetables: Stephen told us 'in the first two weeks of lockdown, I did lots of gardening, painting the fence, taking moss out of kerbstones and planting two vegetable patches. We've been eating lots of the lettuce' (Photo 20). James described how lockdown gave him more time for gardening which he enjoys and he takes pride in photographing his chilli plants (Photo 21)

Both Ellen and Eimhear enjoyed baking during lockdown, Ellen found that this helped her 'relax and it helps me forget about the things I'm worrying about. I've been worrying a lot' while enjoyed baking Eimhear with her little sister as a result of the baking packs sent out by the autism family support group in her area. (Photos 22 and 23)

Also a group autism NI has sent us the ingredients and instructions on how to make buns me and my sister really enjoyed this

Some participants referred to going for works in nature, in the local woods where it was calm while others talked about going for walks with their dogs. For Joe, collecting snails was the chosen hobby; 'a way for me to have company. Having something to interact with is nice.'. (Photo 24).

3.2.3 Being outside

Six of the nine participants stressed the importance of having time outside everyday as a way of alleviating the stresses and worries they were experiencing during lockdown. Time outside was built into the new routine of their days at home and was a welcome and necessary reprieve to online learning and being confined to their houses. What is striking here is how each of the participants have clearly identified the therapeutic aspect of being outside. Darach describes this as a sanctuary for him (photo 25).

Both James and Patricia stressed the importance of clearing their heads outside everyday. James describes everything else continuing to grow but he doesn't feel he is growing intellectually anymore but that being outside is helping (Photo 26) whereas Patricia has recognised in herself a need to be outside away from the overwhelming sensory stimuli of indoors (Photo 27).
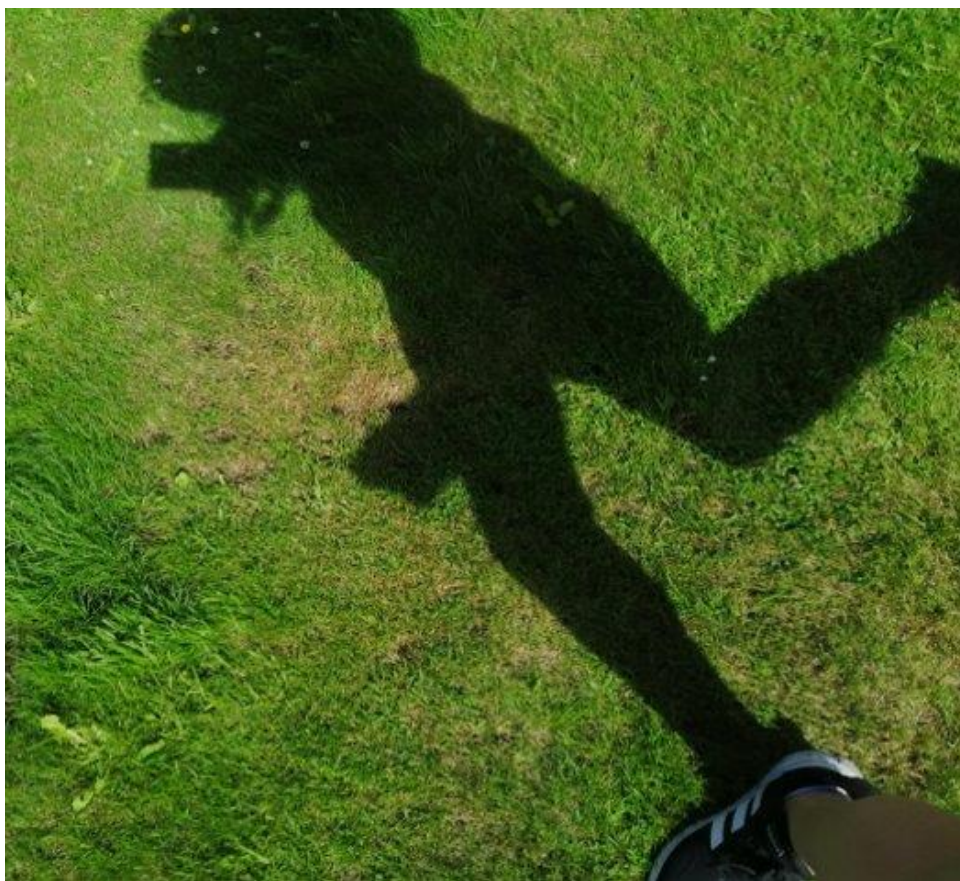
Finally, Sam very clearly articulates the therapeutic benefits of being outdoors in Photo 28: "It's blurred in the background and pixelated in areas because at times I have found myself very, very stressed and there was a lot of frustration and anger building up. The bike is very clear because I find a lot of solace or it'll be like a great escape to go on a bike ride. It was so good to have my bike to have the opportunity to escape from all the school work."

4.0   Conclusion and Recommendations

What is clear from this research is that autistic young people's experiences of lockdown were more negative than positive with 28 of the 43 photographs describing stress, anxiety or worry. There were many challenges for all the participants involved in this research and there was a shared urgency to illuminate these particular challenges to ensure that should a future lockdown occur, these stressors could be taken into consideration when making lockdown arrangements for autistic young people. The co-researchers acknowledge that there is no one size fits all approach to this:

"*There is not one cure for this, we need to look at things individually and figure out things for each different person.*"
(Joe- research advisor)

Recommendation 1

Considering the themes identified individually, from an isolation perspective, autistic young people rely on extended family networks, voluntary groups and statutory

services that provide opportunities for social interaction and these opportunities may not exist within a closed family unit. In restricting contact with these wider key people, levels of isolation soar and contribute to loneliness and associated poor mental health, an adverse factor already associated with autistic young people.

The reliance on communication technologies in offering opportunities for social interaction is not easy for an autistic young person to engage with and can certainly not take the place of face to face interactions for both personal/social engagement and clinical therapeutic interventions. Therefore, any future lockdown restrictions should aim to give specific considerations to autistic young people in terms of movement restrictions within wider family circles and prioritise appropriate face to face access to the services designed to support autistic young people.

Recommendation 2

With regards to home-schooling and online learning platforms there are several points which autistic young people wish to be considered. In the school environment, learning for autistic young people is scaffolded by key support staff: classroom assistants, learning support departments and differentiation from the class teacher from within the classroom and there is an acknowledgment by school staff of the classroom and curriculum accommodations required to enhance learning for autistic young people. In the absence of attending school, all these supports are withdrawn and are replaced with inconsistently used learning platforms where tasks appear ambiguous in terms of structure, length, duration and deadlines. Even identifying where to find the relevant information regarding learning tasks is neither straightforward nor predictable for the autistic young person. Furthermore, there is no acknowledgement of the extra time required by an autistic student to navigate the learning platforms and coordinate their response to the inordinate amount of learning tasks set across all their subjects. This has resulted in some of the participants engaging in school days lasting upwards of 12 hours. Participants felt this was a result of teachers overloading their classes with work without any regard for the learning needs of students within their classes who may be overwhelmed by the volume of work set coupled with the requirement for independent learning and successful navigation of online platforms.

The recommendation here with regards to school-work when required to work from home is quality over quantity. The learning tasks set should be meaningful, adding to learning in a systematic and scaffolded way, mindful of the fact that the pace of teaching new concepts online is a much slower process for autistic students than in the classroom. The volume of work required by teachers needs to be monitored not just within subject departments but agreed across all subjects so there is a coordinated response by schools in terms of setting a time limit for school-work when students are learning from home. This time limit should bear in mind the extra time required to coordinate learning by attending to an online platform to paper based tasks and the subsequent submission of work. There may well be instances where it is inappropriate to set tasks in all subjects and a core set of subjects should be prioritised in terms of a time budget for autistic students. While this would be

appropriate for all students, it should be made explicit to autistic young people that a stipulated amount of time for school-work is sufficient each day instead of a stipulated amount of work.

Recommendation 3

The third and final recommendation is linked to the previous recommendation of a time budget. It is very clear from this research that autistic young people need time to engage with their hobbies and the outdoors in order to mitigate against the negative aspects of life in lockdown. This time should not be seen as simply recreational, but rather a meaningful way of improving mental health wellbeing when other usual supports and clinical services are no longer available. Mental health wellbeing should be formally included as part of the school curriculum when home schooling/online learning is taking place and there should be discrete time for this included in the time budgets for each school day.

While this recommendation would clearly support all students in lockdown, it has particular relevance for autistic young people who may struggle with lack of consistent routines and daily predictability of lockdown education. Furthermore, prioritising mental health wellbeing during lockdown will make it easier for the autistic young person to reengage with learning on return to school. Rather than experiencing protracted disaffection from online learning, a positive home school learning experience where autistic young people have continued support for their mental health coupled with realistic demands of school work will make for a much smoother transition back into mainstream education.

Concluding statement

Our autistic young people have demonstrated through this research that home schooling and online learning was disproportionately difficult for them compared to their peers and contributed to their isolation and loneliness in lockdown. Autistic young people had to devise their own coping strategies for the inordinate stress and pressure they felt during this time coupled with the removal of the key support networks they usually rely on. In moving forward there is one clear and consistent message from autistic young people with regard to the specific consideration that must be given to shaping lockdown for autistic young people:

"*During a pandemic, you cannot leave people with autism without help, without support.*"

(Eimhear – research advisor)

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