AUTISTIC YOUNG PEOPLE'S & FAMILIES' EXPERIENCES OF EDUCATION DURING THE COVID–19 PANDEMIC

PROJECT REPORT

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SUMMARY

This report collates the findings of a qualitative research project carried out throughout 2021. The objective of the project was to explore the educational experiences of autistic young people and families during the Covid-19 pandemic. Documenting the learning that can be taken forward in future educational policy and practice for autistic young people was a priority.

Unlike the mainstream narrative that the pandemic has had an inevitable and enduring negative impact on young people universally, this project discovered a far broader range of accounts, and in some cases, significant improvements in young people's educational experiences due to the dramatic changes education underwent during this time. The following is a summary of the main project findings which sit alongside a digital collection of artworks created by autistic young people and a comic strip.

1. **Young people's social lives changed significantly** during the pandemic in both positive and negative ways. For some, there was a relief from social pressures whilst others deeply missed friendships and physical social connection.
2. **When young people did attend school, changes within school changed dynamics.** Some of these changes had brought noticeable improvements to young people's experiences of school through reducing busyness or unpredictability. Other young people felt changed spaces and changed rules (such as 'bubbles') restricted friendships.
3. **Young people's and families' relationships with exercise changed.** Some talked about being able to move their bodies in ways and at times that felt good for them, rather than the activity and time restrictions of school PE or home education sports. Others were missing the stimulation and socialisation that team sports offered.
4. **Rhythms of daily life changed.** Seemingly small adjustments to young people's levels of physical autonomy meant they felt more able to concentrate on learning as they were working with their natural preferences rather than against them.
5. **Parents felt pressure.** Parents were key workers worrying about what was going to face them at work, working from home, or furloughed, worrying about financial stability. All experienced pressure ensuring their children were educated during this time.
6. **School bled into home.** During home-schooling periods, the lines between home and school became blurred. Some valued support from school while for others school was an unwelcome intrusion into their homes.
7. **Teaching and learning were more recognisably distinct.** While some young people valued structured, taught lessons, others benefited from self-directed, autonomous learning, with explicit teaching giving way to the facilitation of learning.

THE PROJECT

The Covid-19 pandemic first impacted upon the educational provision of young people in the UK in March 2020 and continues to be a significant influence in all of our lives. This project, originally conceived to reflect upon the impact of Lockdown 1 on the educational lives of autistic young people and families became longer and broader than originally planned due to the persistence of the pandemic. Children and young people that the government classed as educationally 'vulnerable' at the onset of Covid-19 included those with Special Educational Needs and Disabilities (SEND) holding Education, Health and Care Plans (Coronavirus Act, 2020). This meant that in the earliest restrictions of the pandemic, young people with EHCPs were in the minority of the population still being offered access to face-to-face education at school if it were deemed safe to do so (UK Government, 2020). Young people with SEND but no EHCP were to remain at home (unless the child of a keyworker). A further group of young people were home educated prior to the pandemic, and further still, a group of young people may have flexibly attended school during, or since Lockdown 1 began. As we now know, the end of Lockdown 1 was not the end of Covid-19-related restrictions in and around education. To date there have been some form of educational mitigations to reduce viral transmission in place for 22 months and counting. This project focussed on the experience of autistic pupils and their families across this full range of educational scenarios to explore how they have fared in this significant period in the history of British education.

There is a wealth of literature evidencing the challenges autistic young people encounter in education (Williams, Gleeson & Jones, 2019; Pluquailec, 2018; Wood, 2018; Dillon, Underwood & Freemantle, 2016; Howe & Stagg, 2016; Parsons, 2015). This project sought to explore young people's and families' experiences of how these challenges have changed during the pandemic, both within the changed school environment and/or while being schooled at home. This project has been valuable in examining the impact of the continued changes to education for autistic young people and how this disruption could actually be an opportunity to explore education done differently in the context of a system that we know often fails disabled pupils. Research findings about this important period are beginning to emerge including the impact of the pandemic upon; disabled young people broadly (Allfie, 2021; Disabled Children's Partnership, 2021), families with autistic children (ACER, 2021), the educational experiences of those with SEND (Shepherd et al., 2021) and autistic pupils in mainstream schools (Oliver et al., 2021).

Disabled young people are often the subject of decisions that don't include their experiences or voices. The same is true for the families of disabled young people who often report that educational and policy decisions don't account for the lived experience of raising a child in an under-resourced system steeped in ableism. It is hoped that this research will, in a small way, contribute to a narrative of young people's experiences as central to collating evidence of educational experiences, particularly during a period of enormous change and long-lasting impacts.

TIMELINE OF RESTRICTIONS IN EDUCATION

March 23rd 2020: schools required to close to pupils (with a limited number of exceptions) and all learning to take place at home

Summer 2020: Exams cancelled (GCSE, AS, A Level and equivalent qualifications)

June 1st 2020: School doors reopen to a limited number of pupils – nursery, reception, year 1 and year 6 with bubbles and social distancing in place

September 2020: reopening for all pupils with bubbles and social distancing in place

January 4th 2021: schools move to remote learning once again

March 8th 2021: pupils began returning to school with a staggered start for secondary school to account for testing

Summer 2021: Exams cancelled (GCSE, AS, A Level and equivalent qualifications)

September 2021: schools reopen for autumn term; no requirement to keep pupils in 'bubbles', nor to routinely send home groups of pupils when one tests positive

January 2022: Schools return from the Christmas break; face coverings temporarily reintroduced for secondary pupils in classrooms & when moving around the school, unless exempt

METHODS

The project data collection took place throughout 2021 which included periods of local and national lockdown. Schools, though remaining open in some form throughout, were not in the position to have researchers on site due to public health guidance, whilst universities were similarly prohibiting researchers from carrying out fieldwork. This called for methods of data collection that could be carried out remotely – methods which were proactively designed, but also responsively adapted as the landscape of 'Zoom life' (Wiederhold, 2020) for researchers, school staff, and families alike, evolved from March 2020 onward.

Data collection phases

Phase A: 3 creative workshops carried out by school staff in an autism special school classroom over 3 weeks: July 2021

Phase B: family interviews: April – September 2021
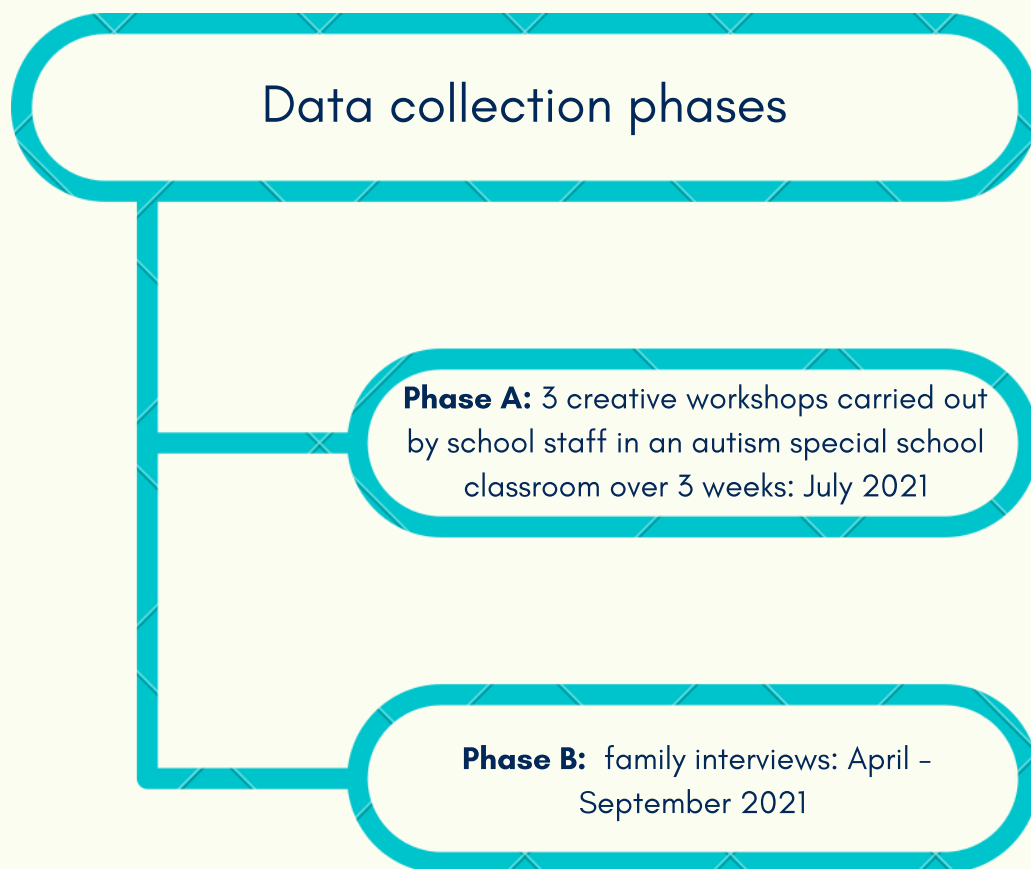
ADVISORY BOARD

The project had an advisory board of volunteers made up of autistic people and parents/carers (most of whom were also autistic or neurodivergent). This group of 10 people shaped the design of the project and focussed the research direction to attend to specific areas that were pertinent within the community. The group drove important conversations about ethical and inclusive research design for which the researchers are incredibly grateful.

FAMILY INTERVIEWS

In recognition of the often voiced autistic community's hesitancy about research that seeks only parents' views, we designed 'family interviews'. Interviewing young people alone online was not possible for ethical reasons, so instead we invited both parents/carers and young people to be interviewed together. Autistic young people are most likely to be living within family homes and are therefore part and parcel of family dynamics, these family dynamics likely to have changed, and often intensified, through the pandemic. Adult family members often had to take on new roles as educators for those young people who were being schooled at home for the first time. It therefore felt important to recognise that this family unit might have had considerably different experiences and interpretations of what education had been like during this time. Young people were recruited to these family interviews via their parents. There are ethical issues regarding gatekeeping and young people's informed consent that need to be recognised; young people were not able to volunteer themselves as participants alone, and young people may have felt less able to make an informed decision about taking part when their parent/carer had already agreed to take part. With the complexity of consent recognised (Pluquailec, 2018), it was emphasised in both recruitment materials and pre-participation email exchanges with parents/carers that a young person was under no obligation to take part.

In total 9 interviews took place, with 3 of those interviews including participation from autistic young people. These families had a range of educational backgrounds prior to the pandemic, from full-time mainstream school (primary and secondary), specialist secondary, mainstream Further Education, and home education. For clarity, 'home education' refers to young people who are educated otherwise than at school. 'Home school' refers to education that happened at home for young people who usually attended school. The broad range of backgrounds was deliberate as we were less focussed on particular provision and more focussed on autistic experiences and the potential learning that could come from hearing that range of experiences, regardless of where or how a young person was educated. Each interview was an hour in length, held via an online meeting platform, audio recorded and transcribed for analysis. The interviews were analysed thematically by the research team and findings drawn that represented the range of experiences participants shared in their interviews.

SCHOOL WORKSHOPS

Traditional modes of engaging in autism research have been criticised for being deficit-focussed and disempowering (Milton, 2014) particularly in relation to children (Pluquailec, forthcoming). The project collaborated with an autism special school for 11-19 year olds to develop methods of working with autistic young people in creative and accessible ways. Ethical practices of centring access and participation (i.e. for those who can't or choose not to speak, or for those who communicate with additional support and technology, to name a few) were employed. A video introduction to the project was shared with the school so young people could learn about what participation would mean without reliance on reading information. This also provided an opportunity for young people to see and hear who was carrying out the research (one of the research team was the speaker in the video) to set a distinction between school staff and school activities, and the research and research activities.

Research with/in schools is notoriously difficult (Oates et al., 2016; Plummer et al., 2014; Harrell et al., 2000) and this has without doubt been compounded by the restrictions that have been at play due to Covid-19. The research team met with the delivering staff to develop workshop materials that enabled a creative exploration of young people's experiences. This included (but was not limited to), paper diaries for completion, art-based tasks with participants creating work relating to their experience, audio diaries/recordings, photographic diaries and creative writing opportunities. During the course of the project, the school was working with a reduced number of students (due to national lockdown at the time) which led to the adaptation of the methods for a narrower group of young people to one specific class. With the input of the class teacher, based on their knowledge of the young people's preferences and areas of interest, the range of workshop activities was more heavily structured into separate tasks to be completed each week, and closer guidance on the completion of the activities were given. For example, rather than broad topics, the topics were refined into a series of questions and a computer-based activity for pupils who enjoyed such tasks, to be completed over a 3 week period.

In total, 9 young people in year 11 took part and all chose to participate by completing a series of artworks in each workshop, mostly one artwork each week. We asked staff to support the young people to share their descriptions of their drawings through written explanations, audio recordings, or scribing for the young people. For the most part these explanations were a handful of words. Rather than integrating the artworks from the young people's school workshops into findings, we instead present them discretely as a digital collection. It is important that we do not speak over these artworks. Instead, we share them in their completeness to document a moment in July 2021 which captured 9 autistic young people's artistic representations of their experiences of the Covid-19 pandemic to date. Where text appears within this collection these are the words written by (or scribed on behalf of) the young people themselves.
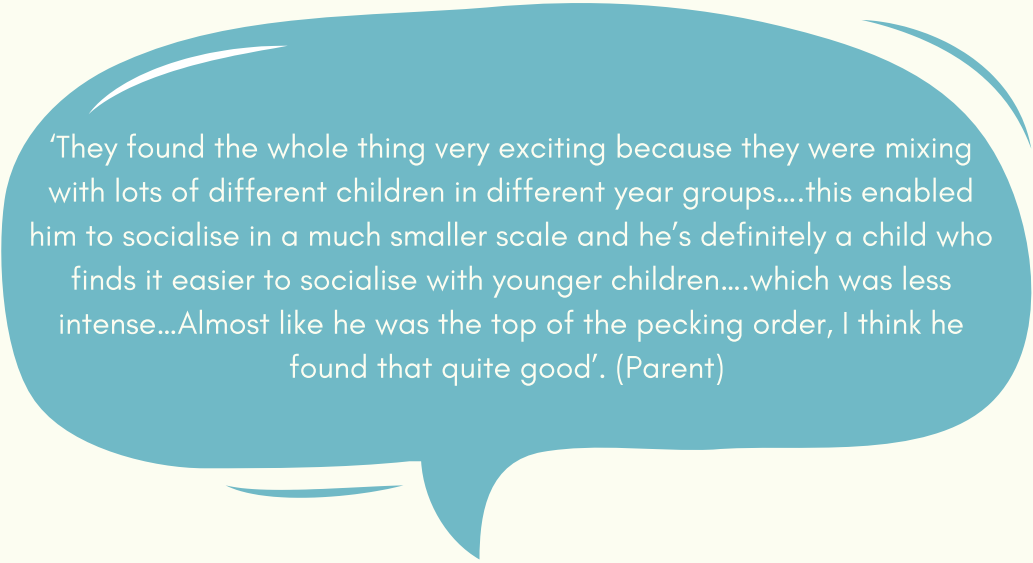
FINDING 1
YOUNG PEOPLE'S SOCIAL LIVES CHANGED SIGNIFICANTLY

Inevitably, as education provision changed, so too did young people's social lives. The impact of those changes was felt in a number of different ways, often dependent on how happy young people had been in relation to their social worlds previously, and wasn't necessarily a static experience throughout the pandemic as restrictions came and went. For some young people they missed being able to see and touch their friends during the periods when attending school or home education activities were not possible or when social distancing prevented them from playing their usual games. For others, being at home more meant relief from the pressure of social relationships often brought. Further still, some young people had moved their friendships online or had always been happiest socialising online regardless of the pandemic. Others had attempted to interact with peers online but had found it both overwhelming and isolating.

'We have to stay 2 metres from each other because me and my friend like to play a lot of games and most of them involve touching each other. So it's hard to not do that. We ended up doing it anyway because we forgot that we're supposed to stay 2 metres.' (Young person)

'He was angry because he couldn't do what he wanted at school, he was angry because he missed out on all the leavers' stuff because they weren't allowed to go in for it. The shirt signing, we could drop a shirt off but they weren't allowed to go in and sign it.' (Parent)

'He hates being on his own. He has kind of got used to it, but he hates being on his own and he wants to be normal and to him normal is going into a classroom with his friends, in a big group, and learning. With all that social hubble-bubble going on around him, that is what normal is.' (Parent)
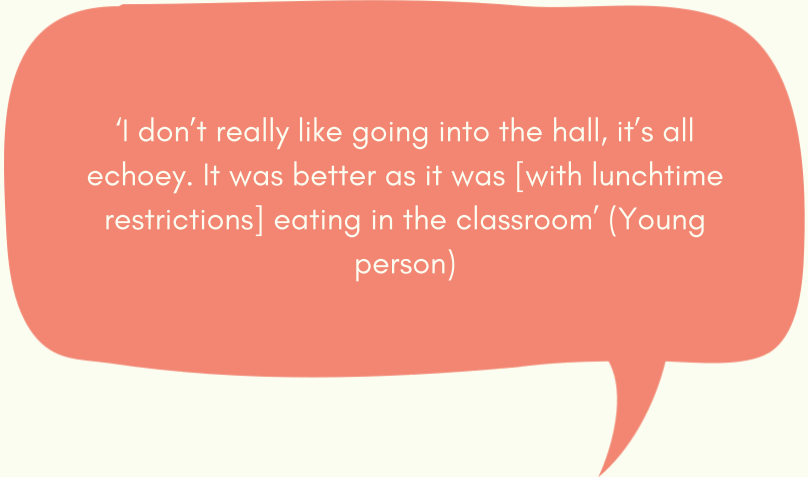
'They found the whole thing very exciting because they were mixing with lots of different children in different year groups....this enabled him to socialise in a much smaller scale and he's definitely a child who finds it easier to socialise with younger children....which was less intense...Almost like he was the top of the pecking order, I think he found that quite good'. (Parent)

FINDING 2
WHEN YOUNG PEOPLE DID ATTEND SCHOOL, CHANGES WITHIN SCHOOL CHANGED DYNAMICS

Most families we spoke to had experienced returning to school at some point with a variety of physical changes to the school environment (such as signage, classroom layout, changes to social and dining spaces) and structural changes (such as changed class sizes, the introduction of 'bubbles', altered timetables, different teaching and support arrangements). Some of these changes had brought noticeable improvements to young people's experiences of school. The introduction of bubbles, for example, made life more predictable for one young person who liked knowing who it was possible for them to come into contact with. Others had friendships restricted through separate bubbles and restrictions on playground mixing. One family who had attended school during lockdown had class groups changed to include mixed age groups. This had been a positive shift in dynamics for that child who had previously found their year grouping difficult.

'I don't really like going into the hall, it's all echoey. It was better as it was [with lunchtime restrictions] eating in the classroom' (Young person)

FINDING 3
YOUNG PEOPLE'S RELATIONSHIP WITH EXERCISE CHANGED

During the earliest phase of the pandemic, 'daily exercise' was one of the only permitted reasons many people had to leave their homes on a regular basis. Joe Wicks' 'PE with Joe' became a common feature of many families' new lockdown life with some schools explicitly building this into the remote learning school day. Perhaps due to this public discourse of the importance of 'daily exercise', this was a topic brought up in almost all family interviews. Each family talked about the way their relationships with exercise, or moving their bodies, had changed in some way. For many, this was new found enjoyment of exercise. Whether this was because moving one's body was no longer reserved for school PE classes, or whether it was because it counteracted the experience of inevitably being more confined during lockdown, it was a significant part of young people's and families' pandemic experience. Some talked about being able to move their bodies in ways that felt good, at times that felt good to them, rather than the restriction of particular forms of exercise at set times of day that school dictated. Others were missing the stimulation and socialisation that team sports had previously offered and found exercise on their own didn't have the same appeal.

'I've never said this before but at school because I'm so constricted it feels like I'm tense, I can't move as well, so when I'm exercising it's not really doing anything for me. I'm concentrating and I've got the pressure because that's what I've been asked to do. I don't want to break the rules and I'll….I won't benefit.' (Young person)

'…he went right I'm going to get fit because I want to and he put a dance mat down and he did an hour a day for like 6 months and his body shape changed dramatically… because he was relaxed…That's autonomous.' (Parent)

'…he doesn't do early mornings very well so having a 9am start was just desperate, [it] just doesn't work for his biorhythms or whatever… [now] we know that if he's got work set that he'll do it independently….whereas hauling him out of bed and then he says he feels sick because he hasn't had breakfast because he hasn't been up in time, and then getting to school and having a headache and all of those sorts of things are just gone' (Parent)

FINDING 4
RHYTHMS OF DAILY LIFE CHANGED

All families talked of the changes to their daily routines and rhythms of life. No longer having the structure of the school day, home education activities, office commutes or similar, meant families had to find actively or naturally, new ways of organising family life. Families had different approaches depending on a number of factors including external constraints such as parent's working arrangements or the competing needs of different siblings, but all talked about this as a significant feature of young people's educational experiences during this time. For some their sleeping and eating habits had been new drivers to how and when learning took place or not; patterns of going to bed and getting up shifted, young people talked about the difference it made to eat when they were hungry rather than following timetables, or wearing clothes that they felt more comfortable learning in which school didn't allow. For some, these seemingly small adjustments to their levels of physical autonomy meant they felt more able to concentrate on learning as they were working with their natural preferences rather than against them.

'…clothes they'd either stay in their pyjamas or just in their pants which is their favourite way to be…There was no pressure from that point of view. Mealtimes were very relaxed. It was on demand rather than you must eat at a certain time.' (Parent)

FINDING 5
PARENTS FELT PRESSURE

Many of the parents spoke of the pressures they felt during the uncertainty and upheaval of pandemic life. Some parents were key workers, on the front lines of the pandemic, worrying about what was going to face them at work. Others were furloughed, worrying about financial stability. Others were attempting to work from home with new or increased work demands. All were dealing with trying to ensure their children were educated during this time. Pressures relating to financial insecurity, keeping families safe, and making sure children were educated were all highlighted. Sometimes pressure experienced by the parents understandably filtered down to young people in families.

'That whole period is a bit of a blur because I spent so much time worrying if I could keep our business afloat... working out how long our capital could last paying us before the business went bankrupt.' (Parent)

'I was getting all stressy about why he wasn't engaging with [home school]...I didn't realise the pressure I was putting him under and I hadn't really appreciated that distinction for him [home and school] and it became, I think, really oppressive.' (Parent)

'I found [home schooling] very intense for me. I'm a nurse so worries from work were perhaps spilling over. I felt like I had a lot of pressures on me...I was very relieved they were able to go back [to school]. I never knew what I was going to be faced with at work.' (Parent)

'I got a bit naughty. He'd got to the point where he'd had enough so I was like, 'Come on, we're off for a walk'. I was just lying to the teachers and saying I've got an appointment. We were off swinging on the rope swings in the woods.' (Parent)

'I associate places with things. School is for working and home is for watching Youtube...so if I have to work it doesn't feel right.' (Young person)

FINDING 6
SCHOOL BLED IN TO HOME

When schools closed and educational and social activities in home educating communities had to stop, social and academic activities began to be organised online. Teachers provided activities to be worked through at home. In some schooling families, there was a clear distinction between home and school: 'school is for work, home is for relaxing'. For those families, support from school seemed to feel more of an intrusion than a help. For others, guidance and structure from school was very welcome, though ensuring that accessibility was prioritised was hard to come by, for example by giving notice of what the activities for the next day were going to be. For others, school seemed to 'disappear' out of their lives, with both positive and negative consequences. Online social time arranged by schools could be helpful, but problems arose when access needs were not prioritised, e.g. when a child wanted to join in but was uncomfortable having their camera on. In schooling families, with the 'school' day and the 'home' day becoming one and the same, expectations of who was 'in charge' seemed to become blurred.

'He needs information prior to the lesson...it was something I was pushing as a reasonable adjustment but I couldn't get anywhere with it.' (Parent)

'He's definitely happier now school isn't pushing into his time at home.' (parent)

FINDING 7
TEACHING AND LEARNING WERE MORE RECOGNISABLY DISTINCT

Something that was already familiar to the home educating families, but became noticeable in other families too, was the young people's engagement in self-directed learning. Where school lessons at home were difficult to engage in, and where home education activities outside the home were no longer available, young people found other ways to learn. The distinction between teaching and learning became apparent. Some young people were happier when provided with structured work whereas others rejected formal teaching in favour of learning in their own way, with support from adults only welcomed when it was needed.

'He's learning how to use Adobe premier pro...He rarely wants help with it. He'd rather just get stuck in & do it himself...I said it's time to do maths & he went, 'I'm very busy,' & he actually was busy editing a review that he'd done... You know, when you've got a goal you can then apply all those things you need for that goal. I mean, he's written scripts, he's critically analysed the text of the source material & so there's all that kind of English language...that he's just learning because he wants to make the video. That's really good. That's self learning isn't it.' (Parent)

'He said, 'Mum, can we do maps?'...so we did maps so he now knows where a load of cities are and he knows the rivers, the towns, the oceans, the continents, we did flags, we did loads of stuff. He did WW1 & 2 and who knows what else...he watched videos then came and discussed it with me...he did lots of baking...he cooked.' (Parent)

RECOMMENDATIONS FOR FUTURE PANDEMIC SITUATIONS

Where young people and families faced challenges through their pandemic educational experiences there are lessons that can be learned both in future policy and practice for autistic young people in general, and, in the case of future public health crises demanding emergency educational interventions. The questions policy makers and practitioners need to hold in mind in their planning include:

1.**What does home schooling mean for friendships and how are they best enabled?** This needs to account for the access needs of autistic young people whose friendships may function differently without physical contact or with the demands of online interaction.

2. **How can whole families be supported to enable their children's learning whilst recognising the incredible pressure of living and working during a pandemic?** This means recognising the flexibility necessary in any school-related expectations whilst parents may be juggling competing demands, and supporting families to be autonomous in their decisions about education.

3. **How might young people experience changes to their education (both in school and at home)?** This means recognising that young people may experience measures in ways that are different to intended. Young people and their families need to hold influence in decision making both prior to, and during, any future public health restrictions.

'When we had the first home school , [it] was glorious, he was just happy. I felt I had my child back from when he first had to be institutionalised at age 5.I think maybe as a result of the pandemic they listened to me for once. The school were able to see that difference in him because I was able to express it hysterically. 'You're not having him back because he's been too happy!'. Maybe that has helped...It's taken us 7 years to get to this point. I do think Covid has been a catalyst'
(Parent)

'I think possibly during that time having that emphasis shift on mental health and easing anxieties and promoting cohesion, I think that's something that's come out of all this...It's brought out the more creative and emotional side of things...I hope the renewed agenda about children's emotional wellbeing, I think it's got to be weaved more into the mainstream curriculum. An emphasis on it.' (Parent)

RECOMMENDATIONS FOR IMPROVING AUTISTIC YOUNG PEOPLE'S EDUCATIONAL EXPERIENCES

What is apparent throughout this research project's findings is that in circumstances where young people and families thrived, it was where previously restrictive or disabling features of education had changed or disappeared. Many of those features are socially conceived functions of education institutions rather than being fundamental to effective pedagogy. For example, where families spoke of improved learning due to lack of uniforms, or timetables dictating when and where one should move one's body, there is a lesson to be learned about how the logistics of mass education impose restrictions on young people being able to learn in the ways most conducive to their natural rhythms. Those logistical decisions and social conventions of education as an institution, both at local and national policy levels, could be conceived otherwise, as the dramatic changes of the pandemic have shown us. It should not take a public health crisis to enable an education system to be more responsive to the needs of young people.

1. **Flexibility is crucial for young people to be able to learn.** This includes flexibility of when, where, and how learning is understood to take place and a recognition of young people's bodily autonomy such as choosing how to dress, when to eat, and when to take breaks.

2. **Young people want, and need, to move their bodies** beyond the tight confines of timetabled PE lessons. Where exercise can be built in to young people's educational lives, and freely chosen, it can lead to young people feeling more ready and able to learn.

3. **Autistic young people don't universally experience change as a negative** particularly when that change brings about positive improvements to their previous educational experiences. This means recognising that autistic young people and their families hold expertise about possible alternatives in challenging situations and that pursuing routine for the sake of avoiding change is potentially detrimental.

4. **Young people's autonomous learning needs to be better recognised** both within schools, beyond the confines of the curriculum or assessments, and within policy and practice relating to home educating families. In schools, this means educational practitioners taking a keen interest in young people's interests and ways of demonstrating their knowledge which might not be immediately apparent in busy, assessment-driven school environments. In Local Education Authorities this means supporting home educators by ensuring that autonomous, child-led learning is valued and respected.

5. **Education policy and practice needs to better account for young people's emotional wellbeing.** Recommendations 1 to 4 already provide a way forward. Each young person comes to their learning environments with their own needs. Learning does not happen in isolation of other life events. During the pandemic, there has been collective awareness of the strain on individuals. This awareness can and should be applied in wider policy and practice.

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ACKNOWLEDGEMENTS

The digital collection of the school participants' artworks can be viewed here.

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