

Continuing the education of autistic pupils while focusing on family wellbeing during the Coronavirus Pandemic

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Editorial comment

Nicola Martin is a professor leading on the Critical Autism and Disability Studies (CADS) and Education for Social Justice (E4SJ) Research Groups and MA Education-Autism at London South Bank University. She has worked in the field of autism for over 30 years. In March 2020, at the start of lockdown in response to the Coronavirus pandemic, she worked with Barbara Peacock to develop this advice which they submitted to GAP for consideration. We were not sure whether this would still be relevant and required by the time of the next issue of GAP (in early November 2020) as, at the time, no one was sure how long the restrictions would last. However, now in autumn 2020, it is clear that measures will have to continue to be taken which might disrupt the education of autistic children and young people. So, we have made the decision to publish this guidance. It is also the case that even without the virus, many autistic children are home schooled either in preference to attending a school or while they wait for a suitable placement to be found. So, this advice and the resources will be of value to all those parents and professionals involved in home schooling.

Barbara Peacock is an experienced senior leader in the public sector having worked for over nine years as a Director of Children and Adult services. She is a Visiting Fellow at LSBU and member of the CADS and E4SJ research groups. Barbara is currently working as a consultant and most recently has been supporting a large county with a Transformation Programme around the requirements of students identified with Special Educational Needs and Disabilities (SEND). LSBU is involved with this project and this guidance is being used within the authority and more widely.

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Introduction

This advice is given in the form of numbered points in no particular order. Some will be very relevant and useful to some autistic children and young people and their families and others will not. It is for the reader to select those that make most sense and seem worth trying. As this document was developed at the start of the pandemic lock

down, transition back in to school /college was not then at the top of the priority list. Supporting learners going back into schools and colleges which may look very different from their pre pandemic presentation is clearly an important consideration now. The first bullet point raises this concern which is unpacked further later in the document.

Ideas which might be helpful in educating autistic pupils at home during the Covid 19 crisis

- 1 The top priority is obviously to keep things as calm as possible for the whole household. This is an extraordinary situation. Autistic people are not usually comfortable with unpredictable change (Milton, Mills, and Jones, 2016), so it is important to create as much predictability as possible in this new situation. Doing so will take some time. (When the time comes, the transition back into routines which have been disrupted will also require careful planning).
- 2 Lower your expectations around school/college work. It is more important to prioritise wellbeing (including nutrition, exercise, fun and rest). Creating calm and security is a higher priority than absolutely keeping up with every aspect of academic work. Other people are not keeping up either. If by the end of the day everyone has remained quite calm, eaten enough, had some exercise (ideally outside), had some fun, rested, and done something they would think of as productive and satisfying, that is a good day. If things have not gone so well it is important to reflect without self-blame. There is always tomorrow.
- 3 The way parents explain the situation will depend on the autistic person's communication style, level of curiosity and understanding. Some will be very engaged in the news and may be quite frightened. Others may be more concerned about the changes to their own routine. Limiting the news to once a day may help to develop a sense of containment. The broadcast could be followed by a reflective activity focusing on what needs to be done by whom and why. This could include consideration of the desired outcome of any action and a recognition of who needs to take responsibility for what. Getting the autistic person to focus on what they/their family can control might be useful. A tangible, achievable, controllable action might be for example to 'Go out of the house for 30 minutes each day for exercise'. Keeping an eye on anxiety triggers and avoiding them where possible is important.
- 4 When creating a new routine, it might be useful to use visual timetables (McLay et al 2019, Perryman and Yoder 2011) and to involve the whole family in the process. School or college work could be included in a daily timetable which also includes other activities (eg meals). These could all be represented visually, for example on a family wall planner. Symbols which are familiar to the autistic person might be useful. If using photographs, it would make more sense to use an image of the autistic person rather than a photo of someone else. Various apps can be utilised, and some examples are included at the end of this paper. Sticking with familiar apps might be the best approach unless the autistic person is particularly interested in researching alternatives. The Outlook calendar might be the most appropriate resource for some autistic people. It may be helpful for the whole family to have such a timetable. The autistic person may benefit from a regular timetabled session at the beginning and at the end of the day so that they can go over the routine and get a sense of what will be happening. Using approaches that are already familiar is likely to be most helpful.
- 5 The autistic person might worry that they are the only person in this situation. It is important to tell them that everyone in school/college is doing the same. Say it, don't imply it.
- 6 Specific areas in the house could be identified for school/college work. These should be minimally distracting and comfortable. It may be useful for the autistic pupil to wear their school sweatshirt while doing schoolwork but only if this makes sense to them.
- 7 Project based work which fits with an individual's particular interests is a good idea.

- 8 Social contact can be maintained via various platforms (eg Skype, Facetime and Zoom). It would be worth planning jointly with other parents about how this might be managed. Maintaining contact with important people this way is likely to be helpful. The autistic person might worry otherwise that these people have disappeared from their lives forever. Gaming is a common interest (Clark and Adams 2020) and this sort of activity may involve interacting with people who are in various time zones. Gaming might have to be timetabled to avoid sleep deprivation.
- 9 It is OK to increase screen time. Parental controls can be used, and it is worth exploring the wide range of learning and wellbeing resources which are being made available via the Internet, especially if these fit well with the interests of the autistic person. School/college is likely to be providing Internet-based learning resources and may assume that families have a level of technological access which is beyond what is actually available. It is important to tell staff if this is the situation and to ask for practical help.
- 10 If learning feels a bit passive, (eg watching a documentary), firstly, it does not really matter and, secondly, follow-up activities such as quizzes can be devised. These can be carried out in groups via platforms such as Zoom or Teams but only if doing so is fun and does not create extra stress. Sticking to one platform avoids confusion (unless the autistic person is especially interested in exploring a range of technological options).
- 11 The autistic pupil or student may like to get involved in educating their siblings through project work which fits in with their interests and expertise. Being given some responsibility can develop a sense of being in control of aspects of a complicated situation. Ideally everyone in the family will have adequate technological access for learning. If not, it is worth contacting schools/colleges for help.
- 12 Academic learning is not the only purposeful activity. It might be useful to use the time to teach skills such as cooking, and for the autistic person to take a turn as teacher too. Some practical and independence skills may appear to be decreasing at this time of great stress. This will be redeemable in less uncertain times. It is important not to give the autistic person the impression that this is a big deal as doing so may well increase their anxiety.
- 13 If using exercise books, it is best to choose those which have detachable pages so that if the autistic pupil makes a mistake, they will not feel like they have spoiled the whole book. Anything which anticipates and circumvents potential anxiety triggers is worth considering (Milton, Mills, and Jones, 2016).
- 14 Family projects can be motivating, for example completing a piece of artwork on a wall, producing meals together or creating a gardening project.
- 15 Sharing family responsibilities can be helpful. Specific job titles and job descriptions (eg 'Head of Laundry') might be fun. Family members could even apply for these jobs.
- 16 It is very unlikely that formal learning can be sustained throughout the school/college day. Focused learning for shorter amounts of time, one to one or in small family groups is probably equally effective. Independent learning at an appropriate level should be encouraged both to give the parents a break and to help the autistic person to develop. The Internet is full of open learning resources which could be appropriate provided they are of interest to the individual. It does not matter if one area of the curriculum takes priority over another. If the school/college appears not to understand that the autistic person cannot be as academically productive as they are in normal circumstances it may be that teachers have not quite realised the strain the autistic person is under. This can

be politely explained, and school may well be a great source of help and support if a mutual understanding can be reached. Prioritising wellbeing is important. Ending up with five rather than eight GCSEs is not the end of the world.

- 17 An autistic person might be spending a great deal of time on a special interest and this can be extremely positive and motivating (Wood, 2019). Activities associated with special interests can be extended, varied and used to underpin learning (Martin and Milton, 2017). LEGO for example has great potential in a variety of curriculum areas as well as for fun. Limited choice between two alternatives or choice about the order of activities can be less disconcerting than being faced with a blank sheet or the whole pick and mix scenario. Some autistic people might like to use a numerical ranking system to help with prioritisation. Prioritising can also help with anxiety.
- 18 Time and space to de-stress is useful if it's all getting too much. (Milton, Martin and Melham, 2016). Autistic people usually have calming mechanisms such as engaging in a favourite activity or something which is physically comforting, like hand flapping, rocking or getting away from sensory overload in a quiet place (Martin et al, 2019). They may want/need to spend 30 or 60 minutes or longer on their own and this is OK as long as they are safe (Calder et al, 2013). They usually have a sense of how much time alone they need and will come to find others when they are ready. Various apps to reduce anxiety could be helpful, particularly if these are already familiar. The need to de-stress and wind down applies to the whole family. The autistic person is not the only one who is stressed out in this global pandemic and enforced 24-hour contact with their entire family at home. Some families comprise of only two people both of whom need time and space to de-stress.

- 19 It is likely that the school/college can offer advice and will be providing learning activities to be undertaken at home. It is essential to work out how this advice sits within your family with the wellbeing of the whole family as a central concern. If completing a piece of work in a way causes distress and disrupts the calm of the household, the activity needs to be reframed or even abandoned in favour of something that works better. Resources, including technology if necessary, should be provided.
- 20 It is possible that parents will find themselves burdened by excessive bureaucratic demands alongside trying to support the autistic person at home. Various agencies involved may not realise that this is happening. It might be necessary to paint a joined-up picture for them and suggest ways they might work together more effectively in order to take the pressure off the family.

Longer term – going back to school

Some pupils have had the opportunity to go into school for odd days in preparation for returning. Their classrooms will not look the same as they did pre pandemic. Neither will the staff who will look unfamiliar in their masks. Photographs of staff members with and without masks would be a useful resource which parents could use to try and explain that these are familiar people even though they look different. The school may well mark out the classroom to aid social distancing. Social stories, with photographs, which explain these differences may be helpful. (Smith et al, 2020). Such resources are likely to come from the school, but parents might need to ask.

Many pupils will be transitioning to a new situation as they are returning near the start of a new academic year. Transitions can be stressful at the best of times (Cribbs et al, 2019), Schools will have made plans accordingly and will keep families in the loop.

If transition is to a new institution or context it would be useful to have a link contact between settings and parents may need to request this and be prepared

to be involved in some coordination. The National Association of Disability Practitioners www.nadp-uk.org has a wide range of resources focusing on the transition to post compulsory education.

Because the situation is evolving another lock down is possible so multiple transitions with built in uncertainty may be on the horizon. Communicating to the autistic person that plans might need to be flexible is important and the approach needs to be relevant to the individual's level of understanding (Brett, 2016). Some will find this uncertainty anxiety provoking. Emphasis on safety and the fact that this situation will not last forever is important.

At the start of lockdown, it is likely that families with limited technological resources and poor Internet access for completing academic work managed as best they could, thinking that the situation would not last long. It is important to alert the school or college to problems with access to technology and to ask for practical help.

Parents and carers need to continue to look after themselves as well as all their children. Services are clearly very stretched, but community based voluntary initiatives have emerged as a result of the Covid 19 crisis and it would be useful to find out about these. Reaching out and asking for help is sensible. This might provide, for example, opportunities for siblings.

Financial stress may well be exacerbated as the situation becomes long term and families may need to reach out for support. School and college staff may be able to advise and organisations such as The Citizens Advice Bureau are likely to be informative.

Networking with other families can be helpful and the school may be able to help with this.

It is important not to minimise the impact of this situation on all the family and for families to reach out for support and voluntary and statutory services to work effectively together in order to help.

References

- Brett, S (2016) Future selves: listening carefully to the voice of a KS5 pupil in a special school, in D Milton, and N Martin (eds) *Autism and intellectual disability in adults: volume 1* Hove: Pavilion Publishing and Media Ltd.
- Calder, L, Hill, V and Pellicano, E (2013) 'Sometimes I want to play by myself': Understanding what friendship means to children with autism in mainstream primary schools *Autism* 17 (3) 296–316.
- Clark, M and Adams, D (2020) The self-identified positive attributes and favourite activities of children on the autism spectrum *Research in Autism Spectrum Disorders* 72.
- Cribb, S, Kenny, L and Pellicano, E, 2019 'I definitely feel more in control of my life': the perspectives of young autistic people and their parents on emerging adulthood *Autism*, 23 (7) 1765–1781.
- Martin, N and Milton, D, (2017) Supporting the inclusion of autistic children in G Knowles (ed) *Supporting inclusive practice and ensuring opportunity is Equal for All* London: Routledge.
- Martin, N et al (2019) The sensory school: working with teachers, parents and pupils to create good sensory conditions *Advances in Autism* 5 (2) 131–140.
- McLay, L, Hansen, S and Carnett, A (2019) TEACCH and other structured approaches to teaching in S G Little and A Akin-Little (eds), *Applying psychology in the school's book series Behavioral interventions in schools: evidence-based positive strategies* American Psychological Association.
- Milton, D, Martin, N and Melham, P (2016) Beyond reasonable adjustment: autistic-friendly spaces and universal design in D Milton and N Martin (eds) *Autism and Intellectual Disabilities in Adults*, Vol 1 Hove: Pavilion.
- Milton, D, Mills, R and Jones, S (2016) *10 rules for ensuring people with learning disabilities and those on the autism spectrum develop 'challenging behaviour'... and maybe what to do about it* Hove: Pavilion Press.
- Perryman, T Y and Yoder, P J, (2011) What is the Picture Exchange Communication System (PECS)? in S Bölte and J Hallmayer (eds) *Autism spectrum conditions: FAQs on autism, Asperger syndrome and atypical autism answered by international experts* 194–197 Hogrefe Publishing: Oxford.

Smith, E, Constantin, A, Johnson, H and Brosnan, M (2020) Digitally mediated social stories support children on the autism spectrum adapting to a change in a 'realworld' context *Journal of Autism and Developmental Disorders*. 9 June 2020 Epub ahead of print.

Wood, R (2019) Autism, intense interests and support in school: from wasted efforts to shared understandings *Educational Review* 71 1–21 published online: Taylor and Francis.

Free resources

The Coronavirus outbreak is having an impact on everybody's life. Social distancing means that most events are cancelled, schools are closed and people must work from home when they can.

This is hard for everyone, but we know that for some autistic people of all ages these things could trigger intense stress and lead to a meltdown or a shut down.

Therefore, we have collected a series of useful resources that autistic people and their families can use during this time of changes.

Important note

The authors have not looked at all of these resources in detail.

Autism Education Trust Resources:

www.autismeducationtrust.org.uk/resources/schools-resources/

Council for Disabled Children Resources:

<https://councilfordisabledchildren.org.uk/resources-and-help>

National Autistic Society Resources:

www.autism.org.uk/services/helplines/coronavirus/resources/helpful-resources.aspx

www.autism.org.uk/professionals/teachers.aspx

Explain changes

Social stories – Carol Gray has created one about Coronavirus – see www.carolgraysocialstories.com

Keep children entertained

Sensory Stuck at Home is a Facebook page where parents of autistic children share ideas of activities to do in the house – see www.sensoryproject.org

Manage anxiety

Mind has created some helpful information about well-being during this unprecedented time of change. – www.mind.org.uk

Activities to do at home with your family

100 things to do indoors

www.schoolofspreadthehappiness.co.uk

SEND School Closure Home Learning Resource Pack

Free from www.twinkl.co.uk