

COMMUNITY CHECK-IN NOTES

Tuesday 20 October: Aerosol Generating Procedures in SEND schools

Organisations represented

- Angelman UK
- Behcet's UK
- Duchenne Family Support Group
- Hereditary Spastic Paraplegia Group
- Medicine in Specialist Schools (MiSS)
- MDUK
- Pitt Hopkins UK
- PKD Charity
- Smith-Magenis Syndrome Foundation UK
- Special Needs Jungle
- SWAN UK
- The UK Mastocytosis Support Group
- Unique
- WellChild
- Wolfram Syndrome UK

Genetic Alliance UK staff attending:

- Jayne Spink (JS), Chief Executive
- Amy Hunter, Director of Policy
- Nick Meade, Directory of Policy
- Farhana Ali, Public Affairs Manager
- Natalie Frankish, Policy and Engagement Manager – Scotland
- Louise Coleman, Policy Analyst
- Jan Bochinski, Fundraising Manager
- Emma Hughes, Policy and Engagement Manager – Wales
- Sophie Peet, Policy and Public Affairs Officer
- Izzy Rundle, Communications and Support Officer

JS – today about children going back to school and specifically focused on children requiring aerosol generated procedures (AGPs). JS notes that the meeting will be recorded for the purposes of Genetic Alliance UK'S policy team to produce a response to an APPG consultation on the matter.

Genetic Alliance UK

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www.geneticalliance.org.uk

Registered charity numbers: 1114195 and SC039299
Registered company number: 05772999

Dominic Wall - Head teacher of coop academy (a special school in Bradford). Dominic shares slides.

- AGPs are number one concern since emerging from lockdown due to poor guidance from the Government causing confusion for families and schools. Likely a long term problem exacerbated by Covid-19. Notes that June, July and August were not used to develop a policy.
- Schools Week – recognised AGP issue was part of the PPE in schools problem that had been well documented in the press.
- Guidance came out in May that schools do not need PPE. In FAQ there is a question about complex needs and tracheostomies – there is clear guidance that PPE was required. Requires a FFP2/3 respirator which is difficult to access and must be fitted to the person. Also requires AGP to take place in a designated room, unused for other purposes, but now needed to be left between uses and properly ventilated. Although schools had staff qualified, PPE was in demand and space maybe limited.
- NTSP produced a paper (lobbying/guidance in nature) fundamentally suggested that PHE guidance was not necessary and that there were other sufficiently safe methods that could be used. DW notes this guidance was released during the lower levels of community transmission – now we have had a significant upturn, particularly in north of England. DW notes that there is disparity across England in how guidance is being implemented – notes that in north of England, less restrictive guidance in place in some areas.

Matt James, WellChild

- WellChild is the national charity for seriously ill children and their families. They have a network of children's nurses across the country. Network of families, the WellChild family tree.
- AGP issue became apparent in early August as families began to think about returning to school. WellChild raised this on a webinar with education leads. The guidance as we see it hasn't been fit for purpose and has resulted in some children being excluded from attending school – where it is working is where schools have trained staff, space and access to PPE. Notes that the problem is that clinical guidance has been dropped into an education setting without recognising the limitations.
- MJ notes other concerns, families see school as respite, for some families they have had to take on a 24/7 complex care role with limited support and help.
- At the moment, guidance is treating children as though they are Covid-positive – notes guidance is also distressing for a child, identifies them as different and secludes them from their classroom. For many children this is a scary experience.
- MJ raises the concern of what happens when an emergency situation requiring suction emerges as there won't be sufficient time to put these guidelines in place.
- MJ notes no evidence to suggest children requiring AGP are any more of a risk than other children who are coughing, sneezing etc. in the class.

- MJ says Wellchild is asking for fairness. Notes children have a right to be in school and wants children to be back after half term.

Laura Sparrow, Special Needs Jungle

- LS is mum to child who has Rett syndrome
- LS notes that she has been effectively shielding since 17 March and her child is still not at school, partly because of AGP guidance. Notes that because of guidance, chose not to have carers and has taken that has taken a toll. Notes started emailing people in June this year as started to thinking about
- Fit test – notes that only three options and if they don't fit, can't be used.
- Became angry regarding AGP guidance. Notes the potential for a life threatening situation – there cannot be hesitation in applying AGP to allow five minutes to locate and put on PPE. Concerned about this as a factor in not sending child to school.
- Concerned about AGP list being ever evolving. Notes doesn't feel confident in guidance or PPE requirements. LS notes that when considering home care, was asked if there was one room that could be used for suctioning. Said no, not practical or in her child's best interest.
- LS notes frustration over guidance, changes, delay in implementing or giving thought. Feels 'always left to last' – notes that for 217 days has had no help, no support, no physiotherapy etc. Notes that the discrimination of disabled children is the saddest thing that has happened in 2020. Notes AGP guidelines accentuate the differences between children with a health condition.
- LS notes that keeping her child off school is having an impact on her social and mental health.
- LS says this has been a scary situation and one she does not think will change anytime soon.

Discussion:

- Participant concurs with speakers with regards to planned and unplanned AGPs. Notes the issue is wider than AGP, it is the designation of what is an AGP. Reiterates the point that our children are being treated as if they have Covid-19 (gives an example of children still being able to brush teeth in school). Notes no provision for providing education either. Notes in her county, children not even allowed to be on camera for a zoom call. Notes also problems with transport - how do we even get children to school? Considers this all as discrimination. Asks why has this guidance been in place for so long, but there is no provision put in place. Why are our children still not at school?
- JS notes that there is clearly a lack of insight into the life and needs of children.
- DW notes how disappointing it is to hear these stories. DW says head teachers have been pushing this issue – explains the need for pragmatic guidance – but thinks a decision has been made by government to not answer the question so as not to take the responsibility for the

issue. Seems to be a focus on local area decisions. Shares the view that this not likely to be sorted soon.

- Participant explains she is angry by this – notes that this would have applied to her daughter and shares the experience that her daughter died as a result of not having suctioning. Notes this will be a problem across the Unique community – need to have a powerful, united voice on this issue.
- Participant shares view of no accountability. Notes postcode lottery.
- Participant notes a petition that she has put forward on this issue and has been shared on the chat. Offers to share opinions and views of those she is working with. Explains has written to MP, Minister of Health in June/July, but no response. Notes son is now back at school, but it was a challenge to do so.
- JS notes the number of people in the zoom chat that have come forward to say they have written to MPs.
- Participant notes the legal requirement for ‘reasonable adjustments’ – could this be brought into the mix?
- NM thanks for contributions and that after this meeting there will be a discussion on the next steps that can be taken. There will be a submission to the APPG on this topic and further steps will be taken as agreed – offers to include those interested and keep the group informed of progress.
- JS final thought is that this has been an enlightening and motivational discussion - thanks everyone for participating and contributing.
- JS notes next meeting is a stakeholder engagement meeting on Rare Disease Day and will be followed by our virtual AGM at 11:00.
- Following week will be a session with Irwin Mitchell.

A.O.B.

- Participant notes research with Ulster University (Hospice Nurse doing work around Advanced Care Planning) and looking for people to participate in this. Will share in the chat
- Participant asks about any experience of getting CCGs to pay for unlicensed medicines? JS says will take topic offline
- Participant notes a letter regarding post-brexit arrangements for ERNs.

Zoom transcript:

- I started a petition on this a while ago: <https://www.change.org/TrachyKids>
- <https://www.dailymail.co.uk/news/article-8633209/Four-year-old-boy-rare-genetic-condition-told-return-school.html>
- There was a child sent home from school yesterday because he “required three suction” !!!
- The link to the Special Needs Jungle survey is: bit.ly/autumn-send
- Dominic Wall - Medicine in Specialist Schools, contact dominic.wall@coopacademies.co.uk
- We stopped using the AGP masks issued to our PA's by our CCG as we were told there was no protection to my daughter, only for the PA. Also it made it harder for her to understand them if they were talking to her when they were having to wear them for a full shift.
- I am a trachy mum. Same issues for trachy kids - exactly as you have explained very well. Being treated as if they have covid.
- Buccal midazolam and dental care are not on the AGP list (<https://www.gov.uk/government/publications/wuhan-novel-coronavirus-infection-prevention-and-control/covid-19-infection-prevention-and-control-guidance-aerosol-generating-procedures>) but this is the problem, the DfE and DHSC are not issuing any clearer guidance and leaving local CCGs and LAs to make their own interpretations.
- MiSS has been hammering the transport issue with DfE and PHE since June, but they are resistant to taking responsibility for solving it; preferring instead to leave each LA to make their own local decisions.
- Precisely - accountability!
- Totally agree the buccolam and teeth brushing shouldn't be AGP, but that's the issue as you say the CCG's have been left to it. If you get 20 people looking at a situation you get 20 different answers, same as with transport.
- We have a different issue for our children — where children (and adults who work in a school setting) react to cleaning products and can have anaphylaxis from certain products. Some schools are allowing parents to identify safe products and then see if they are allowed. But in some situations there isn't the flexibility.
- I didn't realise AGPs included emergency meds for epilepsy as our community hadn't mentioned. Thank you for raising such a serious issue across the board.
- Children rely on adults doing the right thing. SEND children are vulnerable and rely even more on the right things being done.
- The government forgets at the end of all this is a vulnerable child and a family at the end of it
- Victoria's petition on this a while ago: <https://www.change.org/TrachyKids>
- It is disgraceful and quite iniquitous.
- I wrote to my MP – Priti Patel. I was ignored, haven't even had a response.
- The current minister for Children and Families (Vicky Ford) is the best chance as she has the come into post and seen this unravel on her watch; she has a medical background and understands the issues better than most 15 month incumbents in the post.
- Pretty sure the whole legal position about Reasonable Adjustment should be brought into play here.
- My MP Mark Francois who said he would escalate my letter to Matt Hancock – no reply to date
- I wrote to Matt Hancock and Gavin Williamson - no response.
- This is a horrendous situation, I hadn't heard that buccolam was an AGP and this hasn't been raised by my sons college (thank goodness) I am heartbroken for all who are struggling.
- The government are out of their depth but won't listen and take advice.
- Hi all, thanks for letting me join on this. I'm a reporter at an education newspaper Schools Week. I spoke to Dominic about this issue back in September and I'm always looking to keep writing

about it - if anyone would like to be in touch with their experiences, please do reach out on samantha.booth@schoolsweek.co.uk

- Buccal midaz isn't an AGP
- As buccal is implicated you might want to involve the national epilepsy org's to get behind this also
- Buccolam shouldn't be no, but in the absence of joined up thinking some councils have designated it an AGP
- https://www.equalityhumanrights.com/sites/default/files/proving_disability_and_reasonable_adjustments.pdf
- vickimacklin@gmail.com - Mother of a child who has Treacher Collins Syndrome, member of tracheostomy group on Facebook. Happy to help in any way I can
- A key driver for the issue is then need for schools to act responsibly as employers of staff who are willing to carry out AGP care in schools. Where those heads in the NE of England have followed the NTSP care proposals they have been advised that for a publicly-funded school to deliberately depart from DfE and PHE guidance, would open them up to personal liability in the event of a failure in care.