

What do parent carers and families need during the November lockdown?

1. Over 18s with Down's syndrome

The new guidance that classifies young people with down's syndrome as clinically extremely vulnerable is causing difficulties for families

- Many local areas have closed education and social care services for these young people.
- We are also hearing that some schools have also incorrectly asked under 18s with Down syndrome to stay at home.
- In the absence of these services we must make sure that all impacted families are actively contacted and alternative support and provision put in place. This must be coproduced with families and young people.
- Many families are asking for more discussion, discretion and coproduction around the implementation of these rules.

2. Respite care remains and is becoming increasingly important

Many families of children with SEND are on their knees. Respite care is critical:

- Return to school has helped but many are still struggling with access to social and respite care with many services still not open or very limited.
- The closing of sports activities will have a profound impact on many families and their wellbeing and resilience (not to mention the adverse health impact of the closure of health facilities).
- Where such facilities and respite support is not available, local areas should contact families to coproduce alternative arrangements with them. Clear guidance and support to enable respite services to remain open.

"If you're a single parent obviously you do get one (support bubble) but if you are a couple with 3 disabled kids like us .. you don't get one. For example if the schools close like before we got no support, no respite during school hours seems as we don't qualify for respite in general. I think the government should of considered this when making the bubble idea. Just because you're in a couple doesn't mean parents of additional needs children don't need backup."

3. Anxiety around shielding

Many of those who were previously shielding (adults and/or CYP) are anxious and concerned as to why this is no longer required. Many people in previous lockdown



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shielded despite not receiving instruction to do so. Some of those with clinical vulnerabilities (or supporting someone with clinical vulnerabilities) feel overlooked and are anxious about effects of catching the virus. This anxiety has a profound impact upon mental health.

Another concerted effort to reassure families about the limited risk to children is needed. The statistic from the RCPCH that Covid 19 is no more dangerous to children than seasonal flu is needed.

“Stress anxiety and anxiety is further compounded for children of CEV parents / carers as they attend school...the current guidance is that they must keep a 2 metre distance from their CEV parent...so no hugs, no sitting on the sofa together.”

“xxx can't stop vomiting from the anxiety. Going to school now feels like Russian roulette...many kids are scared.”

4. Contact with other people and support from carers

There are some areas in which we need greater clarity around implementation and Interpretation of the guidance. Perhaps, SEND specific Q&A could be developed.

- We need more clarity re caveat of 'severe' disability & 'needing round the clock care' if outside with their parents. Clarity on level of SEND and also who is allowed to accompany CYP i.e. does this have to be parents or could it be two carers where 1:2 ratio required?
- Clearer guidance on what our families can access for support – familial care arrangements and overnight stays as an alternative form of respite, who can visit the child etc.
- Guidance around PA's, childcare and single parents with over 18's regarding bubbles, those caring for both a CYP with send and elderly relatives
- Where children are currently in hospital, there's no consistency as to how many parents/carers are allowed to visit and in many places it's only one parent. There needs to be more recognition of how much of an impact prolonged hospital stays have on parents and how they need support in the form of being able to share decisions & see partners etc.

“Should we allow our DP carers in?”

“I have personally had conversations with our doctors that no parent should ever have to have, those conversations with my husband by my side we're awful



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enough. I can't imagine having those conversations alone and then having to tell my husband later that night."

5. Schools

We continue to hear of very inconsistent practice in schools. Some of the concerns that we have been told of include:

- Clear guidance needed on what will happen with delays in EHCPs and annual reviews
- There continue to be fears about fines and sanctions for non-attendance at school, especially for vulnerable children.
- The quality of remote learning is very varied from school to school. Most schools do not seem to be providing a meaningful differentiated curriculum for those with special needs including SEN support. This needs to be addressed with further national guidance and support otherwise the attainment and learning gap for children with SEND will continue to increase.
- Families seem to have grasped the concept of bubbles but are concerned about bubbles being "porous" with children mixing in other situations such as travelling on transport.
- Some forums report that some schools are still not allowing therapists to visit their premises.
- There is a need for greater understanding around appropriate support for school refusers. In some areas there are specific teams to support this and some areas no support at all. Anxiety around being at school or not being at school, going out or not going out appears to be impacting on many Sen and disabled children whether in special schools or mainstream.
- Uniform Policy. Schools are keeping windows open as advised to keep an air flow current going through school. Pupils are complaining of being cold, and are unable to wear coats in class. Schools need to adapt their uniform policy so jumpers in school colours can be worn if they don't have a jumper as part of the uniform, etc.
- Clarity on PE in schools – where a child uses this for physio or OT delivery this needs to be maintained.

"Will we be fined if we keep medically vulnerable kids and siblings off school?"

"If schools don't close, Parents here are worried about the children not travelling to school in their bubbles. They think having bubbles is pointless at school if they are mixing on the school transport."

Some recommendations

Areas where additional communication / reinforcement of guidance

- Reiteration of the low risk to children and young people from Covid 19 (we will be using our conference to do this – including interviewing Professor Russell Viner – president of the RCPCH)
- SEND focussed Q&A that address how guidance should be interpreted and implemented for families with SEND
- Continued reassurance that no fines and sanctions will be applied around school non-attendance.
- Messages to local authorities and health services that if services must close then alternative provision must be put in place and coproduced with families.
- Reinforce the need to provide a differentiated curriculum for children with SEND when remote learning is necessary. More support and guidance is needed here.

Areas to focus additional resources

- Respite care – including extending to those families who might currently fall below social care thresholds or who be on SEN support
- Early help particularly around mental health. Advice and signposting services (possible SENDIAS) services,. Families need localised, covid 19 support and advice
- Continued technology help for families who need to access remote education.