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## YOUNG THINKER ARTICLE

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### **COVID-19 AND CHILDREN WITH DISABILITY: RESPONDING TO THE NEEDS OF ALL COMMUNITY MEMBERS DURING THE PANDEMIC**

BY SATARA (19 YEARS)  
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Without a doubt, for most of us, the current series of lockdowns have been harshest during this pandemic. With businesses closed, restaurants shut and education moving online, there has been a lot of focus on mental health and the other impacts the pandemic has been having on communities, particularly children. Most efforts of communities to come together and support one another have been admirable, however one group that has been neglected is children living with a disability.

This community includes those with Down Syndrome, intellectual disabilities and those on the Autism spectrum, just to name a few. Children particularly, within this community, are often less likely to have a voice, simply because some are unable to communicate in the way mainstream society expects. For example, my sister who has both Down Syndrome and severe hearing impairment, uses sign language as well as an iPad to express herself. These are practices that the broader community is often unfamiliar with, and hence the voices of children with a disability can slip under the radar of mainstream discourse. However, now, more than ever, it is crucial that we listen to understand some fundamental truths in order to make sure that we do not leave them behind during the pandemic.

Firstly, children with disability find it particularly difficult to cope with educational services including speech therapy, occupational therapy or music therapy being delivered online. These classes are what build children's capacity to learn and enjoy all that is around them. They are crucial, providing personal and individualised support to children who need such learning programs. However, when classes are suddenly moved online and the children find it more difficult to understand what is going on their confusion and distress is compounded

"The services of all support workers and therapists stopped on the first day of lockdown", says Ai Keng, whose son Cayden was accessing services. The sense of face-to-face familiarity that they once had is suddenly taken away from them. It is important that we recognise this and understand that inconsistencies like these can take a major toll on children. As Ai Keng explains,

"We got a routine in place, but I could only keep him engaged in the mornings...it is completely up to me to ensure that therapy goals [and] skills are practised regularly so that they are not forgotten."

The issue of accessing therapies in person is not something we, as a public can control, but if you know someone with a disability, treat them with care and sensitivity, understanding that they may not be feeling as supported as they usually are.

Secondly, expecting children with communication disabilities to comply with demands like wearing masks in public, and sanitising their hands every time they touch something, or observing extra distances between people, is very difficult. Most are naturally restless and as mentioned earlier, find it more difficult to understand the Corona pandemic. We must show patience and understanding if someone appears not to be following the rules. This does not necessarily mean they are purposely avoiding regulations, simply trying their hardest. For example, often my sister forgets that she shouldn't touch items in the shop, the glass barriers in bakeries, or play equipment in the park. As a result, it looks like she is purposely disobeying the rules, when in fact, she is simply confused.

Whilst families will keep trying to teach their children how to follow restrictions, the unnecessary stares from members of the public and judgement is not constructive. Encourage children as they keep trying to understand what is going on in the world around them.

Thirdly and perhaps most importantly, whilst some people might see keeping all children at home rather than sending them to school as the best course of action during the lockdown, for parents of children with certain disabilities, like my own, the time their children are at school often provides the only respite from providing intense care. As school principal David Raphael puts it,

“Most parents are ill equipped to supervise the education of their child at home and teach them with all the pressures they are under if they too are working from home as adults. Our families are often under enormous strain emotionally and financially in normal times coping with the need to manage behaviours and therapies for their child with a disability. If they cannot go to school normally this adds pressure on parents and siblings, who have to manage children at home 24/7.”

Ai Keng’s experience with her family, aligns with this statement. As she explains,

“[We live] in a small house with no separate rooms for his siblings to do online lectures and his dad to do online meetings...When [Cayden’s] dad has important work meetings or when his siblings have online assessments, it is my responsibility to keep him quiet. He has been with me 24/7 for 3 months with no breaks in the daytime. I cannot shower until he goes to sleep. I am always exhausted by the time he sleeps that I too crash and sleep straight after him. Finding time to exercise on my own has been challenging. Going for runs on my own to clear my head has been my priority before lockdown as it keeps me sane. During lockdown the only option is to go for walks around the neighbourhood together.”

Therefore, it is important to recognise that not all parents are in a situation to keep their children at home. They should not have to go through the stress of providing additional care, when already devoting time to their children and their subsequent physical and mental needs. We must show support and care to those who have little to no respite when caring for their child during lockdown.

Furthermore, as mentioned earlier, maintaining consistent schedules, allows most students with a disability to feel secure, safe and happy. As Mr Raphael affirms,

“Our students but really all students want and need structure and routine to feel safe and supported so for St Lucy’s this means we stay open to allow them to attend normally. This gives them some certainty in uncertain times...Remaining open also allows our students to continue to learn academically, spiritually and socially and remain active and socially connected with their peers and all this greatly assists maintenance of good mental health, confidence and resilience.”

Ai Keng also speaks to the importance of consistency, explaining the way the pandemic has disrupted Cayden’s day to day activities, impacting his happiness and wellbeing.

“He has not seen his friends from school all term, soccer ended abruptly, and summer sports may not even start. He does not understand why he cannot go to school and play sports on the weekends. He cannot verbally express himself, but you can tell he is missing the interaction with other kids that is so important to his development. He does not understand why he cannot go grocery shopping with me anymore. Pre lockdown he has learnt how to pick fruits and vegetables for me when we go shopping. This skill will have to be relearnt once lockdown is lifted.”

At times like these, it is critical that we come together to support those whose voices are often unheard. We should not critique without understanding first, nor should we judge without educating ourselves. Some within the community respond differently to the restrictions and therefore we must listen to what they say. We must give a platform to this crucial voice during the pandemic.

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The Young Thinker Forum provides an opportunity for children and young people to express their views about issues that are important to them. While the children’s and young people’s views do not necessarily reflect those of the Children and Young People Commissioner (CYPC), they are used to inform the work of the CYPC and provide important insights into the way that children and young people experience the world. I encourage you to consider how the views in this opinion piece may have relevance to your work and life, and to engage with children and young people as an important stakeholder group.