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## Input on return to learning (Easter Seals Ontario representative)

1 message

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**Nicole Ullmark** <nicole.ullmark@gmail.com>

Wed, Sep 2, 2020 at 6:40 PM

To: sonia nadon <snadon28@hotmail.com>, Leigh Fenton <leigh.fenton@ocdsb.ca>

Hi Sonia and Leigh,

Here is my (lengthy) input on return to school. Could you please distribute it to the LSS team and other SEAC members?

Thanks,  
Nicole Ullmark

Dear Learning Support Services Team and fellow SEAC Members,

First of all, thank you for the tremendous efforts you have all put in over the last several months to help prepare the staff and students for a safe return to school. It is truly appreciated.

As you are well aware, families with disabilities and medical fragile members are often isolated both physically and socially. A pandemic made the rest of the world experience some of this isolation. As the general population slowly returns to some level of normalcy living with covid, these families remain the most vulnerable, and will be isolated much longer, and to a greater degree, than others. They have not had access to most of the help or respite they previously had for the past six plus months and caregivers are exhausted and burnt out.

Easter Seals was founded in 1922 and their mandate remains to support children and young adults who live with a disability. All of the families that I represent on behalf of Easter Seals (including my own) have a student with a physical disability but, I think we would also represent most medically fragile kids as well.

### Concerns with returning to in person learning

Schools previously accommodated the attendance of these at risk students, so there is a comfort in knowing that they could return with some tweaks to maximize safety, but remember we are dealing with the most medically fragile students in OCDSB and therefore potentially those with the highest risk of covid infection and its complications. Students with physical disabilities will not be physically distanced from their source of support, and this places them at increased risk according to public health guidance. PPE will certainly help, but again, by the nature of their disabilities, this may not be used in the optimal manner either (for example: difficulties with placement of their own masks, drooling that soils masks). Some schools may offer to physically segregate these vulnerable students for their safety, but at what cost to their mental health? Getting students to school will look different as well, with many parents and caregivers opting to bring their students. This is concerning for students with physical disabilities as accessing the school and accessible parking spots was often compromised pre-covid and school staff can't always be available to police this issue. This group of students also have many medical absences. The way the secondary curriculum is being presented will make getting caught up even more challenging for those students that are absent for a prolonged period of time. This group of students also uses many itinerant teachers and therapists that travel between schools. While public health is saying that this movement of staff is safe, the cohort they are exposed to will increase substantially for this group of students.

### Concerns with remote learning

Most people would think the obvious choice for students with physical disabilities, especially if they are also medically vulnerable, would be remote learning. As of right now, families and caregivers have been told there is no idea if any nursing support their student received at school will occur if the student chooses remote learning. The same uncertainties remain around therapies. Some opportunities for access to virtual appointments will likely be available, but this leaves the sole burden of implementing the therapies to the families/caregivers once again. At this point, the use of educational assistants for those who choose remote learning is also not clear and they are often the key staff delivering therapies to the students, while at school. Many of these therapies that are

in fact part of the IEP goals for the student. Remote learning will be unable to accommodate many common IEP accommodations (for example: scribing) and parents are concerned about how remote learning can be geared to offer other accommodations such as extended time for some of the class work during synchronous learning. These IEPs have been carefully developed for most of the students over years but there still may be subtleties not listed, as the education team knows the student so well, they are simply implemented, not listed. This loss of student knowledge with minimal connection to the home school team is concerning for many parents. Many are frankly just worried about the amount of screen time with the remote learning choice. To summarize, if a family or caregiver chooses the remote learning opportunity for their student's safety, or as recommended by their healthcare professional, as of this moment, they are expected to do so without any of the support the student would require at school. This isn't an actual choice, at least it wasn't for us.

## **Our story**

I'm going to share our family's personal story because, while unique, we are not alone. Also, the decisions parents and caregivers are making right now are very personal and we all need to remember that.

My son is starting grade 5 this year. This will be his last year at the school and he has been there since junior kindergarten. He has a progressive neurodegenerative condition, diagnosed just before he started school. When he first started at the school, he was just a kid who fell (a lot). He was otherwise independent at home and at school. He is now completely reliant on a wheelchair, unable to walk even a few steps, needs 100% assistance for all transfers, lacks the fine motor skills to feed himself or brush his teeth (let alone write, type or navigate a mouse) and has had such a deterioration in speech that even I struggle to understand him at times. His lack of coordination also affects his ability to track things visually in addition to significantly reduced vision. His condition also comes with a primary immune deficiency and he receives weekly infusions of antibodies from donated plasma to survive even before the pandemic. Unfortunately, he also has a few other chronic medical diagnoses, unrelated to this condition, that we know have been associated with worse covid infection outcomes. His deteriorating condition has meant that the school has needed to constantly adapt to his changing needs and while it's amazing now, it wasn't always this way and it has taken six years of hard work by all involved to get him where he is presently. He has the most wonderful, caring, creative and supportive team, including his own 1:1 EA, 100% of the time, that he has worked with for the past six years.

I reviewed CHEO's "Guidance to Healthcare Practitioners for Children with Chronic Medical Conditions Returning to School". Each one of my son's many conditions lands in the "yellow" zone, as to the suitability to return to in person learning. How many yellow conditions together equal a red? No medical professional would be able to actually predict what might happen to my son should he get covid, given his unique array of conditions. So, many would assume as a family we would choose remote learning for him this fall, given this uncertainty. With his particular and profound disabilities, he needs assistance for every aspect of school. The spring saw us constantly searching for new tech solutions and liaising with his classroom and blind low vision itinerant teacher just to find ways for him to be able to see any visual problems. We read all school work to him and we also 100% scribed all answers (speech to text doesn't work with the dysarthria he has, it's also not helpful for the many google slides projects he had over the spring). This school work was in addition to managing his medications, medical conditions, appointments, all transfers, all feeding, all toileting and all his therapies (vision training, eye patching, cough assist machine, physiotherapy exercises and more recently, post-operative dressing changes and gtube feedings), never mind the rest of the family's needs or trying (rather unsuccessfully) to work in and manage my consulting business. To add 225-300 minutes of synchronous (or asynchronous) learning to school days, that requires 100% assistance with no support is simply unsustainable. Also, due to his speech issues, he is very shy on virtual platforms, even when he knows the people he's talking to. Many often cannot understand him unless they have spent significant time with him. His disabilities have made socialization extremely challenging for him, but his current peer group and the teaching staff have been by his side as he has deteriorated and their support and understanding have been invaluable and the reason we have him at school to begin with.

The night before OCDSB asked for our decision about returning to school, we sat as a family and discussed the options available with both our children. When we asked our son with disabilities what his preference was, he simply said, "neither". That one word so eloquently summed up our feelings and subsequent decision for his return to learning. The remote learning option as offered just doesn't work for him, but neither does the in person learning, due to his and our fears of covid infection. He needs the home school team expertise and peer group, as much as possible, in the safest way possible and remote learning without support isn't actually a choice. Then it occurred to me that this was like every other problem we'd ever encountered during his education to date and the solution was the same. No "off the shelf" solution works for my son, or any of these other students with physical disabilities and medical fragility. The solution for each of these students needs to be as

unique as they are and finding these solutions is something the teaching (and even administrative) staff have been doing with excellence all along.

### **Suggestions**

Parents are craving communication. These families of exceptional students are feeling left out of the conversation but I also don't believe there is any one statement from the board that could adequately address this unique population. My suggestion is for the message from the board to be that they see this unique student population and realize the options available may not be ideal for them, as is. I'd like you to encourage and empower the school staff to reach out to each of these families, that they know very well already, and see how everyone can work together to come up with the best solution for these students - be flexible and adjust as often as needed in this ever changing situation. When I spoke to my son's principal yesterday, the messaging she has from her superintendent and the board is very clear, "your son's support (EA) is assigned to him when he's at school" and she has not been given the flexibility to offer us that support on the days when he cannot be physically attend school. Everyone involved realizes there will be constraints, but these families are very used to dealing with constraints, are some of the best problem solvers, and also know their students the best. We need to offer educational support to these students, regardless of where they choose to learn in these unusual times.

Thanks again for all you have done and for the opportunity to express concerns on behalf of this student population.

Nicole Ullmark  
Easter Seals Ontario SEAC representative to OCDSB