



April 21, 2020

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Subject: Letter from the Honourable Katrine Conroy, Minister of Children and Family Development, and the Honourable Rob Fleming, Minister of Education : April 14, 2020 Ref: 248940

Dear Ms. Conroy and Mr. Fleming,

We are writing to inform the MOE and MCFD of the seriousness of our issues that autism families face and the importance of our requests for help that have not been addressed by MCFD or MOE. Parents of children with Autism have been hit with a triple whammy. They have lost their one-on-one support from schools, they will lose their precious autism funding if their deadlines are approaching, and they are having to live with the stress of the behaviours associated with ASD living in a Covid 19 world.

**FAMILIES ARE IN CRISIS**

**How the MOE and MCFD can *REALLY* help parents:**

- 1) Allow EA's and ABA Support Workers work in the home of a child to provide the one-on-one support that would normally be provided in the school with a safe protocol agreed to by the parents and the school.
- 2) Allow the ASD child to go into the school to work one-on-one with the EA with a safe protocol agreed to by the parents and the school.
- 3) Provide extra funding for school hours home support where families have BI's willing to work with that family.
- 4) Extend Autism Funding deadlines so parents can regain lost ground when the social distancing is lifted.

Relevant comments from Parents:

"I have four children, two of them are on the spectrum. One is so dis-regulated that we nearly had to call the police to help us as she was threatening the family and physically aggressive. We now have three children in the home who are terrified of her and traumatized. I was huddled in a corner with them while my husband did his best to deescalate her. Our other ASD child has been having panic attacks, becoming withdrawn and we are seeing a decline in his social skills already. By the end of the day, I am exhausted. There are no breaks, no respite, nothing. All I can do is cry and hope for a better day tomorrow." (Parent response in survey)

"My kid is starting to exhibit more aggression and self-injury as times goes by."



“I'd love to have our 1:1 EA come to our home to support my son...he won't engage in distance learning.”

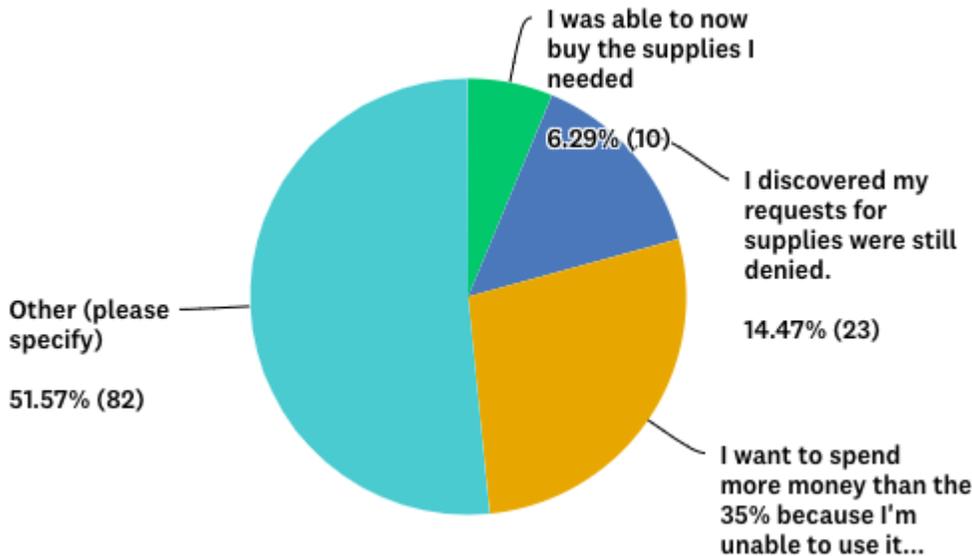
“We will lose any funding because AFU won't roll over or extend his funding period. He is regressing and deregulated from having none of his 1on1 therapies: SLP, OT, ABA therapy”

“My child has regressed, and I will lose the AFU funding due to the cut off date.”

In response to your letter of April 14th, the **Autism Support Network Society** (ASN) has gathered data and feedback on whether these new measures are effective in meeting families' needs. A survey was conducted via email and social media to determine the needs of our community with respect to what was being offered by the government in response to the current public health crisis.

First and foremost, **none** of the points addressed in your letter of April 14 addressed the key, critical issues that parents are experiencing. Further to the lack of funding to address Covid 19 issues our survey also responded to two components of your letter.

**1. We asked parents to tell us how the allotment of 20% to 35% for supplies has benefited them:**



**Only 6% of respondents found the increase in allowance for supplies useful.**

Most of the “other” responses were that funding had already been used up for BIs and Consultants.

“We spend the majority of our funds on wages, not supplies, so it's not helpful.”

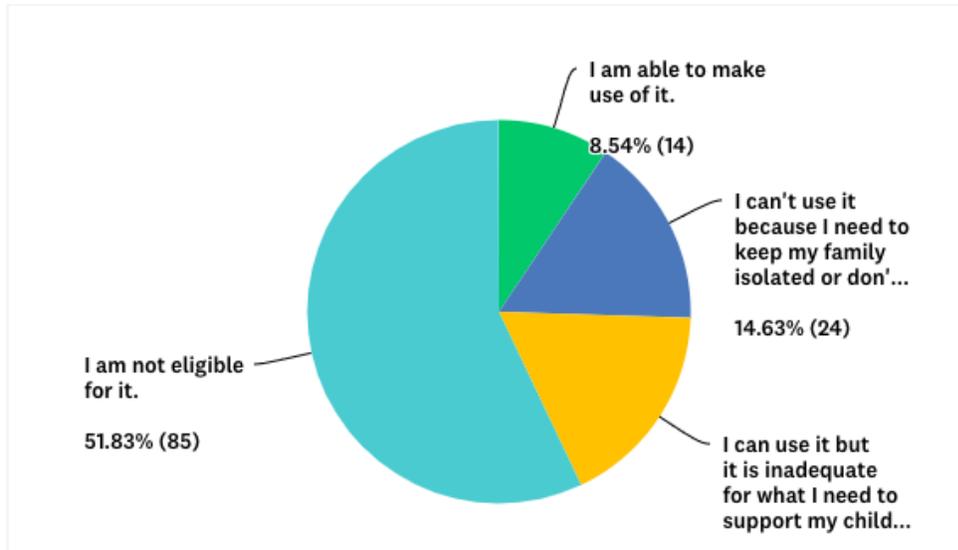
Furthermore, we continue to hear from parents their frustration with AFU in getting approval for materials and equipment necessary for eliminating difficult behaviours and optimizing learning.

“AFU was already notoriously inconsistent and unpredictable with what they will approve for one child and not another, for no obvious reasons - leaving families and service providers wasting time and effort

guessing at the correct magic wording to have legitimate, valuable equipment approved. This is already an ongoing barrier and source of stress for parents. The wording around new equipment rules is also vague and confusing.”

**2. We asked parents to describe how the \$225 respite benefit helps them:**

**76% of families that responded don't qualify or can't use it.**



**In Summary**

The response to the Covid-19 crisis by MCFD and MOE does not address the dire nature of the situation. Allowing existing autism funding to expire combined with the inability to find solutions for the one-on-one support usually provided at school, is nothing short of punitive and is adding to the stress and mental health issues suffered by autism families who are trying to cope with very difficult situations at home.

Below this letter, you will find more comments from desperate parents. These are just a fraction of what came in on our survey. We need you to learn about our plight and make meaningful opportunities.

Sincerely,  
Nancy Walton  
Autism Support Network Society



### More Quotes from the Survey

my child had one on one EA support where he had a connection and was making progress. I have seen huge regression and behaviors. I am a single parent still working from home. trying to manage his work and health and mental wellbeing alone. I was told to be creative by my employer. I am exhausted and dealing with bedwetting nightmares and anxiety from my child. No mention from school on EA or supports that can be offered. It isnt sustainable.

Funding is not enough for more support. Kid is very anxious and easy gets meltdown and rigidly, which is really bad to her improvement. And give parents so much stress too!

Both my husband and I work full time, with me working from home. Online ABA sessions aren't very effective. My son's mental health and aggressive behaviour is getting worse without the structure and support provided at school and out-of-school care. I need to work to keep an income. Weekdays are chaotic, extremely stressful and upsetting for all of us (I have a younger daughter as well). I am very concerned my son will regress significantly without support.

As a front line nurse with two boys with autism with birthdays in April it has been an extreme stress to use the remaining funds, submit JFEs, buy supplies that are on back order, deal with AFU, find child care, do my basic tasks while caring for both my boys. My husband is an essential service worker too. It has been horrendous

I am unable to get my 5 year old to sit through a video lesson and he does not respond to me teaching him. He was also just diagnosed and I am unable to get him started on any therapies and this is his last year under 6. He is anxious and acting out and unable to regulate. Our 13 year old is suffering from anxiety and is now seeing a psychologist by video. Another thing that AFU doesn't realize is that for some families that don't receive respite, full-time school IS like respite and now we have lost that.

We are stuck with 3 autistic kids at home. I'm stay at home mother. Father lost job due to covid 19. We don't receive any help from school.

We are getting very little school support and would like more funding to hire other support to help our child

Prior to COVID-19 we were working with a private OT and an in-home Behaviour Consultant with 2 Behaviour Interventionists. My son was also receiving EA, LISW, and SLP support at school. We had our challenges but were managing fairly well. We're really struggling now as all of that support is gone, and the normal routines that my son was used to and depended on are non-existent. He is regressing in both his behaviour (increased anxiety, meltdowns, tantrums, increased rigidity, hurting his sibling) and academics (refusing to do school work, not able to focus, taking 2 hours to do 5 minutes of work). We have tried a few virtual support meetings with my son but it's not working well as he gets distracted easily and can't focus. We desperately need the funding in the current AFU funding year to be rolled over to the next funding year as we are currently not able to access the supports he needs and will therefore not be able to use our full funding allotment. My son will need extra support when in-person support is allowed again to help him both process all that has happened and help him continue his learning in all areas and regain some of the progress he has lost. My son has been impacted mentally, emotionally, relationally, behaviourally, and academically and our family and family relationships have been impacted as well and it will take both time and finances to help him and us cope with these changes.



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## SUPPORT NETWORK

We have 2 children with autism and our situation is incredibly difficult. Both boys are regressing and losing progress that they had made. We are used to a bit of chaos in our life but having every single one of our support systems ripped out from under us is leaving us barely treading water. We need help!!!!

We are in a financial crisis and I had hope when I heard that special needs families would receive \$225 for a few months. I've since heard it doesn't apply to ASD families - why not? The mental health of not only my ASD child, but his sibling as well as us as parents has been greatly affected. We all need extra support at this time which we are not able to get. At the very least, pls. extend the deadline to use ASD funds so it can roll over to the next year. Doing OT and BI online doesn't work for us, it's not effective. It's the personal, 1-1 interaction that works. Having access to ASD funding has made a huge difference in my child, thank you for this gift. I just wish we could use all of it.

My child is not currently receiving therapy services from a BI due to social distancing requirements. We are worried about losing funding when his birthday arrives.

I spoke with my Social Worker today (April 17th) and indicated that my family is under a great deal of stress at this time. The therapy my youngest grand daughter was attending is now closed. I lost daycare because of her behaviour. Parks and playgrounds are closed. One of the therapies required is physio-therapy. So I bought a small bouncy castle so that she could have some type of play equipment to exercise on. I asked if it would be covered but wasn't given a straight answer, only that it depends. If I could access some of that emergency money, I could purchase more play equipment that would help with the physio-therapy she is not receiving at this time.

We need more flexibility with funding. Having to contact our BCBA for sign off on purchases at this time is a bit much, this requirement needs to be waived at this time. Funding needs to be extended as we can't use it with the required isolation of Covid-19. Mentally my child (11 yrs old) with ASD is really suffering and needs all the support she can get. As a family we are facing hardship, I'm trying to meet all my children's needs at home while trying to complete the tasks of my essential service job from home. The \$225 a month respite benefit should be available to us yet we can't even get a response from our social worker.

Since we can't have in home ABA during the COVID crisis, we will need to make up for lost time after our funding expires on the anniversary date.

I have twins on the spectrum and they can't understand the situation we are in right now, hatred, because they can't do the regular things they do before, going to school, meet friends, having recess with "friends" and I am afraid, they will regress because of not enough time with virtual learning 2 hrs/day. And both my husband and I have to cut our hours at work to be with our kids that need to stay home, and for us living on "paycheck to paycheck" this is a very challenging financially.

It's extremely stressful. My daughter is 5 going on 6. Had an EA in K and was doing great. Now all in home therapy, respite, and school assistance is unusable bc they cannot provide behaviour support. I work full time from home and am trying to manage her therapy through reworking that our BC did of her programs in addition to trying to do her schooling as well. The school said there is nothing they can do that isn't better than what I can myself. 3 other kids in the house that were also trying to school. Birthday in June, we will lose the funding as it can't be used for therapy. Regression in behaviours is starting and we'll have to go backwards before forwards once we can allow therapy again. This costs money and will no tap into the very small \$6k amount of next years funds rather than using us the \$22k allowed for this year. She was only diagnosed last year, so this years therapy was SO essential for her progress. It's tear worthy.



Irate at the lack of government support.

We worked really hard this last year to get our son to attend school 75% of the time. our son turns 6 in July, we are really going to need the funding we weren't able to use due to isolation more then ever when this is all done to prepare him to be in social settings again. The most important step that could be taken at this point is to allow funding roll over to the next year .... please let the success of these children be a priority in these difficult times

I have an auto immune disease (Graves) that is flaring at the moment. We run a home team with three BIs who support my son AND ME by giving me respite when my health is poor. I also work part time. The loss of our in home support has been devastating for my son and his mental health as well as a burden on my physical health which is getting worse by the day. I need to maintain isolation to preserve my health but I also need more support for my son. I am the primary caregiver. The worst part is that the reduction in our income has exposed the gap in funding compared to his actual program cost. Since government support is not sufficient or needs based, We have used our savings to cover the costs of intervention 20 hours per week. Now SCD funding from Kinsight has been frozen, and we don't have any spare cash to pay our team even if they were to return next month. Because of Covid 19, my son will loose MONTHS of crucial under 6 intervention time... and my health may deteriorate past the point of no return.

My son has severe non verbal autism. He is doing more what we consider negative behaviours, dis regulated, regressing day by day, suffering from his 1on1 therapies not having them and unable do online because of his disability, food seeking more, bit of pics coming back , climbing unsafely, just unable regulate his body by himself , sleep issues even worse , my mental health as his main caregiver is not greatest i & him just can't do this for years and wish there was case by case basis for kids who really need therapy in person and precautions put in place , affecting me and his dads marriage, affecting his siblings because literally my son needs 24/7 eyes on him at all times care has no danger safety awareness he is an eloper and runner ... can barely even take him outside in our cul de sac or out in places where not many people around because he'll collapse at any sec making hard get him up, want us pick him up and or try run or do undesirable things . My stress and exhaustion is through roof .

This is incredibly taxing on the siblings and our family. The entire system and routine and support we had were thrown to the wolves. We are at our wits end.

Current funding for over 6 does even cover half of what we spend on our autistic son. Now this virus is going to bankrupt us. Can't stop the sessions as it is the only thing keeping our son from losing his positive control, even if it's online. ABASW support is just getting started, but very slow.

My child will lose \$13,000 funding in July. [Due to] covid19 we are not able to spend this money on BI services. AFU should freeze the funding until next year or start paying families in cash.

Everyone is stressed, no time to do anything. Autistic child has regressed behavior and resists doing school work as overwhelmed and needs 1:1.

Family of 6. Mom is disabled, two children with ASD. One eligible for at home program, and anothe rmay be eligible. One teen with adhd, and a teen who is graduating school. Spouse is working. All kids have regressed, and we are in crisis-mode. (Too much time all together). Mental health as caregiver to high needs children is exacerbating anxiety and my physical health issues. I have no help, no breaks, no money to buy things to keep kids engaged. They refuse virtual learning/work and the constant demand for virtual learning is ableist.



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We currently have no income. My husband is out of work and we have 3 children with ASD and ADHD and 1 is also Gifted. We are attempting virtual therapy sessions to maintain instructional control but my children are not gaining any new skills. All 5 of us are overwhelmed. We are unable to utilize our respite funds to get the respite we desperately need. Our youngest has engaged in SIBs due to the anxiety of the many changes and losing contact with his ABA SW.

I am exhausted. I homeschool...I take care of my 12 year old ASD /ADHD /Anxiety/LD child 24 hours a day. I have virtual BI sessions 3x week booked for him that I must help him regulate through. I do not expect much from his school....they were not letting him attend a full day and calling me to pick him up regularly before this. I am not on a respite list...I should be...but to be perfectly frank I havent talked to our social worker for years....he was diagnosed at 3. I work as a BI and have an honors degree in Psych counselling...if I am this exhausted can you imagine the average parent? The emergency respite should go to all parents of low incidence children...according to the coding in schools. That would be fair for all. I will eventually call to get put on respite list ...but right now my priority is my kid....our family well being should be the governments because if we collapse its going to cost the government a lot more then \$225 a month to do what I'm doing right now.

We NEED the unused funding to roll over into the next year. All of our therapy is 1:1 in person and we will need intense work to recover from the current disruption

I have four children, two of them are on the spectrum. One is so disregulated that we nearly had to call the police to help us as she was threatening the family and physically aggressive. We now have three children in the home who are terrified of her and traumatized. I was huddled in a corner with them while my husband did his best to deescalate her. Our other ASD child has been having panic attacks, becoming withdrawn and we are seeing a decline in his social skills already. One of our children is likely on the spectrum, but not yet diagnosed. He is having a very hard time. He is struggling with emotional control, physical boundaries and safety. By the end of the day, I am exhausted. There are no breaks, no respite, nothing. All I can do is cry and hope for a better day tomorrow. More funding for equipment, or virtual services would be very appreciated. As well, our physically aggressive child does very well when she can exercise to relieve stress and ground herself. We have requested some exercise equipment, as it is the only thing that helps, yet we were declined. With gyms and school closed, she does not have an outlet for her physical aggression, so her new outlet is her family. :(

My son is the only child at home and he has lots of screen time right now due to Covid 19 situation,,, I have already started ABA sessions through Zoom but my funding is not enough to do this every day since the school closed!! How school can help us!!

Worried about my child regressing due to no therapy available at the moment. Funding cut off is in June for us, we're going to lose a fair bit of funding we are not able to utilize due to the pandemic.

My son is now starting to self harm and hit himself in the head and off the floor when he's frustrated and he hasn't done this in years. I can see he's already starting to regress and because both my husband and I are working we don't qualify for much in fact I don't even get child tax yet it's so hard to manage anything when we are all at home how do we get a break.

I have 2 ASD kids who previously had 1:1 care in school. My younger one just lost thousands of his under-6 funding (year ended). We have an amazing BI for him that I can't afford to hire without that funding. My older one is floundering without routine and has had massive regression, particularly with self care (bathing, teeth brushing). Both are fiercely competitive, violent meltdowns, and both have been self injuring for weeks. Our Respite worker is out of the picture and BCBA/SLP team only via Zoom, which my older child won't engage with. Husband was our sole breadwinner (I am primary caregiver to



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our boys) and he was laid off. I feel like everybody else is getting supports, live streamed press conferences, etc. except us.

WE have been in a state of crisis for many months and haven't been able to get CYSN to act even before this crisis. Things have gone from bad to worse for everyone in our family. I am just waiting till the police are at the door again.

Worried that my son will regress without the support he needs, we are attempting to do zoom sessions. Worried our funding will go unused

I am a single mama who cares for my asd son 24/7. Only time I have away is to get groceries at the store once every two wks. Which consists of about a hr away total. Financially I struggle badly. I wasn't able to work before covid19 cause my son was only in school three hours a day and couldn't find any "proper" 1 on 1 care for him that he requires. We don't qualify for social services cause my child support and child tax I make to much by the government. Which goes straight to rent and leaves us with 300 for food for the month. So we have to also go to food banks for help. My mental health has been shot for years. Even mental health has stated I need respite ASAP but yet I sit here on a waiting list for almost a yr now and still feeling a heavy weight wondering when I will get that one moment again to let it all out with a good cry and breathe

My son was just diagnosed and he is 2.5 years old. I was told to start asap to give him the best possible outcome and am unable to start any therapy as he is too young for virtual therapy sessions. The money my son is entitled to will be missed. This is not acceptable that his money can not be used later for therapy. I am appauled

I suffer from anxiety and depression, both of my kids are home, with no help and support and no respite as well I don't know how long I will survive.

critical loss of social skills/environment -serious regression, already seeing sharp increase in aggression, and all mak-behaviours, safety concerns -stress levels of all house members high-critical - no supports offered from school are appropriate -ABA team via Zoom not effective for camera adverse child -loss of OT/PT/SLP skills

Times are tough money is tight and there is little to no support for kids with disabilities. No one is answering their phones or following up on promised call backs

already on social assistance, so finances are always desperate. Son missing all OTPT/music/art/movement/sports/social therapy 10+ sessions/week, necessary equipment unlikely to be funded by AFU

I don't know where to start. We need access to equipment during this time. Due to playgrounds and playgroups being closed my daughter does not have her regular outlets! We need access to things that the workshop normally qualify for. Everyone's mental health is at stake in our home. Very fragile

Session times are reduced as son can only sit for certain period, doesn't seem as effective, skills worked so hard to learn and use in school may be lost. Difficult to teach at home but doing our best esp when we are both still working. Makes no sense why we are pressured to use your AFU funding if it could be better used when covid is over. Regression = more struggle when returning to school and greater long term dependency on the system when they are adults- kids with ASD need all the help they can get now.



The amount of increased meltdowns has been extremely difficult to the point that it has had a direct effect on my mental health. We have had to increase very expensive sessions online with our son's child psychologist, and our behaviour consultant. We budget every penny to be able to make it to December 1st and at this point with me being on EI I highly doubt that would help. If we received the 225\$ we could use it for one psychologist session for my son a month, currently he's having once a week sessions

I'm an essential worker tier with 2 kids on the spectrum can't find a daycare or a bi to help with childcare

We need an extension of his under six funding so when all this is over we can do that slow transition that my son so desperately needs with his social anxiety and to ensure hes Getting the supports that he was entitled to before COVID-19

Honestly, we need the money given to the school system to be given to families. Even a portion of it. We need to stop the mixed messages from MCFD. Some social workers are saying people aren't qualified for the funding, some are giving it. They tell us we can sign our own JFE's but then they are returning JFE's that are submitted without a professional letter. Just take the stress off families and allow us to purchase what we know our kids need. And give us enough funds to do this!

Child is turning six in October. Will not be able to maximize his behaviour intervention, and will lose opportunity when funding is cut to \$6K. Decision will need to be made whether to go into debt or stop therapy.