#WhatWeNeed #WeaAreEssential

We are hearing each day from people with disabilities across the nation around the impact.  The fourth relief package for COVID-19 needs to include people with disabilities. Today we share the story of XXX:

My name is Stephanie Kaznica and I am the mother of two children with autism, Ava and Cole, who reside in Hockessin, Delaware. The COVID-19 emergency has stopped the intensive daily services they used to receive, such as small group speech sessions and sensory regulation through occupational therapy. I am worried about my children regressing in communication skills and behavior during the time they are quarantined, and also about how stressful the changes in routine have been for them. I know you are working on the fourth relief package for COVID-19. I want to learn more about how you are going to help people with disabilities in this package. Thank you very much for your time.

My name is Heidi Mizell and I am a parent of young man with autism. My family is from Wilmington, Delaware. The COVID-19 emergency has kept my son from beginning his job. He was supposed to start a position in our local hospital which would have led to a certification and possibly a career. Without a regular schedule he is very difficult to motivate. He sleeps most of the day and stays up late. He is a pretty rigid man and believes he can only work out in the gym, so he isn’t moving his body anymore. This has increased his aches and pains and this in turn, makes it harder for us to get him out of bed. When he has a purpose he is very good about his sleep/wake/exercise schedule. Our concern is for his health, both physical and mental health. I know you are working on the fourth relief package for COVID-19. I want to learn more about how you are going to help people with disabilities in this package. Thank you very much for your time.

My name is Gary Heckert. I live in Newark, Delaware, I am the parent of an adult with autism, intellectual disabilities, and behavior challenges who lives in an apartment in our town with round-the-clock staff. My greatest concern in this COVID-19 world is what will happen to him if his staff are unable to report for work. His emotional stability and well-being are highly dependent on maintenance of routine, including familiar staff who understand his spoken and unspoken communication. Our state developmental disabilities system does not have sufficient PPE to ensure the health and safety of clients and staff alike. It is important that adequate supplies of PPE are available to both clients and providers to keep all safe and well. I know you are working on the fourth relief package for COVID-19. I want to learn more about how you are going to help people with disabilities in this package. Thank you very much for your time.

My name is Sela Sanberg and a close friend of mine is a Special Education teacher for

high school students with neurodevelopmental disabilities and complex medical

comorbidities. I am writing from Portland, Oregon, whereas my friend resides in an adjacent county.

In the spirit of full transparency, I am writing on my friend’s behalf in an effort to protect the privacy of

her students and her employment status. The COVID-19 emergency has stopped necessary

supportive services, such as access to paraprofessionals, in-vivo direct instruction, and multimodal

educational materials and resources. Moreover, special education students and the staff members

who provide direct services do not have enough food to meet their daily nutritional needs. My friend,

who receives a meager teacher’s salary, generously sent groceries to 3 of her students and $100 to

all 10 of her teaching assistants in order for them to have supplies needed to stay safely at home the

first week of ‘shelter in place’. Although most of her students are able to get adequate nutrition at

home, a majority of students do not have the basic skills and/or access to technology required for

virtual learning. Therefore, students are not able to attend school or engage in meaningful adaptive

and academic learning. I am worried about how students with disabilities and their families and

school community will be further impacted if such inequities and social disparities are not

thoughtfully addressed. I know you are working on the fourth relief package for COVID-19. I want to

learn more about how you are going to help people with disabilities in this package. Thank you very

much for your time.

My name is Cynthia Verduzco and I am mother and my son Leonardo is autistic. I am from Newark, California.

The COVID-19 emergency has stopped my sons speech at home therapy. I am worried about regression, he

works best with a schedule and being taken off creates a huge delay. His visits to his doctor and visits to his

speech therapy have stopped. While we are still being charged full price for our insurance, during this time I

am the only one working as my husband is forced to stay home. I know you are working on the fourth relief

package for COVID-19. I want to learn more about how you are going to help people with disabilities in this

package. Thank you very much for your time.

My name is Rebecca and I am a mother of a boy with autism. My family is from Portland, Oregon, and the COVID-19

emergency has certainly impacted the lives of myself and my family. For many children, they go to school, make

progress in their education, and when summertime comes, they are able to retain some of that progress. My child

struggles over any disruption to his schedule, and regresses over summer breaks, even with attending summer

school. We are currently without adequate resources, and I am concerned about where my child will be by the end of

this. We had previously had a personal support worker, but he has been exposed to someone with COVID-19. With

my husband in a high-risk category, we are no longer able to have support providers come to our home if it may put

his health at risk. We are concerned about meeting the needs of our child, and want to know what can be done to

provide equal education and adequate services during this time of crisis? I appreciate your time and considerations.