How are self-advocates and self-advocacy organisations advocating in these times?

The COVID-19 disease changed the way we all live and work.

We had to adapt ourselves to this new reality.

Most of our organisations and support networks are closed and not available as before.

Our families are also dealing with changes in the way they live.
In some cases, we are now all staying together 24 hours.
This can be stressful for us and for our families.

Some of us are “locked down” inside the institutions or living facilities, without any visits.
This is tough for us and for our families.

We are not able to see our friends or family.

We cannot go to work as usual.

Attending online meetings can be a challenge if our supporters are not with us.

This is especially true for European network, because of the translations.

We are struggling with getting the care and support that we used to have and need.

For the ones that were living independently it is difficult to find ourselves more dependent and left alone.
How did we respond to this?

The most important thing for us is to be connected.
We need to feel that we are not alone.
The situation is not the same for all of us.
In some cases, our organisations were able to distribute smartphones, so we can attend the online meetings and chat with our friends, family, and supporters.
We are organizing online meetings or chats. This is helping us to deal with our feelings of anxiety and fear.

Some of us are also doing online mentoring for self-advocates.
Our supporters are still supporting us, at distance.
But for some of us it’s more difficult to get this type of support.
We may have difficulties in using the new technologies. We may not know how to do it or we may not have computers, mobile phones or internet access.

This is creating differences among us.
It’s really difficult for the ones that do not have access to internet or to smartphones.
What are the main problems we see?

Self-advocates and their organisations may have big problems in connecting with each other. It's really important to be able to share our experiences and how we are dealing with the situation.

We see big problems on the way persons with intellectual disabilities are accessing education now. Distance learning and online classes are not accessible to all of us. We do not see any measures in place to make sure we are not left behind.

We are worried about the effect of the COVID-19 on employment of persons with intellectual disabilities. We know that we are the first ones to be pushed outside the labor market when a financial and social crisis happens.

Violence against women and girls with disabilities and the disrespect for their rights is also worrying us. People have now less access to complaints mechanisms and are less visible. This may cause more violence inside the homes and the institutions.
What do we want?

We want to be included in the discussions about the way the services will be provided in the future. Nothing will be done in the same way.

We need to make sure that our rights are respected and that we are not left behind.

Self-advocates have a voice.

We want to be heard.

Follow the link to learn more about the steps to prevent harm to people with intellectual disabilities and their families in Coronavirus emergency.