

Self-advocacy activities during the Coronavirus emergency

On Friday 22 May 2020, Inclusion Europe held an online meeting with **László Bercse**, Chair of the [European Platform of Self-Advocates](#), **Gary Bourlet**, Co-Founder of [Learning Disability England](#), and **Samantha Clark**, Chief Executive of Learning Disability England, to learn about self-advocacy activities during the Coronavirus emergency.

What are self-advocates doing during the Coronavirus emergency? How are they connecting to each other? What are the issues they are facing? These are the main questions addressed during this meeting.

How are self-advocates and self-advocacy organisations advocating in these times? László Bercse explains how the COVID-19 pandemic affects the lives of self-advocates and the work of self-advocacy organisations in Europe.

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 are we 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.

What self-advocacy are doing in England? Gary Bourlet and Samantha Clark explain it to us.

Something we found very helpful is that people have been very generous. They have been **sharing and making accessible resources on the virus and suggesting activities**. For example, People First Forum published a Survival Guide and a [Coronavirus Diary](#) to help people with disabilities record their feelings about what is happening. People First Dorset published a Coping Calendar with activities that can help people with disabilities during this difficult time. People have also been **connecting with and supporting each other** hosting online events. *“In some ways, we are more connected now than we used to be before the Coronavirus emergency. For us, the most important thing is not to feel disconnect from our family and friends”*, explain Gary Bourlet. One example of supporting each other is the Learning Disability England Peer Support for groups and advocates. Every two weeks, we organise online meetings during which people can share what they are doing and feeling during the lockdown. It has been powerful and helpful for people with disabilities to be able to share problems they are currently facing and ideas to improve their situation.

We had to do some **campaigning about the rights of people with disabilities under the COVID-19 pandemic**. We campaigned to change the government rules on going out or hospital visiting, the treatment decisions, and the checking services. Now, people with disabilities are not the top priority in testing. This must change. We are also running a campaign on social media called **#right2home**. Since the coronavirus lockdown started, people in secure units may not have seen advocates or family carers. We are worried about their welfare. We believe that people have the right to live where they want, in their own home, near their family.

During the Coronavirus emergency, people with disabilities do not always understand what is happening. Why? Because there is not enough easy-to-read information. Moreover, a lot of people with disabilities find digital tools hard. They are also feeling worried or afraid. Some people with disabilities are isolated, others are feeling forgotten, and some are even afraid they will be forgotten when the country will start to move again.

Joe Powell, Chief Executive of All Wales People First, presented the report “The Effect of the Coronavirus Pandemic on People with Learning Disabilities Across Wales”.

Read the full report [here](#).

This report gives an overview of the experiences of people with learning disabilities across Wales and the activities of learning disability self-advocacy groups throughout the initial lockdown period of the Coronavirus Pandemic 2020.

- People with learning disabilities are struggling to various degrees with the situation. Most are reporting feelings of loneliness and isolation and the cancellation of group meetings and events are leading to boredom and frustration. Those with mental health issues are struggling to remember the reasoning behind the sudden changes and a small minority are exhibiting some extreme behaviour including suicidal thoughts and assaults on support staff. People with learning disabilities living independently are feeling more abandoned than those in supported accommodation or those who live with their parents or carers. The lack of an end date or defined timescale is causing confusion as are the multiple news updates from a variety of sources, most of which are difficult to understand. There is a need for more accessible information from a select group of trusted sources.
- There are some small positives being reported. Some people with learning disabilities are gaining new skills and confidence in using social media, communication tools and other apps. Local communities are also rallying around to help their vulnerable people and it is hoped this will lead to more positive and proactive relationships in the future. Those living with others are also forming stronger bonds and working more closely with each other.

Question and answer session

Question: Have you noticed cases where people with disabilities were discriminated on the access of healthcare?

Samantha Clark: We have heard some examples in England, and we have some evidence that some people have not been given fair access to healthcare. However, it is not everywhere in the country. It is not the normal or the majority, but it is still a big worry.

Question: How self-advocated feel about the future? Do they see the light after the tunnel?

Samantha Clark: We are starting to talk with our members about the future. One big message is about fear and anxiety for everyone on how changes is managed. People are worried that their rights are being lost. For example, they are worried that government will cut financial support to people with disabilities.

Joe Powell: We think one of two things will happen. Either mass austerity, or record levels of investment into social care. We feel that if the issues of social justice are not taken seriously now, they never will be.

Gary Bourlet: Employment is a big issue when it comes to self-advocacy. We need to know what is going to happen and people are worried about their benefits. Maybe people with learning disabilities can come up with the new ideas for all our countries. Government can learn from us.

Samantha Clark: Yes, we need to put our heads together.

Inclusion Europe's material about the COVID-19

Inclusion Europe created a webpage gathering the [materials relevant to the Coronavirus emergency](#).

The webpage is updated daily with new content and can be accessed [here](#).

Follow us on [Twitter, Facebook or LinkedIn](#) or [subscribe to our newsletters](#) to know about them first.

[5 steps to prevent harm to people with intellectual disabilities and their families in Coronavirus emergency \(.pdf\)](#)