

Guest Blog by Simone Aspis, life-long self advocate and Director of Changing Perspectives



This covid-19 virus outbreak should have been a big chance for self-advocates to take forward very important campaigns about our lives during lock down around right to life, inclusive education, support and control in our own lives.



But sadly, as a self-advocate I have seen lots of different campaigns about us without us over the past six months and longer.



I think, the pandemic has led to the voice being taken away from self-advocates in too many situations and this needs to change.



I have seen non disabled people, allies, some parents and big charities speaking up for people instead of disabled people doing it for themselves and I have seen government departments ignore us.



Some campaigns have been led by disabled people working together but there has been a lot of activity on social media using twitter, face book, blogs and alike that has not included us.



While we all know things have happened very fast and decisions have sometimes had to be made very quickly, I believe campaigns about people with learning disabilities should always be led by self advocates.



If the campaign is designed by professionals or parents for themselves and their non-disabled allies, it starts from what they think and is not always about what is important about our lives.



If people can not speak up for themselves, it is important that we are still involved.



This is because we can speak up for our peers as well as for ourselves. Our speaking up groups are about speaking up for our peers as well as ourselves.



Chat about us without us, usually on twitter and social media, can make self advocates feel angry, disrespected, unimportant and frustrated.



Non – disabled people working only with themselves means no self-advocates know about the campaign or understand what is going on.



This means self-advocates are not involved in making decisions and making sure priorities are the right ones for everyone.



If no self-advocates are spokespeople, then our voice is missing.



Non disabled campaigners tell us that we should be kind to them because they are only doing their best for their family, friends or the wider community.



I hear that.

But that does not make it OK.



From my experience when campaigns are not accessible and inclusive of us from the start, it is hard for parents, professionals and their non-disabled allies to make changes later on and people can feel angry and frustrated.



We can stop getting angry with each other if the campaigns begin with self-advocates and our organisations right from the start – that is before the campaign goes live – **NOTHING ABOUT US WITHOUT US.**



Yes, the situation with COVID has been stressful for lots of people.



But I am asking others to stop and think before rushing in to try and 'fix' things for us, disabled people.



We all need to be working to the social model of disability – we need to challenge the barriers that stop us from taking part in campaign work.



If we want society to change then we need to lead by example.



For example, always having easy read and accessible formats as they are key for getting us involved.



Let's try and learn lessons so we do things differently and better in the future – after all we are stronger together.

