



National Center on Advancing Person-Centered Practices and Systems

Transcript from a short-video titled “Planning Can Be A Beacon” with Carole Starr for NCAPPS’ Pandemic Wisdom series

Carole Starr has been a brain injury survivor since 1999, when she was broadsided by a vehicle going 50 mph. The injury ended Carole’s career as an educator and her hobby of classical music performances. She still lives with daily brain injury symptoms. One small step at a time, Carole has reinvented herself. She’s now a national keynote speaker, the author of To Root & To Rise: Accepting Brain Injury, and the founder/facilitator of Brain Injury Voices, an award-winning survivor volunteer group in Maine.

Hi, everybody, my name is Carole Starr, and I'm a brain injury survivor. And I'm going to talk to you for a few minutes about the importance of person-centered planning in a pandemic. I've been living with brain injury since 1999, so a very long time. It took me a lot of years to rebuild my life, to rebuild systems and structures and routines. And I figured, you know, nearly 21 years, I know what I'm doing as a brain injury survivor. I have got this; I know how to, how to work with this injury. And then the pandemic happened. And within the space of a week in March, suddenly all of those systems, those structures, those routines that I had spent years cultivating, suddenly just evaporated. They were gone. And I will tell you that I was lost, that I did not know what to do. It felt like my life had ended again, just like it ended after my brain injury has felt very much like going back to the early years after brain injury.

So that brings me to why is person-centered planning an important concept during this time for people with disabilities, because we have had our routines completely upended that the structures that we came to depend on suddenly are no more. The people that we would see, the routines, the doctor's visits that we went to, the support groups that we attended, the things that we looked forward to are no more right now. But what person-centered planning is really good at is looking beyond the specifics of what we do and looking at what are the things that are important to us. The things like connection, community, things that the big picture sorts of activities that there's many ways to, to get community to get connection beyond whatever structure that has been interrupted because of the pandemic. I think that's what, what person-centered planning is really good at



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doing is figuring out those things, figuring out, what's the most important piece for those of us with disabilities. And then how do we how do we create that within what is available right now. And what that does is it gives us a feeling of control. I know for me, the more that I focused on all the things that had been lost during this time, the more out of control, the more scared I felt. But when I focused on how do I meet the needs that I have, and what can I control, then I felt better about this time, feeling like I am not back in the early years of brain injury; I do still have strategies that I have learned that I can use – person-centered planning strategies – to look at the important things to me in my life, and how do I get those needs met.

I chose this graphic behind me [a lighthouse on a foggy coastline] on purpose. Because I think person-centered planning can be like a beacon in the fog that we're all in right now. It can be something to hold on to, a light to, to, to guide us forward. So that's how I think of it and why it is so very important for those of us with disabilities right now to, to work through this challenging time. Thank you.