



# National Center on Advancing Person-Centered Practices and Systems

**Transcript from a short-video titled “If Not Now, Then When?”  
with Marian Frattarola-Sulino for NCAPPS’ Pandemic Wisdom series**

*Marian Frattarola-Saulino is the Co-Founder and CEO of Values Into Action, a family of organizations that includes the first Supports Brokerage in Pennsylvania and one of the original Support Coordination Agencies in New Jersey. Marian is also a co-founder and chair of of The Alliance for Citizen Directed Supports, which is a group of people with disabilities, families, organizations, and advocates dedicated to supporting people with disabilities who wish to take charge of their lives through self-direction.*

As a provider of community services, person-centered thinking, planning and practice are means to an end – the end being one that is determined by the person accepting support, who is, as we all are, the expert of their own life.

What holds true during this time of COVID-19 is what matters at any other time and in any other context – the amount of control a person has over their own lives, not just their planning and their services. What we know now and what we have known is that those with more control, while still at risk, are safer. Everyone who accepts support with the organizations I work for directs their services, no matter what services they choose to use. The only differences in how we are practicing in the midst of this public health crisis are: one, the urgency with which we had to think, plan, and act; and two, the perspective we had to adopt – that is worst case, not best. Each and every person was engaged in this response and their supports adapted to meet their needs, preferences, and the evolving public health mandates. An important consideration was the impact on their supporters. We raised the wages and extended additional benefits immediately to every worker affected. And this was before the U.S. government introduced federal aid to protect them.

Just as when we're not in the midst of a global pandemic, we did not wait for permission to act. We followed the person's lead with the support of the decision-makers they chose, as well as the directives from the public health officials in the states where they live. And then we collaborated to develop plans to help them and their supporters stay as healthy and safe as possible. For example, some people decided to have supporters live in with them for days at a time to reduce their social circle. Some decided to not have staff come in for a few weeks, and some decided to replace physical support with remote support.

Talking about permission; we need to question the need for so much regulation and rules, specifically the ones that were immediately relaxed or suspended. If they are not needed in this unprecedented health crisis, and in fact, they were seen as barriers to safety, why do we need them in typical times? Instead of a focus on compliance during this time, we've been able to put our attention and direct our resources to enabling remote support, working to ensure the availability of independent living technology, and partnering with families to provide the support void left by day programs and other building-centered services. Because we only offer supports in people's homes and communities, we did not stop services. We adapted them to meet the needs of people, their families, and the public health mandates.

People are still taking classes, exercising, baking, going to the museum, even redecorating their living room, doing their spring plantings like everyone else. They're doing a lot of it – most of it virtually – using Alexa or Facebook, or partnering with their supporters using Zoom or FaceTime. Not unlike other fields, like health, banking and education, using technology has its benefits and doesn't have to compromise choice or quality. In fact, many people are saying they feel safer and don't want to return to the old ways once we're on the other side of this public health crisis.

Shouldn't we also be questioning the need for congregate care? We have always known this way of supporting people is not in the best interest. Now without question, we know it is dangerous for both the people living in these facilities as well as for those working in them. This pandemic is showing us that we indeed have more viable options to offer people. While no one is immune to COVID-19, those who are leading their own lives, living where and with whom they want, working in careers of their choice, and in charge of their supporters, are safer. They, like their friends, colleagues, and neighbors, are living with the same mandates and restrictions, not with specialized policies designed for groups of people living in facilities.

As devastating as this is, in some ways, this pandemic is enabling a more everyday life for people, at least for those who are in control of their lives. And so, we need to see this as an opportunity to overcome the institutionalized resistance to person-directed, family-centered supports, and enable everyone using services to be healthier and safer, not just in times of public health crisis, but every day. This opportunity must become the mandate to shift the system. What else do we need to convince us, that in no other time is the use of person-centered approaches more impactful and necessary? If not now, then when.