

Community Living in the Era of COVID-19

Moving Toward a More Flexible, Accessible Future

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As we cope with the disruption of this pandemic, many of us are wondering what our new normal will look like on the other side. Before COVID-19, many people with disabilities went to day programs or had individualized 1:1 staff supporting them at work or in activities in the community. Now, because of COVID-19, we are all being forced to see and make connections to the community in a mostly virtual way.

In the face of COVID-19 our society was forced to make drastic changes in how we live our day-to-day lives. Some of these changes—like moving our work, schooling, doctor’s appointments, and events to a 100% virtual format—busted long-held myths and made services and the work world more accessible to people with disabilities. But we still have a lot of work ahead to maintain and grow the progress made in the area of accessibility. Especially as we move from a pandemic to a post-pandemic world.



Going back to the old way of doing business is not acceptable to the disability community because the old normal did not work for many of us who were denied basic accommodations in our day-to-day lives. Many of us were denied access to the support and accommodations we need to thrive and grow. We must embrace a new normal that accommodates and plans for life with a disability or chronic health issue.

Healthcare and Access

In a pandemic world, one thing that would greatly benefit people with disabilities, seniors, and others is a return of doctors and nurses doing house calls and growth of hospital-at-home programs. Policy changes like this are needed because it is now more important than ever that we get serious about addressing health disparities in people with developmental disabilities and moving away from one-size-fits-all models of medicine and service delivery. I say this because people with disabilities have some of the highest death rates and risk for poor outcomes if they catch COVID-19.



The future is flexibility; the days of a one-size-fits-all way of providing services are over. A one-size-fits-all service or living model is bad policy because it can have a negative impact on our health and quality-of-life outcomes. A one-size-fits-all system is also not very accommodating in meeting our unique needs. And COVID-19 has proven once again that living in segregated settings is hazardous to our health and survival.

Finally, we must use the lessons learned from this pandemic to transform our system to focus more on preventive care. As a society, we need to move away from the model of 'wait for disease and then

rush in to treat it'. Shifting to home visits will allow people with disabilities and other vulnerable populations to receive preventive care and disease management without having to worry about the risk of catching COVID-19 when traveling to a doctor's office. House calls could also help independent doctors stay in business given that many private doctors have reduced services during this pandemic.

(According to a report from the American Medical Association, [81% of Primary Care Doctors are providing fewer in-person visits during COVID](#)). Delaying preventive care can backfire in the long term. We know that by putting off cancer screenings and immunizations against deadly diseases we risk long-term consequences to public health outcomes. Home visits will go a long way toward helping people with chronic health problems, sensory issues, and transportation challenges to access healthcare in a safe way.

In [a recent survey](#), "92% of adults say care at home is equal to or better than facility-based care."

While this change is especially important during the pandemic, in a non-pandemic world these changes are also beneficial, given the many access barriers people with disabilities and other populations face in receiving needed services.

Online Services

During the COVID era, everyone has had to adjust what community means to them. People's community lives are happening online—including their shopping, banking, working, schooling, doctors' visits, and social gatherings. Today's community living requires equal access to technology. But many of us face challenges with this.



Many of us live off of SSI or SSDI and work only part time, which causes us to live in poverty. This makes it difficult for us to pay for the devices, and the internet and phone services, that let us connect to the community. In rural areas especially, access to high-speed internet or internet in general is poor. And many people with disabilities need support to learn how to use various forms of technology. And some of us face challenges with not having control over our lives and technology use, especially if we live in segregated settings or are under guardianship. It is common for staff and parents to restrict our access to technology. Without technology resources though, it is hard to survive and thrive in a fast-growing digital world.

While a virtual community life allows us to avoid catching COVID-19, and eliminates transit barriers we face day in and day out, it is not without other challenges. Moving services online caused issues at the start of the pandemic. For instance, at the beginning of the pandemic we were told that SNAP benefits (formerly food stamps) couldn't be used to pay for grocery delivery. This problem is now solved in some places but not all. We have also found in many cases that [web-based services are not accessible](#) to all people with disabilities.



Peer Mentoring

The COVID-19 pandemic disruption has led to higher rates of anxiety and depression in our society. As we confront this mental health pandemic, we must make peer mentoring and peer support the norm. Peer mentoring is when a person with a disability supports someone else with a disability, and peer mentors can be paid or unpaid. Peer mentors bring unique skills as a result of lived

experience with a disability or mental health challenges. The services they provide are more empowering and less controlling, which is a big difference. I have found that peers with disabilities will often tell it like it is and tell the truth. People without disabilities will often give you biased information or impose their values.

For instance, it is not uncommon for support staff to impose their values or be very opinionated when it comes to giving advice to people with disabilities. For example, giving their opinion on topics like should I breakup with boyfriend, stop taking meds, find a new job or cut hours, end a shared living arrangement, etc.



Peer mentoring can allow folks to learn how to live in their own apartment in the community. You can match someone just moving into an apartment with another person with a disability who has experience living independently. This allows them to learn life skills like cooking, apartment upkeep, community navigation, budgeting, and promote better health by teaching them how to eat healthy and exercise, and it can even offer mental-health support during tough times. By getting support from someone with a disability who has more skills, a person can be supported to achieve the goal of living on their own. Lastly peer mentoring will go a long way toward reducing the social isolation, loneliness and boredom caused by this pandemic.

Housing supports in the community

It is my hope that we move away from group homes and institutions and shift toward providing all services in the community. The pandemic has shown us again of the many risks that life in segregated settings poses, and I think there will be a bigger push for

people with disabilities to live in their own apartments or in shared living arrangements. For this to occur we must fight for massive funding in low-income accessible housing. The housing must be on public transit routes, close to downtown areas. I say this because many people with disabilities do not or cannot drive and it is difficult to get places. This is especially true for those of us who do not get any home and community-based waiver supports.



There will also be a need for funding for the technology and technology programs that can help people to live independently. An example of this is the Howard Center in Vermont where they have a program called Safety Connections. This allows the agency to support folks at night remotely with an alarm system. At night, Suzie Q will arm her system and staff speaks to her over a loudspeaker to check in. After that, if she has a crisis or someone breaks in, they will send a responder over to help.

Working in the Community

The best thing about this pandemic is that it has exposed the fact that many jobs can be done from home. And new ways of doing things are more accepted—like video resumes, remote job coaching, and remote tours of workplaces. To make a change to remote work, some people will need Vocational Rehabilitation services. Some people may be more open to talking about what services they truly need in a remote setting. For those of us with anxiety we may be more open to saying what barriers or challenges we have. And we may need to give VR counselors tips on how they can better address our needs.



For people transitioning from school to adulthood, remote planning sessions have made it easier for parents to attend. And many pre-employment skills trainings, job fairs, and workshops are now being done remotely.

Looking ahead

As a society if we take advantage of the opportunities this crisis has given us, we can come out of this pandemic nightmare to a more disability-friendly world. Our so called “normal” world prior to COVID-19 was not great for a lot of us in the disability community.

The time for systems change is during the pandemic, not after it’s over. I say this because right now the media and society are paying attention to the negative impact of COVID and how our current system and attitudes about people with disabilities puts vulnerable populations at high risk for COVID-19. Now is when we should be designing a system that makes us healthier and safer. The high rates of COVID cases in segregation gives advocates something to point to when unions and pro-segregation groups say we should keep segregated settings open. Prior to COVID, I often heard parents say, “My kid is too disabled to live in the community” and they should have a choice between community and segregated settings.

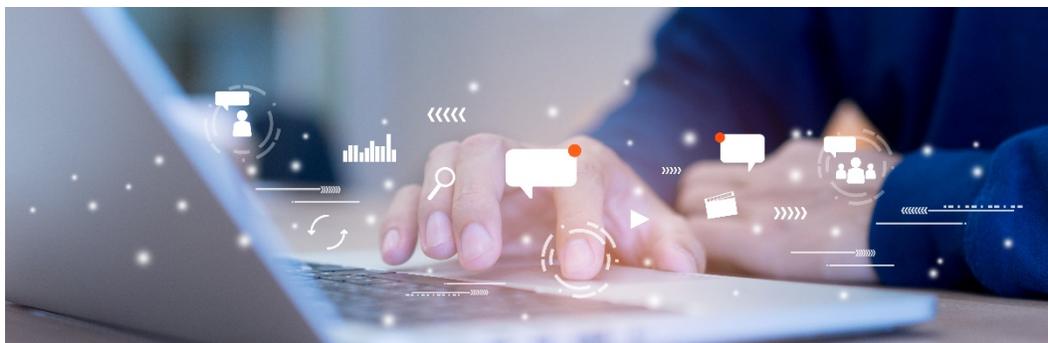
Systems change can be scary, but if done right it will lead to a healthier and more inclusive world. This crisis is the perfect time for us to evaluate how we make businesses more accessible, safer and flexible for customers and workers with disabilities. Flexibility is the “New Normal” in all aspects of community life. Gone are the days when everyone in the business world insists on being face to face 99-100% of the time. Many people with disabilities have dreamed of the day when society would be more accommodating to us. By not

having to be face to face all the time, it goes a long way in allowing us to be active in our community without always having to worry about transit issues, crowds and risking our health.

Having the capacity to make all functions virtual is one of the greatest equalizers of our time. The reason for this is a majority of us in the disability community do not drive, and reliable and accessible public transit is hard to come by—and para transit service is often unreliable or unacceptably slow. But, being able to do our day-to-day business online offers peace of mind to those of us with chronic health issues. The less we have to worry about our health the better.

In a post-pandemic world, it is my hope that we, as a society, can continue to offer both virtual and in-person services. Doing this will allow agencies and businesses to reach a broader audience for events and basic government services.

One area where going all-virtual could help is in agencies that administer public benefits like SSI, SSDI, Medicaid, SNAP and so forth. I personally would like to see Social Security move to all-virtual when it comes to asking for various forms of documentation and filling out paperwork like the work activity report or any other forms they need. Doing things like this online is much easier and less stress than having to run around printing out stuff. If we could allow for this to be done electronically it would save time, energy, stress and money.



More resources

If you'd like to learn more, here are some trainings and resources:

- [Supporting Adults with Autism through Uncertain Times](#), by Ann Sam, PhD., and the UNC FPG Autism Team
- [COVID-19 and autism: Uncertainty, distress and feeling forgotten](#), an article in Public Health in Practice
- [Dealing with the global tsunami of mental health problems during and post COVID-19](#), by the European Society of Clinical Microbiology and Infectious Diseases
- [COVID-19 Has Leveled the Playing Field for People With Disabilities](#), by Gunnar Esiason for US News and World report
- [92% of Adults See In-Home Care as Better or Equal to Facility-Based Care](#), by Joyce Famakinwa for Home Health Care News
- [VR Counselor Huddles: Providing VR Services Remotely](#), Institute for Community Inclusion, UMass Boston
- [VR Counselor Huddles: Providing Transition Services Remotely](#), Institute for Community Inclusion, UMass Boston
- [VR Counselor Huddles: Accessing Virtual Mental Health Services Remotely](#), Institute for Community Inclusion, UMass Boston
- [Grocery and food delivery apps are increasingly crucial amid coronavirus, but these may be out of reach for the most vulnerable Americans during the pandemic](#), by Kate Taylor for Business Insider
- [All the Same mini-documentary series](#) (on Accessibility), from Essential Accessibility
- [Peer Mentoring: What's it all about?](#), by the Michigan Developmental Disabilities Council
- [Peer Mentoring webpage](#) on the ENDependence Center of Northern Virginia website

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