COVID-19 Survey Results

Analysis of the Responses of Council Members, Regional Advisory Committee Members, and Statewide Self-Advocacy Network Members



Who Participated?

- 53 individuals representing all SCDD Regions.
- Participation throughout the entire state helped provide an understanding of the situation. Given the number of participants, the input does not represent everyone in California.



SCDD Resources

More than 70% of the participants found the Council's COVID-19 resources in plain language to be extremely useful.



Status of Services

• Of the participants needing services for themselves or for a family member, 48% are receiving some virtual services, 35% are not currently receiving services, and 13% are receiving all services needed.

Not Enough Information about the Crisis

- Participants believe they do not have enough information on when the crisis will end and how we will recover.
- Participants are receiving their updates from a myriad of outlets, which include webinars, traditional media, and social media (including emails from the SCDD and other nongovernmental organizations).



What Should the Policymakers Do? (1 of 9)

- Participants were asked their three biggest questions for policymakers. Their responses broke into a few themes for questions.
- Many responses were general questions about the current pandemic and how it will be prevented in the future. Examples include:
 - What will need to happen and how much time needs to pass before social distancing requirements can cease?
 - When will people know to go back to work?
 - Where do I go to get tested?
 - How are hospitals dealing with over capacity of patients?

What Should the Policymakers Do? (2 of 9)

- Questions about special education services:
 - What are the expectations for Local Education Agency (LEAs) to provide Free Appropriate Public Education (FAPE) during a public health declaration of emergency?
 - When will the California Department of Education issue guidelines on teaching special education students and delivering related supports and services?
 - Are students with Individualized Education Programs (IEPs) getting their educational rights?
 - What accommodations will be made for the Regional Center clients and students for whom distance learning does not work?

What Should the Policymakers Do? (3 of 9)

- Questions about Regional Center services:
 - How are Regional Centers monitoring service providers for safety?
 - When will my job/day program re-open?
 - What is the long-term commitment to funding for wrap around services for all ages of people with developmental disabilities?
 - In light of the forthcoming state budget crunch, how do we protect our network of services and providers from collapse and preserve the rollout of the Self-Determination Program?

What Should the Policymakers Do? (4 of 9)

- Questions about the In-Home Supportive Services (IHSS) program:
 - How is quality care without harm able to be maintained for those in need?
 - If my husband gets sick, who is also my IHSS provider, how long will it take for someone to come and help me if I call the emergency registry?
 - How does a person access back up attendant care?
 - What back up service is in place for IHSS recipients when their caregiver(s) are not available?

What Should the Policymakers Do? (5 of 9)

- Questions about the Personal Protective Equipment (PPE) for self and providers:
 - How did the shortage of PPE and ventilators happen given that policies and procedures should be in place for a pandemic?
 - Who can supply PPE for caregivers, family and other support personnel?
 - Will my assistants and therapists have access to proper PPE?
 - Why are there still shortages of testing, PPE, and medical equipment?

What Should the Policymakers Do? (6 of 9)

- Questions about healthcare:
 - Will care for people be rationed?
 - How will death by triage be prevented?
 - For those who cannot get to the doctor because they are sick, what can they do?
 - What emergency room services will be offered to an individual with a disability, should they suspect they have COVID-19?
 - Why does Medicaid not have a 90-day refill of prescriptions and medical supplies?

What Should the Policymakers Do? (7 of 9)

- Question about employment:
 - How can the government ensure that people with developmental disabilities who were laid off can obtain competitive integrated employment when unemployment rates are so high and thousands of people are out of jobs?

What Should the Policymakers Do? (8 of 9)

- Questions about technology:
 - How do political leaders know who has Wi-Fi or internet and who may need it?
 - What is the plan to provide supports and services for those who are non-verbal, limited verbal and who need 1:1 providers due to their severity and need the technology to use tele-health/telemedicine/tele-education?

What Should the Policymakers Do? (9 of 9)

- Questions about food and housing:
 - When can I use CalFresh/EBT/food stamps to buy food online?
 - How can food banks get more food?
 - For the people that cannot go out and get food and they have no one that can do it for them, what can they do?
 - How can California increase the post-virus supply of affordable housing especially for people with developmental disabilities?

How has COVID-19 affected you, your family, or friends uniquely because of your connection to disability?

- Cannot go outside
- Cannot spend time with friends
- Feel socially isolated
- Feel more connected (by Internet platforms)
- Behaviors have increased or worsened
- Increased or decreased anxiety or other mental health conditions
- Cannot go out to eat or shop
- Need to use masks and other Personal Protective Equipment (PPE)
- Need for more help from family
- Loss of or disrupted services (specifically, respite)
- Not understanding actual impact
- Not feeling safe
- Lack of motivation or opportunity for physical activity
- Has not had an impact

What do you need most right now that you don't have access to in order to support you during this pandemic?

- Household supplies (hand soap, sanitizer, disinfectant, toilet paper)
- Immune caregivers
- Help with basic needs (grocery shopping)
- Social interaction with providers
- Quality food, use of CalFresh online or different stores, grocery delivery
- Prescription delivery
- Personal Protective Equipment (PPE)
- Nothing

- Additional services (In– Home Supportive Services, relief worker and respite)
- Things to do at home/entertain
- Innovation and creative thinking
- Electronics (Chromebook or other electronics to continue education, computer, iPad)
- Internet
- Walking companion
- Mental health professionals
- Help line to connect people
- Financial security (increased social security)