

**Testimony before the California Assembly Budget Subcommittee #1
on Health and Human Services
by Judy Mark, President
Disability Voices United
February 17, 2021**

Thank you, Dr. Arambula and Committee members.

I'm Judy Mark, a proud mom of Joshua who is 24 and has autism. I'm also the President of Disability Voices United, a statewide advocacy organization directed by people with disabilities and their families. It has been a long day, but hopefully you've saved the best for last.

I am honored to testify today because it is important that you listen first (and hopefully not last) to the people with disabilities and their families. As the panelist here with skin in the game and one who can never retire from advocating for my son and others, I hope to provide you with the realities we face in accessing services.

During the pandemic, DVU has listened to self-advocates and families through 22 webinars and a statewide survey. Here is what we learned, and some recommendations for improving our service system:

1. **Directives from DDS are not getting directly to families:** We were gratified that DDS issued an array of directives giving individuals vitally needed flexibility. Few, however, have taken advantage of them, because they weren't informed or were denied the services. For example, DDS data show that very few families have actually used participant-directed services over the past year.
2. **Communities of color continue to face significant disparities.** Our recent analysis of POS data shows that racial and ethnic disparities persist, despite \$55 million spent to combat this problem. Latinos continue to face the greatest disparities, getting only 42% of what whites received statewide last fiscal year. Not a single regional center is making significant progress, and most are moving backwards. And we fear that these disparities have been exacerbated by the pandemic. There needs to be clear expectations and consequences for regional centers who are not making progress on eliminating disparities.
3. **The Self-Determination Program is being blocked by layers of unnecessary bureaucracy.** The Self-Determination Program was tailor made for a pandemic. Those in the program have had the flexibility to do unique things to make them happy, healthy, and safe. But implementation barriers have been so great that fewer than 20% of phase-in participants have moved into the program. DDS needs to provide more oversight and clearer direction, and regional centers need to reduce bureaucracy in order to eliminate barriers to participation – especially as the program moves to full implementation in less than five months. The Self-

Determination Program, which the legislature created 8 years ago, must be allowed to fulfill its promise.

4. **The needs of many people with disabilities are not being met under the alternative services model.** While DDS quickly developed this system in order to sustain the provider network, we have not yet seen data on consumer satisfaction with alternative services. Before the system was launched, and while providers were still being fully paid, DVU and others conducted surveys finding that only half of individuals in closed programs were continuing to receive services. DDS and regional centers need to ensure that service providers are actually meeting the needs of clients. For many, a 30-minute Zoom class every day is not enough. We have seen that there is a safe way to provide in-person individualized services, and consumers should be able to access that.

The irony is that as awful as the last year has been, we have been presented with opportunities to fundamentally change our system to be more person-centered and outcome-driven.

This is the time to move away from providing services in congregate settings, not only because of the dangers of pandemics, but because of the impending HCBS rules. These settings must be person-centered and community-based to receive federal matching funds in two years. It just makes sense to focus on helping providers make the changes necessary to comply with the rule before they reopen, instead of letting them return to pre-pandemic, outdated service settings.

Ultimately, we need a system where people with disabilities come first. In the past year, providers got paid in order to sustain the service system, and regional centers maintained their operations. But many families had to beg for more hours of respite or didn't even know they could ask for help during this crisis.

I hope my testimony makes clear that our system is upside down. While we should be concerned about service providers and regional centers, we must focus more on improving outcomes, eliminating racial disparities, and meeting the pandemic needs of families through self-determination and flexibility. The system is ours, but sometimes it doesn't feel that way, particularly in the past year.

My organization looks forward to working with the legislature and DDS to meet these challenges to meaningfully improve our system. Thank you.