



COVID-19 and California's Developmental Disability Community

Lessons Learned: Successes and Challenges

Beginning in March 2020, California and its citizens have been confronted with an unprecedented challenge in COVID-19. The onset of the pandemic significantly impacted all vulnerable populations, including the Intellectual and Developmental Disability (IDD) community. The IDD community responded to protect the health and safety of those we serve and ensure that participants and families maintain access to resources and services.

All stakeholders within the IDD community had to make significant changes and deft pivots to maintain continuity of support; especially as local communities and Departments of Public Health made real-time decisions to close down business operations, schools, and for the IDD community, non-residential service settings.

Our community learned many lessons through this crisis. While some significant challenges remain, others have become opportunities and successes. In response, the Lanterman Coalition, representing every component of the state's system of services and supports for people with IDD, offers the following observations:

FACTS

Health & Safety: Based on DDS data as of November 13, 2020, DDS has reported a total of 3,600 (1%) positive cases out of a total of 355,298 consumers within the DDS system, and a total of 177 (0.05%) reported lives lost. When looking at these COVID numbers in comparison with other vulnerable populations served by Health and Human Services (HHS), it is evident that the IDD service community has responded quickly and responsibly to mitigate spread, reduce risk for those served, and ultimately save lives.

PPE Distribution: As of October 2020, the State Council on Developmental Disabilities (SCDD) and its community partners (e.g., Regional Centers, service providers, and other community-based organizations) have distributed more than 102 million items of PPE to the community. DDS has provided Regional Centers with more than 8 million more. Critical items include masks, face shields, hand sanitizer, gloves, wipes, and gowns.

FACTORS CONTRIBUTING TO SUCCESSSES

Existing Infrastructure: As the Lanterman Act designed, all 21 Regional Centers are responsive to local needs and have established connections and leveraged existing communication channels with the Department of Developmental Services (DDS), families, providers, and other stakeholders. Similarly, SCDD has regional offices, and local service providers have direct daily contact with clients and families. Throughout this public health crisis, this existing infrastructure and network of relationships has been instrumental in distributing information, minimizing confusion, and reinforcing health and safety.

Passion of Staff and Commitment of Family: Across the state and throughout the pandemic direct support professionals (DSPs) have demonstrated heroism in their commitment to

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Californians with IDD. Despite risks and despite pressures in their own lives (78% of DSPs are women, 54% have two jobs, more than 42% are enrolled in Medi-Cal, 10% have a child with a disability), these essential workers have proven a passion for this community that cannot be quantified. Many DSPs have filled the need by working overtime for many months in a row, or even leaving their own families to quarantine with those they support. Parents and family members have demonstrated heroism through sacrifices for loved ones' safety and commitment to continuity of support while shelter-in-place orders disrupted their routine schedule of services.

Collaboration: The system came together with an unprecedented level of collaboration and partnership. DDS hosted multiple stakeholder meetings and used input from those meetings to guide its decision-making efforts. Legislators and staff remained engaged throughout the pandemic, providing support and input. Regional centers, providers, families and consumers participated actively in joint efforts to support people with IDD and their families through unparalleled health and safety, fiscal, and operational crises.

Financial Stability: The safety of Californians with IDD was only possible because DSPs, service coordinators, and other service providers were able to focus on preventing the spread of COVID instead of focusing on losing jobs and closing organizations. This financial stability was the result of both state and federal efforts. The California State Legislature heroically saved the IDD community from devastating budget cuts in the 2020-21 budget. DDS quickly allowed for State of Emergency payments that maintained nonresidential services facing absences due to COVID. Congress passed relief efforts including Paycheck Protection Program (PPP) loans, Provider Relief Fund (PRF), and Economic Injury Disaster Loans (EIDL).

Flexibility: California's developmental services system has proven itself nimble and responsive in the face of crisis. The Lanterman Act entitles individuals to person-centered services that are unique to the individual's needs. As such, the system of services and supports created by the Lanterman Act are inherently flexible to meet the needs of individuals and families even when normal daily life is turned upside down. As an example, DDS issued directives for "Alternative Services" to safely meet the needs of the community, and within weeks Regional Centers, service providers, and families pivoted to new modes of service delivery.

CHALLENGES

Vulnerability of Population and System: People with IDD are three times more likely to die of Covid-19, compared with patients without IDD, a new analysis found. Indeed, more than 5% of the individuals in California's DD system who were reported COVID positive died from the virus, a much higher percentage than their neurotypical peers. This unique challenge has caused every decision to carry the burden of potential life and death consequences. Exacerbating this challenge is the vulnerability of the entire service system, mostly as a result of chronic and critical underfunding. Even before the pandemic many Californians with IDD and their families were already in crisis due to underfunding of services and supports, as confirmed in the DDS rate study (currently underfunded \$1.4 billion). This crisis has underscored the frightening reality that the mere uncertainty of reimbursement of a single month can easily force an established service provider to layoff significant staff and close programs. Individuals, families, and support staff have had to live and operate with this heightened vulnerability, and the stress that accompanies it, for several months.

Stressed Workforce: The direct support professional (DSP) workforce is the backbone of our system, delivering the promise of the Lanterman Act to hundreds of thousands of individuals

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throughout the state. Similarly, service coordinators at regional centers are integral to connecting clients and families with community-based services and critical support with navigating complex systems. This workforce was underpaid and undervalued before the pandemic, which also introduced new challenges. In some services, DSPs confront COVID risk to deliver critical hands-on support to individuals who require it to maintain community living. These DSPs have worked long hours, often at a risk to themselves, their families, and their sense of security. Other DSPs and service coordinators had to quickly develop skills to deliver services remotely, adapting technological solutions to meet the needs of their clients. Many DSPs and service coordinators have seen their jobs change overnight and developed new skills to meet the moment.

Meeting the Needs of Everyone: Californians with IDD are as diverse as the general population and meeting each individual need has been a major challenge. Some individuals report higher satisfaction with remote services, while other individuals find them inadequate and are waiting for traditional programs to resume. Some younger adults are able to continue their sense of community online, while referrals for Early Start services by pediatricians have seen a significant decline. There is also a significant digital divide across the state and needs vary greatly by region. In one survey 28% of respondents said that the individual was experiencing “serious difficulties” with regard to “mental and physical health and overall well-being” due to changes in their services. Continued, sustainable, and dedicated efforts to reach all individuals are needed.

Reality of System Operations and Direction from Administration: In response to the public health crisis, DDS enhanced lines of communication with stakeholders and the public. DDS directives removed barriers for families and allowed greater flexibility. The fast-moving situation and multiple entities involved (DDS, HHSA, CMS, etc.) at times resulted in directives being released just days before they were effective. Regional centers and service providers dependent on that information struggled to make informed service and staffing decisions.

Signed and supported by:

The Arc & UCP California Collaboration
Association for Regional Center Agencies (ARCA)
California Disability Services Association (CDSA)
L.A. Provider Coalition
East Bay Legislative Coalition
Developmental Disability Provider Network (DDPN)
Infant Development Association (IDA)
Family Resource Centers Network of CA
Autism Business Association
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