STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Over 50 years ago, the State Councils on Developmental Disabilities were established in federal statute. The Councils are currently authorized in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) in each of the 56 states and territories to “promote self-determination, independence, productivity, integration and inclusion in all aspects of community life” for individuals with intellectual and developmental disabilities (I/DD) and their families through advocacy, capacity building, and systems change. The Lanterman Act established the California State Council on Developmental Disabilities (Council) to fulfill those rights.

The Council is comprised of 31 members appointed by the Governor including individuals with I/DD and their families, representatives from the DD Act partners (Disability Rights California and the three University Centers for Excellence in Developmental Disabilities), and mandated state agencies that provide services and supports to individuals with I/DD. To implement the rights in the DD Act, the Council develops and implements a five-year state plan that contains goals, objectives, strategies, and outcomes designed to improve and enhance the availability and quality of services and supports. In addition to the Council’s Sacramento headquarters, regional offices support individuals with I/DD and their families through activities such as advocacy, training, monitoring, and collecting and disseminating public information.

The Council works with policymakers and other stakeholders to ensure policies pertaining to the rights of individuals with I/DD are protected and enhanced by ensuring individuals with I/DD can experience equality of opportunity, full participation, independent living, and economic self-sufficiency. These four pillars are enshrined in the Americans with Disabilities Act of 1990 (ADA). The Council supports the full and robust implementation and enhancement of state and recent federal policies that enshrine the values of the ADA such as the Workforce Innovation and Opportunities Act (WIOA), Home and Community-Based Services Setting Rule (HCBS), Every Student Succeeds Act (ESSA), and Achieving Better Life Experience (ABLE) Act.

The Council believes that individuals with I/DD and their families must be included and consulted in all aspects of the policy making process to ensure their needs are adequately and appropriately addressed. The Council works to address disparities in access, outcomes, and quality for all services and supports. The Council believes in ensuring transparency and accountability for state and federal programs providing services and supports to individuals with I/DD. Furthermore, the Council believes that complexities in the service delivery system must be reduced and that assistance in navigating services
and supports should be provided to individuals with I/DD and their families. The State of California must ensure that funding is used to achieve positive outcomes for individuals with I/DD and their families.

Disparities in services and supports can result in severe health, economic, and quality of life consequences. Services and supports must be distributed equitably so that individual needs are met in a culturally appropriate and linguistically competent manner regardless of race, ethnicity, income, intellectual or physical ability, age, and geographic location. Information and materials must be provided in plain language and/or alternative formats as requested.

PROMISE OF THE LANTERMAN ACT
The Lanterman Act promises to honor the needs and choices of individuals with I/DD by establishing an array of quality services throughout the state. Services must support people to live inclusive lives in their communities. Access to needed services and supports must be inclusive and not be limited through service caps, means testing, median rates, family cost participation fees, or other financial barriers. California must not impose artificial limitations, delays, or reductions in community-based services and supports that would compromise the health and safety of people with I/DD.

SELF-DETERMINATION
Individuals with I/DD and their families must be given the option to select and direct their services and service dollars through Self-Determination. The person with I/DD is in charge. With the support of those they choose and trust, individuals with I/DD and their families are empowered to develop their own unique needs, develop their own life goals, and construct those services and supports most appropriate to reach their full potential. The process begins with a Person Centered Plan (PCP) which details their unique needs, competencies, and aspirations. Self-Determination gives individuals with I/DD the tools and the basic human right to pursue life, liberty and happiness in the ways that they choose.

SELF-ADVOCACY
Individuals with I/DD must be in charge of their lives and be respected for the choices made. They must be provided the opportunity and support to be heard and be leaders in the service system and society including voting and other civic responsibilities. Individuals with I/DD must be protected against voter suppression and provided the same access to vote independently as individuals without disabilities. Self-advocates must have access to training, assistive technology, information, and materials in plain language and opportunities to participate in the policy making process.

EMPLOYMENT AND ECONOMIC SELF-SUFFICIENCY
Every person with a developmental disability should have the opportunity to be employed in competitive integrated employment (CIE). CIE means full or part time work at minimum wage or above, with wages and benefits similar to those without disabilities, fully included
with co-workers without disabilities, and located in the community. California must invest in systems change efforts that will result in a measurable increase in CIE for people with I/DD. This priority is consistent with California’s Employment First Law that states CIE is the priority outcome for working age individuals with I/DD regardless of the severity of their disability.

Policies, service delivery practices, and financing must set expectations for CIE, microenterprise training, and/or self-employment. Individuals with I/DD must have access to information, benefits counseling, transition planning, job training, and inclusive post-secondary education. Adequate provider rates must be established for the provision of services and to incentivize quality and inclusive employment outcomes.

Employers must be engaged, prepared, and supported to employ individuals with I/DD. New or expanded pathways to CIE, including apprenticeships and internships, must be developed and supported for all individuals with I/DD regardless of severity of disability. The Council supports the phasing out and elimination of subminimum wage and/or segregated employment for all individuals with I/DD.

TRANSPORTATION

Access to transportation is essential to education, employment, healthcare, and inclusion of individuals with disabilities. Timely accommodations must be available to people with I/DD that are available to people without disabilities. Mobility training must be a standard program among transportation providers to increase the use of available transportation and reduce reliance on costlier segregated transportation systems. Barriers between geographic areas and transportation systems must be addressed so people with I/DD can travel as safely and easily as people without disabilities. Emerging transportation options must be available and accessible to people with I/DD. Opportunities for car ownership must be increased.

HEALTH CARE

Every person must have access to comprehensive, timely, quality, and affordable health care, dental care, and wellness services as well as access to plain language information and supports to help in understanding health plans and making informed decisions about their health care. This requires informed consent, individualized and appropriate medication and treatments, and an adequate network of health professionals. Individuals with disabilities must have equal access to intensive medical services, testing, and vaccinations for communicable diseases as individuals without disabilities. Testing for communicable diseases must be provided in the same timeframe as it is provided to individuals without disabilities regardless of the person’s living situation (live at home, live with family, or live in congregate living.)

All individuals with disabilities, including individuals with multiple health care needs, must have access to routine preventative care, mental and/or behavioral health treatment, dental care, durable medical equipment, and reproductive health needs. Service system complexities must not delay, reduce, or deny access to services. Individuals must be
reimbursed for insurance co-pays, co-insurance, and deductibles when their health insurance covers therapies that are on their Individual Program Plans (IPPs).

EDUCATION

Every student has the right to be safe in school and to receive a quality education with their peers that prepares them for post-secondary education and/or competitive integrated employment (CIE). Schools must ensure robust implementation of the Individuals with Disabilities Education Act (IDEA), Every Student Succeeds Act (ESSA), and other federal and state laws and regulations. Students with disabilities must be provided a free and appropriate public education and have access to the same opportunities for learning, in the classroom and online, as students without disabilities. School districts and other educational agencies must be held accountable for implementing all state and federal laws.

Students with disabilities must be educated alongside their peers without disabilities in the least restrictive environment (LRE). The needs of the student must not impact the child’s placement in LRE. Parents must be provided information and training regarding how to access Free Appropriate Public Education (FAPE) and LRE. Students with disabilities must have access to the same virtual learning models as students without disabilities, and all related services must be provided for students with disabilities to access their education. Parents and students must have equal participation in the Individual Education Program (IEP) process including the ability to give informed consent. Comprehensive transition planning must be considered as part of the IEP process.

Teachers, school leaders, paraprofessionals, and other school-based professionals must be trained to use valid, positive, and proactive practices such as individualized school-wide positive behavior interventions and supports with fidelity. Schools must ensure that robust policies and practices are created and implemented to reduce bullying and harassment of students with disabilities. The Council opposes the use of all forms of seclusion and restraint. All school-based professionals and staff must be provided training on how to interact with students with disabilities.

HOUSING

Statewide inclusive living options for individuals with I/DD must be increased and enhanced through access to housing and subsidies that are paired in a timely manner with needed supports and services. Community education and integration must be provided to reduce discrimination. Permanent, affordable, accessible, safe and sustained housing options must be continually developed to meet both current and future needs.

COMMUNITY PARTICIPATION

Individuals with I/DD must have access to and be fully supported to fully participate in their communities with their peers without disabilities through opportunities in all areas of community life including but not limited to education, employment, recreation, organizational affiliations, spiritual development, and civic responsibilities that provide a life similar to individuals without disabilities.
TRANSITION TO ADULT LIFE

All services, including education, rehabilitation, independent or supported living, and regional center services, must support students and adults to transition to competitive integrated employment, post-secondary education, or other opportunities including volunteering that will lead to meaningful employment in the community. Transition services must be considered at the earliest possible opportunity and across the lifespan. Adults with I/DD must have access to meaningful activities of their choice with the appropriate services and supports including aging adults.

SAFETY

All people have a right to be safe. Every person must be provided emergency preparedness training for all types of emergencies or disasters. Individuals with I/DD experience a much greater rate of victimization and a far lower rate of prosecution for crimes against them. The same level of due process protections must be provided to all people. Individuals with I/DD should be trained on personal safety, how to recognize crimes, how to protect themselves against becoming victims of crime including on the internet, how to protect themselves from human trafficking, and how their participation in identification and prosecution can make a difference. In addition, too many interactions between law enforcement and individuals with I/DD end in avoidable tragedy. Law enforcement personnel, first responders, emergency medical professionals, and people in the judicial system must be trained in how to work with individuals with I/DD during the course of their duties including those who are suspects, victims, or witnesses of crimes. The Council opposes the use of all forms of seclusion and restraint.

QUALITY AND RATES FOR SERVICES AND SUPPORTS

Having access to and receiving quality individualized services and supports is the cornerstone for individuals with I/DD to be safe, healthy, and to promote self-determination, interdependence, and inclusion. An adequate safety net must be in place to immediately and timely address medical, mental health, behavioral, residential, staffing, equipment, or other needs when those services or supports fail, are interrupted, are not available, or additional services and supports are necessary for urgent or immediate need.

The state must streamline burdensome and duplicative regulations and processes that do not lead to positive, inclusive outcomes for individuals with I/DD and their families. Quality and timely assessment and oversight must be provided. The state must measure what matters, and the results must be administered in a culturally competent manner. The results must also be made public and be used to improve the system of services and supports. The state must restore and provide ongoing monitoring of rates to adequately support the availability of quality services for individuals with I/DD. A planned and systematic approach to rate adjustments must prioritize and incentivize quality services and supports.

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