Date of Hearing: April 9, 2024

ASSEMBLY COMMITTEE ON HUMAN SERVICES
Alex Lee, Chair
AB 2383 (Wendy Carrillo) – As Amended March 21, 2024

SUBJECT: State Department of Developmental Services: services for medically fragile children: training program

SUMMARY: Requires the Department of Developmental Services (DDS) to develop or contract for the development of, and implement by July 1, 2025, a required training program for hospital and regional center care management professionals. Specifically, **this bill**:

1) Requires DDS to develop or contract for the development of, and implement by July 1, 2025, a required training program for hospital and regional center care management professionals including:

   a) Case managers;

   b) Social workers;

   c) Early Start liaisons;

   d) Coordinators;

   e) Navigators; and,

   f) Medical discharge planners.

2) Requires the training program to include an initial training and an annual refresher course.

3) Requires the training program to provide care management professionals as described in 1) with an understanding of Medi-Cal home- and community-based waivers under Section 1915(c) of the federal Social Security Act (42 United States Code § 1396n (c)), including the Home and Community-Based Alternatives Waiver, the Home and Community-Based Services Waiver for Californians with Developmentally Disabilities, the Self-Determination Program Waiver for Individuals with Developmental Disabilities, and the Medi-Cal Waiver Program.

4) Requires the training program to provide care management professionals with information on how to identify a newborn who is likely to qualify for any of the waivers specified in 3) above.

5) Requires the care management professional to provide the family of a medically fragile child with information and a navigation plan on Medi-Cal home- and community-based waiver programs when the care management professional has reason to believe that it is more likely than not that the child would qualify under one or more waiver. Requires the information and navigation plan to be provided upon discharge from the hospital, including if the child is being discharged from the neonatal or pediatric intensive care unit, or as part of the regional center's individual program plan (IPP) process, as applicable.

6) Requires DDS to solicit and consider stakeholder input when developing the training program. In addition, permits DSS to consult or collaborate with the California Department of Health Care Services (DHCS), the California Department of Public Health (CDPH), or both, for purposes of developing the training program, as necessary.

7) Requires a care management professional to receive the initial training within 60 days from the date the training program is implemented.

8) Requires a care management professional employed after the program is implemented to receive the initial training within 60 days of their employment.

9) Defines "medically fragile" as having an acute or chronic health problem that requires therapeutic intervention and skilled nursing care during all or part of the day. Medically fragile problems include, but are not limited to, HIV disease, severe lung disease requiring oxygen, severe lung disease requiring ventilator or tracheostomy care, complicated spinal bifida, heart disease, malignancy, asthmatic exacerbations, cystic fibrosis exacerbations, neuromuscular disease, encephalopathies, and seizure disorders.

EXISTING LAW:

1) Establishes an entitlement to services for individuals with developmental disabilities under the Lanterman Developmental Disabilities Services Act (Lanterman Act). (Welfare and Institutions Code [WIC] § 4500 *et seq.)*

2) Grants all individuals with developmental disabilities, among all other rights and responsibilities established for any individual by the United States Constitution and laws and the California Constitution and laws, the right to treatment and rehabilitation services and supports in the least restrictive environment. (WIC § 4502)

3) Establishes a system of nonprofit regional centers throughout the state to identify needs and coordinate services for eligible individuals with developmental disabilities and requires DDS to contract with regional centers to provide case management services and arrange for or purchase services that meet the needs of individuals with developmental disabilities, as defined. (WIC § 4620 *et seq.*)

4) Requires the development of an IPP for each regional center consumer, which specifies services to be provided to the consumer, based on their individualized needs determination and preferences, and defines that planning process as the vehicle to ensure that services and supports are customized to meet the needs of consumers who are served by regional centers. (WIC § 4646)

5) Requires the IPP planning processes to include:

   a) A statement of the individual's goals and objectives, a schedule of the type and nature of services to be provided and other information and considerations, as specified;

   b) Review and modify, as necessary, by the regional center's planning team no less frequently than every three years; and,

   c) Statewide training and review of the IPP plan creation, as specified. (WIC § 4646.5)

6) Defines “developmental disability” to mean a disability that originates before an individual attains 18 years of age, continues, or can be expected to continue, indefinitely, and constitutes a substantial disability for that individual. As defined by the Director of DDS, in consultation with the Superintendent of Public Instruction, this term shall include intellectual disability, cerebral palsy, epilepsy, and autism. This term shall also include disabling conditions found to be closely related to intellectual disability or to require treatment similar to that required for individuals with an intellectual disability, but shall not include other handicapping conditions that are solely physical in nature. (WIC § 4512)

FISCAL EFFECT: Unknown, this bill has not been analyzed by a fiscal committee.

COMMENTS:

Background: *Lanterman Developmental Disabilities Act* originally became statute in 1969. The Lanterman Act provides entitlement to services and supports for individuals three years of age and older who have a qualifying developmental disability. Qualifying disabilities include autism, epilepsy, cerebral palsy, intellectual disabilities, and other conditions closely related to intellectual disabilities that require similar treatment. To qualify, an individual must have a disability that is substantial that began before the individual attains 18 years of age and is expected to be lifelong. There are no income related eligibility criteria. Direct responsibility for implementation of the Lanterman Act’s service system is shared by DDS and a statewide network of 21 regional centers, which are private, community-based nonprofit entities, that contract with DDS to carry out many of the state’s responsibilities.

As of August 2023, the 21 regional centers served 459,395 consumers, providing services such as: information and referral; assessment and diagnosis; counseling; lifelong individualized planning and service coordination; purchase of necessary services included in the IPP; resource development; outreach; assistance in finding and using community and other resources; advocacy for the protection of legal, civil and service rights; early intervention services for at risk infants and their families; genetic counseling; family support; planning, placement, and monitoring for 24-hour out-of-home care; training and educational opportunities for individuals and families; and, community education about developmental disabilities. Regional centers services vary at each location. One location might offer one program and the next might offer what they consider an alternative or offer nothing comparable. Geographically, regional centers’ spending also varies.

Home and Community-Based Services (HCBS) are long-term services and supports provided in home and community-based settings, as recognized under the federal Medicaid Program (Medi-Cal in California). These services can be a combination of standard medical services and non-medical services. Standard services can include, but are not limited to, case management (i.e. supports and service coordination), homemaker, home health aide, personal care, adult day health services, habilitation (both day and residential), and respite care. States can also propose “other” types of services that may assist in diverting and/or transitioning individuals from institutional settings into their homes and communities.

In California, DHCS in collaboration with DDS, CDPH, and other entities developed a multi-year Statewide Transition Plan (STP) to bring California into compliance with new rules.

According to DDS,

> *"The purpose of the rules is to ensure that individuals receive services in settings that are integrated in and support full access to the greater community. This includes opportunities to seek employment and work in competitive and integrated settings, engage in community life, control personal resources, and receive services to the same degree as individuals who do not receive regional center services. It means that settings need to focus on the nature and quality of individuals' experiences and not just about the buildings where the services are delivered. Individuals have an active role in the development of their plan, the planning process is person-centered, and the plan reflects the individual's service and supports and what is important to them."*

HCBS for Californians with Developmental Disabilities. The HCBS- Developmental Disabilities Waiver program recognizes that many individuals at risk of being placed in medical facilities can be cared for in their homes and communities, preserving their independence and ties to family and friends at a cost no higher than that of institutional care. This waiver provides home and community-based services to regional center consumers as an alternative to care provided in a facility that meets the federal requirement of an intermediate care facility for individuals with developmental disabilities.

The HCBS-DD Waiver funds certain services that allow persons with developmental disabilities to live at home or in the community. Costs for these services are funded jointly by the federal government's Medicaid program and the State of California.

Self-Determination Program (SDP) Waiver for Individuals with Developmental Disabilities offers HCBS not otherwise available through a participant's Medicaid program. The purpose of the SDP Waiver is to serve participants in their own homes and communities as an alternative to receiving services in an intermediate care facility for persons with developmental disabilities. The SDP Waiver allows participants the opportunity to accept greater control and responsibility regarding the delivery of needed services. With the receipt of appropriate supports and information, participants will be able to manage their service mix within an individual budget amount to achieve the goals and objectives of their IPPs.

In 2018, Centers for Medicare & Medicaid Services approved the SDP waiver and 2,500 individuals were selected in 2018, and then a second set of participants again one year later were selected. The 2020-21 Annual Budget included $4.4 million total funds ($3.1 million General Fund) ongoing to support administration of the SDP. As of July 1, 2021, the SDP is available to all eligible individuals receiving services from a regional center. While enrollment has steadily increased since the full rollout, the enrollment broken down into racial and ethnic demographics is not proportionate.

The Legislative Analyst Office (LAO)'s 2023-24 Budget report on DDS reveals that "white consumers comprise a plurality of [SDP] participants (45 percent), despite making up only 30 percent of all DDS consumers. By comparison, Latino consumers comprise only 23 percent of [SDP] participants, but 40 percent of all DDS consumers."

The 2021-22 Budget provided money to establish the following to increase service access and equity, and reduce disparities:

- An Office of the SDP Ombudsperson within DDS to provide information and assist regional center consumers and their families in understanding their rights under the self-determination program;

- Participant Choice Specialists to provide timely transition to program participation and access to regional center staff; and,

- Enhanced Transition Support Services for individuals and their families who need greater assistance in transitioning to the SDP.

Existing HCBS- Specific Trainings. DDS collaborated with two consulting groups, Public Consulting Group and Support Development Associates, to organize a series of training sessions focusing on the HCBS Final Rule, along with person-centered planning and practices. Beginning in August 2019 and through June 2021, these sessions have encompassed both face-to-face workshops and online webinars conducted statewide. DDS has the following archived recordings on its website:

- Developing a Community of Practice;
- Developing Outcomes through Person-Centered Planning;
- Partnership in Person-Centered Planning;
- Person-Centered Practices & Cultural Considerations;
- A Person-Centered Approach to Risk;
- Continuing Person-Centered Engagement in Challenging Times;
- HCBS Final Rule Webinar: Strategies for Providing Services in Alignment with the Final Rule;
- HCBS Final Rule Self-Assessment Training;
- HCBS Final Rule and How it is Supported by Person-Centered Planning; and,
- Overview of the HCBS Settings Final Rule

This bill requires specified staff from regional centers and hospitals to be trained in Medi-Cal home- and community-based waivers including the Home and Community-Based Alternatives Waiver, the HCBS Waiver for Californians with Developmentally Disabilities, the SDP Waiver for Individuals with Developmental Disabilities, and the Medi-Cal Waiver Program in order to assist families navigate options available.

Author's Statement: According to the Author, "AB 2383 will ensure that state programs to support middle income families with Medically Fragile Children are utilized to the maximum extent possible. These waiver programs allow for a child to receive services and care through Medi-Cal, without the parent's income taken into consideration. By training hospital and regional center staff to recognize when a family would likely benefit from a waiver program and requiring that they be informed, loved ones can save the expense and planning time required to coordinate care, allowing them to spend more time being a family."

Equity Implications: This bill attempts to educate families about possible choices when they are caring for someone with a developmental disability. Currently, there are many options for a family to choose from when planning care, but it is complicated and time-consuming to understand all the choices to make a decision. Staff at regional centers having one comprehensive understanding of available options for a family could help expand the use of these services, ultimately leading to better person-centered care.

Policy Considerations: This bill requires a training program to be created for both hospitals and regional centers. Hospital and regional centers are vastly different settings because they serve people at different times in their lives. Regional Centers assess clients for eligibility and then help guide and navigate services and therapies. Hospitals see people when they are ill and help treat acute problems. While there might be an overlap in clients and patients, the information provided should reflect the different settings. As such, creating one training might create unintended harm and not be helpful.

The Author may wish to create separate trainings for separate settings to ensure staff are providing the most appropriate information.

This bill requires DDS to be the lead department for creating trainings on Medi-Cal programs and only permits consultation with DHCS and CDPH. DDS is the expert in developmental disabilities. DHCS is the expert in Medi-Cal. Both departments need to be involved in the development of trainings for Medi-Cal.

The Author may wish to require DDS to collaborate with DHCS so that trainings are appropriate and accurate.

This bill uses the terminology "medically fragile," which refers to people who have an acute or chronic health problem that requires therapeutic intervention and skilled nursing care during all or part of the day. Medically fragile problems include, but are not limited to, HIV disease, severe lung disease requiring oxygen, severe lung disease requiring ventilator or tracheostomy care, complicated spina bifida, heart disease, malignancy, asthmatic exacerbations, cystic fibrosis exacerbations, neuromuscular disease, encephalopathies, and seizure disorders. These disorders do not line up with developmental disabilities.

In order to qualify for regional center services, an individual must have a disability that originates before an individual attains 18 years of age, continues, or can be expected to continue, indefinitely, and constitutes a substantial disability for that individual. As defined by the Director of DDS, in consultation with the Superintendent of Public Instruction, this term must include intellectual disability, cerebral palsy, epilepsy, and autism. This term must also include disabling conditions found to be closely related to intellectual disability or to require treatment similar to that required for individuals with an intellectual disability, but cannot include other handicapping conditions that are **solely physical in nature.**

While there might be overlap in the terminology, the terms are not analogous. Telling people they qualify for something they do not can be harmful and misleading.

The Author may wish to remove medically fragile and instead replace the terminology with developmentally disabled to avoid confusion.

Proposed Committee Amendments: The Committee proposes amendments to address policy considerations stated above to do the following:

- Separate regional center and hospital training programs and requirements by drafting requirements in separate code sections.
- Require DHCS to consult on the development of a training program.
- Remove permissive language allowing DDS to consultant with DHCS and CDPH in regional center training requirements.
- Strike reference to medically fragile, and instead, reference developmentally disabled as defined in WIC § 4512.

Double referral: Should this bill pass out of this committee, it will be referred to the Assembly Committee on Health.

RELATED AND PRIOR LEGISLATION:

AB 1244 (Chesbro) of 2011, would have created a self-determination program to provide individuals with a single, capitated funding allocation they may use to purchase services that support goals identified in their IPP. *AB 1244 failed passage in the Senate Human Services Committee.*

AB 9 X4 (Evans), Chapter 9, Statutes of 2009, Fourth Extraordinary Session, created an option for the individual choice budget, which allowed for the purchase of otherwise suspended services but required savings of $35.1 million. *AB 9 X4 has not been implemented.*

AB 131 (Committee on Budget), Chapter 80, Statutes of 2005, established a self-directed services option statewide, contingent upon approval of a federal waiver. A waiver was never obtained, and it has not been implemented.

SB 1038 (Thompson), Chapter 1043, Statutes of 1998, authorized the creation of pilot projects for self-determination at three regional centers. Two other regional centers also created independent self-determination pilots under an alternative service delivery model, bringing the number of regional centers engaged in the pilot to five.

REGISTERED SUPPORT / OPPOSITION:

Support

The Arc and United Cerebral Palsy California Collaboration (Sponsor)

Opposition

None on file.

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