Date of Hearing: April 2, 2024

ASSEMBLY COMMITTEE ON HUMAN SERVICES Alex Lee, Chair AB 2360 (Rendon) – As Amended March 21, 2024

SUBJECT: Developmental services: family services: counseling

SUMMARY: Requires the Department of Developmental Services (DDS) to establish a Family Wellness Pilot Program under which regional centers provide counseling and peer support group services to the families of regional center consumers. Specifically, **this bill**:

- 1) Establishes a Family Wellness Pilot Program with the following eligibility requirements:
 - a) Commencing with the 2024–25 fiscal year, families of regional center consumers who are 6 years of age or younger; and,
 - b) Commencing with the 2025–26 fiscal year, families of all regional center consumers.
- 2) Requires DDS to evaluate and submit a legislative report on or before July 1, 2029, on the Family Wellness Pilot Program's effectiveness by looking at all of the following outcomes:
 - a) Reduction in psychological distress of the individual and improvement in psychosocial functioning;
 - b) Improvement in relational functioning of the family;
 - c) Learning coping strategies for possible use in the future when another stress is encountered; and,
 - d) Feasibility of virtual versus in-person counseling sessions.

EXISTING LAW:

- 1) Establishes the Lanterman Developmental Disabilities Act (Act), which states that California is responsible for providing an array of services and supports sufficiently complete to meet the needs and choices of each person with developmental disabilities, regardless of age or degree of disability, at each stage of life, and to support their integration into the mainstream life of the community. (Welfare and Institutions Code [WIC] § 4500 *et seq.*)
- 2) Establishes a system of nonprofit regional centers, overseen by DDS, to provide fixed points of contact in the community for all persons with developmental disabilities and their families and to coordinate services and supports best suited to them throughout their lifetime. (WIC § 4620)
- 3) Provides the Director of DDS the authority to issue directives to regional centers when necessary to protect a consumer's health, safety, and welfare, or when needed to ensure that regional centers comply with the Act or other state or federal law. (WIC § 4639.6)
- 4) States the intent of the Legislature that regional centers provide or secure family support services that do all of the following:

- a) Respect and support the decision-making authority of the family.
- b) Be flexible and creative in meeting the unique and individual needs of families as they evolve over time.
- c) Recognize and build on family strengths, natural supports, and existing community resources.
- d) Be designed to meet the cultural preferences, values, and lifestyles of families.
- e) Focus on the entire family and promote the inclusion of children with disabilities in all aspects of school and community. (WIC § 4685 (b))

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

COMMENTS:

Background: *The Lanterman Developmental Disabilities Act* was originally enacted in 1969. The Lanterman Act provides entitlement to services and supports for individuals ages three 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 began before the age of 18, 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 with more than 40 offices located throughout the state. According to DDS, both geographic accessibility and population density were considered when selecting locations for the 21 regional centers. The boundaries for the regional centers largely conform to county boundaries, except in Los Angeles County, which is by health districts and not by county.

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 atrisk 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.

Regional Centers' Responsibilities. Direct responsibility for implementation of the Act's service system is shared by DDS and a statewide network of 21 private regional centers, and community-based nonprofit entities, established pursuant to the Act, that contract with DDS to carry out many of the state's responsibilities. Regional centers are governed by a Board of Directors (Board) who are a part of the community, receive services, or a representative of someone who receives services from the regional center. The Board is responsible for hiring (and firing) the Executive Director who is tasked with the day-to-day management of the regional center. DDS establishes contracts with regional centers that include specific, measurable,

performance objectives. Every year, DDS reviews each regional center's performance data for compliance with their contracts and posts them on their website.

Impact on Families with a Loved One Living With Autism and Intellectual Developmental Disability (IDD). Often individuals with an IDD require exponentially more appointments including evaluations, occupational therapy, doctor's appointments, and other various therapies than a neurotypical person would generally need. Individuals with an IDD also require more assisted family tasks for living than a neurotypical person, which can place added stress on a family.

According to the Center for Disease Control, "meeting the complex needs of a person with an [autism spectrum disorder] ASD can put families under a great deal of stress—emotional, financial, and sometimes even physical." Due to the various demands of being a parent, guardian, or sibling to someone with an IDD, it is important to consider what support families might need as well. In an academic study titled *Implications of Parental Stress on Worsening of Behavioral Problems in Children with Autism during COVID-19 Pandemic: "The Spillover Hypothesis"* by Eshraghi, A.A., Cavalcante, L., Furar, E. et al., they concluded that,

"Due to the high likelihood of a "spillover" of negative attitudes and behaviors from parent to child, there is an urgent need to develop strategies for alleviating the negative symptomatology experienced by the parents of children with ASD. High demands placed on parents of children with ASD take a toll on these parents, leading to both physiological and mental fatigue. One potential solution is family training to alleviate the emotional burdens and practical demands of the entire ASD family system during this time. Another potential approach can be to implement parental interventions for mitigating stress along with the therapy services provided for the child. The therapy providers can incorporate programs that focus on the mental well-being of the parents of children with ASD."

This bill aims to address family stress and coping strategies to support the family by establishing a pilot program to have regional centers provide counseling and peer support group services to the families of regional center consumers so that they can be successful as well as best care for their loved ones.

Valley Mountain Regional Center Family Wellness Pilot Project. One of 21 regional centers currently runs a Family Wellness Pilot Project. Valley Mountain Regional Center (VMRC) started this pilot program in May 2023 using America Rescue Plan Act (ARPA) funding which will fund this pilot until approximately December 2024. This pilot focused on early-start consumers, ages 0-3, and their families. This pilot offers free counseling to families with no waiting list and families are seen as early as a few days after they call or are referred. This program is the basis for the concept of this bill which will expand this pilot to all 21 regional centers and expand applicability to be for families of all clients, not just early start. Due to the relatively new nature of this pilot at 10-11 months old, a final program analysis or outcomes have not been measured yet. However, according to VMRC,

"Preliminary findings show significant reduction in psychological distress of the individual and slight improvement in the psycho-social functioning. There is significant improvement in the relational functioning of the family. The preliminary findings also show slight improvement in the couple's relational functioning. The preliminary data also show that families can learn coping skills that they can use in the future in case they encounter another stressful event in life. And lastly, the preliminary data shows that when comparing virtual versus in-person counseling, we have found no significant difference in the family's assessment of the quality and satisfaction with the service."

Author's Statement: According to the Author, "Most individuals with intellectual and developmental disabilities (IDD) live at home and are cared for by family members. Because of this, the family unit takes on a tremendous responsibility as caregivers, and therefore must be nurtured along with their family member with special needs. AB 2360 creates a pilot program to allow Regional Centers across the state to provide supportive and mental health services to the family members of those with IDD in order to help them manage this experience, which can be emotionally taxing on families. Doing so will ensure that all members of a family with a child who has IDD can lead happy and fulfilling lives."

Equity Implications: Family therapy is often not a covered benefit for health insurance. As such, many families cannot afford therapy or find ways to overcome stressors or how to manage or cope with life on their own. In a 2021 National Survey on Drug Use and Health, only 25% of Asian Americans, 36% of Hispanic and Latino Americans, and 21% of Black Americans received mental health services compared to 52% of non-Hispanic White Americans. There is a well-documented lack of access to mental health services. This bill is aimed at helping families navigate the difficulties of providing support and providing more direct access to IDD families.

RELATED AND PRIOR LEGISLATION:

AB 1957 (Wilson), Chapter 314, Statutes of 2022, added additional data points to the set of data that DDS and regional centers must report. These additional data mostly relate to services that were cut during the pandemic and recently restored, including social recreation, camping, educational services, and nonmedical therapies such as art, dance, and music. AB 1957 also added untimely translations of an IPP in a threshold language to be included in the set of data.

AB 1 X2 (Thurmond), Chapter 3, Statutes of 2016, authorized the Service Access and Equity grant program through which \$11 million in ongoing General Fund resources for DDS was provided to assist regional centers in reducing purchase of service disparities.

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, 4th 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 to five the number of regional centers engaged in the pilot.

REGISTERED SUPPORT / OPPOSITION:

Support

The Arc and United Cerebral Palsy California Collaboration (Sponsor) Association of Regional Center Agencies Educate. Advocate.

Opposition

None on file.

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