

-Date of Hearing: April 23, 2024

ASSEMBLY COMMITTEE ON HUMAN SERVICES

Alex Lee, Chair

AB 3291 (Committee on Human Services) – As Amended April 16, 2024

SUBJECT: Developmental services

SUMMARY: Updates regional center requirements regarding the planning process for the individual program plan (IPP). Specifically, **this bill:**

- 1) Requires, when a regional center consumer is being cared for in the family home, and no later than the consumer's 22nd birthday, a discussion regarding caregiver succession and, if determined by the consumer or the consumer's representative to be necessary, development of a caregiver succession plan, which may include, but is not limited to, both of the following:
 - a) Identification of individuals who may provide care to the consumer when the current caregiver is no longer able to perform the necessary tasks; and,
 - b) Identification of possible housing options for the regional center consumer when the consumer can no longer live at home.
- 2) Defines for the purpose of 1) above "caregiver succession" to mean the point at which the primary caregiver is no longer able to fully care for a regional center consumer.
- 3) Permits regional centers to make rent, mortgage, or lease payments on a supported living home, or pay for household expenses of consumers receiving supported living services, except services under specified circumstances.
- 4) Adds "risk of homelessness" to the list of circumstances when a regional center may help with housing costs as described in 3) above.

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 an IPP as the process to ensure that services and supports are customized to meet the needs of consumers who are served by regional centers for the purpose of alleviating a developmental disability or toward the social, personal, physical, or economic habilitation or rehabilitation of an individual with a developmental disability, or toward the achievement and maintenance of independent, productive, and normal lives. (WIC § 4512(b))
- 3) Requires decisions concerning the consumer's goals, objectives, and services and supports included in their IPP to be made by agreement between the regional center representative and the consumer or, when appropriate, the consumer's parents, legal guardian, conservator, or authorized representative, at the program plan meeting. (WIC § 4646(d))

- 4) 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 specified information and considerations;
 - b) Review and modification, 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. (WIC § 4646.5)
- 5) Prohibits a regional center from making rent, mortgage, or lease payments on a supported living home, or pay for household expenses of consumers receiving supported living services, except under the following circumstances:
 - a) If all of the following conditions are met, a regional center may make rent, mortgage, or lease payments as follows:
 - i) The regional center executive director verifies in writing that making the rent, mortgage, or lease payments or paying for household expenses is required to meet the specific care needs unique to the individual consumer as set forth in an addendum to the consumer's IPP, and is required when a consumer's demonstrated medical, behavioral, or psychiatric condition presents a health and safety risk to themselves, or another;
 - ii) During the time period that a regional center is making rent, mortgage, or lease payments, or paying for household expenses, requires the supported living services vendor to assist the consumer in accessing all sources of generic and natural supports consistent with the needs of the consumer; and,
 - iii) The regional center is restricted from making rent, mortgage, or lease payments on a supported living home or paying for household expenses for more than six months, unless the regional center finds that it is necessary to meet the individual consumer's particular needs pursuant to the consumer's IPP. Requires the regional center to review a finding of necessity on a quarterly basis and for the regional center executive director to annually verify in an addendum to the consumer's IPP.
 - b) The regional center that was contributing to rent, mortgage, or lease payments or paying for household expenses prior to July 1, 2009, shall at the time of development, review, or modification of a consumer's individual program plan determine if the conditions in a) are met. If the planning team determines that these contributions are no longer appropriate under this section, a reasonable time for transition, not to exceed six months, shall be permitted. (WIC § 4689)

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

COMMENTS:

Background: *Individual Program Plans.* IPPs are developed by a series of planning discussions and interactions with the IPP team—including, among other individuals, the consumer, their legally authorized representative, and one or more regional center representatives—and is based

on the consumer's needs and choices. IPP meetings are designed to help people with developmental disabilities outline in a person-centered manner a "preferred future" by identifying a preferred place to live, favorite people with whom to socialize, and preferred types of daily activities, including preferred jobs.

As required by the Act, the IPP promotes community integration and maximizes opportunities for each consumer to develop relationships, be part of community life, increase control over their life, and acquire increasingly positive roles in the community. The IPP must give the highest preference to those services and supports that allow minors to live with their families and adults to live as independently as possible in the community. The recommendations set forth in each IPP are the foundation for each individual's care as it guides services received, eligibility for services, and can help assist in the quality of life for that individual.

Regional Centers' Responsibilities. Direct responsibility for implementation of the Act's service system is shared by the Department of Developmental Disabilities (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 representatives 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.

Aging Caregiver Crisis. An increase in the aging population hits the intellectual/developmental disabilities community particularly hard. Those living with intellectual/developmental disabilities are living longer than ever before due to medical advancements, which in turn means they are living past the ability for their caregivers, who are likely parents, to provide safe and proper care.

The life expectancy for people with intellectual/developmental disabilities is now similar to the general population, ranging from the late-50s to the mid 70s, depending on the severity of the disability. (Bittles et al., *The Influence Of Intellectual Disability On Life Expectancy*. 2002) In California, there are currently about 47,058 individuals with developmental disabilities with caregivers who over 60 years of age (California Policy Center for Intellectual and Developmental Disabilities, 2024).

In the U.S., the population of adults with intellectual/developmental disabilities over the age of 60 will nearly double from 640,000 in 2010 to 1.2 million in 2030 (Heller, Tamar. *People with Intellectual and Developmental Disabilities Growing Old*).

These individuals need a plan moving forward to prevent homelessness or being forced to enter into a housing situation that is not of their choosing.

The Alta California Regional Center launched a Coordinated Future Planning Taskforce with this looming problem in mind. The initiative calls on a group of stakeholders: clients, family members, advocates, and service providers to join with regional center staff in both developing and delivering training to service coordinators. This training focuses on the need for caregiver succession plans for each regional center client, as well as seeking to increase the competencies

of service coordinators in discussing a range of living options at IPP meetings. The training has four learning objectives:

- 1) Recognize the benefit of reflecting on your own beliefs about dying and end of life care and the impact that may have on your ability to help others with future life planning.
 - Dialogue with clients and families, in a culturally respectful, sensitive and humble way, regarding caregiver succession planning using appropriate language.
- 2) Articulate the benefit to clients and families of early planning for caregiver succession.
- 3) Describe a range of living options, including independent living, supported living, family home agencies, and residential care, to clients and their families.
 - Create a person-centered IPP narrative that captures the wishes of the client and planning team in relation to future living options.
- 4) Share future planning tools that can assist clients and families related to accessing affordable housing, power-of-attorney, special needs trust, CalABLE, conservatorship, and end-of-life care decisions.

This bill aligns with Alta's efforts by making caregiver succession planning a part of the IPP process for all 21 regional centers.

Homelessness Within the Disabled Community. The longstanding goal for establishing care for individuals living with disabilities is to be "person-centered." Meaning, that throughout planning for day-to-day services and supports the individual is centered in decision-making on how they like to live and what supports are required to meet the needs of the individual in the living option of their choice. Currently, adult regional center consumers have several different living options including their own family homes; adult residential facilities for persons with special health care needs; community care facilities; family home agencies; independent living programs; intermediate care facilities; and state-operated developmental centers and community facilities. While there are institutional settings, these are not always the setting of choice, but rather the only option. According to the National Core Indicators data, 52% of adults with intellectual and developmental disabilities have no choice or input regarding where they live, and 62% have no choice as to who they live with. Choices are often limited due to financial constraints.

People with disabilities experience disproportionate rates of poverty and an even higher rate of disproportionality for those with a disability among communities of color. People with disabilities are the most likely population to experience homelessness, be rent-burdened or unable to afford housing, and face the highest rates of housing discrimination. This is due to most of these individuals living on fixed incomes that are at or near poverty-level thresholds and the increased need for ADA-compliant homes.

Although generally accepted as an undercount due to challenges with identifying developmental disabilities among the homeless population, over 1,200 individuals with developmental disabilities have been identified as experiencing homelessness, and another 24,000 regional center consumers who are likely to experience being rent-burdened or seriously rent-burdened (California Policy Center for Intellectual and Developmental Disabilities, 2024).

Author’s Statement: According to the Chair of the Committee on Human Services, “This bill proposes to take a preventive approach, enabling independent living service consumers to use their regional center benefits for housing assistance, as well as allowing individuals to plan for their future when their caregiver can no longer assist in care and/or provide housing.”

Equity Implications: This bill seeks to ensure individuals with developmental disabilities are getting the necessary future planning and housing support to prevent homelessness. Future planning is essential to ensuring more individuals do not face homelessness or housing insecurity. According to a February 2024 report released by the California Policy Center for Intellectual and Developmental Disabilities, “The larger housing issue facing the [Intellectual and Developmental Disabilities] community is the lack of affordable and accessible housing. The vast majority of adults with [Intellectual and Developmental Disabilities] who live in [Independent Living Services] or [Supportive Living Services] are rent burdened or severely rent burdened which places them at greater risk of housing instability or homelessness. At least 50% of adults with [Intellectual and Developmental Disabilities] live with a family member or in the family home, and of those living in the family home up to 50% are highly likely to be living with an aging caregiver.” This bill will help to start addressing these issues and allow for a better understanding of the depth of the need.

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 1595 (Chesbro), Chapter 409, Statutes of 2014, broadly revised the statutory responsibilities of the State Council on Developmental Disabilities (SCDD), including restructuring the role and scope of the state’s 13 area boards, to comply with the requirements of the federal Administration on Intellectual and Developmental Disabilities. Additionally, revised the authorization for DDS to contract with SCDD for advocacy services within its state developmental centers.

AB 1041 (Chesbro), Chapter 677, Statutes of 2013, created a statewide Employment First Policy and set forth requirements related to the inclusion of employment opportunities and services in a regional center consumer's IPP.

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.*

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

Association of Regional Center Agencies
California Community Living Network
Easterseals Northern California
Lanterman Housing Alliance

Opposition

None on file.

Analysis Prepared by: Alexandria Smith / HUM. S. / (916) 319-2089