



ADVOCACY and DIRECT INDIVIDUAL ADVOCACY SERVICES

Introduction

State Councils exist to provide advocacy, capacity building, and system change activities that contribute to a comprehensive system of supports and services that is centered around and directed by clients and families. This system is to include needed community services, individualized supports, and other forms of assistance that promote self-determination for individuals with developmental disabilities and their families. Councils are to promote self-determination, independence, productivity, integration, and inclusion in all facets of community life, through culturally competent programs. (Developmental Disabilities Assistance and Bill of Rights Act of 2000 [DD Act] Section 101[b], 101[b][1], and 101[b][1][B].)

The federally funded network serving people with intellectual and/or developmental disabilities (I/DD) and their families also benefits from the protection and advocacy systems, which protect the legal and human rights of individuals with developmental disabilities. (DD Act Section 101[b][2].) In California, Disability Rights California is the federal developmental disabilities network partner who is responsible for providing direct advocacy services and other legal supports and assistance to ensure that individuals with I/DD are able to exercise their rights to make choices, contribute to society and live independently. The federally funded network also benefits from the University Centers for Excellence in Developmental Disabilities Education, Research, and Service as well as from the Parent Training and Information Centers.

Given the focus on advocacy in the I/DD network, this paper clarifies advocacy activities that are and are not allowed to be provided by the State Council on Developmental Disabilities (Council). Such clarification may be issued as a departmental policy. The following addresses issues specific to the role and activities of the Council as authorized under the Developmental Disabilities Act. (Public Law 106-402).

Types of Advocacy

Advocacy involves promoting the interests or cause of someone or a group of people. An advocate is a person who argues for, recommends, or supports a cause or policy. Advocacy is also about helping people find their voice. (West Virginia University Center for Excellence in Developmental Disabilities.)

For the purposes of Council activities, there are two types of allowable advocacy: systemic advocacy and self-advocacy.

Systemic advocacy is about changing laws, rules, or agency practices that will improve outcomes for Californians with developmental disabilities and their families. The Council is directly responsible for systemic advocacy. In this capacity, the Council is responsible for conducting a comprehensive review and analysis of the state disability system, which informs the State Plan. This work assists individuals with I/DD by addressing barriers at the local, state, or national level. The focus can be changing laws or changing written or unwritten policies. Activities supporting systemic advocacy include outreach, training, barrier elimination, system design, system redesign, and informing policy makers.

Self-advocacy refers to an individual's ability to effectively communicate, convey, negotiate or assert his or her own interests, desires, needs, and rights. Self-advocacy means understanding one's strengths, needs, personal goals, legal rights, and legal responsibilities. It also means communicating these to others. Self-advocacy is speaking up for oneself. The Council facilitates and supports self-advocacy for people with I/DD and their families.

Facilitating and supporting family and self-advocacy focuses on empowering individuals to create change in their lives. The Council supports and facilitates self-advocacy by informing individuals of their rights, instructing individuals on how to make complaints, providing information about the correct organizations to help create change, and encouraging individuals and families to speak for themselves.

Direct Individual Advocacy Services

As stated above in the background section, State Councils engage in advocacy, capacity building, and systemic change activities that contribute to a coordinated, comprehensive system that includes needed community services and individualized supports. The Council does not directly provide these services and supports to consumers and their families. The intent is for State Councils to impact the service delivery system, not become part of the delivery system. (Information and Technical Assistance Center for Councils on Developmental Disabilities.)

Speaking or acting on behalf of an individual or family to obtain or access services may be a form of direct service and should not be a primary activity for the State Council with federal funds. However, engaging in individual advocacy when undertaken as part of another Council activity, such as system advocacy. Some of these activities, such as attending meetings for agency based supports and services (e.g. Regional Center, schools or school districts, Social Security, Department of Rehab) or making calls to these agencies on an individual's behalf, may not be allowable when done solely for the purpose of assisting an individual consumer or his or her family. However, the activity may be allowable if it is undertaken as part of a system advocacy strategy. For example, it may be appropriate to call an agency to request consumers' service records

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when needed to obtain the records to verify a systemic issue regarding a failure to translate documents into a consumer's native language. It may also be appropriate to file a systemic compliance complaint following the Council's receipt of information that an entity has a policy or practice of not providing services authorized by law.

The Council acknowledges that direct individual advocacy services are a critical need in the system. For example, parents need support when meeting with schools to discuss an individual education plan. Nationally, the perspective is that Parent Training and Information Centers (PTIC) are to provide this service. A review of the PTICs in California and assessing whether they meet the needs of families would be an allowable Council activity. Advocating for funding or better services is the role of the Council unless it is used as a strategy to fulfill the Council's other responsibilities, particularly those related to barrier removal and systems change activities.

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State Council Advocacy Activities

There are many activities that are effective and consistent with the DD Act when working with individuals who are seeking advocacy support: information and referral, technical assistance, and training. These activities provide a benefit beyond helping individuals and families seeking advocacy supports. It leverages the strength of the California Council, with its headquarters in Sacramento and regional offices throughout the state, to provide an ongoing comprehensive review and analysis of the service system. Additionally, staff may conduct surveys to collect information on problems that are emerging within their regions, which helps identify statewide trends, and communicate their findings to the Council for action.

Staff typically does not need to personally attend direct service meetings to collect this type of information. The mere presence of staff at these meetings brings the State Council into the room, which can have the effect of direct individual advocacy services and make the Council a party to the action, also a direct service.

Conclusion

While this paper focuses on the division between advocacy activities that are allowed and not allowed, there is a large universe of advocacy activities that fulfill the State Council's purpose. Systemic advocacy marshals the Council's limited resources to serve the greatest number of people. Focusing on activities that impact the greatest number of individuals is a responsible and efficient way of changing the system of supports and services for people with I/DD and their families. With its headquarters and regional offices, the Council is structured to identify and change systemic issues at local, county, regional, and state levels.