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Centers for Independent Living and their Role in the Transition Service Delivery System

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As one of the latest Disability Innovation Fund (DIF) Program grants, Pathways to Partnerships (84.421E) is poised to make a big impact in the world of transition service delivery for youth with disabilities. 84.421E is a discretionary spending initiative of the US Department of Education's Rehabilitation Services Administration (RSA). Through this initiative, 20 states across the country were awarded five-year grants that began in October 2023 to engage in partnership development that supports children and youth with disabilities in their pursuit of competitive integrated employment (CIE). The purpose of this brief is to discuss the role of Centers for Independent Living (CILs) and their place in the transition service delivery system.

What is the Transition Service Delivery System?

It is no secret that the postschool outcomes of youth with disabilities continue to lag significantly behind the outcomes of their peers without disabilities. This is especially true in specific areas like engagement in CIE. Although there are many factors that contribute to this reality, the way transition services are delivered is particularly important. Given the breadth of the transition-related support that youth with disabilities may need and the number of publicly funded entities with responsibilities to provide that support, it is critical that such services are coordinated purposefully.

In simple terms, the *transition service delivery system* refers to the formal and informal professional partnerships that inform, direct, coordinate, and provide transition services for youth with disabilities. Widespread efforts like those of the National Technical Assistance Center on Transition: The Collaborative (NTACT:C), have focused on building the capacity of interagency teams at the state level. Such efforts both affirm and provide structure to a purposeful approach for stakeholders to engage in co-creating the transition service delivery system. Interagency teams at the state level provide a foundation for interagency teaming at the local and individual levels (Magee & Plotner, 2022; Noonan et al., 2012). As *Figure 1* details, interagency teaming in this fashion can mobilize resources where they are most needed to ensure a dynamic and responsive transition service delivery system.



Figure 1. Levels of Teaming

At the state, local, and individual levels, CILs can and should be playing an integral role in the interagency teams working to support transition-age youth with disabilities. To understand how CILs can be meaningfully integrated within the transition service delivery system, it is important to understand what CILs are.

What are CILs?

An outgrowth of the independent living (IL) movement, the first CIL was started in Berkeley, California in 1972. It was founded on three basic premises about people with disabilities: (1) they best understand the needs of others with disabilities, (2) their needs should be met by programs that provide a wide variety of services, and (3) they should be able to live their lives integrated within their communities (Center for Independent Living, n.d.). Since the Berkeley CIL started in 1972, more than 350 other CILs have formed across the United States (ACL, 2024), rooted in the principles of the IL movement.

CILs are organizations that are required to have a staff and board composition that is at least majority composed of people with disabilities. As such, the CIL approach to service delivery is characterized by the peer-to-peer approach. Rather than organizations that maintain a professional distance from the barriers their consumers face, the CIL approach to disability service issues is from the vantage of people who have experienced and addressed such barriers firsthand.

Another core principle of the IL movement, consumer control, has become enshrined in the structure of modern CILs. The principle of consumer control dictates that CIL services be provided at the direction of those they serve, in service of their own goals for living more independently. Through the principle of consumer control, CILs engage in systemic advocacy and provide an array of services to people of all ages and all types of disabilities. These services include but are not limited to, independent living skill development, information and referral, youth and institutional transition services, and peer support (ACL, 2024).

At the national level, CILs are governed through the Rehabilitation Act of 1973 and its subsequent amendments. CILs receive oversight and funding from the US Department of Health and Human Services Administration on Community Living (ACL). CILs receive technical assistance and support from national bodies such as the

- National Council on Independent Living (NCIL; <https://ncil.org/>),
- Association of Programs for Rural Independent Living (APRIL; <https://www.april-rural.org/>), and
- Independent Living Research Utilization program (ILRU; <https://www.ilru.org/>).

CILs do not intend to, nor do they, all function in the same ways. They have important commonalities, but CILs vary in many ways including the size of their service area, staff, and budget; their approach to engaging in the communities they serve; and the ways in which they work together towards common aims within a single state. It is important to recognize the diversity in programmatic approaches that can be seen across CILs. Regardless of such differences between them, CILs are critical to healthy, robust, and outcomes-driven transition service delivery systems.

Why Are CILs Important to the Transition Service Delivery System?

Since their inception, CILs have upheld the unparalleled expertise that comes from lived experience with disability. For CILs, this belief is foundational to the work they do, the programs they facilitate, and the services they provide. For many entities, strengths-based, person-centered, and consumer goal-directed approaches to service delivery are aspirational. For CILs, by and large, these approaches are inherent to what they represent as organizations.

When faced with the question of the role CILs should play in the transition service delivery system, the most common response may be to consider CILs as service providers in their own right. After all, many CILs are highly accomplished in transition service delivery (Plotner et al., 2022a). It may be far more worthwhile, however, to consider the many roles, both direct and indirect, that CILs can fill. As detailed in the *Conceptual Framework for CIL and School Transition Service Delivery* (Walters & Plotner, 2023), these include a variety of roles such as content expert, service connector, and peer mentor. Collaboration with CILs that pre-determines or limits the role they play is ill advised. The reasons to engage CILs in interagency collaboration to enhance the postschool outcomes of youth with disabilities are as varied as their dynamic approaches to carrying out their federal mandates and organizational missions.

What Can State and Local Partners Do to Engage CILs?

One important step to better integrate CILs into the transition service delivery system is self-evident yet worth mention: know who they are and how to contact them. The ILRU website has an easy-to-use feature for searching for CILs by state (visit <https://www.ilru.org/projects/cil-net/cil-center-and-association-directory>). With this information, the next suggestion is equally simple and important: ensure CILs have a seat at the table. If state and local interagency teams are convening to plan about transition service delivery, make sure that CILs are involved. It is necessary to understand that CILs have not historically been sought out as integral parts of the service delivery system. CIL and school collaboration has been especially limited (Plotner et al., 2022). If an interagency collaborative wants to know what may foster or impede the inclusion of CILs in their work, ask them. Like any other organization, CILs may face constraints from staffing, funding, or training that affect their ability to engage in collaborative efforts. Approaching CILs as a prospective partner with a willingness to invest in their capacity for partnership is a positive orientation to collaboration that any state or local team can take.

Given the unique make-up and strengths of any given CIL, it may also be helpful to begin by working with them on resource mapping efforts (Walters & Allison, 2024). Such work can help

identify the ways in which CILs may already be supporting transition-age youth and the strengths they bring to the table as an organization. Resource mapping hearkens to a simple but often overlooked truth; if you want to know about the value CILs can bring to the transition service delivery system, ask them.

What Can CILs Do?

When youth transition was added as part of the core services CILs are required to provide, the addition came without extra funding for the mandate (Hammond et al., 2018). With many already experiencing the harsh reality of the need for CIL services far exceeding available resources, every CIL must approach their support of transition-age youth in a way that works best for them. Nevertheless, there are some simple propositions for CILs, especially those with a limited footprint in the delivery of youth transition services, to support their capacity as a partner in the transition service delivery system.

First, it is important to identify and address staff training needs as they relate to knowledge about transition service delivery. Some key areas for training include:

- Federal transition service mandates (e.g., transition as prescribed by the Individuals with Disabilities Education Act and vocational rehabilitation services for clients vs. potentially eligible youth as mandated by the Rehabilitation Act),
- State and local policy that affect transition-age youth with disabilities, and
- Research that informs that which is considered best practice in transition service delivery.

Such areas of content knowledge are often taken for granted in the field at large. Ensuring the preparation of staff with such content knowledge is essential to their ability to engage meaningfully in the transition service delivery system. As the adage goes, “you don’t know what you don’t know;” it may be helpful for CIL administrators to engage with transition content experts to guide them in their orientation to preparing their staff in this manner.

Next, it is important for CILs to plan strategically about their role in the transition service delivery system. Such planning can facilitate a critical appraisal of what youth with disabilities need but may not be accessing, the unique skills and resources a CIL brings to meeting those needs, the ways in which a CIL can expand their capacity to meet those needs, and the partnerships that may need to be leveraged to increase their capacity. As CILs engage in such planning, it may be helpful to remember they are (1) uniquely situated to provide transition services and (2) already providing many services that would be considered transition services when offered for transition-age youth (Hammond et al., 2018).

Finally, the federally prescribed data elements for CIL performance reporting may fall short of adequately evaluating the impact of the youth transition services that they are providing. By

working together with partners through data sharing or co-planning evaluation mechanisms for collaborative endeavors, CILs can tap into novel and important data to gauge the effects and importance of their work. While the integrity of the values that guide CIL services in youth transition are often of paramount importance to them (Plotner & Walters, 2022a), increasing their capacity for this work depends upon robust, ongoing efforts in evaluation.

Conclusion

Transition-age youth with disabilities both need and are entitled to a transition service delivery system that is as strong as it possibly can be. This strength is a product of the collaborative partnerships that support, shape, and engage within that system. CILs can and do enhance these collaborative structures in many ways. To maximize this potential, interagency initiatives at the state and local levels should approach and include CILs in organic and impactful ways. As they do, CILs should continue doing the work needed to take on the mantle of being an integral part of the transition service delivery system. As states funded through RSA's 84.421E –Pathways to Partnerships initiative work to realize such ambitions, the field at large, youth with disabilities, and their families stand to benefit tremendously.

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