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Introduction to Community Life Engagement (Engage: A Brief Look at Community Engagement, Issue No. 1, 2015)

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Introduction to Community Life Engagement

Jennifer Sullivan Sulewski & Jaimie Ciulla Timmons

Introduction

As national disability policy prioritizes greater support for community-based integrated employment for individuals with intellectual and developmental disabilities (IDD), the level of participation in services for other daytime activities continues to grow (Winsor & Butterworth, 2012). The role of services related to engagement and participation in community life has to date been largely undefined. The purpose of this brief is to offer a definition of Community Life Engagement, share reasons for its relevance and timeliness, and present results from a Community of Practice with administrators and personnel from seven state IDD agencies hosted by the Institute for Community Inclusion (ICI) in collaboration with the State Employment Leadership Network (SELN). It represents the first in a series of briefs by ICI on Community Life Engagement with the intention of providing guidance on its parameters for the field.

What is Community Life Engagement?

Community Life Engagement refers to supporting people with IDD to access and participate in their communities outside of employment as part of a meaningful day. Also referred to as community-based non-work, wraparound supports, holistic supports, or community integration services, Community Life Engagement activities may include volunteer work; postsecondary, adult, or continuing education; accessing community facilities such as a local library, gym, or recreation center; participation in retirement or senior activities; and anything else people with and without disabilities do in their off-work time. Such activities may support career exploration for those not yet working or between jobs, supplement employment hours for those who are working part-time, or serve as a retirement option for older adults with IDD.

Why is Community Life Engagement relevant now?

There are several reasons why Community Life Engagement is especially important.

#1: States and providers report growing numbers of individuals with IDD in non-work services.

The National Survey on Day and Employment Services, conducted annually by ICI under the Access to Integrated Employment project (www.communityinclusion.org/aie), categorizes day and employment supports into four quadrants based on whether they are work or non-work and community- or facility-based. Community-based non-work (CBNW) services, those services in the non-work and community-based quadrant, have seen considerable growth. CBNW services have the potential to support Community Life Engagement when used effectively, yet there has been limited regulation or study of CBNW to date.

#2: Although CBNW service users are increasing, the category remains undefined.

Research conducted at ICI indicates that CBNW generally involved a wide range of activities supported, populations served, and goals. States also had inconsistent use of specific guidelines such as staffing ratios, group sizes, or proportion of time spent in community settings. Prior research by the first author also indicated considerable variability in implementation. The desire to provide individualized supports was counterbalanced by structural and budgetary constraints, resulting in varied levels of individualization, choice of activities, and hours of support offered. The relationship between CBNW and work was also inconsistent, with some individuals receiving both work and CBNW supports, but more often CBNW serving as a substitute for employment.

#3: Recent federal guidance has further illustrated the need to define and provide high-quality Community Life Engagement supports.

Department of Justice (DOJ)

DOJ has clearly stated that in order to be in compliance with the ADA and the Supreme Court decision in *Olmstead v. LC*, states must provide day and employment supports in integrated settings (U.S. Department of Justice, 2014; *United States v. State of Rhode Island*, 2014), placing pressure on all states to move individuals from segregated settings to more community-based models of support.

Center for Medicare and Medicaid Services (CMS)

In January 2014, CMS also released new rules that defined, described, and aligned home and community-based setting requirements (Center for Medicare and Medicaid Services, 2014). The new rules specify that states must maximize the opportunities for individuals to access community living in the most integrated setting. To meet this standard, states are turning to both supported employment and Community Life Engagement supports.

The Centers for Medicare and Medicaid Services (2014) have specified that “The Home and Community-Based setting... Provides opportunities to seek employment and work in competitive integrated settings, engage in community life, and control personal resources. Community Life Engagement is thus an essential part of the new vision for home and community-based services.”

What are state IDD agencies saying about Community Life Engagement?

On May 29, 2014, ICI staff, in conjunction with the SELN, hosted a Community of Practice of interested member states to discuss emerging issues in CBNW and Community Life Engagement. A Community of Practice is a group that shares a common interest and interacts regularly as a method of sharing and co-learning about related domains or areas (<http://www.kstoolkit.org/Communities+of+Practice>).

A combination of twelve state IDD agency administrators and other personnel representing a total of seven states participated (AZ, CO, FL, HI, NV,

RI, and VA). After an introduction to the overall issues by SELN staff, agency staff members from each state were given five minutes to speak. State participants were asked to reflect on the question, “What are your state’s biggest priorities for CBNW?” Six of the seven participating states responded to the question. Themes emerging from this discussion were:

Supported employment and Community Life Engagement are not mutually exclusive. States are starting to move from an exclusive focus on employment to thinking about how other community engagement activities relate to and can promote employment. Nevertheless, states wish to ensure that focusing on Community Life Engagement doesn’t detract from the employment focus. They want to learn how Community Life Engagement supports can be better designed to promote and/or wrap around employment as the primary expectation.

- States want guidance from CMS on how to incorporate Community Life Engagement into their home and community-based services waivers. State agency administrators seek information on what constitutes an acceptable environment (setting) in which service or support may be provided under the new HCBS rule, and what to include in their HCBS state plans. They also want clarification on what Medicaid will reimburse: for example, can Medicaid HCBS funds be used to pay for a gym membership or community education class in lieu of segregated programming?
- Community Life Engagement activities should promote community inclusion and integration. For example, volunteer work should be an activity that is meaningful to each individual and occurs alongside community members without disabilities in whatever capacity the individual chooses.
- States struggle with how to fund the conversion from facility-based to high-quality Community Life Engagement activities. Although state systems are often designed around a congregate model of service delivery, quality Community Life Engagement supports should be individualized. Providers need support to make the conversion, including additional staff training. Other related challenges include determining how to support activities outside traditional day programming hours and how to engage natural supports.

- Community Life Engagement should be incorporated into transition plans and person-centered plans. This is particularly important given the emphasis on person-centered planning in both CMS and DOJ guidance. Community of Practice members wanted Community Life Engagement to be incorporated in these plans and needed assurance that providers can find appropriate community activities, volunteer work, and civic engagement opportunities based on individual choice.
- States would like to connect Community Life Engagement with family-centered approaches. Determining the role of family members in supporting activities outside of work is a key area of focus in some states. Particularly essential is determining what are the roles of families versus the service system in supporting non-work activities, especially outside of traditional day programming hours.
- There is a lack of clear goals, definitions, and measurements for Community Life Engagement. As one state participant said, “How do you measure success?” Success is harder to define with non-work activities than with employment outcomes. States need to determine how they can effectively provide quality assurance and ensure compliance with HCBS and Olmstead requirements.

What's next?

This brief is only an introduction to the definition, relevance, and emerging issues related to Community Life Engagement. Over the next three years, ICI is embarking on a new initiative to conduct further research on this topic and to develop guidance for states and service providers. Major activities will include expert interviews, case studies, identification of promising practices, a survey of state agencies, and development of guideposts and toolkits for states and service providers on how to design, conduct, regulate, and measure quality Community Life Engagement. Subsequent briefs in this series will provide findings and insights as they emerge from these activities.

References and resources

- Butterworth, J., Smith, F. A., Hall, A. C., Migliore, A., Winsor, J., & Domin, D. (2014). *StateData: The national report on employment services and outcomes*. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- Center for Medicare and Medicaid Services (2014). *Home and community-based services*. Retrieved from www.medicare.gov/Medicare-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html
- Domin, D., & Butterworth, J. (2013). The role of community rehabilitation providers in employment for persons with intellectual and developmental disabilities: Results of the 2010–2011 national survey. *Intellectual and Developmental Disabilities* 51 (4), 215–225.
- Olmstead v. L.C., 119 S. Ct. 2176 (1999).
- Sulewski, J. S. (2010). In search of meaningful daytimes: Case studies of community-based nonwork supports. *Research and Practice for Persons with Severe Disabilities*, 35(1–2), 39–54.
- Sulewski, J. S., Butterworth, J., & Gilmore, D. S. (2008). *Community-based non-work supports: Findings from the National Survey of Day and Employment Programs for People with Developmental Disabilities*. *Intellectual and Developmental Disabilities*, 46(6), 456–467.
- Sulewski, J. S., Butterworth, J., & Gilmore, D.S. (2006). *Community-based non-work services: Findings from the National Survey of Day and Employment Programs for People with Developmental Disabilities*. *Research to Practice Brief*. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- Sullivan, J. A., Boeltzig, H., Metzger, D. S., Butterworth, J., & Gilmore, D. S. (2004). *The National Survey of Community Rehabilitation Providers, FY2002-2003. Report 2: Non-work services*. *Research to Practice Brief*. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.
- U.S. Department of Justice. (2011). *Statement of the Department of Justice on enforcement of the*

United States vs. State of Rhode Island. (2014). Retrieved from <http://www.ada.gov/olmstead/documents/ri-olmstead-statewide-agreement.pdf>

Walker, P. M., & Rogan, P. (Eds.). Make the day matter!: Promoting typical lifestyles for adults with significant disabilities. Baltimore, MD: Paul H. Brookes Publishing Company.

ThinkWork!

Advancing employment and opportunity for people with intellectual and developmental disabilities



Community Life Engagement is a project of ThinkWork! at the Institute for Community Inclusion at UMass Boston. ThinkWork! is a resource portal offering data, personal stories, and tools related to improving employment outcomes for people with intellectual and developmental disabilities.

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