

Introduction to Community Life Engagement

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INTRODUCTION

As national disability policy prioritizes greater support for competitive integrated employment for people 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 is largely undefined. The purpose of this brief is to offer a definition of community life engagement (CLE), 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 (CLE) refers to people accessing and participating in their communities outside of employment as part of a meaningful day. CLE is not a type of service or support, but an outcome that is important for everyone regardless of disability status. High quality services, especially day services, should support CLE as an outcome for people with IDD. A high-quality CLE outcome is individualized according to the person's skills and interests, community membership, and contribution. CLE 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 people 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 \(www.thinkwork.org\)](http://www.thinkwork.org), categorizes day and employment services into four quadrants based on whether they are work or non-work and community- or facility-based. Community-based non-work (CBNW) services are those services in the non-work and community-based quadrant. CBNW services 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.

The role of services related to engagement and participation in community life has been largely undefined.

#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 people receiving both work and CBNW supports, but more often, CBNW has served as a substitute for employment.

#3: Recent federal guidance has further illustrated the need to define and provide high-quality CBNW services to facilitate meaningful community life engagement outcomes.

Department of Justice (DOJ)

DOJ has clearly stated that to be in compliance with the Americans with Disabilities Act (ADA) and the Supreme Court decision in *Olmstead v. LC*, states must provide day and employment supports in integrated settings (US Department of Justice, 2014; *United States v. State of Rhode Island*, 2014), placing pressure on all states to move people 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 (HCBS) requirements (Center for Medicare and Medicaid Services, 2014). The new rules specify that states must maximize the opportunities for people to access community living in the most integrated setting.

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.” CLE is thus an essential part of the current vision for HCBS.

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 CLE. 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.

A combination of 12 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 supports and activities relate to and can promote employment. Nevertheless, states wish to ensure that focusing on CLE doesn’t detract from the employment focus. They want to learn how services supporting CLE outcomes can be better designed to promote and/or wrap around employment as the primary expectation.

- **States want guidance from CMS on how to incorporate supports that promote meaningful CLE outcomes into their HCBS 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?
- **CLE activities should promote community inclusion and integration.** For example, volunteer work should be meaningful to the person, take place in community settings, and involve similar roles to other volunteers without IDD.
- **States struggle with how to fund the conversion from facility-based to individualized supports that promote meaningful CLE outcomes.** Although state systems are often designed around a congregate model of service delivery, quality day and employment services 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.
- **Activities that promote and facilitate high-quality CLE outcomes 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 CLE outcomes 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 activities that promote good CLE outcomes 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 the roles of families versus the service system are in supporting non-work activities, especially outside of traditional day programming hours.
- **There are a lack of clear goals, definitions, and measurements for CLE outcomes.** 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.

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 CLE activities relate to and can promote employment.

Community based non - work services have the potential to create meaningful CLE outcomes when used effectively, yet there has been limited regulation or study of CBNW to date.

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. https://scholarworks.umb.edu/ici_pubs/73/
- Center for Medicare and Medicaid Services (2014). Home and community-based services. Retrieved from www.medicaid.gov/Medicaid-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., Metzel, 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 integration mandate of Title II of the Americans with Disabilities Act and Olmstead v. L.C. Retrieved from www.ada.gov/olmstead/q&a_olmstead.htm
- 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.

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