

State Roles in Promoting Community Life Engagement: Themes from the State Employment Leadership Network's Working Group

Jennifer Sulewski & Jaimie Timmons

INTRODUCTION

As states focus on expanding integrated employment opportunities for people with intellectual and developmental disabilities (IDD) and phasing out sheltered work, they are finding a need to concurrently examine Community Life Engagement (CLE) supports as a wrap-around to ensure individuals' engagement in the community is maintained and they continue to receive sufficient levels of support, despite fluctuations in job status and hours.

In January through June of 2017, the State Employment Leadership Network (SELN) hosted a working group of member states to discuss ideas and share strategies for encouraging quality CLE supports while maintaining a focus on Employment First (see below for more on *Employment First*). The SELN is a membership-based network of state IDD agencies committed to making changes in their service systems to ensure access to competitive integrated employment for people with IDD (www.selnhub.org/home).

This CLE Working Group (CLEWG) was comprised of 17 SELN state administrators and met five times. The meetings focused on the four CLE guideposts (See yellow box to the right for a definition of CLE and an explanation of the four guideposts).

WHAT IS EMPLOYMENT FIRST?

Many states have been developing policies that prioritize integrated employment as the first choice and preferred outcome for individuals with IDD. Collectively, these actions have been united under the framework of Employment First.

WHAT IS COMMUNITY LIFE ENGAGEMENT?

Community Life Engagement, or CLE, refers to how people with intellectual and developmental disabilities (IDD) access and participate in their communities outside of employment as part of a meaningful day. 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.

The Institute for Community Inclusion has been conducting research to identify the elements of high-quality CLE supports. Through expert interviews and case studies with providers, four guideposts in delivering high-quality CLE supports were identified:

1. INDIVIDUALIZE SUPPORTS FOR EACH PERSON.

To be individualized, supports must show understanding of personal preferences, goals, interests, and skills; emphasize person-centered planning and discovery; and consider creative grouping, staffing, and scheduling approaches.

2. PROMOTE COMMUNITY MEMBERSHIP AND CONTRIBUTION.

Supports should start with inclusive settings and activities; ensure staff presence does not limit connections with other community members; place value on not just presence, but membership in the community; and always consider the individual's preferences.

3. USE HUMAN AND SOCIAL CAPITAL TO DECREASE DEPENDENCE ON PAID SUPPORTS.

Individuals should be actively engaged in the community with the minimal supports that meet their needs. Social capital, or connections with other community members, can create natural supports and enhance skill building that increases human capital (individual skills for employment and community living).

4. ENSURE THAT SUPPORTS ARE OUTCOME-ORIENTED AND REGULARLY MONITORED.

Supports must be oriented toward measurable outcomes related to life satisfaction, community membership and contribution, and decreased dependence on paid supports. States and providers should emphasize goals in addition to processes, hold CLE supports to clear state and federal expectations, and ensure that CLE always leads to or complements employment.

For more on the four guideposts, see: www.thinkwork.org/high-quality-community-life-engagement-supports-four-guideposts-success



FINDINGS

This publication describes the themes that emerged from these CLEWG meetings, illuminating the states' perspectives on accomplishments, gaps, and their roles as they relate to each CLE guidepost.

GUIDEPOST 1: Individualize supports for each person.

To optimize guidepost 1, CLEWG members recommended the following:

INCREASE FLEXIBILITY IN DEFINITIONS, STAFFING RATIOS, AND RATES. This would allow for more individualization of supports based on interests and needs. CLEWG members recommended moving away from fixed staffing ratios to more flexible requirements that allow group sizes to ebb and flow. Flexibility also allows time-limited, intensive 1:1 supports to support an individual to explore the community, identify their interests, find community opportunities that are a good fit, learn the skills and routines needed to succeed in those opportunities, and start to establish relationships, all with the goal of later fading paid supports for that individual.

THINK CREATIVELY ABOUT THE ROLES OF EMPLOYMENT, NON-WORK DAY, AND RESIDENTIAL SUPPORTS. CLEWG members described this as essential to supporting an individualized life vision. There was agreement that CLE supports should be provided at appropriate times and places for the individual and their interests, and that doing so requires thinking outside the usual "day program" schedules.

Moving away from set schedules, however, creates a new challenge for states: If different service types are not delineated strictly by time of day, how does one draw the line between them and determine which supports are whose responsibility? For example, if an individual needs supports to attend an adult education class in the community, are those supports part of their CLE support package or a responsibility of the residential support provider?

PROMOTE PERSON-CENTERED PLANNING AND THINKING. States can take on this role by providing training to both IDD agency staff and provider staff. They can also provide person-centered planning training and resources to families and individuals, using tools such as the Charting the Life Course (<https://www.lifecoursetools.com/>). Self-determination training can further facilitate individuals' taking the lead in their own life planning.

GUIDEPOST 2: Promote community membership and contribution.

To optimize guidepost 2, CLEWG members recommended the following:

MOVE FROM JUST PRESENCE TO PARTICIPATION. There is a growing appreciation that simply moving supports to community settings does not accomplish CLE. CLEWG members described the needed shift from programming that simply takes people on outings to individualized supports that emphasize true engagement. This means providing opportunities for interaction, contributions, and developing friendships. This requires an evolution in service planning.

OFFER VALUES-BASED TRAINING. Such training, provided to state agency and/or local provider personnel, can create a culture of viewing people with IDD as individuals and having high expectations for their inclusion in the community. Some specific examples of values systems include Social Role Valorization (www.socialrolevalorization.com/en/) and Person-Centered Thinking (<https://dds.dc.gov/page/person-centered-thinking-philosophy>).

RETHINK SERVICE DEFINITIONS, UNITS OF SERVICE, AND FUNDING MECHANISMS. Service definitions might require that a certain percentage of each individual's time be spent engaged in community activities alongside community members with and without disabilities, and/or require that each individual be supported to try new things. Service definitions and reimbursement rates can also specify that agency funding will cover fees for activities, such as gym memberships or community education classes, as a preferred substitute for providing programming at the provider site. Self-directed funding can also be an effective approach to CLE supports, enabling individuals to hire support staff who have flexible schedules and/or whose interests, area of residence, or social networks overlap with the individual's.

DESIGNATE A STATE IDD AGENCY STAFF MEMBER TO CHAMPION CLE. CLEWG members recommended that this person understand CLE policies and practices, and train and mentor others in the agency. Just as it is a recommended strategy for Employment First to have a staff member focus on employment policies and practices, having one person focus on CLE provides both an expert and a champion for the cause.

GUIDEPOST 3: Use human and social capital to decrease dependence on paid supports.

HUMAN CAPITAL is the set of personal skills people bring to their job or community experiences. Increasing human capital can build the individual's comfort level and ability to function with fewer supports. CLE can build human capital by teaching job search skills, travel training, or financial awareness.

SOCIAL CAPITAL is a person's network of relationships and the value they get from those relationships. CLE can help grow social capital by supporting activities that lead to social connections and by providing supports in a way that facilitates those connections.

To optimize Guidepost 3, CLEWG members recommended the following:

PROVIDE TRAINING OR TECHNICAL ASSISTANCE TO INCREASE PROVIDER CAPACITY. States can offer training on how to build human and social capital. For example, direct support staff can be taught to model appropriate behavior in community settings, provided curricula and training on ways to teach soft skills, and learn techniques for encouraging social connections.

BALANCE OPPORTUNITY, RISK, AND ACCOUNTABILITY. Increasing both human and social capital can enable fading of paid supports, but encouraging fading also requires changing accountability measures and mechanisms. States need to embrace the "dignity of risk" by reviewing policies and procedures from this perspective. They can then redesign quality assurance and monitoring processes to ensure they encourage healthy and appropriate risk taking. Doing so can reduce the perception that providers and their staff will be blamed if problems arise. There is also a growing role for technology such as cell phones and tablets in providing an additional safety net while encouraging more independence in the community.

ENSURE THAT FADING PRESENTS NEW OPPORTUNITIES. State agencies can work with providers to look at overall program budgets and determine how the resources that are freed up by fading will be used. Ideally those funds should be redirected to provide more individualized supports and more community engagement opportunities.

GUIDEPOST 4: Ensure that supports are outcome-oriented and regularly monitored.

To optimize Guidepost 4, CLEWG members recommended the following:

DETERMINE THE DESIRED CHARACTERISTICS OF CLE.

CLEWG members described several potential outcomes: the individual (1) is a part of groups or clubs, (2) has meaningful roles, (3) makes a contribution, (4) is moving toward self-identified goals, (5) knows their neighbors, and (6) has real social connections. Real social connections are people who save the individual a seat, are excited to see them, notice if they are not there, and invite them to do things. Yet determining how to measure these outcomes, especially in any quantitative or systematic manner, remains a gap.

EXAMINE EXISTING MEASURES. States may already be collecting data that can be reviewed in new ways to develop a better sense of CLE outcomes across the system. For example, the National Survey of State IDD Agencies' Day and Employment Services includes data on participation in community-based non-work services (www.statedata.info/about/data-sources#mrdd). The National Core Indicators include measures of participation in paid and unpaid community-based activities, as well as questions about participation in specific activities such as exercise, attending religious services, and going out for entertainment (www.nationalcoreindicators.org/). The CQL Personal Outcome Measures include assessments of use of community facilities, interaction with community members, and participation in the life of the community (<https://c-q-l.org/the-cql-difference/personal-outcome-measures>).

DEVELOP AND IMPLEMENT NEW MEASURES. CLEWG members thought this would be particularly helpful in the process of writing new service definitions and/or regulations. For example, mechanisms can be put in place to track whether individuals have a person-centered plan in place, and whether progress is being made on the goals in that plan. By encouraging or requiring that person-centered plans be not just created, but used regularly to plan and monitor supports provided, states can move in the direction of monitoring the other three guideposts.

CONCLUSIONS AND NEXT STEPS

The CLEWG identified a growing interest in, and commitment to, including community life engagement alongside community integrated employment as part of a vision for a fully included life for people with IDD. However, several gaps in states' capacity to make that vision a reality also clearly emerged. These gaps frame the next areas of focus:

- » Determining how to redesign quality assurance systems to balance accountability with dignity of risk.
- » Designing funding mechanisms to encourage individualized lives with a combination of work and CLE, including braiding and blending of resources across agencies (e.g., vocational rehabilitation and IDD).
- » Engaging the broader disability community (outside the IDD system) to be more inclusive and supportive.
- » Using existing and new tools to assess CLE supports and outcomes.

ThinkWork!



Community Life Engagement is an initiative 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.

FOR MORE INFORMATION

Jennifer Sullivan Sulewski
Research Associate
Institute for Community Inclusion
UMass Boston
100 Morrissey Blvd.
Boston, MA 02125
(617) 287-4356
jennifer.sulewski@umb.edu

FUNDING SOURCES

Funding for Community Life Engagement is provided in part by the Access to Integrated Employment Project, supported by the Administration on Intellectual and Developmental Disabilities, Administration for Community Living, U.S. Department of Health and Human Services, under cooperative agreement #90DN0216, and by the State Employment Leadership Network, a membership-based network of state intellectual and developmental disability agencies committed to employment-related systems change.

www.CommunityLifeEngagement.org

www.ThinkWork.org

www.CommunityInclusion.org



State Employment Leadership Network

The SELN is a place for states to connect, collaborate, and create cross-community support regarding pressing employment-related issues at state and federal levels for individuals with developmental disabilities.

The SELN was launched in 2006 as a joint program of the National Association of State Directors of Developmental Disabilities Services and the Institute for Community Inclusion at the University of Massachusetts Boston.



NASDDDS

www.selnhub.org