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HIGH-QUALITY COMMUNITY LIFE ENGAGEMENT SUPPORTS: FOUR GUIDEPOSTS FOR SUCCESS

Jaimie Ciulla Timmons and Jennifer Sullivan Sulewski

INTRODUCTION

Community Life Engagement refers to supporting people with intellectual and developmental disabilities (IDD) to access and participate in their communities outside of employment as part of a meaningful day. States and providers report growing numbers of individuals with IDD in Community Life Engagement, yet the role of services related to engagement and participation in community life has to date been largely undefined.

Furthermore, the Department of Justice's guidance around the provision of day and employment supports in integrated settings (U.S. Department of Justice, 2014; *United States v. State of Rhode Island*, 2014) has illustrated the need to define and provide high-quality Community Life Engagement supports. Placing additional pressure on states and providers, the Center for Medicare and Medicaid Services released new rules that defined, described, and aligned home and community-based setting requirements specifying maximum opportunities in the most integrated settings (Center for Medicaid and Medicaid Services, 2014).

The purpose of this brief is to:

1. Present findings from 13 expert interviews regarding essential elements of high-quality Community Life Engagement, organized into four guideposts.
2. Consider these guideposts as a set of key principles states and providers can use to move their Community Life Engagement efforts forward.

Where this information came from: expert interviews

A series of 45- to 90-minute semi-structured telephone interviews were conducted with 13 experts

WHAT IS COMMUNITY LIFE ENGAGEMENT?

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

in the field of Community Life Engagement. Experts were chosen based on their level of expertise and diversity of perspectives. These 13 participants included researchers, state and local policymakers, community rehabilitation provider staff and management, self-advocates, and family members.

Topics covered included the goals of Community Life Engagement, evidence of effective implementation of Community Life Engagement, barriers encountered and strategies used, and the role of Community Life Engagement as a support to other outcomes, including employment.

We have synthesized the feedback from these experts into four main guideposts to inform states and service providers as they increase and improve their Community Life Engagement activities.

These guideposts are meant to frame the most essential elements in order to create a roadmap for those wanting to improve their Community Life Engagement supports.

WHY DO WE NEED THESE GUIDEPOSTS?

Community Life Engagement currently represents a wide range of activities and variable implementation, and is delivered without consistent guidelines. The desire to provide individualized supports is often counterbalanced by structural and budgetary constraints, resulting in varied levels of individualization, choice of activities, and hours of support offered. The relationship between Community Life Engagement and employment remains inconsistent, with some individuals receiving both work and Community Life Engagement supports, but more often Community Life Engagement serving as a substitute for employment. These guideposts establish a set of quality indicators as states and providers focus their change efforts around Community Life Engagement.

FOUR GUIDEPOSTS FOR COMMUNITY LIFE ENGAGEMENT

Guidepost 1: Individualize supports for each person

Community Life Engagement supports should be tailored to the interests and needs of each unique person. In order to be individualized, supports must:

SHOW UNDERSTANDING OF PERSONAL PREFERENCES, GOALS, INTERESTS, AND SKILLS.

Regardless of the process used to uncover interests and passions, the goal should always be the same: to identify and pursue activities that appeal to the individual and/or support their longer-term goals. Furthermore, as interests are pursued, professionals must consider each person's unique support needs to ensure success. In contrast to this individualized approach are, as one expert put it, "group models [that] emphasize general ideas about what outsiders feel everyone with disabilities should be doing."

EMPHASIZE PERSON-CENTERED PLANNING AND DISCOVERY.

Experts agreed that providers must take the time to get to know the individual through some form of person-centered planning or discovery, whether formal or informal. This includes allowing time for an investigative period to uncover the most accurate and detailed information.

While some experts preferred formal plans, others

warned not to overcomplicate the process of developing goals. Community Life Engagement supports can also provide an excellent opportunity to determine interests and skills for employment and for networking toward finding jobs.

CONSIDER CREATIVE GROUPING, STAFFING, AND SCHEDULING.

One often-noted challenge is providing individualized supports when existing funding is based on group staffing ratios. Experts agreed that many providers do manage to individualize supports despite this constraint. To do this, providers use strategies including creative and purposeful grouping of individuals; careful attention to scheduling, logistics, and staff communication; re-defining staff roles to include community facilitation and to encourage natural supports; and accessing, braiding, or blending funding resources.

Guidepost 2: Promote community membership and contribution

In order to promote community membership and contribution, supports must:

START WITH INCLUSIVE SETTINGS AND ACTIVITIES.

The starting point for promoting community membership is that individuals are being supported "out in the community [in activities that] provide opportunities for interaction with community members." Experts agreed that high-quality implementation means supporting people "in an inclusive environment...in our community where adults would be...learning meaningful skills in the community, in inclusive and integrated settings with people without disabilities."

Accessing inclusive opportunities often involves service providers partnering with other local, non-disability-specific organizations to identify community resources and to generate new community-based options. Experts noted the value of fully inclusive settings, not only for the individual with a disability, but also for the larger community.

ENSURE STAFF PRESENCE DOES NOT LIMIT CONNECTIONS WITH OTHER COMMUNITY MEMBERS.

Another factor in increasing community connections is ensuring staff presence does not interfere with developing relationships with community members. Experts described the need to "[train] staff to get out of the way" and to retool staff training so that it is aligned with new expectations and new settings.

PLACE VALUE ON NOT JUST PRESENCE, BUT MEMBERSHIP IN THE COMMUNITY.

This includes being known by people in one's community, forming relationships, and making a contribution to the community through work or volunteer activities. Said another expert, "What we want to do is to discover how we can identify places and activities where people can...go beyond presence to participation to contribution." Providers can help people make community connections by tapping into the social networks of individuals, their families, and support staff.

CONSIDER AN INDIVIDUAL'S PREFERENCES.

A couple of experts noted that a focus on community connections should not be pursued unilaterally for all people. Some individuals may prefer a less connected life, and that should be an option as long as it is an informed choice. An expert noted that people may already have community connections through other aspects of their life, such as their job.

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

Essential to high-quality Community Life Engagement supports is decreased dependence on paid supports. In other words, individuals should be actively engaged in the community with the minimal supports that are commensurate with their needs. In order to achieve this, Community Life Engagement supports must:

USE SOCIAL CAPITAL TO CREATE NATURAL SUPPORTS.

As individuals make more connections in their communities, the social capital they are building can be used as natural supports. Tapping into this social capital then leads to a level of interdependence with others in the community that enables fading of formal, paid supports.

For example, by participating in the same yoga class every week, an individual will get to know other class participants as well as some of the gym staff. This level of familiarity can reach the point where staff support is less necessary and the individual can simply be dropped off for the class, knowing that "she's in an environment where she's safe, she's secure, and everybody within those activities knows her."

One expert described the goal as "not necessarily about the person becoming more independent

[but] just as much about creating an intentional community around somebody." Relying on natural supports can enable participation in activities without a paid support person, stretching service dollars and enabling more natural and sustainable interaction and participation.

TEACH SKILLS TO BUILD HUMAN CAPITAL.

Human capital refers to the specific skills an individual brings to his or her job and/or community. Community Life Engagement activities can be used to build individuals' human capital by teaching specific skills for community access and employment. This initial investment in skill-building enables more fading of supports over time. This can also include peer-to-peer strategies, for example, having a person with more mastery of a particular skill, such as riding the bus, teach someone who is still working on that skill.

An expert described using Community Life Engagement supports to "build employment skills, both hard and soft. So we're working on communication, initiative, problem solving." The skills gained can range from soft skills such as appropriate hygiene and behavior, to hard skills such as office or culinary work, to related skills such as accessing public transportation to get to work.

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

In order to achieve outcomes such as life satisfaction, community membership and contribution, and decreased dependence on paid supports, Community Life Engagement supports must be oriented toward, and monitored in relation to, those outcomes. Here are some examples of how to do so:

EMPHASIZE GOALS RATHER THAN PROCESSES.

When asked what constitutes quality Community Life Engagement, experts focused on outcomes such as satisfaction, individualization, and connectedness to community, rather than on process measures such as times and locations of activities. Furthermore, as hours in activities are tracked, measures should include the extent to which such activities are "focused on what the person wants to focus on, not just what happens because they go to this particular program or that particular program."

HOLD CLE SUPPORTS TO CLEAR STATE AND FEDERAL EXPECTATIONS AND GUIDANCE.

While being goal-oriented is the ideal, the consensus among experts was that the current guidance from the Centers for Medicare and Medicaid Services (CMS) and from state IDD agencies fails to set such expectations. While CMS has stated an expectation for community-based day supports under the Home and Community-Based Services waivers, the specifics of what that means have not been proposed, either at the federal level or by most states.

This lack of outcome-focused guidance can be problematic when Community Life Engagement supports are funded and regulated as day habilitation centers. This leads to reliance “on the payment schedule rather than on a value system to support a life that’s fully valued and inclusive in the community.” Experts also emphasized the role of state agencies in creating standards and expectations to offer guidance to providers and hold them accountable. Without such standards, providers lack direction, which results in limited investment.

LEAD TO OR COMPLEMENT EMPLOYMENT.

Experts also agreed that the individual goals upon which each person’s Community Life Engagement supports are based should include age-appropriate roles in the community, with an emphasis on employment. In general, these supports should move individuals “in the direction of integrated employment for those that are in the working age category.” For those who are younger, goals may involve postsecondary education or specific job training; for older people, the goal may be a healthy and sociable retirement. Regardless of age, the basic expectation is that people with IDD have the same kinds of roles as their same-age peers without disabilities.

Community Life Engagement can also supplement employment supports to create more of a full life, filling in any gaps in time, engagement, or interests, particularly for the many people with IDD who work limited hours. For example, someone may be working two days a week in a quiet office setting and using Community Life Engagement supports on the other three days to make more social connections or to be more physically active.

WHAT’S NEXT?

This brief offers an overview of the guideposts and key findings from the interviews with Community

Life Engagement experts. Our case study research, currently in the analysis stage, reinforces the guideposts and provides more practical guidance on their implementation.

The next several briefs in this series will examine each guidepost in more detail based on the case study findings. In addition, over the next year we will be developing and piloting toolkits for states and service providers on how to design, conduct, regulate, and measure quality Community Life Engagement.

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ThinkWork!



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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