

GUIDEPOST 4: Ensure That Supports Are Outcome-Oriented and Regularly Monitored

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INTRODUCTION

Community Life Engagement 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. (See *“What Is Community Life Engagement?”* in the box on page 3.) The Community Life Engagement team has been conducting research to identify the elements of high-quality Community Life Engagement (CLE) supports.

We have created a series of four Engage Briefs to examine the guideposts in detail.

Guidepost 1:

Individualize supports for each person.

Guidepost 2:

Promote community membership and contribution.

Guidepost 3:

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

Guidepost 4:

Ensure that supports are outcome-oriented and regularly monitored.

In addition to further description of the guidepost, we present examples of how this guidepost is being implemented by service providers. These examples are drawn from expert interviews and from case studies of exemplary providers of CLE supports.

WHERE THIS INFORMATION CAME FROM

The information in this series of briefs came from two sources: expert interviews and case studies.

EXPERT INTERVIEWS

A series of 45- to 90-minute semi-structured telephone interviews with experts in the field of Community Life Engagement were conducted. Thirteen experts were chosen based on their level of expertise and diversity of perspectives. They included researchers, state and local policymakers, service provider administrators, self-advocates with IDD, and family members. Topics covered included the goals of Community Life Engagement, evidence of effective implementation of CLE, barriers encountered and strategies used, and the role of CLE as a support to other outcomes, including employment.

CASE STUDIES

Case studies of three service providers with a focus on high-quality Community Life Engagement supports were also conducted. The three service providers were selected from 38 initial nominees based on a number of factors, including number of individuals served, geographic location, quality of CLE services, and interest in participating in the research study. Across the three locations, the project team interviewed a total of 51 individuals: 23 provider administrators, managers, and direct support staff; 7 community partners; 16 individuals with IDD; and 5 family members.

SITE VISITS WERE CONDUCTED AT THREE LOCATIONS:

WorkLink, a small San Francisco-based provider of day and employment supports to 38 individuals
LOQW, a larger provider of day and employment supports (600 individuals served) located in Northeast Missouri

KFI, a Maine-based provider of residential, day, and employment supports to 66 individuals

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, CLE supports must be oriented toward, and monitored on, those outcomes. Toward this end, service providers and state IDD agencies must:

- » Emphasize goals rather than processes
- » Hold CLE supports to clear expectations and guidance
- » Expect CLE to lead to or complement employment
- » Use data to guide continuous improvement

Emphasize goals rather than processes

Interviewees emphasized the importance of focusing on individual goals and outcomes including satisfaction, individualization, and connectedness to community, rather than on process measures such as times and locations of activities. Each case study location used data collection methods such as daily shift logs, monthly reports, quarterly reports, and annual reports to track each individual's progress. As part of the emphasis on goals, interviewees described the importance of collecting detailed and descriptive individual data and engaging individuals in assessing progress and satisfaction.

Collecting detailed descriptive individual data is essential to be accurate about measuring goals. As one provider administrator explained, it's important to *"make it measurable and make it visual...so that people are not writing 'Johnny had a good day' every day."*

Another administrator described the need for detail and description, but complemented with specific tallies of outcomes such as interactions in the community:

"Besides just measuring what actually happens during a service period...you could measure how many times there might be an interaction between a person served and community members...(plus) whether those interactions during the service day end up resulting in interactions outside of the service day."

Similarly, a staff member explained how collecting detailed data regarding task analysis enabled the organization to monitor each individual's unique progress towards their goals and the extent of the human capital built:

"We just switched over to a task analysis system, which is great, where we tally how many verbal prompts we gave, how much modeling we did, how much gesturing we did, all this stuff. So we can closely monitor the progress through the course of a month, through the course of a year, through the course of four years."

Through such data collection and analysis, providers not only assess progress toward goals and the level

of human capital built, but also can ensure supports are being properly faded, as described by a direct support provider:

"And so we do it daily by logs, and then we do a monthly summary, a monthly report... where we can check their progress and give it to our supervisors and then the service coordinators...so they can monitor their progress as well. And then at the end of the year, goals might need to be tweaked, or, if somebody is completely independent, which best case scenario, just drop the goal. If they can do it on their own, you know, we don't even want that to be a goal for them anymore, and work on something else."

Provider administrators explained that in addition to using data to assess individual progress towards goals, they use data collection efforts to engage individuals in this process as well:

"Everything from going to the gym and taking their weight once a month and then they graph it so that they (individuals) can see if they're gaining or losing, number of laps in the pool, stuff like that. And I think it really tightens up the instruction, really keeps it goal focused, and then we know when... they've learned it, it's pretty obvious and we can move on to something else. We kind of say, "Look at you. Look at you go," and it's much more reinforcing and fun than just going to the gym and working out and not knowing what the benefit of it is."

Engaging individuals in collecting their own data toward goal attainment has become an interesting incentive in one case:

"We've had people sit in their meetings and say, "I'm going to be a 5 [out of 5 on the goal attainment scale] on the bus. I'm riding the bus by myself," and really fighting back against their parents who are saying, "No, you're not." They just want the 5 in the box. So it's a really interesting little tool and we've seen it really change the tenor of the meetings too. And it also helps us to really plan and do goal setting that is meaningful and keeps them moving forward."

One of the case study sites extends the individual engagement one step further to the community.

Because they are in a very small town, this organization locates and asks community members to comment on the community contribution and social roles of the individuals. This organization values not only the staff, but also the community's feedback that further improves its performance and thus its outcomes. In this sense, both the organization and the community as whole make an effort to improve CLE supports and identify CLE outcomes contributing to individuals' success.

Hold CLE supports to clear expectations and guidance

While the Centers for Medicare and Medicaid Services (CMS) have stated an expectation for individuals receiving home and community-based services to be engaged in the life of their communities, clear guidance on how to do so has not yet been provided either at the federal level or by most states. Interviewees expressed concerns about this gap. As one provider administrator said,

“Right now [CMS is] doing a pretty decent job of saying those words, but they’re not putting any meaning behind them, so there’s no guidance coming as to what the expectations from the funding source is.”

A state agency leader encouraged state IDD agencies to become proactive, thoughtful, and prepared in advance, asking for

“...very robust, thought-out requirements, in the sense of what is your evaluation requirement; what’s your expectations for programming and planning; what’s your expectation for reporting; how are you going to monitor and evaluate the quality...”

In the absence of clear state and federal guidance, service provider agencies have relied on their own organizational values in developing outcome-oriented goals and the standard for quality of CLE supports. All three of the case study providers operate from a belief that individuals with IDD can and should have lives similar to those without IDD. The focus is on achieving, in the words of one administrator,

“regular lives. Typical lives...you want to have a home of your own, you want to have a job that you enjoy, you want to have friends and

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.

relationships, and that’s the standard that we should have for people that we provide supports to.”

Said a manager from another provider,

“Since we’re so strong in believing that people should work in the community, it just fits perfectly with that ... community-life engagement policy. We really don’t support any segregated anything.”

A staff member from another provider said,

“If you look at any of the other firms, we are standing for independence, where a lot of them are [still standing for] sheltered work.”

The third provider is guided by the concept of Social Role Valorization (www.socialrolevalorization.com).

As an administrator explained,

“[our] mission, at its core, is to help people achieve and maintain socially valued roles. ... And it’s going to sound silly, but we actually try and track it. I mean, we actually try and say who has achieved a valued role.”

Expect CLE to lead to or complement employment

In order to achieve meaningful CLE outcomes such as life satisfaction, community membership and contribution, and decreased dependence on paid supports, high-quality CLE supports must either complement or lead to employment, and be monitored on this outcome as well. This emphasis on employment was consistent across all our interviewees. As one state agency leader said:

“It really ties back to...a real outcome focus, and that outcome... is looking out further than just that immediate activity or skill that they’re trying to learn, but it’s really got a long-term goal in mind, in the sense of helping somebody become a real included member of the community or part of a community group or leads to a volunteer opportunity or leads to employment...”

Similarly, others explained their ongoing prioritization of employment. One provider administrator said:

“[Our state] is an Employment First state, [we are] very involved in that effort. And so there’s an intense discussion during the planning with people about employment, and we don’t ask the question, “Do you want to work?” It’s, “Would you like to earn some money doing something you really like to do?”

Another provider administrator described CLE as being *“an entry portal to work through exploring volunteer opportunities, [and/or] discovering the nature of certain kinds of demands.”* Another stated how at their organization, each individual’s CLE goal is

“usually tied to a goal of getting either more employment or a different kind of employment or a way of easing into employment for people who have never ever worked at all. It has an employment goal at the end.”

A staff member likewise described CLE as a

“kind of forerunners really for employment, for people to be developing kind of concrete skills, but also developing a sense of what work is and how they need to present themselves and how they need to relate to other people.”

CLE activities can also be used to build networking opportunities or as a form of exploration to discover the individual’s interests, strengths, and challenges, all of which leads to employment. One provider administrator pointed out that sometimes individuals

“might have an idea of what they want to do, but unless they’ve had experience they might not know what it actually means to do that [job].”

For example, using CLE supports for volunteering enables individuals to explore and discover their career choice and preferences, and how their own job expectations might differ from actual work tasks. Another administrator from the same provider explained,

“that’s like a huge benefit to integrated work...So that’s more discovery that we use when shaping the job search.”

Use data to guide continuous improvement

Interviewees described the importance of not only collecting data, but also using it to identify support gaps, guide training needs, and monitor quality. They explained that using data collection techniques such as shift logs, which illustrate the individual’s progress as well as intervention strategies, often becomes the basis of further training. Organizations used data not only to review the individual’s progress towards their goals, but also to identify and address gaps in supports and areas for staff improvement or to identify effective strategies that can be implemented again.

Similarly, agency management noted that staff meetings could provide an important opportunity for staff to review and track progress, monitor quality, and discuss strategies for improvement. One provider staff member described using weekly meetings to *“talk about annual goals for the upcoming annual meeting for a certain client.”*

An administrator from another provider spoke about using staff meetings to track progress on goals:

“We’re not out there looking over their shoulder, so we know what their documentation says. We know what the planning process is like. But, in terms of the day-to-day real execution of that, we’re not there. And so a lot of things happen and get discussed in staff meetings.”

“And so we do it daily by logs, and then we do a monthly summary, a monthly report...where we can check their progress and give it to our supervisors and then the service coordinators... so they can monitor their progress as well. And then at the end of the year, goals might need to be tweaked, or, if somebody is completely independent, which best case scenario, just drop the goal. If they can do it on their own, you know, we don’t even want that to be a goal for them anymore, and work on something else.”

In this sense, the staff meeting became an important vehicle to monitor and regulate supports, staff needs, and individual progress.

Having unscheduled site visits by supervisors was another strategy for monitoring how services and support were delivered to individuals, as described by a provider manager: *“There are a lot of check-ins and randomly stopping in to see how things are going. It’s not necessarily planned ahead of time.”* This organization also monitors the staff’s performance by reviewing the data collected on individuals’ progress.

Furthermore, case study participants explained how they shared outcomes with board members to highlight success and maintain buy-in. One provider had what their organization called “mission moments” at monthly board meetings, whereby staff offered a brief presentation of an accomplishment that warrants celebration:

“... we require our staff, as part of their performance appraisal, to give us a success story annually. So many times they write about an individual that they’ve worked with, how they felt like they made a difference. And sometimes they just write about themselves and how working here has made a difference...”

While not considered a hard data collection activity, taking small steps to actively document individual and organizational progress is a way to share accomplishments with board members, reinforcing the organization’s investment in individualized, community-based supports.

WHAT’S NEXT?

This brief is part of a series of four, each expanding on one of the four Guideposts for Community Life Engagement. These briefs serve as a core element of the Community Life Engagement toolkit for states and service providers. The toolkit provides further guidance on how to design, conduct, regulate, and measure quality Community Life Engagement. For more information on the toolkit, please contact Jennifer Sulewski at the information provided.

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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www.CommunityLifeEngagement.org

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