ENGAGE...
A BRIEF LOOK AT COMMUNITY LIFE ENGAGEMENT

Guidepost 2: Promote Community Membership and Contribution

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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:
Develop relationships and build skills to decrease reliance 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

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PROMOTE COMMUNITY MEMBERSHIP AND CONTRIBUTION

Promoting community membership and contribution is essential to Community Life Engagement. Engagement in the life of one's community must go beyond simply being physically present in the community to being an active and included member. Ensuring that supports promote community membership and contribution requires

- starting with inclusive settings and activities
- ensuring staff presence does not limit connections with other community members
- placing value on not just presence but membership in the community, and
- considering the individual's preferences, goals, and other activities

Start with inclusive settings and activities

The starting point for promoting community membership is that individuals are, in the words of one state agency administrator, supported *"out in community [in activities that] provide opportunities for interaction with community members." Doing this with quality meant, in the words of one state agency leader, providing supports "in an inclusive environment…in our community where adults would be…able to be learning meaningful skills in the community, in inclusive and integrated settings with people without disabilities"*

Accessing inclusive opportunities often involved service providers partnering with other local organizations to identify community resources and generate new community-based options. One provider administrator who is also a family member summarized the concept in this way: *"We have to look at getting business folks as part of that conversation, getting universities as part of that conversation. Just rethink that whole partnership so we can figure out how to do services in a different model."*

Interviewees explained the value of fully inclusive settings not only for the individual, but also for the larger community. One parent talked about her daughter's opportunity to attend a local university. This experience *"gave all of [the] students an opportunity to get to know people … in a much more human and personal way… And just made a really rich life for my daughter."*

Other interviewees described examples of individuals being engaged in local organizations, including local arts and theater organizations, church communities, postsecondary or adult education programs, volunteer sites, fitness centers, and businesses.

Engagement with local organizations was particularly important for the two providers operating in rural areas, although interviewees acknowledged the challenges associated with having fewer options. As one direct support professional described: *"Our closest Y is about 35 miles away… we have two restaurants, maybe three… [but there are] a couple churches that open their doors to us, two nursing homes that any events that they have, we're allowed to come and participate in… and a nice lake that is kept up by the city."*

Another interviewee from the same town described partnering with a lifelong friend who worked in the parks and recreation department to create new opportunities. Others also cited the ease of making connections in a small-town setting. One agency manager said,

> *"For sure, everybody knows everybody, and you are constantly seeing the same people everywhere." A direct support staff likewise said that making connections in town "really was just going out and starting to talk to people and frequenting their businesses… because [my town] is small enough that I can go to every restaurant every week for my lunch."*

Another case study site, in a more urban setting, made use of the considerable resources of its home city to identify a wider variety of options. These included a drama class at a local college, a knitting group at a yarn store, and volunteer opportunities at a diverse array of organizations.

Sometimes this involved deliberately creating partnerships and opportunities, as happened with the knitting group:

> *One of the people was crocheting, her mother had taught her to crochet, and two of the other young women in the program said, "I want to learn to do that." So our community instructors were like, "Okay, go, go find someplace to learn to knit." And [they identified] a yarn store... [and] the community instructor said to the woman at the yarn store, "Do you know of anything during the day?" and she said, "Bring them here at lunch time; I'll teach them." So they set up a weekly knitting lesson.*

Tapping into the social networks of individuals, their families, and support staff also played an important role in identifying inclusive opportunities. One family member talked about the importance of having support staff that know the community and are *"aware of potential employment opportunities, potential volunteer opportunities, the recreational resources and physical activity resources that are available."*

A direct support professional shared his experience tapping into his own networks:

> *"We have a girl [who] wants to become a teacher's aide at the early childhood center. So I did an internship there. And I'm actually going to go in with her and talk to the head director of the special education program because that's who got me an internship, and I'm going to see if she can volunteer there."*

Networking was considered so important, in fact, that both of the rural providers explicitly considered the extent of potential staffers' social networks at the point of hiring. One manager described how during the application process, *"They have us write down what organizations we're involved in, making sure we're members of our communities."*

Interviewees across the sites were also encouraged to participate in local organizations such as the chamber of commerce or the United Way, in order to make such connections. An administrator said, *"What we look for ... is people with just a wide variety of interests and community connections themselves."*

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.

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 the development of relationships with community members. One provider administrator described it as *"[training] staff to get out of the way"* and another suggested the retooling of staff training so that it is aligned with new expectations and new settings:

> *"I think what you have in many cases is well-intentioned people who simply don't know what to do. And so because they don't know what to do, they default to what seems to be easy, whether that's the mall, or everybody goes volunteering at the same place because that place happens to be receptive to having people with intellectual disabilities ... You get into these default relationships rather than something that's thoughtful."*

Several interviewees emphasized the importance of staff not over-supporting individuals, and avoiding other aspects of the agency's operations becoming barriers to social connections. One manager described,

> *"the anonymity with which we try to provide our supports. You're not going to see any vans emblazoned with [our] name. You're not going to see any staff with [our] T-shirts on. We really try and be in the background. This is this person's life. We want to be the liaison, the bridge, not the barrier."*

In order to ensure staff presence does not interfere with the creation of authentic community connections, staff members have to maintain a mindset of being in a support role rather than a caregiver role or even a teacher role. Said one direct support professional, *"[We] have to remember that this is their lives. We are not directing them; we are filling in the blanks that they can't manage and helping them gain skills."*

Ensuring that staff are constantly aware of supporting individuals only to the extent that it is necessary is often connected to one's values, and interviewees specifically looked for this mindset and values base when hiring staff. Two agency administrators stated that they avoid hiring people with previous disability experience because, as one explained, *"We find a lot of people who have worked in facility-based services or segregated services really are non-believers. So starting fresh with a blank slate for us is kind of a strategic move… We try to instill that … they are just people."*

Another administrator said,

> *"People with disabilities deserve and need to just live a typical life, an ordinary life in the community, so it's kind of like the opposite of being special and [the people we hire] must have those values. We can teach people to do anything; they got to walk through the door with those values."*

Place value on not just presence but membership in the community

Community membership goes beyond simply being in community settings to a more active level of engagement. Supports should enable people with IDD to be, in the words of a self-advocate, *"in the community and part of the community, both."* Community membership included being known by people in one's community, forming relationships, and making a contribution through work, volunteer activities, or engagement in other community activities. Interviewees strongly believed that community participation and contribution are paramount to true membership.

Consistent involvement in community activities can lead to interactions and relationships with others, forming a sense of membership. As one individual said, *"When I go out, I go to the Dollar Tree and talk to them, and they talk to me, and I get to know somebody."* A fellow volunteer working alongside individuals with disabilities commented, *"If the individual is here for a consistent period, the relationship is great. If it's revolving doors, then, obviously, there's not much of a relationship."*

An agency administrator pointed out that this applies to anyone in any situation: "If you go to the same places all the time then you get to know people. You go to the coffee shop and get your coffee every morning; before long they know who you are, and it's not any different than the folks that we support." The same person went on to describe using this strategy to develop community membership for the individuals through consistency:

> *"We deliver magazines to the Quality Inn. We try to make sure that the same individual does it every month so they get to know the front-desk person or the owner or the shopkeeper or whoever it is. And then, in a couple of months, you would hope to see, "Hey, [so and so], thanks for the magazines," … And then the merchants start seeing the value of not only the volunteer work, but the value of the folks that we support."*

Community membership includes developing relationships that enhance the quality of people's life. These may include relationships with coworkers that extend beyond the workplace. For example, one provider manager recalled a story where ten coworkers drove two hours to show their support for an individual participating in Special Olympics. Another talked about an individual's newly built friendships at his job:

> *"Some of the other guys there are really into sports and wrestling as well, and they actually*

pick him up from his house… and drive to [where] they have the big… tournaments…at night or on the weekend, not work related. They have no obligation to [this individual] at all and they're including him."

Community membership is established not only through relationships but also through contribution to the community. As one researcher explained, *"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."* Many individuals used their CLE supports to volunteer at various local organizations in need of assistance. A direct support professional described a volunteer experience at a local nursing home:

"They loved to have our people volunteer, come out and just help, and then just be included in the activities to the nursing staff and administration level. Our consumers love being able to go out there and help the elderly."

An interviewee from a local Meals on Wheels program also described individuals' contributions to elderly residents:

"They go out on the route and they deliver the meals door-to-door for us. They also do errands for people in town. If some of the seniors can't go to the store or do something, they can call. And if they have the grocery list, you know, and they give them the money, they can go to the store and do that for them."

Community contribution also included opportunities for individuals with IDD to create positive change in their larger communities. For example, one individual gave a guest lecture about her employment experience to a human resources class at a local college, promoting disability awareness to a professional audience. A member of the community reflected,

"It was fantastic…[The professor has] actually asked us to come back because her class…commented on how refreshing that was and how much they learned about the disability population and working."

Another individual took art lessons with an instructor without disability experience, and ended up contributing to the instructor's skills. His mother recalls, *"[He]…has art lessons once a week. And [the teacher] wasn't sure how she was going to work with him, but she has learned, and she loves it. She said she's not sure which of them learned more in the art classes, her or him."*

In yet another example, individuals volunteered by welcoming new members to their neighborhood. As one community partner indicated, *"Once a month they would get the list and the addresses of the new people that are in the community. And then they would go out and deliver the welcome packet, and just kind of welcome them and answer any questions they might have."* These examples reveal individuals' ownership of their community and the larger positive impact as a result of their contribution.

Consider individual preferences

Interviewees noted the important caveat that a focus on community connections should not be pursued unilaterally. Some individuals may prefer a less connected life, and that should be an option as long as it is an informed choice. One researcher noted that people may already have community connections through other aspects of their life, such as employment, *"So if somebody has a lot of relationships and that part is fine and they want to [engage] in a community life kind of activity where they're not surrounded and they're more working alone or not necessarily with a group, that may suit them."*

A state agency leader shared that for some people, particularly those with autism spectrum disorders, *"The idea of engaging a bunch of people in the community, while it's important, may not be exactly what they're comfortable with or may not be exactly how they ultimately find employment."*

Finally, a manager also shared a similar perspective:

"There are some people who just don't feel comfortable with other people, don't want people in their homes and, again, that may be not what our ideal is and maybe we feel like their life would be richer, but if they don't [want that] we have to recognize [it]."

COMMUNITY LIFE ENGAGEMENT

Toolkit

The Community Life Engagement toolkit was developed to help service providers develop and improve high quality supports for community life engagement (CLE). Inside you will find guideposts for success, a self-assessment tool, real-world examples of service providers making CLE happen, and other helpful resources and tools.

CLE Guideposts

Visit the CLE Toolkit:
CLEtoolkit.communityinclusion.org

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Explore Community Life Engagement is ICI's hub for activities that enhance systems and services that support meaningful engagement of people with intellectual and/or developmental disabilities in their communities.

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