

Guideposts for High-Quality Community Life Engagement Supports:

Results of Expert Interviews

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GUIDEPOSTS FOR COMMUNITY LIFE ENGAGEMENT

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Abstract

While the benefits of community life engagement (CLE) for individuals with intellectual and/or developmental disability (IDD) are clear, high-quality day services and supports remain largely undefined. This study interviewed “experts” in the field of CLE in order to seek agreement about what constitutes “best practices” for day services and supports that lead to CLE. Using a semi-structured interview protocol, we asked 13 experts in the field, representing diverse standpoints, about their delivery and utilization of supports. Four overarching themes emerged: (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; and (Guidepost 4) Ensure that supports are outcome-oriented and regularly monitored. Recommendations are offered for the field.

Key words: Intellectual and developmental disability, community engagement, systems change

Recent federal actions have paved the way to support opportunities for people with disabilities to have meaningful lives in their communities. In particular, legislation and regulation governing Medicaid Home and Community-Based Services (HCBS Advocacy Coalition, 2015) and settlement agreements between states and the Department of Justice have clarified federal intent (Lane et al., v. Brown et al., 2015; United States of America v. State of Rhode Island, 2014).

The Centers for Medicare and Medicaid Services (CMS) released the Home and Community-Based Services Final Rule in March 2014. The rule created clarity in the definitions of HCBS, rather than basing those definitions solely on a setting's location, geography, or physical characteristics (CMS, 2014). The rule requires that all HCBS settings must be integrated within and facilitate access to the community, optimize autonomy and independence, be chosen by the individual, and provide an opportunity to work in the community (HCBS Advocacy Coalition, 2015). The rule supports “full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, *engage in community life*, control personal resources, and receive services in the community, to the same degree of access as individuals not receiving Medicaid HCBS” (CMS, 2014, p. 249; emphasis added). Initially, all states had until March 17, 2019 to meet the new settings requirements, but in 2017, CMS extended the deadline for compliance with the rule by three years, to March 17, 2022 (CMS, 2017).

In addition to the CMS HCBS rule, the U.S. Department of Justice has applied the *Olmstead vs. L.C.* decision related to the unnecessary segregation of people with disabilities to day and employment settings in multiple states. Settlement agreements with Rhode Island (United States of America v. State of Rhode Island, 2014) and Oregon (Lane et al v. Brown et

al., 2015) have extended enforcement of the Americans with Disabilities Act and the Olmstead decision to mandate access to inclusive community employment and day supports.

These policy priorities indicate a need for research and guidance on how to support individuals with IDD to, in the words of CMS, “engage in community life” (CMS, 2014, p. 249). Community life engagement (CLE) is a key outcome of day services and supports (see definitions, Table 1), yet many day services and supports continue to isolate and segregate individuals with IDD. Nearly half of recipients of day services and supports are in facility-based programs that “are located in a setting where the majority of participants have a disability” (Winsor et al., 2018, p. 14). Even in service models that were purportedly community-based, case study research has found that both outcomes and supports were limited (Sulewski, 2010). Many individuals still spent much of the day in a segregated day program setting, and activities that did take place in the community only achieved inclusion at the most basic level of being present, as opposed to being fully included and engaged.

Despite the evidence of mixed quality, the available data indicate substantial and increasing participation of people with IDD in day services and supports. States responding to the National Survey of State IDD Agencies’ Employment and Day Services have indicated an upward trend in those receiving day services and supports as a result of downsizing the population of individuals in sheltered workshops (Winsor et al, 2018). In fiscal year 2016, close to 500,000 people with IDD in the United States received day services and supports through a state IDD agency, representing over 69% of IDD agencies’ spending on day and employment services, for a total cost of well over \$2 billion (Winsor et al., 2018).

Consistent with this evidence on participation and expenditures, Friedman and Spassiani (2017) found that 48% of 1915(c) Medicaid waivers included some type of community support services such as community guides or specialists, with \$447 million in spending on such services nationally. As the number of states offering this service grows, and as states direct more resources toward this service category, additional focus is needed on purposeful design of high-quality day services and supports that lead to CLE.

Despite this growing role for day services and supports, individuals with disabilities, including those with IDD, are underrepresented in community engaged activities such as volunteering or involvement in community groups (Miller, Schleien, & Bedini, 2003; Reilly, 2005; Verdonschot, Witte, Reichrath, Buntinx, & Curfs; 2009). Barriers to participation include lack of transportation, limited staff training and qualified supervising personnel, and inadequate recruitment of individuals with disabilities in volunteer processes (Miller et al., 2003). It is also well demonstrated in the literature that persons with IDD often have limited social circles, which typically include other people with disabilities (Emerson & McVilly, 2004; Lippold & Burns, 2009; Verdonschot et al., 2009). This lack of meaningful CLE outcomes is further evidence for the need to improve day services and supports.

With better day services and supports, individuals with IDD could reap many benefits from CLE. Participation in one's community, including civic and social aspects of such participation, has long been understood as an essential part of human functioning, physical health, and emotional well-being (Brown, Consedine, & Magai, 2005; Jenkinson et al., 2013; World Health Organization, 2001). Engaging in activities like volunteering, community service, or community organizing can increase feelings of self-worth and psychological empowerment for individuals with disabilities (Balandin, Llewellyn, Dew, Ballin, & Schneider, 2006; Lindsay,

2016; Meinhard, Greenspan, Paterson, & Livingstone, 2007; Miller et al., 2002; Speer, Peterson, Armstead, & Allen, 2013). A qualitative study involving 23 young adults with disabilities indicated through self-report that their levels of happiness and stimulation increased by spending time meaningfully, which they defined as being active in their community with same-age staff and peers, doing purposeful activities (Rossetti, Lehr, Lederer, Pelerin, & Huang, 2015). People with disabilities who participated in community service reported feeling empowered to experience the role of a “provider” and problem-solver instead of the role of “recipient” of services, as well as a sense of ownership and accomplishment (Timmons & Zalewska, 2012). Finally, increased CLE can improve a person’s employability, through gaining both hard and soft skills useful for future employment (Held & Granholm, 2007; Hirst, 2001; Lindsay, 2016; Makharadze, Kitiashvili, & Bricout, 2010; Timmons & Zalewska, 2012).

While the benefits of CLE for individuals with IDD are clear, and the field is evolving, high-quality day services and supports remain largely undefined. Literature citing potential definitions include supports that will foster connections and relationship-building with community members outside the service system, and contributions to one’s own community (Balandin, Llewellyn, Dew, Ballin, & Schneider, 2006; Brown, Consedine, & Magai, 2005; Miller, Schleien, Rider, Hall, Roche, & Worsley, 2002). Walker (2007) defines successful day services and supports as those that include the pursuit of individual interests, being in social spaces, and having opportunities for social relationships.

Without a guiding model, the effectiveness of day services and supports in creating meaningful CLE outcomes is challenging to measure. The development of core competencies for direct support professionals is challenging, the development of specific guidance and supports

from states is perplexing, and individuals remain in less than satisfactory day services and settings. The current study sought to fill this gap by answering the following research questions:

1. How do experts in the field of CLE define high-quality CLE outcomes?
2. How do experts in the field define high quality day services and supports that lead to CLE?

Method

The research design employed a qualitative, grounded theory approach (Corbin & Strauss, 2015; Creswell, 2013; O'Brien, Harris, Beckman, Reed, & Cook, 2014). Grounded theory was chosen due to its basis in theoretical sampling. This study specifically chose “experts” in the field of CLE to be interviewed to seek agreement about what constitutes “best practices” by various people coming from diverse standpoints. Furthermore, the interviews were intended to produce themes that, along with existing and new research, could be triangulated to support the development of “guideposts” for delivering high-quality day services and supports that lead to CLE. Using a semi-structured interview protocol, 13 experts in the field of CLE were asked about how they define CLE and what day services and supports are needed to produce CLE outcomes. All research activities were approved by the Institutional Review Board at the University of Massachusetts Boston.

Sample and Participant Selection

The research team used purposive sampling to identify people knowledgeable about day services and supports and CLE for people with IDD. An initial list of 32 experts in various roles was compiled. This list included authors, presidents of national organizations, service provider

administrators, and others based on their contributions to the field and to the literature. The project team also consulted senior staff at the Institute for Community Inclusion (www.communityinclusion.org), the State Employment Leadership Network (SELN, www.SELN.org), and the National Association of State Directors of Developmental Disabilities Services (NASDDDS, www.nasddds.org), asking for their nominations. From this list, 16 experts with an average of 25 years each in the field were selected based on level of expertise and representation across roles. These 16 potential interviewees were sent an invitation letter via email, and the researchers then followed up by email and/or telephone to obtain verbal consent to participate and schedule an interview. Three people either declined or could not find a time to participate in the interview. The final set of 13 interviewees included 2 self-advocates, 5 parents of adults with IDD, 4 service provider administrators, 2 state agency leaders, and 2 researchers. Some participants represented more than one role (e.g., both a service provider administrator and a parent of an adult with IDD). The experts were geographically spread over 8 states and the District of Columbia.

Data Collection

Each expert participated in a 45- to 90-minute semi-structured telephone interview. Prior to starting the interview, the interviewer reviewed the content of the study consent form and confirmed the individual's consent to participate. Topics included their definition of high-quality CLE outcomes, their perspectives on effective day services and supports that lead to CLE as well as barriers that get in the way, and the role of CLE as a support to other outcomes, including employment. Sample questions for program staff, family members of individuals with IDD, and researchers included "What does quality CLE look like? What measures can be used to assess CLE?" and "What approaches can providers use to provide high-quality day services and

supports that lead to CLE within existing budget and resource constraints?” Sample questions for self-advocates included “What do you think CLE should look like?” and “What should be done when helping people with disabilities to be part of the community?” All interviews were recorded, and those recordings were sent to a third-party service for transcription.

Data Analysis

Research staff used elements of comparative and thematic analyses (Glaser & Strauss, 1965). Thematic analysis allowed the researchers to identify and describe patterns that emerged from the data. Audio recordings were transcribed in preparation for coding and qualitative analysis. Coding is an early and ongoing way of labeling data to sort it and assign meaning (Miles & Huberman, 1994). Operational definitions for each code were developed to ensure that all members of the research team had a shared understanding of the code. A qualitative software program (Atlas.ti) was used to conceptualize themes, store coded transcripts, and sort data. The researchers simultaneously coded and analyzed the data, often meeting as a team to compare specific passages, improve the team’s understanding of the data, and explore the similarities and differences between participant experiences (Charmaz, 2000). Once all transcripts were primary-coded and then secondary-coded (reviewed by a second coder to ensure consistency), Atlas.ti was used to generate “query reports” for memo-writing. Memo-writing helped to organize themes from the data, allowing the research team to further develop, interpret, and analyze the data (Creswell, 2013).

Results

Consistent with our original research questions, themes emerged regarding both the vision of CLE as an outcome and the elements of day services and supports that are needed to facilitate that outcome.

How do Experts Define High Quality CLE?

Experts described a vision of CLE that is individualized, inclusive, and part of a whole life vision. They described what CLE should ideally look like and how current service models fall short of that ideal.

Ideal vision for CLE. First and foremost, experts agreed that CLE has to be rooted in the individual's preferences, goals, interests, and skills, as described by a researcher:

What are the things that matter to them ... what do they find satisfying, fulfilling?

What do they find comforting? ... who do you enjoy spending time with, what are their characteristics, ... and what does it look like for you?

Furthermore, as individual interests are pursued, each person's unique support needs must be taken into consideration and supports tailored to meet those needs.

A second key element of CLE was that individuals with IDD should be, in the words of a self-advocate, "in the community and part of the community, both." Day services and supports should be in the same settings adults without IDD access and should provide opportunities to interact and develop relationships with fellow community members. CLE includes being known by people in one's community, forming relationships, and making a contribution to the

community through work or volunteer activities. Experts described the value of full inclusion, not only for the individual with a disability, but also for the community as a whole.

Finally, experts identified that CLE should be part of a purposeful life plan. A state agency leader emphasized that CLE should ultimately 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, retirement. CLE can also supplement employment to create a richer life, filling in any gaps in time, engagement, or interests, particularly for the many people with IDD who work limited hours. Regardless of the particulars, the basic expectation is that people with IDD have the same kinds of roles as same-age peers without disabilities.

Current day services and supports fall short of the ideal. There was wide agreement that existing day services and supports often are not set up to support this vision. There is currently a reliance on facility-based and/or community-based group models of support. In addition to failing to engage individuals’ interests, group activities foster a sense of unapproachability, furthering discrimination and creating barriers to community belonging. Another barrier to CLE is a lack of focus on bigger-picture goals such as employment, community service, and other meaningful roles. Filling days with fun activities, in or out of a facility, can lead to a degree of complacency on the part of both staff and individuals, contributing to a lack of vision for each individual’s growth and opportunities.

What are the Characteristics of Day Services and Supports that Lead to CLE?

Four overarching themes emerged from the expert interviewees’ guidance for effective day services and supports: (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, and (Guidepost 4) ensure that supports are outcome-oriented and regularly monitored. These four themes serve as indicators for state agencies and service providers seeking to improve day services and supports that lead to CLE.

Guidepost 1: Individualize supports for each person. The provision of day services and supports should be tailored to the interests and support needs of each unique person. Individualization of supports starts with a) emphasizing person-centered planning and discovery, b) being intentional about grouping, and c) using creative funding strategies.

Emphasize person-centered planning and discovery. To deliver truly individualized supports, experts agreed that service providers must take the time to get to know the individual through some form of person-centered planning or discovery process, whether formal or informal. This includes allowing the necessary time for an investigative period to uncover the most accurate and detailed information. The goal is to uncover what is uniquely important to that person. As one state agency leader noted:

Person-centered planning has to be at the core ... So having to do person-centered ... assessments, discovery, positive personal profiles, and using those assessments, [to build] into guided discussions and really guided questioning: Can this goal be implemented in the community in an inclusive setting? Does this goal or activity tie back to the person's person-centered interests and skills and needs?

While some experts preferred formal plans, other warned not to overcomplicate the process of developing goals through time-consuming checklists, inventories, and surveys.

Besides identifying interests and activities, another important goal of getting to know the person is to identify how much social connection that individual is seeking. Some individuals may be craving more engagement; others may prefer a less connected life; and still others may already have a lot of community connections through employment or their families.

Be intentional about grouping. One often-noted challenge is providing individualized supports when existing funding is based on group staffing ratios. Experts agreed that many service providers do manage to individualize supports despite this constraint. A parent who also had a professional background in service provision said, “The question is, can you do it with the existing funding? And some of us say you absolutely can if you’ll just think of creative ways to spend it.” One approach to individualizing group supports is to be purposeful about grouping people. Instead of grouping the same people together all week, one service provider executive explained that they try to pair individuals for specific activities based on interests:

So we have white boards around the office, where people say, “I want to learn to knit.” So we’ll put knitting up there and we’ll put the one person that wants to learn to knit. And then if someone else comes along and someone else, when we have a critical mass, we then go research that opportunity and find it in the community.

Similarly, a parent described the strategy of taking a small group of people to one location but then offering different activities. Therefore, individuals can be exploring different interests and meeting different community members while the staff are still nearby to support all of them. Such strategies are often supported by detailed schedules to ensure that each individual is appropriately matched to the people and activities that are best for them. However, schedules

must also remain fluid to account for changes in individuals' personal schedules, such as doctor's appointments or illnesses.

Using creative funding strategies. As another means to providing more individualized supports, experts identified creative ways to access, blend, and/or braid funding resources. A service provider executive described negotiating with the state agency to "set up the opportunity to take group rates and translate them into much higher hourly rates, but for less hours, for the same amount of money, and have our funding source buy into that." Other service providers used funds from their state's department of vocational rehabilitation for work-related activities while tapping into developmental disabilities agency funds for non-work supports, thus enabling both funding sources to go further. Sometimes multiple home and community-based services waivers can be tapped into, and some service providers also turn to donations, grants, or other non-government funding to enhance supports for activities that the individual wants to engage in, but that may not be covered through traditional funding streams.

Guidepost 2: Promote community membership and contribution. Essential to the vision of CLE is full community membership. Community membership and contribution require seeking out inclusive settings and activities and placing value on not just presence but membership in the community. In order to achieve this vision, day services and supports must a) start with inclusive settings and activities, and b) place value on not just presence but membership in the community

Start with inclusive settings and activities. The most basic starting point is getting out of the program building to provide day services and supports in inclusive community settings. Accessing inclusive opportunities often involves service providers partnering with other local

organizations to identify community resources and generate new community-based options. A service provider administrator summed it up by saying, “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.” Community partners can also include local parks and recreation agencies, community gardens, civic organizations, and any other organizations that have a presence in the community.

Place value on not just presence but membership in the community. While Guidepost 2 must start with inclusive settings, day services and supports must also ensure that each individual achieves full community membership, including making a contribution, forming relationships, and generally becoming a part of the fabric of the community. Service providers can help people make community connections by, as one parent described, “identifying within a family or a neighborhood or siblings the immediate networks that are available to the person and that person’s friends and support network, and then building upon that network.” Specific strategies can include identifying the individual’s existing network of community connections, meeting with the individual’s family and friends to tap in to their personal networks, facilitating relationships with people from community organizations as described above, and supporting the individual to make new social connections based on his/her interests.

Guidepost 3: Use social and human capital to decrease dependence on paid supports. As individuals make more connections in their communities, the social capital they are building can be leveraged as natural supports. Day services and supports can also be used to build individuals’ human capital by teaching specific skills. This combination of human and social capital can then be accessed to decrease individuals’ dependence on paid supports.

Therefore, day services and supports must a) use social capital to create natural supports, and b) teach skills that build human capital.

Use social capital to create natural supports. Social capital, which consists of both a person's network of relationships and the value they get from those relationships, can be built by making connections in the community (see Guidepost 2). Tapping into this social capital as a source of natural supports can then lead to a level of interdependence with others in the community that enables fading of formal, paid supports. One service provider executive described it 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, both stretching service dollars and enabling more natural and sustainable interaction and participation. For example, community members can provide rides, companionship, instrumental assistance with participating in an activity such as an exercise or art class, or be in touch with the service provider in case any problems arise.

Experts presented specific examples of individuals blending natural and paid supports as a way to engage in community activities. For example, a service provider executive described a process of deliberately fading paid supports to enable an individual to participate independently in a chess club:

He'd never really played chess before. But he's kind of got the mind for chess and he thinks that way. So we found a chess club at a local rec center, and we travel-trained him to that rec center. We went to the chess club with him for the first two to three weeks until he got acclimated and understood kind of the culture of the

chess club. And then we pulled back. We made sure, you know, who are the people at the rec center, if he doesn't show up, are [they] going to call us? And who's the person they're going to call? So it takes a lot of setting up.

This example of fading bridged both aspects of this guidepost. The agency staff built the individual's social capital by getting to know others at the chess club and recreational center and growing to rely on them as natural supports. They also facilitated the individual's independence by providing travel training and by supporting the individual to gain a sense of the culture of the club. These skills fall under the category of human capital, as described in the next paragraph.

Teach skills to build human capital. Human capital refers to the specific skills an individual has. Support staff can help individuals to build human capital by directly teaching skills, including daily living skills, community access and navigation, and more specific skills related to the activity at hand. For example, one service provider executive described how her agency will provide time-limited one-to-one supports to teach individuals new skills that will then allow them to participate in community activities with less ongoing support. This initial investment in skill-building enables more fading of supports in the longer term. Another service provider executive described how "building their independence is another thing that we work on. You know, making sure that they learn to take the buses, learn to problem solve, all those things in the community." The same organization sometimes uses peer-to-peer strategies: having a person with more mastery of a particular skill, such as riding the bus, teach someone who is still working on that skill.

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

To achieve outcomes such as life satisfaction, community membership and contribution, and

decreased dependence on paid supports, day services and supports must be oriented toward, and monitored on, those outcomes. Toward this end, day services and supports must a) emphasize goals rather than processes and b) be held to clear state and federal expectations and guidance, and c) be envisioned as either leading to or complementing employment for working-age adults.

Emphasize goals rather than processes. Experts stressed the importance of focusing on outcomes such as satisfaction, individualization, and connectedness to community, rather than on process measures such as times and locations of activities. As a state agency leader said,

you have to have real outcome-oriented requirements for each person that is evaluated. Goals can't simply be that they're going to be doing activities, but they have to be outcome-oriented in terms of the number of relationships people are building, the number of groups they're able to join, the types of skills that they're actually adding.

Suggested outcome measures included percent of time in meaningful activities, number of community connections or relationships formed, and how individualized those activities are to the person's goals and desires. Satisfaction measures, collected directly from the individual, were also described as an important tool.

Hold day services and supports to clear expectations and guidance. While being goal-oriented is the ideal, the consensus among experts was that the existing guidance from CMS and from state IDD agencies failed to set clear expectations. While CMS has stated an expectation for community-based day supports under the HCBS waivers, the specifics of what that means have not been proposed either at the federal level or by most states. As one service provider executive explained, "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." This lack of outcome-focused guidance can be particularly problematic when supports are funded and regulated as day habilitation centers. Using day habilitation as a model encourages group activities and perpetuates the mindset of fitting individuals into program slots rather than designing a set of supports matched to the individual.

Experts also emphasized the role of state agencies in creating standards and expectations to offer guidance to service providers and hold them accountable. Without such standards, providers of day services and supports lack direction, which results in limited investment. A researcher noted that "humans take the path of least resistance and, in doing that, in a system, they respond to pressure ... what's funded, what's inspected, what's required." To avoid this lack of standards, state agencies need to be proactive, thoughtful, and prepared in developing service definitions and quality measures. Experts recommended particular strategies including focusing on state agency review of individuals' schedules, using drop-in monitoring visits to ensure community access is taking place as planned, and engaging with service providers to identify challenges and modify requirements as needed.

Expect CLE to lead to or complement employment. Experts also agreed that CLE for working -age adults should not be seen as a substitute for employment, but rather as related to employment. A provider executive described CLE as being "an entry portal to work through exploring volunteer opportunities, [and/or] discovering the nature of certain kinds of demands." This role can be particularly important for those who didn't previously have a lot of exposure to the community. Day services and supports can also play an important role as a wraparound to

employment, particularly as a way for individuals who are working part-time to maintain opportunities for engagement and growth outside of their work hours.

Discussion

One critical factor emerging from this work is the need to clearly distinguish CLE as an *outcome* from the *day services and supports* that are needed to achieve that outcome. An individual can be engaged in community life without having any day services and supports; conversely, an individual can have extensive day services and supports yet still have meaningless or limited CLE as an outcome. Our findings in both areas reflect and extend the existing literature and national policy priorities.

Defining a High-Quality Outcome

The vision of the ideal CLE outcome, as described by our experts, is that the individual participates in activities related to their interests and goals, with supports tailored to their needs. It involves inclusion in the community as a full and contributing member and it leads to and supports longer-term goals and age-appropriate roles, including employment. This vision clearly reflects values identified in our literature review, including pursuit of individual interests (Walker, 2007), making social connections in the community (Amado, 2013; Balandin, Llewellyn, Dew, Ballin, & Schneider, 2006; Miller et al., 2002; Walker, 2007), being a contributor (Brown, Consedine, & Magai, 2005; Timmons & Zalewska, 2012), and being purposeful in activities with same aged peers (Rossetti, Lehr, Lederer, Pelerin, & Huang; 2015). Finally, it is consistent with the intent articulated in CMS's requirement that HCBS services facilitate full access to the community (CMS, 2014) and in DOJ's settlement agreements

indicating that the *Olmstead* precedent applies to day and employment services and supports (Lane et al., v. Brown et al., 2015; United States of America v. State of Rhode Island, 2014).

Defining High-Quality Day Services and Supports

The four guideposts presented here provide a clear road map for quality day services and supports that lead to CLE, one that has continued to hold up through ongoing development and testing. Since these interviews were conducted, the four guideposts for CLE have been validated through case study research on three exemplary providers of day services and supports that lead to CLE (Curren, Hall, & Timmons, 2017; Curren, Lyons, & Timmons, 2017; Tanabe, Sulewski, & Timmons, 2017; Tanabe, Timmons, & Sulewski, 2017). They have also served as the framework for a CLE toolkit for service providers (Sulewski et al., 2016), which has been pilot-tested with seven service providers in two states. Each of these efforts has continued to reflect and reinforce the utility of the four guideposts.

The guideposts also demonstrate consistency with existing research and policy. Guidepost 1, Individualizing supports for each person, emphasizes person-centered planning, reinforcing CMS's requirement that HCBS "settings options are identified and documented in the person-centered plan and are based on the individual's needs [and] preferences" (CMS, n.d., p. 4). Experts had a number of specific recommendations of how to enhance individualization during the provision of day services and supports, taking steps toward addressing an overreliance on group activities that was noted in earlier case studies of day services and supports (Sulewski, 2010).

Essential to Guidepost 2, promoting community membership and contribution, is accessing inclusive settings and activities, which is consistent with CMS' requirement that

HCBS “supports full access of individuals receiving Medicaid HCBS to the greater community... to the same degree of access as individuals not receiving Medicaid HCBS” (CMS, 2014, p. 249). Strategies focus on increased integration and foster connections with community members, particularly through volunteering and involvement in community groups, which are outcomes frequently identified as a defining element of CLE (Verdonschot, Witte, Reichrath, Buntinx, & Curfs; 2009; Sulewski, 2010; Walker, 2007).

Guidepost 3, using social and human capital to decrease dependence on paid supports, builds natural supports and personal skills for increased independence. This guidepost clearly reflects CMS’s vision that HCBS optimizes individual initiative, autonomy, and independence (HCBS Advocacy Coalition, 2015). Previous literature also emphasizes skill development as both a key outcome for CLE and a bridge to employment (Held & Granholm, 2007; Hirst, 2001; Lindsay, 2016; Makharadze, Kitiashvili, & Bricout, 2010; Timmons & Zalewska, 2012).

Guidepost 4, ensuring that supports are outcome-oriented and regularly monitored, is essential to both achievement and documentation of CLE outcomes that result from day services and supports. Guidepost 4’s emphasis on goals over processes, and on holding day services and supports to clear expectations and guidance, relates to essential changes in service provider and state roles (Rogan & Rinne, 2011; National Quality Forum, 2016; Sulewski & Timmons, 2015). Furthermore, Guidepost 4’s expectation that CLE will lead to or complement employment is particularly important in bridging CMS’ requirements that HCBS provide opportunities for both (HCBS Advocacy Coalition, 2015). This expectation also indicates the place of CLE within the context of the Employment First movement (Hall et al., 2018; Nord et al., 2015), which has as its goal increasing competitive integrated employment of people with IDD. As that movement has grown, it has become clear that even when individuals with IDD are employed, many will

inevitably face gaps in employment (Ross, 2017), or will work only limited hours (Hiersteiner, Bershadsky, Bonardi, & Butterworth, 2016), requiring additional day services and supports to fill the gaps. Consequently, state IDD agencies (Sulewski & Timmons, 2018) and service providers (Kamau & Timmons, 2018) are seeking holistic models of systems transformation that address a whole life vision including both employment and CLE.

Directions for Further Work

While the relevance of the four guideposts remains clear, there is still a lot of work to be done to bring this guidance to fruition. Further development is needed to facilitate progress in the field, including the following recommendations: a) develop fidelity and outcome measures, b) build a holistic model of CLE and integrated employment, c) involve individuals and families in research and knowledge translation, and d) guide state agencies on how to define, track, and monitor CLE.

Develop fidelity and outcome measures. Previous research has revealed that day services and supports are a broadly defined category and both standards and outcomes vary greatly (Clement & Bigby, 2009; Sulewski, Butterworth, & Gilmore, 2008; Sulewski, 2010). There are existing scales measuring the outcomes of services designed to increase community integration (Baker, 2000; Bruns, Burchard, Suter, & Leverentz-Brad, 2004; Hacking & Bates, 2008; Stewart et al., 2010), and others that evaluate service quality (Bond, Becker, Drake, & Vogler, 1997; ECHO, 2016; SAMHSA, 2008), but there is no one tool that the field has agreed upon that provides a valid measurement for CLE or for related day services and supports (Lyons & Hall, 2015). These limitations point to a clear need for development of valid and reliable

measures for CLE, including both measures of fidelity to the CLE guideposts for service providers and measures of CLE outcomes for individuals with IDD.

Build a holistic model of CLE and integrated employment. Over the past 15 years, the concept of Employment First has emerged as guiding philosophy and policy among state IDD agencies, increasingly setting the standard “that employment should be the very first option offered to any adult with a disability, before any kind of nonemployment option” (Kiernan, Hoff, Freeze, & Mank, 2011, p. 300). As Employment First has taken hold, however, there is a growing realization that employment and other forms of CLE go hand-in-hand (Lyons, Timmons, Hall, & LeBlois, 2018; Murphy, Easterbrook, Bendetson, & Lieberman, 2014; State Employment Leadership Network [SELN], 2017; SELN, 2016). To create a community-based, person-centered set of supports requires looking across previously siloed service types. Future research should explore the intersection between the four guideposts for CLE described here and other employment-focused models, such as the seven elements of higher-performing states in integrated employment (Hall, Butterworth, Winsor, Gilmore, & Metzel, 2007) and the ten characteristics for organizational transformation (Lyons et al., 2018).

Include individuals and families in research and knowledge translation. Family engagement is a key component in building a vision for an individual with IDD’s full and meaningful life. Yet families frequently experience low expectations for the future (Almutairi, 2016; Blustein, Carter, & McMillan, 2016) and often are considered the stakeholder group most resistant to the move away from segregated settings (West, Revell, & Wehman, 1998). Intentional engagement of families in research and systems change activities can ensure that their needs and concerns are taken into consideration.

Guide state agencies on how to define, track, and monitor day services and supports. The federal pressure on states to deliver high-quality and clearly defined day services and supports and the concurrent growth of day services and supports as a service category have created a pressing need for guidance to state agencies on how to better promote CLE. With a deadline of 2022 for all Medicaid HCBS waivers to be in compliance with the new settings rule (CMS, 2017), the need for guidance is substantial and immediate. Meeting this deadline will require a strong focus on increasing integrated employment and CLE supports, a transition that can be facilitated by research-based capacity-building tools and resources that allow for greater standardization of supports and more clearly defined methods of implementation. While the guideposts provide a basic framework, state IDD agencies have indicated a need for further guidance on developing quality assurance systems to balance accountability with the types of risk involved in community-based supports; creating funding mechanisms that encourage the combination of CLE and integrated employment in an individualized life; and engaging communities to be more inclusive and supportive (Sulewski & Timmons, 2018).

Limitations

While valuable as a starting framework for thinking about CLE, this study was exploratory in nature. As such, it involved interviewing a small, hand-selected group of people. While this approach is appropriate for a little-studied topic such as CLE and related day services and supports, it also limits the generalizability of the findings. An additional limitation is that the interviews were conducted in early 2015, so the data are over three years old. As described above, however, ongoing research and development activities since the original set of interviews have continued to reinforce the guideposts.

Conclusions

Without a guiding model of CLE, day services and supports that lead to CLE are challenging to measure, the development of core competencies for direct support professionals is challenging, the development of specific guidance and supports from states is perplexing, and individuals remain in less than satisfactory services and settings. This study analyzed data from expert interviews, producing themes that defined both desired CLE outcomes and the essential “guideposts” for delivering high quality day services and supports. The four guideposts presented in this paper serve as indicators for states and service providers seeking to better define, improve, and increase the delivery of effective and meaningful CLE.

Table 1

Key Definitions

Term	Definition
Day services and supports	Services and supports provided to people with IDD during the day, outside of employment services. These services and supports may take place in a facility (facility-based non-work) or in the community (community-based non-work). They have many different names, including day habilitation, day programming, community-based day services, wraparound supports, holistic supports, and community integration services. They vary from state to state, but are generally funded under a Medicaid home and community-based services (HCBS) waiver and administered by a state IDD agency.
Community life engagement (CLE)	Access to and participation in the community 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, including faith-based activities such as membership at a church or synagogue (Sulewski & Timmons, 2015). Ideally a key outcome of day services and supports, as identified by Center for Medicare and Medicaid Services [CMS]

regulations (CMS, 2014a). For the purposes of this work, CLE is defined as distinct from competitive integrated employment, which is generally viewed as a separate service type and outcome.

Service providers Local organizations that provide day services and supports to people with IDD, primarily with funding from state IDD and vocational rehabilitation agencies. ICI survey research indicates that over 3,000 service providers nationwide provide day services and supports (Domin & Butterworth, 2013).

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