

Community Life Engagement: Data Sources, Definitions, and Measurement

By Oliver Lyons & Allison Hall

ISSUE NO. 2

Introduction

As state and federal policy makers and Community Service Providers work to refine the concept of Community Life Engagement, they are able to draw upon multiple, public, national data sources.

These include:

- » Institute for Community Inclusion (ICI)'s National Survey on Day and Employment Outcomes. www.statedata.info
- » National Core Indicators (NCI). www.nationalcoreindicators.org
- » ICI's National Survey of Community Rehabilitation Providers. www.communityinclusion.org/article.php?article_id=336

This brief provides an introduction to these data sources. It examines emerging Community Life Engagement trends shown in each source, as well as the implications for developing a better understanding of Community Life Engagement based on how it is currently being classified and measured.

This brief is the second in a series on Community Life Engagement. For a detailed introduction, access our first brief: www.thinkwork.org/sites/thinkwork.org/files/files/CLE_issue1.pdf

Data sources and key findings

This section reviews each of the three data sources, and presents findings related to Community Life Engagement supports and outcomes.

DATA SOURCE #1:

ICI's National Survey on Day and Employment Outcomes

ICI's National Survey on Day and Employment Outcomes is part of a longitudinal study commissioned by the Administration on Intellectual and Developmental Disabilities to analyze day and employment service trends. The survey is conducted annually by ICI as part of the Access to Integrated Employment project www.thinkwork.org/content/access-integrated-employment/

The survey categorizes day and employment supports into four quadrants, based on whether they are work or non-work and community- or facility-based. States report based on the service a person participates in, and not their actual activity during the day.

The data primarily come from state billing records, and states' definition and implementation of service categories vary. For the purposes of this brief, we consider Community-Based Non-Work (CBNW) services the closest equivalent to Community Life Engagement activities, as they both describe community-based service categories where the participant does not engage in paid work. For FY2013, data was available for 45 states.

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.

Key finding:

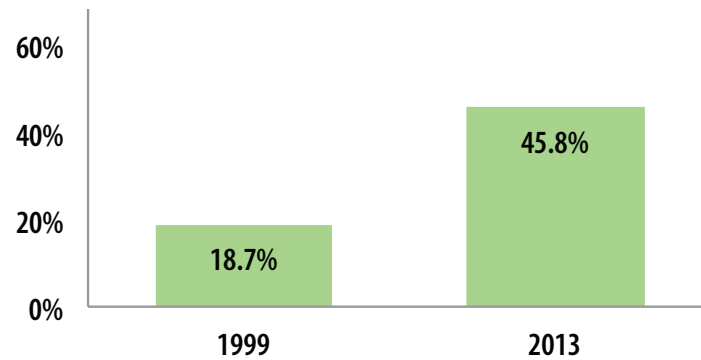
Community-Based Non-Work (CBNW) services are increasing, but there is a lack of clarity about how states define the service category.

In the National Survey on Day and Employment Outcomes, the category of CBNW refers to programs where individuals engage in recreational, skill training, or volunteer activities in settings where most people do not have disabilities. These activities may typically be referred to as community integration and/or community participation services.

The number of states reporting the provision of CBNW has grown from 18 in FY1996 to 30 in FY2013. Nationally, reported participation in CBNW has grown steadily for states that report it as a service, from 18.7% (n=29) in FY1999 to 45.8% (n=29) in FY2013 (Butterworth et al., 2015) (Figure 1).

While some states report service requirements for how much time CBNW participants spend in the community, it is possible that in some cases states have reclassified services from facility-based to community-based as the emphasis on community participation grows, with substantial time still spent in facility-based settings. The trend toward CBNW services also raises concerns about the clarity of the service system's goals for community employment (Butterworth et al., 2015).

FIGURE 1: PARTICIPATION IN COMMUNITY-BASED NON-WORK SERVICES



Source: ICI's National Survey on Day and Employment Outcomes

DATA SOURCE #2:

ICI's National Survey of Community Rehabilitation Providers

ICI's National Survey of Community Rehabilitation Providers (CRPs), funded by the Administration on Developmental Disabilities and the National Institute for Disability and Rehabilitation Research, offers findings on individuals with all disabilities who are served in employment and non-work settings by community rehabilitation providers (CRPs). This survey provides a longitudinal description of CRPs by collecting data on agency characteristics and employment outcomes.

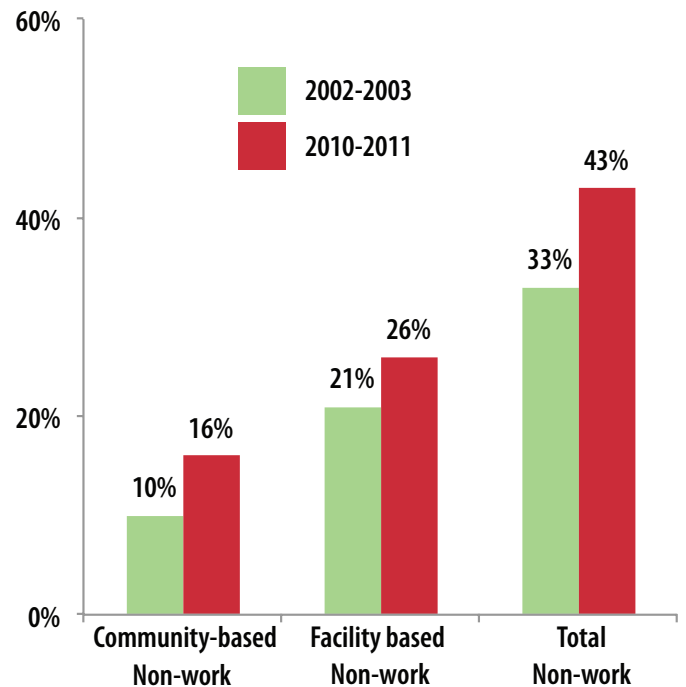
The CRP survey defines CBNW as services where people with disabilities spend the majority of their day in the community, in places where most people do not have disabilities. The primary focus may include general community activities, volunteer experiences, recreation and leisure, improving psychosocial skills, or engaging in activities of daily living. As in the National Survey on Day and Employment Outcomes, respondents are reporting on the service category in which an individual participates.

Key finding:

While facility-based non-work continues to be the dominant non-work service reported for individuals, CBNW services showed the greatest reported increase.

As Figure 2 shows, there was significant growth in all non-work participation for people with IDD between 2002–2003 and 2010–2011 (33% to 43%). Facility-based non-work remains the most common type of non-work (26%) compared to CBNW (16%) for individuals with IDD. However, participation in CBNW services showed the greatest reported increase in that time.

FIGURE 2: NON-WORK PARTICIPATION FOR PEOPLE WITH IDD



Source: ICI's National Survey of Community Rehabilitation Providers

DATA SOURCE #3:

National Core Indicators

National Core Indicators (NCI) is a collaborative effort between the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI). The purpose of the project, which began in 1997, is to support NASDDDS member agencies to gather a standard set of performance and outcome measures to track their own performance over time, to compare results across states, and to establish national benchmarks. Thirty-nine states are planning to contribute data in 2015.

NCI reports data on several individual indicators, including Health, Wellness, Safety, Service Coordination, Work, and Community Inclusion. The survey captures Community Life Engagement data in two domains: 1) the Work domain; and the 2) Community Inclusion domain.

The Work domain includes questions about whether an individual participated in a paid job in a community-based setting, an unpaid activity in a community-based setting, a paid job in a facility-based setting, or an unpaid activity in a facility-based setting during the most recent typical two-week period. The Community Inclusion domain includes questions about whether individuals have engaged in community activities over the past month, and if so, how often. These activities include going out for entertainment, exercise, errands, religious services, shopping, and vacations.

Key findings:

One quarter of individuals report participation in daily, unpaid community activities, but there is limited information on how that translates to quality Community Life Engagement.

NCI's Work indicator data shows that in 2013–2014, 25% of respondents reported participating in a daily unpaid activity in a community-based setting (Figure 3). Seventy-two percent of this sub-group received supports or public funds to participate in these activities. Over half of the individuals (59%) reported participating primarily as part of a group of people with disabilities.

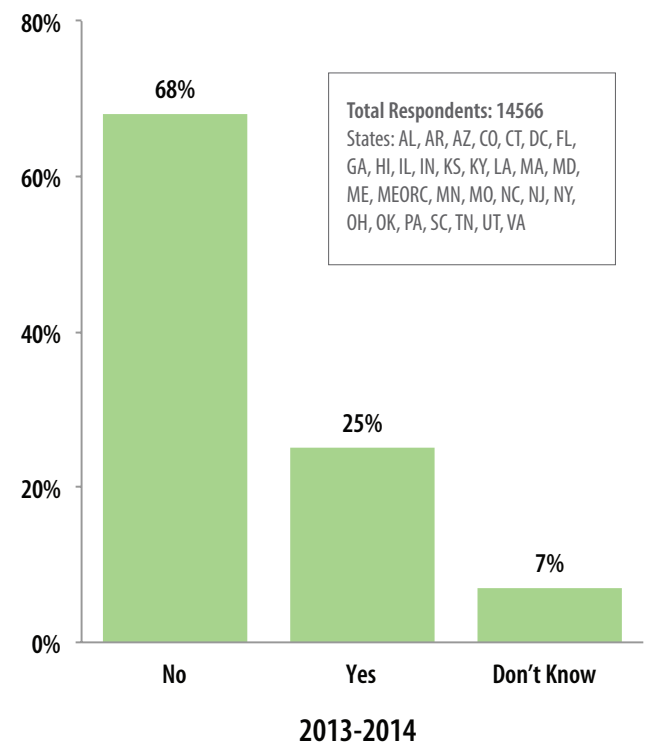
NCI's community inclusion data suggests that individuals are participating in a wide range of community activities, but to what extent the individual is fully engaged in their community during the activity is less fully explored.

Considerations for using these data towards a better understanding of Community Life Engagement

This brief offers an introduction to the three main sources of data on Community Life Engagements for individuals with IDD. Both the National Survey on Day and Employment Outcomes and the National Survey of Community Rehabilitation Providers suggest a growing emphasis on Community Life Engagement services. National Core Indicator data emphasize outcomes over services, and provide a window into where people are spending time and how much of that time is in integrated settings. Yet there is limited information from any of these sources on how time in the community is being used, and the extent to which the person is fully engaged and integrated in activities of their choosing.

It is worth noting that the CRP survey indicates a considerably lower rate of participation in Community-Based Non-Work (16%) than does the survey of state agencies (46%). The NCI figure (25%) falls in between the two.

FIGURE 3: PERCENTAGE OF RESPONDENTS PARTICIPATING IN A DAILY UNPAID ACTIVITY IN A COMMUNITY-BASED SETTING



Source: National Core Indicator Survey

CRPs are more likely to know which individuals actually spend their time in community settings, versus those who are simply placed in that service category; likewise, the NCI data may be more directly reflective of what individuals are actually doing with their day.

This disparity raises concerns about how state agencies are defining and categorizing services, suggesting that some individuals in the CBNW category may not be spending the majority of their time in community settings. There is a limited amount of data on the structure, activities, and outcomes of this service, and states have not established clear service expectations or quality-assurance strategies (Sulewski, Butterworth, & Gilmore, 2008; Sulewski, 2010).

Examining the data presented in this brief is a step towards a better understanding of Community Life Engagement strategies. Despite some differences, each data source indicates that Community Life Engagement supports are rapidly expanding to meet the increasing demands. Moreover, the differences between the data sources indicate the limitations of our current understanding of Community Life Engagement supports and where there is need for more clarity.

What's next?

This brief is only an introduction to these data sources and their key findings, offering considerations for those in the field working towards improving Community Life Engagement. ICI is in the midst of a three-year initiative to conduct further research on this topic and to develop guidance for states and service providers. Major activities will include expert interviews, case studies, identification of promising practices, a survey of state agencies, and development of guideposts and toolkits for states and service providers on how to design, conduct, regulate, and measure quality Community Life Engagement. Subsequent briefs in this series will provide findings and insights as they emerge from these activities.

This brief is a product of Explore Community Life Engagement at the Institute for Community Inclusion, UMass Boston. Funding is provided in part by The Administration on Intellectual and Developmental Disabilities, Administration for Community Living, U.S. Department of Health and Human Services, under cooperative agreement #90DN0216, the National Institute on Disability, Independent Living, and Rehabilitation Research under grant # 90IFRE0025, and by the Access to Integrated Employment Project, a project of ThinkWork! at the Institute for Community Inclusion at UMass Boston.

Suggested Citation

Lyons, O., & Hall, A. (2015). Community Life Engagement: Data Sources, Definitions, and Measurement. Engage, Issue #2. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.

For more information on this research brief, please contact:

Jaimie Timmons | Jaimie.Timmons@umb.edu

Principal Investigator: Jennifer Sullivan Sulewski, PhD



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.

For more information on Explore Community Life Engagement, please contact:

Staci Jones | Staci.Jones@umb.edu

www.communityinclusion.org/cle

**Despite some differences,
each data source indicates that
Community Life Engagement
supports are rapidly expanding to
meet the increasing demands.**