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Research Progress Report

Peer Support in Centers for Independent Living: What Do We Know?

Peer support is ubiquitous. It is defined as a helping relationship between an individual who has experience living under certain conditions assisting another person to cope with and adapt to similar circumstances. It has been gaining in popularity and use since its early adoption in Alcoholics Anonymous (AA), and has been used widely, and with good effect, with people experiencing a variety of both physical and mental health conditions.

Peer support, also known as peer counseling, is one of the four core services that Independent Living Centers receiving funding from Part B, Title VII of the Rehabilitation Act of 1978 are mandated to provide. These services help a person with a disability move from the patient role to the consumer role, empowered to make independent choices (DeJong, 1979). Additionally, peer support assists people with similar disabilities to cope and adjust following the onset or exacerbation of a disability. Even more, peers often have intimate knowledge of community resources to reduce environmental barriers to independent living, which are essential to the Independent Living (IL) philosophy of consumer choice and control.

Due in large part to the stress of living with a disability (i.e., lack of accessibility or accommodations), people with disabilities may experience mental health conditions such as depression and anxiety. Unfortunately, the mental health system in the US has struggled to meet the needs of people with psychiatric disabilities and is largely ill-prepared and underfunded to address the mental health needs of individuals with other disabilities. This is due in part to the “silo-style funding” we have for disabilities—a silo for persons with psychiatric disabilities, another for persons with developmental disabilities, another for physical, sensory, etc. Until policies are changed to create a system that provides for peoples’ functional needs rather than diagnosis or disability label, there will continue to be large gaps in the constellation of supports for persons with any kind of

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disability, especially those with multiple disabilities. Therefore, the mental health of people with mobility and sensory impairments is an area that clearly needs more effective interventions. One such intervention to consider is the implementation of targeted peer support through Centers for Independent Living (CILs).



Although a body of literature on peer support for persons with psychiatric disabilities exists, not much is written about peer support in independent living, and very little is written about IL and persons with mental health conditions (Shreve, 1990; Deegan, 1992; Solomon, 2004). In a recent literature review, no articles were identified that examine the effectiveness of peer support provided in CILs (Ravesloot, Thorsen & Liston, 2011).

In response to the need for more mental health care options for people with disabilities, the Research and Training Center on Disability in Rural Communities (RTC:Rural) is developing and testing a peer training program for peers to

increase their capacity to support people who experience mental health conditions secondary to their mobility and sensory impairments. We believe this is a tool that CILs, mental health organizations, and others can replicate to better meet the needs of many rural consumers. Because the professional literature contains little empirical work to guide intervention development, we conducted this survey study about CIL peer services and training. Specifically, the purpose of this study was to examine the degree to which CILs implement peer services and use a formal training program in their peer support programs.

Methods

We sent a survey with seven questions to the home offices of all Centers for Independent Living (not including satellite offices). The survey was printed on a bi-fold post card that was self-addressed and stamped for ease of return to RTC:Rural. Following the initial mailing, a second mailing was sent approximately one month later. We received a total of 148 responses from the 380 Centers for a 39% response rate.

The questions in the survey included peer support modality (i.e., one-on-one or group), frequency of group activities (i.e., weekly, monthly, quarterly, yearly), reimbursement of peer providers (i.e., paid staff, stipend volunteers, unpaid volunteers), and whether or not the CIL uses a peer training curriculum and if so, which curriculum it uses.

Findings

Overall, the majority of CILs indicated they provide peer support services at least monthly. Approximately two-thirds of the CILs (96) maintain a list of peers for one-on-one peer support. Also common are peer group activities, with 23% (34) of the CILs indicating they provide services weekly, 37% (55) monthly, 11% (16) quarterly, and 6% (9) annually. Consistent with previous research

(Shreve, 1990; Solomon, 2004), 23% (34) of the CILs pay staff to provide peer support, 12% (18) offer volunteers a stipend, and 53% (79) reimburse volunteers for cost outlays.

There also appears to be a tendency to use group activities more than one-on-one peer support. While 65% provide one-on-one peer support, 90% provide group support. Respondents indicated weekly or monthly “group activities” comprise about 60% of the group peer services delivered. Previous studies have noted that CILs often preferred to have people start in groups and then move to one-on-one peer relationships (Shreve, 1990). This may be consistent with current practice(s) reflected in the survey used in this research.

One of the key findings of this study was that less than half of respondents use a curriculum for training peers. Of those that use a manual, most do not use their own, but use a curriculum developed by others. Some of the more prevalent curriculums cited were by Summit ILC, (Missoula, MT); Arizona Bridge to IL, (Phoenix, AZ); Tennessee Mental Health Consumer Association, (Nashville, TN); Access Living, (Chicago, IL); and RTC:Rural, Living Well with a Disability, (Missoula, MT).

Discussion & Recommendations

We surveyed CILs to determine the state of peer services and peer training. Responses indicated that over 90% of CILs provide some type of peer support service, which is consistent with it being a core service defined in the Rehabilitation Act of 1973¹. While encouraging, these results also suggest that many CILs provide peer support services without training peer providers. Alternatively, the survey may underestimate the rate of training. Peer providers who are paid staff may have gone through orientation and training for their position, which could include information and/or training about peer support. Even so, some volunteer peers may provide support with no training, which could put peers in a tenuous situation with much responsibility but without clear, consistent direction from the CIL. Not only can this put the CIL in a position of potential liability, but it can be a recipe for causing unintended harm to the person seeking support.



Consistent with previous evaluations of centers and their peer programs, CILs report substantial diversity in who provides the peer counseling/mentoring service. In the present study, a range of peers exists, from volunteers with no training to well-trained staff. Previous research noted that some CILs have professional counselors with disabilities who provide peer counseling. The CILs that have used staff as peer counselors, however, may have considered any interaction between staff and consumer as a “peer relationship” (Shreve, 1990).

While many peer support programs may not be well developed, they have the potential to provide a much needed service. To a large extent, interventions and services have been developed for specific disability groups (i.e., consumers with psychiatric impairments and consumers with physical

¹ Online at <http://www.dotcr.ost.dot.gov/documents/ycr/REHABACT.HTM>

impairments). Because the funding for these services and supports has been based on diagnosis rather than function, there is little or no cross-over from one disability to another. This leads to “falling through the cracks,” where someone needs and deserves a service but does not qualify due to “diagnosis.” Cross-impairment approach peer support provided through CILs can help “to fill” these cracks.

Our review suggests a need for more research in this area to better understand the role of peer support in CILs, the efficacy of peer support, and whether there is best practice(s) in providing peer support. Evidence for the efficacy of CIL peer support may lead to increased use by CILs and could become a “reimbursable service” provided for other agencies that serve persons with disabilities (i.e., vocational rehabilitation, workers’ compensation, mental health agencies, private insurance, etc.).

As researchers examine the effectiveness of services provided by CILs, the value and reputation of these services are likely to increase and may be adopted by others (e.g., aging services). As this occurs, it is imperative that the principles laid down by the pioneers of IL are not lost in this process—this is a consumer run movement.

Next Steps

The RTC:Rural, in partnership with Boston University’s Center for Psychiatric Rehabilitation and three CILs, is developing, piloting, and implementing a training program to prepare peers to work with people who have mental health conditions secondary to mobility and sensory impairments. The training includes basic information about IL history, issues related to being a peer, using one’s personal experiences in peer support, grief and loss support, communication skills, advocacy skills, common mental health conditions,

treatment practices, community resources, and crisis issues. It is not intended to turn peers into mental health counselors but to help them understand common mental health conditions such as depression and anxiety, to make referrals to mental health providers as appropriate, and to provide support as individuals learn to address mental health conditions. Once trained, the peers will meet one-on-one with individuals from the community who self-identify as someone with a disability who desires peer support for living with and recovering from mental health symptoms. Program outcomes on IL and mental health measures will be reported in another research project report.

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