Research Plan for Examining Centers for Independent Living (CILs) Outcomes

Past and Present Research and Areas for Future Exploration and Collaboration

ICDR

INTERAGENCY COMMITTEE ON
DISABILITY RESEARCH

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About CILs

The movement for independent living services in the United States began with deinstitutionalization in the 1960s, when many individuals who had long-term disabilities were discharged from institutions (National Council on Independent Living (NCIL), 2020). Two early activists were Ed Roberts and July Heumann. They helped form the first Center for Independent Living (CIL) in 1972 in Berkeley, California, leading many other CILs to develop around the country shortly thereafter through local funding (CESSI, 2003). In 1978, in Section 702 of the revised Rehabilitation Act of 1973, the federal government funded increases in CIL development to provide services to people with all types of disabilities (Innes et al., 2000). In Section 702, CILs are defined as "consumer-controlled, community-based, cross-disability, nonresidential private nonprofit agencies that are designed and operated within a local community by individuals with disabilities and provides an array of independent living services" (Independent Living Research Utilization (ILRU), 2020a). Currently there are 403 CILs throughout the country, along with 56 Statewide Independent Living Councils (SILCs), which work with CILs across their state to develop a Statewide Plan for Independent Living (NCIL, 2020). At least 51% of staff at CILs and at least 51% of the board members must be persons with disabilities (ILRU, 2020a).

Interagency Committee on Disability Research and CILs

As part of the Interagency Committee on Disability Research's (ICDR) Strategic Plan for 2018–2021, the ICDR Community Participation and Integration Workgroup identified that the impact of CIL service types and delivery methods need to be studied further (ICDR, 2018). This workgroup suggested that a research plan be developed to focus on CIL service delivery and outcomes in order to identify and share effective practices. The ICDR emphasizes the importance of CILs optimizing and expanding their services, as they are key local providers for their consumers (ICDR, 2018). New Editions Consulting, Inc. was contracted to develop this research plan, which starts by describing CIL services and recent relevant legislation. Then, past research is discussed by time period and topic area, and current research and best practices are examined by topic area. Lastly, this research plan discusses considerations for future studies, to include possible topic areas, interagency collaboration and goals, and promising practices related to study design. This research plan is designed to examine past research on CIL services and outcomes and to identify topic areas and research design elements that can help move forward our understanding of CIL impacts on consumers.

CIL Key Services

CILs offer a wide range of services for people with all types of disabilities; however, the services they offer and how they operate vary based on the needs of the specific region they are located in. A defining feature of all CILs is involvement of people with disabilities in all aspects of their services and operations (O'Day, 2006). The main services provided by all CILs include: information and referral services, training on independent living skills, individual and systems advocacy, peer counseling, housing transition assistance, assistance avoiding institutional placement, and transition for youth after finishing secondary education (ILRU, 2020a). Additional services CILs commonly offer include: personal assistance services, home modification and accessibility services, assistance with income benefits and health insurance, and assistance with finding and maintaining employment (O'Day, 2006).

The Workforce Innovation and Opportunity Act and CILs

The Workforce Innovation and Opportunity Act (WIOA), passed in 2014, moved CILs from the Rehabilitation Services Administration in the U.S. Department of Education (ED) to the Administration for Community Living (ACL) in the U.S. Department of Health and Human Services. WIOA created additional guidelines for CILs, requiring them to assist individuals with disabilities at risk of being institutionalized with remaining in the community and to help youth with disabilities successfully transition from secondary education into adult life (ACL, 2016). Guidelines for SILCs are outlined in WIOA, including the specific elements that all Statewide Plans for Independent Living should include. These elements are "staff/personnel, operating expenses, council compensation and expenses, meeting expenses, including public hearing expenses, such as meeting space, alternate formats, interpreters, and other accommodations, resources to attend and/or secure training for staff and council members, and other costs as appropriate" (ACL, 2016). WIOA clarifies that SILCs are separate from other state agencies and provides SILCs with the authority to assist CILs with resource and training development and to support the services offered by the CILs in their state (ACL, 2016).

CIL Research — Focus on Services and Outcomes

Initiating research on CIL services and outcomes for people with disabilities is important to bring best practices to all CILs across the U.S. CILs serve a vital role for people with all types of disabilities and are essential for linking individuals with services in their community for employment, housing, self-advocacy, peer-led support groups, mental health services, and a variety of other services.

The following are some success stories from CIL users across the United States:

CIL Consumer Success Stories

> *"An 18-year-old high school student with learning disabilities and Attention Deficit Disorder enrolled in BCIL's Transition Internship Program (TIP), landing a paying job with a state agency for the summer. She was charged with expanding the agency's social media presence and doubled the number of Twitter followers. She's now attending her first year of college at Mt. Ida."*
>
> — Boston CIL

> *"Consumer was told that her SSI was being discontinued and she was afraid she would lose medical coverage since she was under her mom's policy as a disabled adult child. Met with her and assisted with SSI appeal as well as Medicaid application as a backup insurance plan. She won the appeal and her SSI was reinstated, and she also enrolled in Medicare for additional medical coverage."*
>
> — AIM-CIL (Illinois)

> *"A consumer requested assistance regarding employment, he had not worked for several months due to a foot injury. He attended LEAPS (Locating Employment Avenues though Peer Support) classes regularly and provided great support and enthusiasm to fellow consumers. LEAPS participants were encouraged to take part in the MENA (Metro Employment Network Association) Job Fair and through connections made there he learned about and applied for a driving job at New Connections Pathway Career Services in Jonesboro. The hiring manager contacted the Independent Living Specialist to be a reference for him. He was offered the position, and he says he loves it so far and is working hard to make a good first impression."*
>
> — disABILITY LINK (Georgia)

In order to quantify these outcomes to ensure other individuals with disabilities can have similar positive outcomes, more research must be conducted. Most research on CILs has been funded through the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). However, future research should bring federal agencies together to collaborate on these issues. Past research, current research, and current best practices in CILs are examined in this research plan to help determine where the future of research on CILs should go and how it can be most effective.

Previous Research on CIL Management and Effective Practices

Access to CILs

NIDILRR funded several studies related to access to CILs throughout the 1990s. One of the first major access issues identified for CIL users in 1992 was that rural areas had reduced access to CILs (Seekins et al., 1992). This disparity in access was determined to be the result of decreased funding, as many rural CILs operated off of state or local funds instead of federal funding. Additionally, a 1998 study estimated that 40% of counties in the U.S., most of which were rural, did not have access to a CIL (Seekins et al., 1998). In order to achieve access to CILs for all people with disabilities, this study estimated that $71.2 million would be needed to increase access. Moreover, a 1999 study confirmed that around 40% of people with disabilities in the country did not have access to a CIL in their county (Seekins et al., 1999). And another study shortly after showed that rural counties are more likely to be unserved and individuals in rural areas are less likely to be served than individuals in urban areas (Innes et al., 2000). In addition, less than 1% of eligible individuals for CILs were found to be receiving direct services. Since these studies were published, the U.S. has seen growth in the number of CILs, funding for CILs, and direct services delivered to individuals. In addition to CIL access, management operations and services have also been explored in past research.

CIL Operations and Service Delivery

COMPREHENSIVE EVALUATIONS OF CIL MANAGEMENT AND SERVICE DELIVERY

1980s–1999

At the start of the 1980s, research began to be conducted to determine best practices across CILs in an attempt to standardize service delivery. In 1982, the ILRU project put together guidelines for how to operate an independent living program, encouraging new programs to engage in systematic planning (Nosek & Smith, 1982). The goal was to spread knowledge among CILs regarding best and effective practices from all over the country.

The first major comprehensive evaluation of the CILs was conducted in 1986 by Berkley Planning Associates (CESSI, 2003). This evaluation found that CILs were successful at assisting consumers with disabilities with maintaining or improving independent living. Recommendations focused on the need to have increased technical assistance, exchange of information between centers, increased funding, and standardization of definitions and measures when collecting information about services and consumers. In 1998, a study of independent living programs run by the Rehabilitation Services Administration (in ED) was conducted by the Research Triangle Institute (CESSI, 2003). This study examined the relationship among three independent living programs, how these independent living programs measured program outcomes, and changes that might be needed in regulations and statutes to address barriers to service delivery.

2000–2010

During this time frame, several more comprehensive examinations of CIL service delivery were conducted. In 2003 the Rehabilitation Services Administration funded a study to inform CILs of effective services and advocacy strategies and to provide CILs with clear recommendations for how to improve services (CESSI, 2003). Elements of CILs examined included: systems advocacy, consumer satisfaction,

consumer change resulting from independent living services, center operations, relationships with other agencies, and evaluation and monitoring. This evaluation identified that a panel of experts that met three times to consult about elements of the study's design was essential to achieving their results. The major recommendations of this study were to increase funding for training and technical assistance, to conduct an in-depth study of SILCs to ensure they are achieving their objective, to ensure the Rehabilitation Services Administration changes their report to address the needs identified in this study, to specify changes CILs should make, and to conduct a study of CILs in rural areas to see if their number has increased.

Another study examined 246 practices of CIL management through surveying a sample of CIL stakeholders across the U.S. (Stone et al., 2007). The nine categories of management practices examined were: administrative operations management, community relations management, consumer involvement management, fiscal management, governance management, human resources management, organizational culture management, physical plant, and programs and services management. The study used four main categories for each management practice: (1) expected practices (essential), (2) revealed practices (seen as important to examine and improve), (3) exciting practices (would be "nice to have," which may not have been considered feasible before), and (4) "no difference" practices that CILs are aware of but do not think are relevant. Applying the knowledge from this study allows CILs to guide their service planning and identify areas in which they might need further training. Further research should examine if practice preferences differ by demographics, size, or types of communities across CILs.

Another major study of CIL service delivery occurred in 2010. The Research and Training Center (RTC) on Measurement and Interdependence in Community Living at the University of Kansas conducted research to examine various methods of CIL service delivery and consumer satisfaction (White et al., 2010a). This study found that the independent living philosophy was emphasized among a majority of

participants. Additionally, participants determined that how CIL services are delivered to people with disabilities is just as important as what services are offered. They determined that the following 10 services were most important:

1. Empowering consumers to make their own choices;

2. Advising on benefits such as Medicaid, Medicare, Social Security, etc.;

3. Encouraging consumers to participate in self-advocacy;

4. Working to advocate for rights of people with disabilities;

5. Partnering with other local agencies to fulfill consumer's needs (transportation, housing, etc.);

6. Assisting with community integration through peer support and independent living skills training;

7. Connecting people with disabilities to personal assistance services needed;

8. Remaining sensitive to consumers' confidence and readiness levels when determining service plans;

9. Educating the community about people with disabilities and increasing their sensitivity to consumers' needs; and

10. Encouraging local providers in the community to ensure services match the independent living philosophy focused on choice and empowering consumers.

Three other CIL-related studies in this decade examined the following, more narrow topics: how CILs handle emerging disabilities, CIL training needs, and a conceptual model of independence versus interdependence for CILs. In 2004, the RTC on Independent Living at the University of Kansas examined how CILs handled emerging disabilities and recognized five possible expanded roles for

CILs to address emerging disabilities (KyungMee & Fox, 2004). These included the following: outreach, disability awareness, health referral, employment assistance, and improved help at home. Also in 2004, the Rehabilitation RTC at the University of Buffalo examined management practices of CILs in order to determine where further training is needed (Usiak et al., 2004). Stakeholders determined nine areas of CIL management practices: independent living philosophy, programs and services, fiscal responsibility, physical plant/resources, personnel, governance, administration, community presence/systems change, and consumer involvement. Lastly, a conceptual model for CILs describing a continuum from independence to interdependence approaches toward services for CIL consumers was developed (White et al., 2010b). The purpose of this model is to allow CIL users to participate more fully in their community by encouraging CILs to adopt practices that promote interdependence. The interdependence model for CILs illustrates that if core independent living services are met, then people with disabilities will naturally get involved in their communities. This model stresses the importance of helping consumers build social capital, fostering increased community participation.

2011–2020

One of the most comprehensive and well-designed examinations of CIL outcomes was conducted in 2012. NCIL, IL-NET, and the University of Kansas RTC on Independent Living funded an Outcome Measures Task Force of 10 nationally known CIL, SILC, support organization, and academia representatives that worked to develop indicators for CIL outcomes (NCIL, 2012). The outcomes the Task Force examined included three main categories: the independent living services stream, the information and referral stream, and the systems advocacy stream. The Task Force developed these indicators through four approaches: expertise from the Task Force members and its consultant, an extensive literature review, personal contact with independent living researches across the world, and a public competition with prizes for individuals offering the most useful suggestions. To measure the indicators chosen, NCIL developed three instruments to gather

information: "an interview guide for calls to CIL customers, an interview guide for calls to information and referral callers, and an information-gathering form for each Center." These instruments were transferred to SurveyMonkey for CILs to record the information electronically. Data was collected during 2 consecutive years. Analysis from this Task Force show that the findings seem credible, the findings are largely positive, and that there is room for improvement in certain areas such as advocacy and transitions from institutions. From its 2012 report, the NCIL recommended the following action steps for relevant entities in the Independent Living field:

- Work closely with the Rehabilitation Services Administration (ED) to determine what outcomes are appropriate to measure and how they can be most effective;

- Encourage all CILs to focus on outcomes management to improve services;

- Work with management information services companies to modify their systems to allow CILs to gather, store, analyze, and report information about outcomes;

- Train other CILs in outcomes management and host a CIL training session;

- Learn from others working on this same topic, such as four Massachusetts CILs that conducted a similar process; and

- Help CILs know how to use the information regarding their outcomes to identify weaknesses and make improvements.

Two more recent studies examine WIOA-related training needs and strengths and weaknesses of CILs according to CIL staff and board members. In 2015, IL-NET conducted a needs assessment of CILs in order to gain a better understanding of their training and technology assistance needs related to the changes presented in WIOA in 2014 (IL-NET, 2015). Some of the most prevalent topic areas identified for increased training included: understanding and analyzing CIL Suite data, developing finance policy handbooks, rural marketing strategies, using outcome measures,

maintaining quality performance, managing training services for independent living skills, and bringing together competencies for people who are marginalized in more than one way.

A survey of CIL staff and board members in 2017 examined what CIL services were most effective in increasing consumers' community participation (Ravesloot et al., 2017). The survey found participants had a "high regard for the value and quality of CIL services" and that the independent living philosophy was one of the most important aspects of service to the survey participants. CIL board members and CIL staff agreed on the overall strengths and weaknesses of CILs, but they differed on the focus of CIL services, with CIL staff focusing on specific consumer needs and CIL board members focusing on larger community issues. Participants all ranked using partnerships with other community agencies as one of the top 10 important elements of a CIL, indicating that CILs that use community partnerships may be better able to assist consumers with independent living needs.

MARKETING STRATEGIES FOR CILS

One of the most important parts of offering CIL services to consumers is that the community is aware of the various services available. A study examining effective marketing strategies for CILs to reach older adults with disabilities found that the most cited barrier to receiving services was not knowing about the organization (76.6% of participants) (Moone & Lightfoot, 2009). A majority of participants (61.7%) also reported not being familiar with the types of services that CILs can provide. To address these barriers, Moone and Lightfoot (2009) determined that CILs should provide their service information in areas that older adults with disabilities frequent, such as medical centers, senior centers, or senior living facilities. Furthermore, CILs should ensure that their services are in accessible locations, as some participants cited transportation issues with reaching CILs. Participants in the survey cited a formal marketing campaign with TV and radio ads as being potentially effective; however, with limited funding, the authors suggest

CILs engage in targeted campaigns to reach out to older adults with disabilities. CILs should collaborate with state agencies and departments that focus on aging services to ensure that older adults with disabilities are aware of the services CILs provide. Further research should be done on effective marketing strategies for CILs, as this was the only study available in the literature.

SPECIFIC CIL PROGRAM TYPES

PEER-LED SERVICES

Peer-led services are an innovative method of service delivery common across CILs, yet further research is needed. In a preliminary study to determine use of peer-led services in CILs, 65% of CILs reported offering one-to-one peer supports, while 90% of CILs reported offering group peer-led services (Ravesloot et al., 2011). Less than half of CILs in this study reported using a curriculum or manual for training peer leaders; however, some of the curriculums mentioned were from 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).

The first study on the outcomes of peer-delivered services through CILs compared individuals with psychiatric disabilities receiving peer-led CIL services with those with psychiatric disabilities who were receiving the usual services at a mental health center (Salzer et al., 2016). One of the main findings was that over 80% of individuals in the peer-led CIL program had at least one contact with the peer specialist, but only a little over half met with the peer specialist two or more times. Over half of the participants who met with a peer specialist reported receiving information about a "substantive support" in at least one area, and half of those reporting a substantive support described a tangible new resource that they gained as a result. Participants in the CIL program reported continuing engagement in the community and higher scores on quality of life and recovery indicators than those receiving only the standard mental health services. This study had limited

engagement of participants with peer-led specialists, as well as a small sample size; therefore, the results are difficult to determine and future research on peer-led interventions through CILs is needed.

HEALTH AND WELLNESS

Health and wellness is a program area many CILs offer that has the potential to result in health care cost savings for people with disabilities. Health and wellness programs include nutrition programs, information about health insurance, wellness or fitness peer support groups, tobacco cessation, and substance abuse support. A health promotion program called Living Well With a Disability was developed in 1998 and launched again in CILs across eight different states in 2005, where researchers found "reductions in limitation from secondary conditions, symptom days, and health care utilization" (Ravesloot et al., 2005). Additionally, this program was associated with an overall cost savings of $807 per participant (a total of $151,716 for all participants) because it reduced health care utilization. The Living Well With a Disability Program was also shown to lead to "less limitation from secondary conditions, fewer unhealthy days, and less health care utilization" for people with mobility impairments.

Rates of smoking cigarettes are higher for people with disabilities versus their peers without disabilities (Moorhouse et al., 2011). A 2011 study examined tobacco cessation services across CILs by interviewing CIL directors. When presented with a variety of health services, CIL directors indicated that tobacco cessation was the "most inadequately delivered health service" (Moorhouse et al., 2011). CILs were observed to have a high volume of tobacco cessation referrals, yet very few on-site tobacco cessation programs or interventions. Due to the unique challenges with tobacco cessation for people with disabilities, a targeted, on-site program at CILs could address these unique issues and help facilitate cessation.

From 2009 to 2012, the National Cancer Institute funded a study at the University of Florida that created a tobacco cessation program for people with disabilities (King et al., 2016). This study drew participants who use tobacco from CILs in North Central Florida, and it used a community-based participatory research approach that innovatively involved people with disabilities in the research study. Since this tobacco cessation program was hosted at the CIL where participants were often also receiving other services, it was a convenient and accessible location for them. Participants described their value for "social support, accessibility, and a tailored program" during the qualitative interviews. Lack of tobacco knowledge and excess idle time were two unexpected themes that emerged from the participant interviews. This study found that creating a tobacco cessation program tailored to the needs of people with disabilities is possible in collaboration with CILs using a community-based participatory research approach. For a tobacco cessation program to be meaningful to this population, their specific characteristics and needs must be addressed.

A study funded by a Medicaid Transformation Grant from the Centers for Medicare and Medicaid Services looked at health-promoting activities across CILs (James & Shireman, 2010). CIL case managers stated that they viewed health promotion as one of the main methods of facilitating independence and improved quality of life for people with disabilities. Nevertheless, they spent less time on case management activities related to medical services compared to social services. CIL staff reported having low levels of confidence when discussing preventive health services with clients, and over half expressed desiring more training on managing chronic diseases and tracking clients' medication compliance.

A study in 2017 surveyed CIL program directors in order to determine health needs and conditions of people served across CIL programs (Nary & Summers, 2017). The top five disabilities of CIL program consumers were arthritis, back pain, spinal cord injury, cerebral palsy, and multiple sclerosis. The most frequent chronic conditions

reported were diabetes, depression, hypertension, respiratory diseases, and obesity. The top six secondary conditions reported in the survey were depression, chronic pain, respiratory problems, side effects of medication, urinary tract infections, and pressure ulcers. While surveying health needs across CILs, this study also explored how expanding roles of CILs to include delivery of health promotion information might assist consumers with disabilities.

INTERNET-BASED SERVICES

With the development and accelerated growth of the internet, CILs are using their websites as a main platform to inform consumers about available services. One study examined the websites of 200 CILs across the United States, studying what features were highlighted on their websites and if the websites were accessible (Ritchie & Blanck, 2003). This study determined that the element most common to CIL websites was information and referral resources, which was present in 75% of the websites examined. One of the most common issues noted with accessibility of CIL websites was the "lack of or inconsistent use of ALT tags." However, if these issues were addressed, then 87% of the CILs examined would have fully met the accessibility standards. This study was the only study to date regarding CIL services presented on their websites or in an online format.

EMPLOYMENT-RELATED REFERRAL SERVICES

Studies regarding existence and effectiveness of referral programs at CILs are limited. A study of people with a variety of disabilities revealed that employment and vocational rehabilitation issues were major concerns for this demographic (Nary et al., 2004). Furthermore, increased collaboration in the fields of independent living, vocational rehabilitation, and employment services is needed to address their concerns about lack of coordinated employment services. However, a program that has been identified as a model for these types of services is a collaboration between the U.S. Social Security Administration (SSA) and CILs in New England (Malloy & Otto, 2006). SSA has a program known as the Benefits Planning, Assistance, and

Outreach Program, which has the purpose of assisting individuals with disabilities with obtaining accurate, current benefits and work incentives information. This program partnered with two CILs in New England, the Vermont Center for Independent Living and New Hampshire's Granite State Independent Living. Both of these CILs worked to construct partnerships with employers and employment supports in their communities. Additionally, they both offer unique benefits advisement services, where the information is provided within a peer support framework.

CIL TRANSITION SERVICES FOR YOUTH

Prior to WIOA, a study examining professionals who facilitate transitions from secondary education to adult life for youth with disabilities showed that CIL staff frequently participate in transition services (Oertle et al., 2013). However, these authors note that CIL staffs' role in transition is significantly understudied in the literature. They describe that CILs' ability to provide mentors, promote advocacy, and link with community resources places them in a vital role for supporting youth with disabilities as they transition to adulthood. This study recommends further research in order to determine the most effective roles of CILs in assisting with transition to adulthood for youth with disabilities.

In 2016, the CIL Transition and Diversion Services Survey Study was conducted to determine what resources CILs would need to implement the three new core services mandated in WIOA (Putnam et al., 2017a). These new core services include community transition services for people with disabilities residing in institutions, diversion services to prevent people with disabilities from entering institutions, and transition services for youth with disabilities moving into adulthood. The purpose of this study was to use this information to understand what resources CILs would need to implement WIOA guidelines. One main finding was that less than half of CILs (44%) stated that they currently provide transition services as a part of the work they already do with youth with disabilities. Most CILs reported transitioning only a few youth with significant disabilities per month. CILs located

in urban and suburban areas were more likely to have specific youth transition programs than CILs in rural or mixed-density areas. Only around half (52%) of CILs had a specific independent living specialist dedicated to transitions for youth with disabilities on staff. This study found that most of the funding for youth transition at CILs came from the Rehabilitation Act or State Vocational Rehabilitation Agencies; however, 90% of the study participants reported that their CIL did not have adequate funding to provide the core services outlined in WIOA. Lack of affordable and accessible housing and transportation options were also noted as barriers to providing these CIL transition services to youth with disabilities.

In a study of transition services, 77.3% of participants stated that transition services from high school to adult life were a priority; however, only 19.2% of transition-age youth with disabilities reported participating in transition initiatives "often or very often" (Plotner et al., 2017a). Almost three-fourths (72.7%) of the participants said that coordination with high schools was "extremely important," yet the majority of participants (57.1%) stated that the coordination with high schools was "adequate, poor, or non-existent." This study suggests CILs find ways to incorporate young adults with disabilities into their programming and assist them with becoming peer mentors. Another way to improve transition services is to ensure special educators and vocational rehabilitation counselors are coordinating with CILs to combine their services. Since WIOA's mandate for CILs to assist with transition services did not provide additional federal funding, CILs should attempt to diversify their funding to support these activities.

A study of CIL professionals regarding transition services found that agency and individual characteristics, such as number of schools partnered with, amount of training in transition services, etc., were not predictors of greater collaboration with local education agencies (Plotner et al., 2017b). However, high ratings on three elements of collaborative team structure were predictors of more frequently providing services to transition-age youth. Furthermore, when predicting frequency

of youth transition services, elements of a collaborative team structure, such as governance and administration, were found to be more important factors than social capital-related dimensions like trust and mutuality.

CIL INSTITUTIONAL TRANSITION AND DIVERSION SERVICES
In 2016, ILRU conducted the first national survey on CIL transition and diversion services (Putnam et al., 2017b). This survey found that most CILs already provide these services to their consumers. When CIL staff were asked about their experience and knowledge with contracting with other organizations like managed care organizations to provide transition services, 40% stated that they had a lot of knowledge and 45% reported some knowledge on the topic. Two-thirds of CILs surveyed reported that their center had a specific nursing home or institutional transition program, and 58% of CILs reported offering between 21 to 25 different transition-related services. Some of these included: locating affordable and accessible housing, working with family members, assessing for service needs and supports, providing financial assistance, learning or relearning independence skills, creating connections with medical providers, and building social networks. The institutions CILs had the most experience providing transitions from were hospitals, nursing homes, and rehabilitation facilities.

Despite the significant amount of transition services provided, CILs reported that they were not adequately funded to make significant expansion in the transition services they provided (Putnam et al., 2017a). Over half of the CIL respondents reported seeing their budget decrease over the past several years. Almost half (40%) of CILs' transition services budget is funded through Title VII, Part C of the Rehabilitation Act, which covers CIL operations, and another portion (30%) is funded by Title VII, Part B of the Rehabilitation Act, which covers independent living services. Further research is needed to determine CILs' relationships with other community organizations and how they can leverage these business relationships to obtain expanded funding for transition services.

When surveyed about diversion services, most CILs (66%) reported not having a specific method for determining whether someone with a disability is at risk for being admitted to an institution; however, the respondents largely agreed on what some of the main risk factors are (Putnam et al., 2017c). A majority (77%) of participants stated that there is not an adequate supply of community-based providers in their region for the demand for the services. A lack of affordable services for those who do not qualify for Medicaid and social isolation were noted as two main issues for the individuals they serve. Further research into determining the outcomes of these specific CIL program areas will assist them with making improvements to benefit their consumers with disabilities.

Cultural Diversity in CILs

Cultural diversity within CILs was first examined in a study in 1996 that looked at the demographics of CIL staff (Flowers et al., 1996). Out of the CILs that responded, 19% of the directors and 15% of the management staff were persons of color; however, with 40% of the CILs in this study not responding, this study suggests a lack of responsiveness and concern with these issues. It is unclear if the demographics determined in this study were reflective of the communities of the responding CILs, so this study suggests further research on service provision of CILs to individuals with diverse backgrounds.

A study on the effect of cultural brokering workshops for CILs found that 84% of the participants in these workshops experienced increased knowledge scores afterwards (Moffat & Tung, 2004). Increases were seen in 35 out of the 36 elements of cultural competence. While this study shows the effectiveness of cultural brokering workshops for CILs at increasing staff knowledge, it points to additional research needed to examine the effectiveness of cultural competence training on community outreach and consumer satisfaction.

CIL Advocacy

Advocacy is an important core function of CILs. A 2006 study interviewed CIL directors; 99% reported that their CIL participates in systems change activities (O'Day, 2006). Out of nine issue areas, the highest level of CIL involvement was related to transportation (93%) and deinstitutionalization (92%). Most of the CIL directors (90%) indicated working on the passage or enforcement of civil rights laws at the local, state, or federal level. CIL advocacy efforts were mostly focused on efforts at the state and local levels instead of the federal level. Methods of advocacy for CILs in this study included:

- Participating in committees or working groups;

- Collaborating with agency or organization representatives;

- Working together with decision-makers;

- Providing in-service training;

- Training local groups of people with disabilities;

- Working with the media;

- Taking legal action; and

- Conducting demonstrations.

Level of involvement in these advocacy activities differed by participants' roles. For CIL staff, between 94% to 98% engaged in these advocacy actions (O'Day, 2006). For consumers, participation ranged between 74% to 91%, and for board members involvement ranged from 37% to 69%. Advocacy is one of the main functions of CILs, and high participation rates show that it is important to their consumers as well. To date, studies have not examined the outcomes of CIL advocacy activities.

Determining the impact of these advocacy activities is an important area for future research in order for CILs to demonstrate their important role for their consumers.

CIL Training

A study that examined training on the Americans with Disabilities Act (ADA) for CILs asked about their current capabilities and future training needs (Nguyen et al., 2019). Almost all CILs (95.3%) reported that their centers "provided training, information, or referrals relating to the ADA." One limitation voiced by the CILs surveyed was that around two-thirds of respondents indicated inadequate levels of staffing to respond to these needs. Additionally, one-third of respondents mentioned that a "lack of training or staff development available to them" limited their ability to provide these ADA-related services to consumers. Some of the respondents (28%) also mentioned not having adequate information about the availability of legal services or formal complaint processes related to ADA. This study determined that around 80% of CILs reported using their regional ADA Center as a resource. However, some CILs may not be aware of the ADA National Network resources, as only half of respondents reported using ADA National Network produced documents like fact sheets or publications.

Current Research

Current Program Evaluations by ACL

ANNUAL REPORT ON CILS

As mandated in WIOA, ACL must publish a report discussing the performance of CILs over the prior year (ACL, 2020). ACL piloted the Compliance and Outcome Monitoring Protocol (COMP) tool in 2018 in order to conduct thorough reviews of key risk indicators for all CILs annually. COMP consists of three main elements: standard monitoring, comprehensive review, and targeted review. Standard monitoring is the ongoing annual review that occurs for each CIL grantee. Comprehensive review is a thorough, detailed review that examines all components of CIL operations that ACL tracks. And targeted review uses remote and/or on-site reviews to identify areas CILs need to improve, such as operations and financial management. In 2018, six different CILs received remote reviews, and in 2020 six CILs are set to receive on-site reviews. COMP's aim is to help identify and track problem areas for CILs before they become more significant and encourage overall improvement across all CIL programs.

COMP Guidebook

Since PY 2016, CILs have seen a 5% growth in services to assist with diversion from institutions and 17% growth in services guiding transitions into the community for people with disabilities (ACL, 2020). The most significant growth noted in FY 2018 was a 31% increase in transition services for youth with disabilities, resulting from WIOA's mandate to CILs to provide these services. Two of the major issues noted in this report include issues with affordable, accessible,

CIL Evaluation Tool — FY 2020

and integrated transportation and housing options for people with disabilities. The pilot of the COMP tool allowed CILs that volunteered to strengthen their programs, and ACL encouraged them to resolve any identified problem areas within a certain time frame.

NIDILRR-Funded Research Projects

NIDILRR-funded research focuses on improving outcomes for people with disabilities in three areas: community living and participation, health and function, and employment (NIDILRR, 2018). NIDILRR's 2018–2023 Long-Range Plan focuses on further developing current research and moving it forward toward evidence-based programs, practices, and policies by using ACL staff expertise to expand research related to aging and disability and conducting health policy research to guide national policymakers. NIDILRR emphasizes a focus on including people with disabilities into research, as well as expanding person-centered planning into decisions impacting people with disabilities. The new agenda for the community living domain includes:

- Community living and participation measurement;

- Transportation access;

- Family caregivers;

- Community access; and

- Accessible homes.

The new agenda for the health and function domain includes:

- Aging with and into disability;

- Development of interventions that improve health and function outcomes;

- Implementation of existing evidence-based practices; and

- Policy impacts on access to health care services and outcomes.

- The new agenda for the employment domain consists of the following:

- Disability statistics;

- People with psychiatric disabilities;

- Employment disincentives;

- Young adults;

- Employer practices; and

- Return on investment.

A variety of NIDILRR-funded projects currently exist to address these topic areas. The following section will discuss projects specifically related to CILs and their consumers.

THE COLLABORATIVE ON HEALTH REFORM AND INDEPENDENT LIVING

One ongoing NIDILRR-funded research project is the Collaborative on Health Reform and Independent Living (CHRIL), which consists of academic research and disability advocates dedicated to contributing to public policies that address the needs of people with disabilities (CHRIL, 2020). CHRIL's stated mission is "to provide disability stakeholders with accurate, current, accessible and actionable information on how changes in US federal health policy, such as the Affordable Care Act of 2010, affect community living and participation for working-age adults with disabilities." CHRIL has created and conducted two large web-based surveys of adults with disabilities, the National Survey on Health Reform and Disability and the National Survey on Health and Disability. In 2017, CHRIL conducted a needs assessment survey of 150 CILs to determine staff perspectives on consumer needs,

health insurance, and enrollment counseling at CILs as well as questions CILs had regarding the health insurance marketplace. CHRIL's goal with this project was to identify specific training, information, and technical assistance needs CILs had in regards to helping their consumers obtain health insurance.

MINORITY YOUTH AND CENTERS FOR INDEPENDENT LIVING

The **Minority Youth and Centers for Independent Living** research project (2019–2024) at Hunter College is focused on sharing knowledge with CILs regarding practices for supporting the transition of youth with disabilities from minority backgrounds (National Rehabilitation Information Center (NARIC), 2019a). Some of their activities include a survey of CILs, qualitative interviews, pilot testing practices, testing a randomized control trial intervention, and providing technical assistance with outreach, data analysis, and collaboration among CILs. Overall, this project aims to improve transition outcomes for out-of-school youth with disabilities from minority backgrounds.

HEALTH INSURANCE LITERACY ACADEMY

The **Health Insurance Literacy Academy** is a project (2019–2022) with the goal of creating a health insurance literacy academy of CIL staff in order to assist them with empowering people with disabilities to gain knowledge and make decisions about private and public health insurance options (NARIC, 2019b). This project is a partnership with the American Association on Health and Disability, ILRU, CHRIL, including NCIL, and the Association for Programs in Rural Independent Living. This project aims to identify important topics for the training curriculum, develop and draft the training curriculum, and develop a technology transition plan to ensure access to this training is maintained. The ultimate goal is to ensure that people with disabilities are supported to make informed choices regarding health insurance options.

SECURING EMPLOYMENT AND ECONOMIC KEYS TO STABILITY

The **Securing Employment and Economic Keys to Stability** project (2019–2024) is designed to help people with disabilities in Colorado improve their education and employment outcomes, increase their income, and expand their participation in the community (NARIC, 2019c). This project achieves this through matching people who are applying for SSA disability benefits with an employment specialist and a comprehensive benefits planner through a CIL in conjunction with the Department of Vocational Rehabilitation. The major objectives the project is working toward are connecting people with disabilities applying for supplemental security income (SSI) and social security disability insurance (SSDI) with competitive employment, training CIL staff to use SSI/SSDI Outreach, Access, and Recovery (SOAR) strategies, training CIL staff in Customized Employment, providing people applying for social security benefits with comprehensive benefits counseling, providing CIL staff with Community Partner Work Incentives Counseling training, and increasing connections for people with disabilities inquiring about independent living services.

RURAL COMMUNITY LIVING DEVELOPMENT PEER MENTORING: A STRATEGY FOR KNOWLEDGE TRANSLATION

The **Rural Community Living Development (RCLD) mentoring program** (2019–2024) run by the University of Montana aims to address the concerns of people with disabilities living in unserved or underserved rural areas (NARIC, 2019d). Their team is using participatory curriculum development in order to create a peer mentoring training curriculum by implementing RCLD processes with CIL staff to identify what products would work best in a rural environment, collaborating with partners in all phases of the project to develop mentoring as a way for knowledge translation to occur, evaluating the RCLD process, and disseminating a variety of products and strategies for consumers to voice their needs. Two project partners are the Association of Programs for Rural Independent Living and the RTC on Place-Based Solutions for Rural Community Participation, Health and Employment. The final

products of this project will include an RCLD peer mentoring training model, peer-reviewed publications, project reports, ready-to-use NIDILRR products, consumer and service-provider oriented materials, and presentations.

National Institute on Nursing Research

COMMUNITY WELLNESS PROMOTION PROGRAM FOR MIDDLE-AGED ADULTS LIVING WITH LONG-TERM PHYSICAL DISABILITY

The **Community Wellness Promotion Program for Middle-Aged Adults Living with Long-Term Physical Disability** project (2018–2023) involves a partnership with three regional CILs spanning 14 counties in the Northwest (Federal RePORTER, 2019). This project's goal is to test the Enhance Wellness for Disability program for people with long-term physical disability to see its effect on participation in community activities. This program's effects will be measured through self-report, but also through objective measures such as GPS tracking and travel diaries in a subset of those studied. The aim is to determine if the intervention program results in "improved disease management self-efficacy, decreased interference due to pain and fatigue, or improvements in psychological resilience." If this intervention proves effective it could be extended to able-bodied older adults in addition to adults with long-term physical disability and could improve community access for this population.

Best Practices at CILs

Despite the need for more formal research on CILs, a knowledge base of best practices in various operations and service areas is beginning to develop. ILRU works to collect best practices from CILs around the country and has put together various manuals and reports on best practices in specific topic areas, several which will be highlighted below.

Transition Services for Youth

ILRU developed a youth transition manual to guide CILs in creating or enhancing effective transition services for youth (Hammond et al., 2018). This guide provides information about the core services for youth in transition as well as additional services that can be provided. It offers in-depth discussions of promising practices to involve youth and young adults with disabilities in CIL activities and describes current examples of what CILs are doing to facilitate this. ILRU identifies successful peer mentoring programs for youth as including the following elements: effective recruitment, training, supervision, evaluation, and recognition. ILRU also offers recommendations about possible funding sources for programs for youth transition.

Nursing Home Transitions

ILRU developed a nursing home transition manual, with elements that can apply to other types of institutional transitions in the community (Holt et al., 2020). Best practices in this area focus on increasing self-direction of services and decision-making by the consumer. The main elements that contribute to the success of a transition are "developing a trusting relationship and having a comprehensive assessment that clearly reflects needs, concerns and priorities; developing and implementing a Transition Plan (Independent Living Plan) that addresses

the individual's needs; and critical follow-up and post-transition services."
Assessments prior to transition should include health services and durable medical
equipment, social supports, housing, transportation, volunteering/ employment,
advocacy, and financial resources. Transition planning refers to the "process of
identifying how the needed supports can be provided in the community," and
CILs develop these in conjunction with the consumer and other members of the
team. It is essential that these plans address needs such as housing, health care,
and social networks. Since the goal is for an individual to move out of a nursing
home (or other institution) and gain control back of their lives, CILs should ensure
that during transition services the person moving is in charge in as many ways as
possible during this process. ILRU's guide provides a sample transition assessment
instrument, transition planning worksheets, a timeline of transition processes,
and laws that apply to transition services. While few formal studies have been
conducted, this guide to best practices for nursing home transitions provides
detailed guidance for CILs on improving this area of their services.

Financial Management

A 2014 survey conducted by ILRU examined the implementation of fees-for-service,
business-related activities, and the success of these programs across 96 CILs (ILRU,
2014). Most of the respondents (85.4%) indicated that their CIL currently received
fees-for-service. Some of the main areas in which CILs received fees-for-service
included ADA consultations, employment services, and nursing home transition
services, with the main purchasers of these services being vocational rehabilitation,
Medicaid, and businesses. A little less than half of the CILs (44.1%) reported having
between 10 to 20 years of experience with fees-for-services or business ventures;
however, 58.5% of the CILs that did reported being open to training other CILs to
develop similar practices.

ILRU and the National Center for Aging and Disability put together a **"How-To" Guide** for the Aging and Disability Business Institute to provide to CILs on establishing relationships with payers and health insurers (Petty et al., 2018). This guide identifies some of the most common services that are provided by community-based organizations through contracts. As CILs build partnerships with payers, this guide encourages CILs to consider joining networks of community-based organizations since health plans often seek to maintain services over a wide geographic area and provide a wide range of services to consumers. Information on payment methodologies is included, as well as ways to demonstrate that CILs support health outcomes for consumers.

Finally, a project by ILRU examined CILs' role in institutional transition and diversion practices and put together some of the experiences and best practices from CILs around the country (Putnam et al., 2018). With the growth of Medicaid managed long-term services and supports and managed care organizations that contract with the states, CILs have a unique ability to provide some of the supports in achieving health outcomes that these organizations must contract out. CILs that participated in this project provided information regarding who they partnered with, how their services were funded, what they perceived to be strengths and weaknesses of the marketplace, barriers that they faced in this work, who their competition was, and what types of support would be useful to help them develop these program areas.

Services for Consumers with Psychiatric Disabilities

The Temple University Collaborative on Community Inclusion of Individuals with Psychiatric Disabilities created a **fact sheet** for CILs on how to best serve individuals with psychiatric illness (Temple University Collaborative on Community Inclusion, 2017). This fact sheet describes the various reasons that people with psychiatric disabilities might seek CIL services and ways CILs can support them. Some

of the common reasons people with psychiatric disabilities might seek CIL services is for information about services they are entitled to, assistance with finding a job, help moving to a new home, information about local mental health programs, or peer support services. The individual's own goals should be the starting point, just as with any other CIL consumer. CIL staff should offer their range of services just as they do for people with other types of disabilities, and they can also respond to disability-specific needs through targeted mental health services as well. Important principles when serving clients with psychiatric disabilities include self-determination, recovery, community inclusion, peer support, psychiatric advanced directives, and integrating mental health with primary care. This fact sheet also suggests CIL staff familiarize themselves with emotional CPR and local mental health resources.

Peer Support Programs

In a course manual on peer support programs, ILRU outlines best practices for building peer support programs and provides an example from the Arizona Bridge to Independent Living program in Phoenix, Arizona (Kruck et al., 2011). This program began in 1990, uses over 50 volunteer mentors, and has shown benefits for both mentors and mentees. While all CILs provide peer support in some form, in a 2008 survey 61.3% of CILs reported having an organized peer support program. An organized peer support program "recruits, trains, assigns, and supervises a group of individuals with disabilities whose role is to provide one-on-one or group support to other individuals with disabilities." Programs vary greatly based on a CIL's needs and approaches, and peer mentoring programs can be formed with all volunteer mentors, professional mentors, group mentoring sessions, one-on-one mentoring sessions, or a mix of these elements. Peer mentors should be individuals who are living independently, integrated into the community, and have a desire to help their peers. Qualities of good peer mentors include empathy, listening and communication skills, trustworthiness, competence, and approachability. Mentees in peer support programs describe gaining a better understanding of the

rehabilitation process, learning about resources in their local area, sharing common experiences, and feeling a greater sense of connection and acceptance.

ILRU's manual discusses detailed information on examples of peer support programs, tools, strategies for recruiting peer mentors, training, coordination techniques, and evaluation strategies (Kruck et al., 2011). Furthermore, it identifies barriers to building peer support programs and offers various solutions. The manual also explains some of the various benefits of implementing and maintaining an effective peer mentoring program. In a CIL survey, "a lack of consumer progress or apathy, a sense of disconnection with the Center and feeling overwhelmed by paperwork" was related to burnout and discouragement among CIL peer mentors. A majority (79.2%) of CILs that do not have a current organized peer mentoring program stated that they would like assistance with developing or re-establishing a peer support program. This manual includes a planning tool for creating a peer mentoring program so CIL personnel can work together to assess their strengths, determine any barriers they face, plan their action steps, and create a time frame for accomplishing them.

Emergency Management

While many emergency planning agencies are not fully educated about the concerns of people with disabilities, CILs can provide valuable information to these organizations on improving community emergency plans. ILRU created a guide with practical tips for how CILs can partner with local emergency planners in their community (Holt et al., 2007). It highlights three main ways CILs can be involved in emergency planning: communication and public information, emergency procedures, and exercises and training. CILs are suggested to ask emergency planners about communication access and if notification methods about an emergency will be effective for all individuals with a variety of disabilities. Some localities are exploring creating a "Special Needs Registry" that would list people

who need assistance in emergencies. This could be a valuable resource in an emergency, allowing first responders to know where to assist and what types of assistance people need. However, there are also downsides, such as the voluntary nature of such a registry, confidentiality issues, and a potential to create a false sense of security. CILs are also encouraged to work closely with organizations like the Red Cross to educate and advise on emergency shelters. CILs should provide input on an identified emergency shelter's ability to accommodate the needs of community members with disabilities. There are a variety of best practices for emergency management that CILs are beginning to engage in, and this guide summarizes practical ideas CILs can use to develop this.

Integrated, Affordable, and Accessible Housing

ILRU developed a guide on integrated, affordable, and accessible housing options for people with disabilities that showcases a variety of funding sources (Klein et al., 2016). This publication also highlights various innovative programs and includes action steps for CILs. Comprehensive descriptions of available resources are included so CILs can understand what programs are already available and what some of the advantages and disadvantages to each of them are. Contact information for state and local funding sources are listed so CILs can find further information where needed.

Staff Training

While few studies have been done on CIL staff training, ILRU put together a large collection of trainings on best practices for CIL staff to put to practice at their centers. ILRU hosts trainings on a variety of topics, such as independent living, the ADA, assistive technology, and sensitivity to disability (ILRU, 2020b). Their trainings take a variety of formats, to include live webinars, teleconferences, online, in-person, and on-demand.

Cultural Diversity

ILRU examined nine case studies of CILs and their progress toward promoting cultural diversity at their centers (Harrison et al., 2018). The common areas among all nine CILs included: showing unconditional respect, having objectivity, stepping outside the box, asking for input and listening, avoiding assumptions, taking the time necessary to connect, and staffing the right people. More research will need to be done in this area to continue to shape best practices regarding cultural diversity.

Research Considerations for Future Studies

Research Objectives

The focus on outcomes began through individual CILs desiring a better way to measure their accomplishments and find areas for improvement. Additionally, the Office of Management and Budget in 2003 applied their Program Assessment Review Tool to the CILs and found that the program did not demonstrate results, meaning that the program was not identifying outcomes, measuring outcomes, and using that information to review and improve the program (NCIL, 2012). Some CILs had developed their own methods of tracking outcomes, which inspired an effort to make outcome measurement standardized on a national level. NCIL since 2006 has led the effort to improve identifying and measuring CIL program outcomes across the 400 centers in the U.S.

The ICDR desires to promote further CIL-related research in order for CILs to understand their value to the disability community. Future research should highlight how CIL service delivery impacts outcomes for consumers. The following will explore possible topic areas and government agencies involved in related activities, as well as discuss effective research methods for CIL-focused studies.

Topic Areas for Further Exploration

There are a variety of topics related to CIL outcomes and services that have been underexplored or yet to be explored at all. After reviewing past and current research, one area that emerged as a potential topic area for future research is the potential role of CILs in managing chronic diseases and tracking medication compliance (James & Shireman, 2010). Promoting health-related information has

been identified as an area of possible expansion of the CIL role and needs further research. Another topic area that should be studied further is the effectiveness of peer-led services. Peer-led services have been an essential element of CIL services since their inception, yet only one 2016 study has been done specifically on peer-led services. A similar important key service of CILs, referral services, also has very little representation in the CIL-focused research. Referral services, especially to federal-level programs for employment, transportation, or housing, should be studied to examine the effectiveness of CILs at linking people with disabilities to resources. Housing and transportation have been specifically identified as barriers to youth with disabilities in their transition to adulthood; therefore, more research relating to CILs in these two areas would be valuable (Putnam et al., 2017a). Most CILs have reported not having a standardized way to track who is at risk of institutionalization, so this could be another important avenue for research in order to develop a way to better track this risk for CIL consumers (Putnam et al., 2017c).

Government Agencies' Interest in CIL Research

To better coordinate future CIL-related research, government agencies should collaborate in order to study CIL outcomes that directly affect their programs and overall mission. Several federal agencies are identified below, along with CIL outcomes of interest and how they might relate to current programs. Several collaborations already exist in relation to assisting people with disabilities, which will be briefly highlighted below. These interagency groups and collaborations could collaborate with CILs and researchers in their future work to study outcomes of interest across many federal agencies as well as for CILs to improve and measure service quality.

INTERAGENCY COLLABORATION

FEDERAL PARTNERS IN TRANSITION WORKGROUP

Federal Partners in Transition is a workgroup formed in 2005 consisting of staff from multiple federal agencies, including the Departments of Labor, Education, and Health and Human Services as well as SSA (Federal Partners in Transition Workgroup, 2015). Its main purpose is to ensure youth, especially youth with disabilities, are successfully supported as they make their transition out of the school setting and into adulthood.

Some areas of future research related to transitions for youth with disabilities identified by the Federal Partners in Transition include:

- Bridging the gap between youth and adult programs to expand opportunities for youth up to age 24;

- Developing states' ability to design developmental opportunities for youth with disabilities during and after school;

- Communicating the value of hiring youth and young adults with disabilities;

- Fostering collaboration and coordination between youth and adult service systems, education agencies, state vocational rehabilitation and workforce development agencies, schools, and youth with disabilities and their families to help them achieve education and career goals for their lives; and

- Creating opportunities for financial independence for younger SSA disability beneficiaries through programs similar to Ticket to Work.

Research related to the CIL role in youth with disabilities' transition to adulthood could be coordinated more easily since the Federal Partners in Transition Workgroup is already in place across multiple federal agencies. The respective

agencies would benefit from knowing more about the CIL role in youth transition, and CILs would be able to improve their services based on research findings.

COORDINATING COUNCIL ON ACCESS AND MOBILITY

The Coordinating Council on Access and Mobility is an interagency council focused on increasing the availability, accessibility, and efficiency of transportation services for older adults, people with disabilities, and people with low income (Federal Transit Administration (FTA), 2020a). They work on a variety of projects coordinated across federal agencies to improve public transportation, ride sharing, health-related transportation needs, universal design of autonomous vehicles, and a variety of other topics. Council members would likely be interested in research that tracks transportation-related needs and services for people with disabilities by looking at how CILs link people with disabilities to transportation services.

THE NATIONAL AGING AND DISABILITY TRANSPORTATION CENTER

The National Aging and Disability Transportation Center (NADTC) is a program that provides national technical assistance, community grants, and information related to transportation options for older adults, people with disabilities, and caregivers (NADTC, 2020). NADTC is funded by the U.S. Department of Transportation's FTA, run by Easterseals and the National Association of Areas on Aging, and guided by ACL. Similar to potential interests of the Coordinating Council on Access and Mobility, NADTC would likely be interested in how CILs link people with disabilities and their caregivers to transportation resources in their area.

WIOA YOUTH AND VOCATIONAL REHABILITATION PROGRAMS

The U.S. Department of Labor administers the WIOA Youth Program, which focuses on providing work experiences for youth in or out of school with at least one barrier to employment, which includes disability (Meminger, 2019). ED administers the vocational rehabilitation program, which provides a continuum of vocational rehabilitation services to people with disabilities, including youth transitioning to

employment after school. This program focuses on identifying strengths, resources, and capabilities so youth can gain competitive, integrated employment upon completing school. Coordinating activities between these two programs have been identified as the following:

- Coordinating referrals across the two programs;

- Developing linkages for recruitment and placement;

- Promoting information-sharing between the two programs; and

- Collaborating to evaluate and improve programs.

These two programs are encouraged to collaborate since they share many of the same indicators of performance (Meminger, 2019). However, as CILs are also mandated to provide WIOA-related services to youth transitioning from school to employment, it appears that the collaboration, information-sharing, and evaluation activities could include CILs as well. Future research could incorporate all three of these programs in order to track WIOA-related progress and outcomes.

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
ADMINISTRATION FOR COMMUNITY LIVING

As CILs are housed under ACL, they are concerned with the overall outcomes and best practices of CILs. With the 2014 transition of CILs from ED to the U.S. Department of Health and Human Services as a result of WIOA, it is essential that ACL can assess current CIL outcome measures and continue to do so in the future to gauge improvements. Since WIOA expanded CIL scope to include supporting transitions for youth with disabilities and supporting people with disabilities at risk of institutionalization with remaining in the community, these are two outcome areas that ACL is especially interested in. While there are a few studies on youth transition and CILs, more studies need to be conducted. Additionally, there are

very few studies looking at the CIL role in keeping people with disabilities at risk of institutionalization in the community. ACL would benefit from studies on any areas in relation to CILs, although these two topic areas would prove most useful.

U.S. DEPARTMENT OF HOUSING AND URBAN DEVELOPMENT

The U.S. Department of Housing and Urban Development (HUD) has several programs specifically targeted to housing options for people with disabilities. These programs include Section 8 vouchers, non-elderly disabled vouchers, the Section 811 program, and the Section 202 program (HUD, n.d.). HUD would likely be interested in research studies examining CILs and their ability to link people with disabilities with housing options, specifically HUD programs. Despite these programs, housing has been identified numerous times in the research as a major barrier for adults with disabilities. Research focused on housing outcomes for people with disabilities could benefit HUD and also help track and eventually improve CIL outcomes.

U.S. DEPARTMENT OF TRANSPORTATION

The U.S. Department of Transportation (DOT) has several programs specifically designed to improve transportation access for people with disabilities. In late 2019, DOT held an Access and Mobility for All Summit highlighting DOT and other governmental agency efforts to increase accessibility and mobility for older adults, people with disabilities, and individuals in low socioeconomic status (DOT, 2020). In June 2020, DOT awarded $3.5 million for mobility and access to public transportation projects in 16 different states for these populations (FTA, 2020b). DOT also leads the Coordinating Council on Access and Mobility, which helps state and local governments work toward creating access to transportation for people with disabilities, older adults, and individuals with low income in their communities (FTA, 2020a). Another current effort of DOT is to collaborate with the auto industry to work toward the development of autonomous vehicles and ensure universal design and access for people with disabilities (Office of Disability Employment Policy (ODEP), n.d.).

Research regarding CIL transportation programs and services would be beneficial to DOT and contribute information to the work that they do for people with disabilities.

U.S. DEPARTMENT OF LABOR

The U.S. Department of Labor tracks employment statistics for people with disabilities. In 2008, new questions regarding the employment status of people with disabilities were added to the Current Population Survey conducted by the Bureau of Census for the Bureau of Labor Statistics (U.S. Department of Labor, n.d.). The U.S. Department of Labor's ODEP would likely benefit from collaboration regarding research that examines effective CIL practices for linking people with disabilities to employment opportunities as well as other employment-related services. ODEP also collaborates with DOT on automated vehicles and the Coordinating Council on Access and Mobility (ODEP, n.d.).

U.S. DEPARTMENT OF VETERANS AFFAIRS

The U.S. Department of Veterans Affairs (VA) works to ensure veterans have the best possible outcomes through collaboration with community organizations (Hale-Gallardo et al., 2017). Research has noted that CILs could potentially be a resource hub for veterans with disabilities who have limited VA care access or are hesitant to seek VA services. Furthermore, CILs can offer services to veterans with disabilities who might not live near VA care centers. Because CILs focus on community integration, they could assist with helping veterans with disabilities reintegrate into the community after serving. More research should be done on potential VA collaborations with CILs to determine if CILs can help meet the nonmedical care needs of veterans who have disabilities.

U.S. DEPARTMENT OF JUSTICE

The U.S. Department of Justice (DOJ) Disability Rights Section of the Civil Rights Division is responsible for enforcing the ADA. DOJ actively participates in enforcing the ADA in health care, education, housing, electronic and information technology,

and a variety of other arenas (Gupta, 2015). DOJ created a guide to solving common ADA problems. DOJ likely has interest in how CILs link people to information and resources related to the ADA. In addition, they track progress related to diversion from institutions as mandated by the *Olmstead* decision. Since 2009, DOJ has been involved with 50 matters across 25 states in regards to *Olmstead* enforcement. As of 2015, DOJ reached eight *Olmstead* settlement agreements with states, allowing 46,000 people with disabilities to be able to leave institutions or not have to enter one. DOJ could partner with CILs to conduct research related to progress toward diversion from institutions.

U.S. DEPARTMENT OF EDUCATION

ED is responsible for implementing key provisions of the Individuals with Disabilities in Education Act and the Rehabilitation Act by helping youth with disabilities transition from school to activities in adulthood, to include further education of integrated employment opportunities (Office of Special Education and Rehabilitation Services, 2017). ED has cited CILs as resources for mentoring opportunities for youth with disabilities. However, ED could likely benefit from research exploring how CILs can help achieve transition outcomes for youth through collaboration between the education system and CILs. While a few studies have examined these potential collaborations, further research should be conducted to determine the prevalence and effectiveness of collaboration between the education system and CILs to assist youth with disabilities transitioning into adulthood.

Approach to the Research — Promising Practices

When considering future areas for CIL research, it is essential to consider research methods that have proved effective in the past and those that were not. A study examining nonprofit organizations undertaking evaluation of services found that the main barriers to doing so were a lack of financial resources, a lack of technical and evaluation capabilities, and difficulty identifying evaluation systems and

outcome indicators relevant to services provided (Bach-Mortenson & Montgomery, 2018). The same study found that three factors that facilitate service evaluation are receiving adequate support, creating an organizational culture that values evaluation, and possessing the motivation to hold themselves accountable to their stakeholders. CILs will need to receive adequate financial and technical support, be provided with adequate evaluation systems, and create a culture that sees the value in evaluating their services to improve them and ultimately benefit their consumers. The following section will examine promising practices in evaluation research related to participant recruitment, defining outcomes, outcome measurement, data collection, data analysis, and reducing the burden on CIL staff during research studies.

PARTICIPANT RECRUITMENT

In terms of participant recruitment, it is essential for researchers to understand the importance of ensuring people with disabilities are an integral part of the research. A study by Stack and McDonald (2014) reviewed a significant portion of disability-related research in the U.S. and the U.K. and found that in many studies describing equal research participation, community members were only used as data sources and to provide feedback on the accuracy and meaning of the research rather than being involved in all steps of the research. It is important that future researchers continue to develop their "belief in the ability of adults with developmental disabilities to contribute to research, their commitment to providing accommodating to enable full inclusion, and their knowledge of action research and how to achieve its aims" through offering opportunities for people with disabilities to be co-researchers and participate in areas such as data collection.

DOJ's First Steps Toward Solving Common ADA Problems

A study on intellectual disability research reviewed 10 interviews and identified themes regarding participant factors that impact studies, such as interview anxiety, problems understanding the concept of the research, or worry about negative feedback (Nicholson et al., 2012). Two effective ways researchers can engage participants were identified: using a personal approach and meeting potential participants prior to recruitment. A main motivator that was identified for participants was enjoying the interview process. A

NIH Toolbox: Reasonable Accommodations

motivator identified for caregivers was obtaining a medical assessment for research participation. Future research on CILs should ensure a focus on applying a personal approach in their research, developing the recruitment process to allow for frequent meetings with participants, and keeping participant and caregiver motivators in mind when designing a study.

When studying populations of individuals with disabilities, it is important to have a protocol that includes variations that will need to occur for participants in order to give researchers guidance and eliminate variations that might occur from "on-the-spot" decisions (Rios et al., 2016). Protocols should reference information on screening for study accessibility and accommodations that might be needed, training, and quality control. Upon contacting participants in a study, they should be screened using a list of guiding questions to determine what accommodations might be needed. When accommodations and alterations need to be made, it is important that these are thoroughly documented so that the results of the study can be accurately interpreted.

Another important factor in participant recruitment is ensuring participants from a diverse set of CILs are sampled. A study found that across most CILs, consumer characteristics such as age, gender, and disability type are similar; however,

the percentage of consumers who are Black varies greatly depending on the CIL location (CESSI, 2003). Therefore, to ensure accurate representation of consumer demographics, researchers should ensure they sample from CILs across rural, urban, and suburban areas.

INCREASING PARTICIPANT RESPONSE RATES

Researchers should be aware that CILs are frequently identified as locations to recruit participants for disability research, which can lead to consumers at CILs developing "research fatigue" (Kroll et al., 2007). Therefore, it is important to consider the saturation of research in the area research is being conducted; for example, if a study is already being conducted at a CIL that serves a very small population of individuals in a rural area, it might lead to low participation rates if another study were to be conducted simultaneously.

The 2012 First CIL Outcome Field Test experienced a low CIL participation rate of 66% (NCIL, 2012). It is important when designing future studies to consider how to retain high participation rates across CILs. The following are some suggestions on how to increase response rates:

- Send an advance postcard or letter;

- For mailed surveys, include a transmittal letter clearly stating the study's purpose to improve services;

- Do not give up after the first try;

- Include stamped, self-addressed return envelopes if mailing;

- Make the questionnaire easy to complete;

- Provide incentives, such as bus passes, coupons to local restaurants, etc.;

- Use multiple modes; and

- Ask caseworkers to encourage clients to participate (The Urban Institute, 2003).

Increasing participant response rates will ensure findings about outcomes are accurate.

DEFINING OUTCOMES

ILRU suggests the following as sources of ideas for outcomes: program staff, volunteers, program participants, participants' parents, records of complaints, program agencies that are "next steps" for participants, programs with similar missions, and outside observers of the program (Hendricks & Michaels, 2011a). Some of the most important outcomes to examine are often some of the most difficult to measure, such as consumer and systemic changes attributable to the CIL (CESSI, 2003). A few examples of possible outcomes to track are:

- Increased access to services for consumers, including employment, housing, income, and other programs directly related to CIL intervention;

- Documented reduction of barriers to participation in community life; and

- Levels of consumer satisfaction and reported changes in quality of life.

Research related to outcomes should focus on outcomes management. A 2012 NCIL report emphasizes the importance of outcomes management versus outcomes measurement. The goal of measuring CIL outcomes should be to identify and make improvements on outcomes that are identified as lower than the national average (NCIL, 2012). Research activities that are designed with outcome management in mind are integrated into CIL operations, identify program weaknesses, identify improvements, identify best practices, implement best practices, and then

remeasure outcomes. After outcomes are determined and defined, it is equally important to determine how to measure them.

MEASUREMENT

An outcome indicator is defined as "the specific item of information that tracks a program's success on an outcome" (Hendricks & Michaels, 2011b). The NCIL Task Force in 2012 described measurable indicators as the "heart of any outcomes effort" and used four main methods to identify outcome indicators: using the expertise of Task Force members and evaluation consultants, conducting a literature review, using personal contact with independent living researchers worldwide, and creating a public competition with a reward for the best suggestion (NCIL, 2012). This technique could be recreated in future studies examining CIL outcomes and determining measurable indicators of these outcomes.

It is important that indicators are measurable and relay to what extent the outcome is being achieved (Hendricks & Michaels, 2011b). Indicators should be SMART: specific, measurable, achievable, relevant, and timely. Some challenges exist when developing indicators related to CIL outcomes as it can be difficult to quantify outcome goals such as "increased community integration" or "increased independence." Researchers studying quality of life for people with disabilities note that the number of outcome domains is less important than ensuring the study framework has multiple elements and understanding that participants know what is important to them (Bonham et al., 2004). Quality of life can be explained in both objective and subjective manners; however, researchers note that it is "primarily the perception of the individual that reflects the quality of life that he or she is experiencing".

The 2012 NCIL Outcome Measures Task Force used three different measurement instruments to gather needed information to include: an interview guide for calls to CIL consumers, an interview guide for calls to information and referral callers,

and an information-gathering form for each Center (NCIL, 2012). These instruments were also recreated in SurveyMonkey to ensure the CILs could easily transfer information gathered on the paper form into an electronic format. Their technique of using both closed- and open-ended questions proved effective at examining the outcomes selected. Some examples of measurement tools will be described below.

One existing measurement tool is the Personal Outcome Measures® developed by the Council on Quality and Leadership (The Council on Quality and Leadership, 2020). It is an interview-based tool that consists of 21 different outcome indicators covering topics such as choice, health, relationships, rights, employment, etc. It measures individuals' quality of life in a person-centered way and is designed to be used with youth, adults, and older adults with intellectual, developmental, and psychiatric disabilities.

The National Core Indicators (NCI) is another measurement and tracking tool created by participating states, the Health Services Research Institute, and the National Association of State Directors of Developmental Disabilities Services (NCI, 2020). The NCI uses core indicators to track outcomes across the areas of employment, rights, service planning, community inclusion, choice, and health and safety. The NCI is used across participating states to track program outcomes and services to individuals with developmental disabilities. Research on CIL outcomes could use the NCI to guide how CIL outcomes research is designed and measured.

NIDILRR Tools Collection

NIDILRR has a collection of more than 40 surveys, checklists, needs assessments, and measurement devices in order to support dissemination of NIDILRR grantees' research, training, and demonstration projects.

The RTC on Measurement and Independence in Community Living developed three different surveys for people with disabilities that have been suggested for use at CILs (NARIC, 2011). The Characteristics of the Respondent survey collects demographic information about respondents. The Participation of People with Impairments and Limitations survey collects participation rates and evaluates 24 different activity areas. Lastly, they developed the Survey of Participation and Receptivity, which examines community participation in 19 different community settings. These surveys are taken online, but they can also be administered via phone if participants do not have access to a computer. Researchers can request these survey instruments from the RTC on Measurement and Independence in Community Living.

NARIC maintains a collection of measurement instruments and tools used by NIDILRR grantees. Future researchers should examine this collection when building their measurement tools in order to build off of effective past research in this field.

DATA COLLECTION

One way in which data collection from CILs can be improved is to ensure the data is compatible with a geographic information system (GIS) so CIL access can be better examined (Greiman & Seekins, 2015). GIS is used to analyze, visualize, and manage data, usually in map format, from a variety of industries. In relation to CILs, GIS offers a unique way to examine and analyze the distribution of CILs across the U.S. Changing how data is collected from CILs will allow this information to be compatible with a GIS analysis, improving further decision-making regarding CILs. The current issues with data from CILs are inconsistent data and reporting, lack of location information, and missing data. A 2015 study suggests that some solutions include: creating unique IDs for CILs, improving data consistency, collecting location information from CILs, and linking to geographic identifiers consistent with the U.S. Census. With these improvements in data collection, the reliability of data

reporting will increase, data constraints will be reduced, and a map of the distribution of CILs will be more accurate, indicating underserved areas.

Qualitative research methods, as well as mixed-methods research strategies, have proven effective in disability research. Some practical problems with quantitative research in this field include low prevalence of certain impairment groups, making it difficult to draw conclusions for such a small sample group (Hartley & Muhit, 2003). In addition, due to the nature and broad definition of disability, researchers are often looking at very heterogenous groups, which can be difficult to draw conclusions on based solely on quantitative data. Qualitative research methods can be especially effective for special populations, such as those underrepresented in research, with low literacy, or who might be intimidated by a long survey (Curry et al., 2009). Furthermore, qualitative data collection allows for an iterative process to occur, moving between data collection and data analysis as new ideas emerge. Mixed-methods can combine multiple quantitative and qualitative strategies together, providing a complimentary approach to the research (Kroll et al., 2005). Furthermore, mixed-methods in disability research allows people with disabilities to be involved in the study at various stages, to include commenting on the content, wording, length, layout, and available formats of the assessment tools.

Urban Institute — Analyzing Outcome Information

One effective way of including consumers in the research process is through focus groups. Focus groups allow consumers voices who typically are excluded from other forms of data collection to be heard (Kroll et al., 2007). Researchers should provide necessary accommodations to ensure the focus group meets its objectives. Preparation and planning are key to ensuring that focus groups conducted with individuals with disabilities are effective at meeting their research goals.

DATA ANALYSIS

When analyzing outcomes for needed program improvements, the Urban Institute identifies the following important steps: (1) identify outcomes that need attention, (2) identify client groups that need attention, (3) identify service procedures and policies that need improvement, and (4) identify possible improvements in service delivery (The Urban Institute, 2004a). In addition, the Urban Institute describes how outcome analysis can be used to motivate staff and volunteers through communicating program results, scheduling regular program reviews, identifying needs related to training or technical assistance, and recognizing staff and volunteers who produce good outcomes. Other important internal uses of analyzing data can be to: include identifying successful practices, test changes in a program or new programs, help plan and budget for programs, and motivate consumers.

It is estimated that only about 14% of health research makes its way to inform day-to-day practice (Dew & Boydell, 2017). While there is no data on this for disability-related research, it can be difficult for research on CILs to make its way to inform the day-to-day services provided. The field of knowledge translation suggests that researchers should develop innovative ways to disseminate their findings to encourage the incorporation of this information into service provision. Knowledge translation in disability research helps with "ensuring that research agendas and results are led by, and communicated in partnership with those with most to gain — people with disabilities, their support networks, and practitioners." Using a knowledge translation conceptual framework can assist with ensuring the findings of disability research are applied in the field of disability services.

Sample Client Surveys — The Urban Institute

REDUCING CIL ADMINISTRATIVE BURDEN DURING STUDIES

As CILs are often recognized as recruitment locations for studies related to people with disabilities, it is important to consider the way future studies will interact with CIL staff and consumers to ensure research fatigue does not occur. For studies where CIL staff are highly involved and must collect data, it is important to reduce administrative burden wherever possible. One important way of reducing CIL administrative burden during research studies is to ensure that those providing direct services are not given the burden of analyzing data (The Urban Institute, 2004b). They should participate in the process of viewing the relevant data; however, the role of analyzing it can be assigned to program managers. CILs can be very small organizations, making data collection burdensome in addition to regularly assigned roles. To remedy this, CILs could seek a volunteer from a local university to assist with elements of data. However, CIL staff can be an important way to develop trust with study participants and a vital resource in informing consumers about studies currently being conducted and their purpose. Future studies should consult directly with CIL staff to determine feasibility of study requirements and documentation.

Conclusion

The ICDR identifies CILs as an integral part of services for people with disabilities in the community. The ICDR promotes future research and collaboration related to the impact of CIL service types and delivery methods. Future research should focus on outcomes management, where outcomes are tracked and used to modify existing practices in an iterative process. Future research should also examine specific CIL service types, such as peer mentoring, advocacy efforts, health and wellness groups, and transition and diversion services. CILs empower people with disabilities within their respective communities, and outcome-focused research can further examine the ways CILs are successfully impacting their consumers.

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