Collaboration Between University Centers for Excellence in Developmental Disabilities (UCEDDs) and Independent Living Networks

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Collaboration between University Centers for Excellence in Developmental Disabilities (UCEDDs) and Independent Living Networks

Student and Committee Information

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Placement Site: Association of University Centers on Disabilities (AUCD), Washington D.C.

AUCD’s mission is to advance policies and practices that improve the health, education, social, and economic well-being of all people with developmental and other disabilities, their families, and their communities by supporting its members in research, education, health, and service activities that achieve their vision. (AUCD, 2017) AUCD is the national Technical Assistance Center for the network of University Centers for Excellence in Developmental Disabilities.

Describe service learning activities to be performed: Sarah will work with AUCD staff and support them in their efforts. This includes but is not limited to grant writing, conducting research for grant submissions, helping with the development of policy briefs and other types of educational materials.

Abstract

In every state and U.S. Territory, there is a University Center for Developmental Disabilities (UCEDDs), which is part of the state Developmental Disabilities network and an Independent Living (IL) Network,
composed of Centers for Independent Living and Statewide Independent Living Councils. Each of these receive federal funding (and frequently state funding) to support people with disabilities and their families. However, each has different federal funding sources, different origins within federal legislation and different requirements. Through discussions with IL and UCEDD leadership it is clear that there are collaborations between the two, yet this is not widely recognized. This research proposal seeks to identify past and present collaborations, potential activities for future collaboration and barriers between collaboration at the state and federal levels. As a direct extension of this research, an anticipated outcome is to identify an action-oriented project which could drive innovation and improve collaboration between the UCEDD and state IL networks, specifically in Nebraska.

**Problem Statement**

There is a need to identify and evaluate collaborations between University Centers for Developmental Disabilities and Independent Living networks in order to identify best practices to maximize limited funding and draw upon the strengths each offers to complement the other.

**Introduction:**

Federal legislation has created both the structure and funding for University Centers for Developmental Disabilities (UCEDDs) and state Independent Living (IL) networks in every state. However, different federal legislation has authorized each entity and outlines different requirements. UCEDDs are required to be part of a University system and employ a variety of professionals including faculty. Many UCEDDs employ ‘family as faculty’ and ‘self-advocate faculty’ to demonstrate the unique expertise of the ‘lived experience’ and to demonstrate how individuals and families need to be partners in care and independent living. Additionally, a requirement of the Developmental Disabilities Act is that UCEDDs facilitate a Consumer Advisory Committee (CAC) whose membership reflects the ethnic and geographic representation of the state with the majority of members being made up of people with developmental
disabilities and family members. IL networks, composed of Statewide Independent Living Councils (SILCs) and Centers for Independent Living (CILs) are typically non-profit, community-based organizations that are required to be run by 51% of people with disabilities. (National Council for Independent Living [NCIL], 2017) UCEDD’s core functions include conducting research, providing services, training students and professionals and disseminating information to improve services and supports for people with disabilities and their families (especially those with intellectual/developmental disabilities). (AUCD, 2017) Centers for Independent Living are required to provide five core services which includes: teaching people with disabilities independent living skills, assisting with individual and systems advocacy, facilitating peer-to-peer support, providing information and referral services, diverting and transitioning people from nursing facilities and helping youth transition from high school. (Administration for Community Living [ACL], 2017) Statewide Independent Living Councils are required to have the majority of their council be composed of people with disabilities representing all types of disabilities who work to create, monitor and evaluate the State Plan on Independent Living and expand the network of Centers. (Independent Living Research Utilization [ILRU], 2017) All this is done to create systems that allow people with disabilities to have appropriate services and supports to live independently.

Recent structural changes at the federal level created the Administration on Disabilities by merging the Independent Living Administration with the Administration for Intellectual and Developmental Disabilities (AIDD) and are now part of the Administration for Community Living. Funding for both the IL Network and the Network of UCEDDs come from the Administration on Disabilities and which also has created the impetus for the IL and DD networks to work together more closely.

Historically, the Independent Living and Developmental Disabilities Networks have worked in parallel. For example, both promote the full inclusion of people with disabilities into all facets of society. They have worked to promote services and supports for people with disabilities and their families and also
worked to decrease institutionalization. While many of the same underlying principles have shaped their individual service delivery, opportunities to benefit from collaboration have rarely been realized or, at minimum, maximized. It is also worth noting that federal policy and legislation most often impact both. For example, the Americans with Disabilities’ Act (ADA) prevents discrimination of people with disabilities and requires entities that receive federal funding to be accessible for people with all types of disabilities. The ADA became the premise of Olmstead, a 1999 Supreme Court ruling that found that states must set up systems to allow individuals with disabilities to live in the least restrictive setting and that they cannot be required to live in institutional settings. The Olmsted case was carried forward by two women with Intellectual/Developmental Disabilities. However, the Court ruling impacts all people with disabilities who are at risk for institutionalization. The Workforce Innovation Opportunity Act (WIOA) recently passed in 2014 and which reauthorized the Rehabilitation Act of 1973, prioritizes employment—especially employment for youth with disabilities and established the fifth core service for CILs; nursing home transition and youth transition. This means that the IL network in each state is to support youth (likely those with DD) to help them transition from high school into post-secondary education or obtain competitive, integrated employment. (ACL, 2017) Further, WIOA allowed for State Independent Living Council’s (SILCs) to change their Designated State Entity (DSE). WIOA designated the DSE as the fiduciary agent for the SILC and at a minimum, the Part B federal funding in each state. The DSE is a required partner in signing the State Plan for Independent Living. Nebraska became the first state in which the UCEDD became the DSE for a SILC. This has garnered national attention as it was not an expected outcome of the federal law. However, this innovation could establish a precedent that other states could follow and help facilitate future collaborations between UCEDDs and IL networks.

Importance of Proposed Project

Include historical significance and relevance of the project to public health, including the background information, gaps in knowledge.
Approximately 19 million people in the United States have a disability, translating to 1 out of every 5 individuals. (U.S. Census, 2012) Over the years, people with disabilities have faced many barriers. These include low rates of employment (Bureau of Labor, 2013), inability to access insurance or be charged higher premiums due to pre-existing conditions (Jarchow, 2016), and barriers to inclusion in educational and environmental settings. In addition, many individuals with disabilities have often been forced into institutional settings. The Centers for Disease Control (CDC) reports that there are frequently multiple barriers that can make it extremely difficult or even impossible for people with disabilities to function. These include attitudinal barriers, communication, physical, policy, programmatic, social, and transportation. Frequently, many of these barriers occur at the same time. (2017)

Gloria L. Krahn, Deborah Klein Walker, and Rosaly Correa-De-Araujo believe that because of many barriers faced by people with disabilities they should be considered as a population that experiences health disparities (2015). In 2000, the US Department of Health and Human Services authored *Healthy People*, and included a specific chapter on goals and objectives specifically for people with disabilities for the first time. (Krahn, et. al., 2015) The Disability and Secondary Conditions Focus Area of Healthy People from the 2010 version was expanded to include a broader range of objectives, with increased emphasis on health determinants in Healthy People 2020. (Healthy People 2010, Chapter 6)

While University Centers for Excellence in Developmental Disabilities (UCEDDs) serve as liaisons between academia and the community (Administration for Intellectual and Developmental Disabilities [AIDD], 2017), the Association of University Centers on Disabilities (AUCD) serves as the technical assistance (TA) center for UCEDDs. They also serve as a TA to fifty-two Leadership Education in Neurodevelopmental and other Disabilities (LEND) training programs. (AUCD, 2017 and Health Resources Services Administration)
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[HRSA, 2017] LENDs are funded by the Health Resources Services Administration. IDDRCs are funded by the Eunice Kennedy Shriver National Institute for Child Health and Human Development (NICHD), and are also members of AUCD. (AUCD, 2017)

Centers for Independent Living (CILs) and Statewide Independent Living Councils (SILCs) are mandated as a consumer-driven system. CILs must employ at least 51% people with disabilities to offer peer-to-peer support and to help other people with disabilities to determine their goals and then assist them to achieve independent living. SILC membership must be composed of 51% people with disabilities. (ILRU, 2017) In every state and territory, there is a SILC and Center(s) for Independent Living (IL), which makes up the state IL Network. Like the UCEDDs, the IL Networks also have a membership organization and is offered technical assistance. For example, the National Council for Independent Living (NCIL) and the Association of Programs for Rural Independent Living (APRIL) are both membership organizations that support CILs and SILCs. Yet, each has a specific niche. APRIL’s focus is on rural programming and NCIL’s focus is on policy and infusion of global IL philosophy and services. However, there is also overlap between the two. NCIL is based in Washington D.C. and provides its members legislative updates, holds an annual conference in D.C. for its members to learn best practices, network with and receive technical assistance from other IL leadership. APRIL also holds a conference annually for its members but unlike NCIL, this conference travels to different locations across the country and specifically offers support for IL organizations in more rural locations. Both are run by and for people with disabilities. The Independent Living Research Utilization (ILRU) is the national center for information, training, research, and technical assistance in independent living. Based out of TIRR...
Memorial Hermann Rehabilitation and Research, ILRU and its faculty and staff provide training and technical assistance to CILs and SILCs through its IL-Net programs. (ILRU, 2017) The IL-Net partners include Utah State University which provides on-line courses and evaluation; APRIL, which oversees the mentoring program and IL Conversations; and NCIL, which oversees webinars and on-site training. (McElwee, 2018)

Both UCEDDs and IL networks work to identify the needs of people with disabilities and their families throughout the state, must complete a needs assessment to identify these and work to remediate the identified barriers. A primary requirement of SILCs is to create the State Plan for Independent Living (SPIL) in collaboration with the Centers for Independent Living in the state. The SPIL is renewed every three years and must be signed by the SILC Chair (acting on behalf of the SILC), 51% of the CILs in the state and the Designated State Entity. (McDaniel, A., McElwee, P., Jones, D.L., Heinsohn, D., 2016) The SPIL requires the SILC to identify gaps and barriers to independent living, collaborate with the CILs to identify activities and allocate funding to help address these barriers. Finally, the SILC is to monitor the implementation and progress of meeting the goals and objectives identified in the 3-year SPIL. (Hammond, M., Jones, D. L., McDaniel, A., McElwee, P., Holt, J., Eubanks, C. 2017)

As University affiliated programs, UCEDDs have historically had a focus on academia, providing research, training and services to build capacity while IL programs have a focus on providing peer-to-peer supports and service delivery to ensure people with disabilities are able to achieve independent living. IL networks have typically been led by people with disabilities while UCEDDs have historically employed faculty with expertise in disability services. However, it is important to note that this does not mean that the IL network cannot employ non-disabled individuals nor a person with a disability cannot work within or lead a UCEDD. Both work for systems change for and with people with disabilities and their families. Combining the data from UCEDDs and the personal stories of people with disabilities who are affiliated with IL networks through work and/or services could innovate and improve the services and
supports of people with disabilities. For example, together they could be translational research networks which work to accelerate clinical research into direct services or improve the oversight and transparency of home and community based services. They might also be able to contract with managed care organizations or hospital organizations to help improve health outcomes for people with disabilities and their families.

The President’s Budget of 2018 proposed to combine the Statewide ILCs, Developmental Disabilities Councils and Traumatic Brain Injury Councils. (Meltzer, 2017) This would fundamentally alter the services and supports for people with disabilities in every state. Combining these Councils would also limit state funding to IL networks and DD Councils, reducing the federal allocation to these entities by approximately $51 million. (Health and Human Services, 2017) In a time when many people, especially those with disabilities, are concerned about the future of programs that have historically provided their lifeline to the community, there is a need to recognize allies and rally together to maintain current allocation levels. Medicaid, for example is being proposed as a block grant to states in the current Republican proposals. (Luthra, 2017) Block granting Medicaid is essentially capping funding allocations and limiting services. For many people with disabilities, for which Medicaid is their lifeline to the community, this could have a significant and deleterious impact. Additionally, when federal law is passed down to the states for implementation, there are opportunities for involvement in shaping how these services at the state level will be set up. Often times there are requirements for involvement of people with disabilities and family members of people with disabilities to be on advisory councils to help guide the development of such policies or solicit comments on new initiatives or changes. As one example, when a state creates a home and community based (HCBS) Medicaid waiver or renews a Medicaid waiver, the state must take public comments for 30 days, respond to the comments and submit these with the waiver application to the Centers for Medicare and Medicaid Services (CMS) to review with the waiver application. (Lollar, 2014 and CMS, 2015) This is significant as often its people with disabilities or family members who have direct experience with the service delivery and who likely
know the gaps and barriers firsthand. With this requirement, members of the public are able to report to the state what their concerns are and these also go to the federal government for further oversight. The public comments are reviewed by CMS before the state waiver gets approved. (Lollar, 2014) This is one very specific opportunity for systems change, yet, who teaches people with disabilities or families that they have this option or that their comments may result in direct changes to the implementation of a HCBS Medicaid Waiver? Who teaches them how to be effective members of advisory councils or boards? The state may ask for public comments but likely most individuals with disabilities or family members do not know that the state has to respond and submit both their comment/s and the state’s response to CMS for review. It’s also unlikely that the individual will have a background of the policy or a national perspective to understand what is possible to drive systems change. The collaboration (or enhanced collaboration) between the federally-funded IL networks and UCEDDs could serve the aforementioned roles.

Literature Review

In 2012, the Secretary of Health and Human Services (Kathleen Sebelius, at the time) established the federal Administration for Community Living (ACL) using her authority. This decision brought together the Administration on Aging, the Office on Disability, and the Administration on Developmental Disabilities. (ACL, 2017) Then in 2014, the passage of the federal Workforce Innovation and Opportunity Act (WIOA) transferred the Independent Living Administration to the ACL. Organizational Chart displaying relationship between AIDD, the grantor for the UCEDDs and ILA, the grantor for the state IL networks.
Living programs from the federal Department of Education to the ACL. (NCIL, 2017) This structural change has led to increased focus by many on harnessing the power of both networks to partner with the Center for Medicare and Medicaid Services (CMS), the Department of Labor and other agencies at both the federal and state level to improve systems of support for people with disabilities and families. However, there are likely additional ways to improve collaborations.

Currently there are sixty-seven UCEDDs with at least one in every state and territory. UCEDDs work with people with disabilities, members of their families, state and local government agencies, and community providers on projects that provide training, technical assistance, service, research, and information sharing, with a focus on building the capacity of communities to sustain all their citizens. (AUCD, 2017)

The national network of UCEDDs is authorized under Public Law 106-402 (The Developmental Disabilities Assistance and Bill of Rights Act of 2000 or "DD Act") and core funding is administered by the Administration on Intellectual and Developmental Disabilities (AIDD). The technical assistance arm for UCEDDs is the Association for University Centers on Disabilities (AUCD). Funding for what are now University Centers for Developmental Disabilities (UCEDDs) was initially authorized in 1963, after President John F. Kennedy, who had a sister with an intellectual/developmental disability (IDD), convened a panel on Mental Retardation. (Walker-Jackson, L., Ellerbusch, K., Swanson, S., 2011) The initial Act allocated funding for University Affiliated Facilities (UAF) in 1970, then changed to University Affiliated Programs (UAPs) The UAPs became UCEDDs which were grants tasked to build capacity to support individuals with developmental disabilities and their families. The primary goal of the UAP was to train professionals to help provide interdisciplinary services and supports to individuals with IDD and their families. (ACL, 2017) UCEDDs were (and still are) required to leverage their core funding to partner with other federal, state, and local resources. (AUCD, 2017)

Additional amendments to the DD Act provided funding to support Protection and Advocacy organizations and state Developmental Disabilities (DD) Councils. Combined, UCEDDs, the DD Council and the Protection and Advocacy Organization make up the DD Network in each state and Territory.
When the DD Act was reauthorized in 2000 there were nine "areas of emphasis." These include: child care, education, employment, health, housing, quality assurance, recreation, transportation, and other formal/informal community supports. (Walker-Jackson, L., Ellerbusch, K., Swanson, S., 2011)

According to the Administration for Community Living (ACL), “The Independent Living Discretionary Grant Program is authorized Under Title VII, Chapter I, Part C of the Rehabilitation Act, as Amended by the Workforce Innovation and Opportunity Act (WIOA) of 2014. The Centers for Independent Living (CILs) Program provides 354 discretionary grants to part C centers that are consumer-controlled, community-based, cross-disability, nonresidential, private nonprofit agencies who provide the five core IL services. Each center is required to provide the five core services which include:

- Information and referral;
- Peer to Peer mentoring;
- Independent Living skills training;
- Individual and systems advocacy; and
- Supports that help transition and divert individuals from nursing homes and other institutions to the community, and support youth with disabilities as they transition to post-secondary life.

While the five core services identified above are required, CILs may also provide other services in order to improve the ability of individuals with disabilities to function independently and gain access to their community. Examples of other services include: assistance in securing housing or shelter, supports to transportation, personal assistance services, physical therapy, mobility training, rehabilitation technology and recreation.

To continue receiving CIL program funding, eligible centers must demonstrate minimum compliance with the following standards:
• Promotion of the IL philosophy;
• Provision of IL services on a cross-disability basis;
• Support for the development and achievement of IL goals chosen by the consumer;
• Efforts to increase the availability of quality community options for IL;
• Provision of IL core services and, as appropriate, a combination of any other IL service;
• Building community capacity to meet the needs of individuals with significant disabilities; and
• Resource development activities to secure other funding sources.

A population-based formula determines the total funding available for discretionary grants to centers in each state. Subject to the availability of appropriations, ACL is required to provide continuation funding to existing centers at the same level of funding they received the prior fiscal year and to provide them with a cost-of-living increase. Funding for new centers in a state is awarded on a competitive basis, based on the state’s State Plan for Independent Living and the availability of sufficient additional funds within the state.” (2017)

The Administration for Community Living also appropriates funding to IL Networks in each state to expand, and improve the provision of independent living services under Title VII, Chapter I, Part B of the Rehabilitation Act, as Amended by the Workforce Innovation and Opportunity Act (WIOA) of 2014. This funding allocation requires the establishment of a Statewide Independent Living Council and the development and approval of a State Plan for Independent Living (SPIL). (ACL, 2017)

According to the Administration for Community Living, “The allocation of Part B funding is to support the work of the SILC and the Designated State Entity (DSE), (the state entity responsible to receive, account for, and disburse the ILS funds) with the remainder of the funds used for the following activities as reflected in an approved SPIL:
1. Providing independent living (IL) services to individuals with significant disabilities, particularly those in unserved areas of the state;
2. Demonstrating ways to expand and improve IL services;
3. Supporting the operation of CILs;
4. Increasing the capacity of public or nonprofit organizations and other entities to develop comprehensive approaches or systems for providing IL services;
5. Conducting studies and analyses, developing model policies and procedures, and presenting information, approaches, strategies, findings, conclusions, and recommendations to federal, state, and local policymakers;
6. Training individuals with disabilities and individuals providing services to individuals with disabilities and other persons regarding the IL philosophy; and
7. Providing outreach to populations that are unserved or underserved by programs under this title, including minority groups and urban and rural populations.” (ACL, 2017)

The origins of the Independent Living movement came as a response to the historical barriers (attitudes, behaviors) people with disabilities faced. The IL movement rebelled against the traditional system – especially the medical model in which the practitioner is the expert and the person with a disability must assume the position of ‘sick’. (Shreve, 2011) According to Maggie Shreve, an independent consultant who has researched the IL movement, “in the 1960s people with disabilities joined together to protest their exclusion from society’s mainstream and to demand more humane, non-medical attention from the nation’s service delivery system. (2011) Much like the civil rights movement of the 1960s, people with disabilities became frustrated by their inability to live in and participate in communities of their choice and the barriers to transportation, housing, employment and education that they faced. (Americans with Disabilities Act [ADA] Legacy Project, 2017) Ed Roberts and Judy Heumann, were two such individuals who experienced such barriers. Both Roberts and Heumann had personally experienced barriers and discrimination based on their disability. Roberts at the age of fourteen contracted polio and
needed an iron lung to breathe. He advocated to attend the University of Berkeley and because of his disability had to live in the infirmary. (Reasoner, 1989) Heumann, also contracted polio as a child and was a teacher who was told she would not be hired because she was in a wheelchair. (ADA Legacy Project, 2017) Roberts started a group of students with disabilities at Berkley, California that called themselves the ‘Rolling Quads’ (Reasoner, 1989) and Heumann lived in New York City and started a group called ‘Disabled in Action’ (DIA). (Hall, 2008) Both the Rolling Quads and DIA held sit-ins in federal buildings to protest the failure to pass legislation that required accessibility and anti-discrimination of people with disabilities by entities that receive federal funding. Through their advocacy (and others), the Rehabilitation Act of 1973 passed which included Section 504, the first civil rights statute for persons with disabilities which helped pave the way for the 1990 Americans with Disabilities Act (ADA). (ADA Legacy Project, 2017) The ADA is a federal law that requires places that receive federal funding to be accessible to all people with disabilities. It is interesting to note that both Heumann and Roberts had a developmental disability but spent much of their careers in the Independent Living movement. This is but one example of the crossovers between IL and DD.

In 2011, the National Council on Disability wrote a report that revisited the DD Act, when the topic of ‘self-advocacy’ was discussed, the authors questioned whether the DD Act was the correct funding source for such a movement. Instead they questioned whether it would be better funded and placed within the IL movement and built upon a similar peer-to-peer structure. (National Council on Disability, 2011)

Since one of the primary goal of UCEDDs is research, the UCEDDs could can help to measure the impacts of IL programs. For example, they could help with required needs assessments and help to ‘make the data case’ or calculate the return on investment for sustainability of programs. They could also could help to facilitate additional funding to CILs through grants and contracts to help carry out diversion to and transition from nursing homes or secure other types of funding to carry out IL activities. In 2011, in a
review of the DD Act, the National Council on Disability suggested that UCEDDs could use their national network to do:

- Nationwide research and development: Many UCEDDs have developed a track record in research and development that could be harnessed into a nationwide approach.

- Nationwide demonstrations: With a presence in all 50 states, the District of Columbia, and the trust territories and a history of collaborations, the UCEDD network is in a unique position to implement nationwide demonstrations focused on people with DD.

- Nationwide dissemination: The UCEDDs are connected to providers, advocacy groups, parent groups, and state governments, and could serve as credible sources to inform stakeholders of new initiatives, findings, and best practices.

- Translation of research to practice: With expertise in both research and service provision, the UCEDDs are able to quickly translate research into practice. A stronger formal connection with various research-based agencies such as NIH, the Institute for Educational Sciences, and National Institute on Disability Research and Rehabilitation would enhance this opportunity.

While there are likely many opportunities for collaboration between UCEDDs and IL Networks, there are also likely many barriers. For example, anecdotally it has been reported that CILs are not accessible for individuals with intellectual disabilities and that there is a hierarchy of disability. (Swenson, 2010) Thus, this research proposal seeks to identify the specific opportunities for collaboration and barriers to collaboration between the IL networks and UCEDDs.

**Goals and Objectives**

- **Goal I:** Identify collaborations and barriers to collaboration between UCEDDs and IL networks at the state and federal level.
## Objective 1.1:
By the end of May, a minimum of 10 leaders at all levels of leadership (top management, middle management and consumers) within the IL and UCEDD Networks will be contacted to identify past, current and future collaborations and barriers to collaboration between the UCEDDs and IL networks.

## Objective 1.2:
By the middle of June, a survey will be created to further capture UCEDD and IL leadership responses to collaborations and barriers to collaboration between the two entities.

## Objective 1.3:
The survey will be piloted by a minimum of 7 people to ensure that the survey is functional and revisions made by the end of June.

## Objective 1.4:
The survey will be disseminated broadly by the middle of June 2018.

## Objective 1.5:
Results of the survey will be reviewed to determine if there is an appropriate number of responses. (End of June)

## Objective 1.6:
Specific UCEDD and IL leadership will be contacted to help disseminate the survey using their influence and social networks to increase survey participation.

### Goal 2: The survey results will be analyzed and results compiled.

**Objective 2.1**
By the end of June, the survey results will be aggregated for interpretation.

**Objective 2.2:**
By the first week of July, results of the survey and interviews will be summarized into general themes.

**Objective 2.3:**
By the middle of July, the themes and overall results will be compiled into a research paper that identifies historical collaborations, future opportunities to collaboration and barriers to collaboration between the UCEDD and IL networks.

### Goal 3: Innovations and an actionable activity which can be implemented in Nebraska will be identified as a next step to completion of the Capstone project.

**Objective 3.1:**
Through the steps of interviewing, analyzing and compiling themes, innovations that could be implemented in Nebraska as ‘best practice’ will be identified.
Objective 3.2: A submission to the National Council for Independent Living (NCIL) conference, the Association of Providers for Rural Independent Living Centers and/or the Association of University Centers on Disabilities (AUCD), regarding findings related to innovations and research results will be disseminated and shared.

Methods:

Background:

At a time when funding is either being reduced or reductions are being proposed in federal and state programs, there is a need for disability organizations to work together to strengthen and maintain current programming. Both the IL and UCEDD networks support individuals with disabilities and their families in order to create systems to better support their inclusion and full participation in all aspects of society. From observations and interviews with individuals who participate in each network, it seems that there is overlap in programming and policy initiatives but that these are not formally recognized. Therefore, research is needed to establish a baseline of current overlaps, barriers to collaboration and also opportunities for future, more formalized collaborations.

Research Question:

What are the current collaborations, barriers to collaboration and opportunities for future collaborations between UCEDDs and IL Networks?

Application of Theories

It is anticipated that both the Institutional and Resource Dependent Theories would likely describe existing collaborations between the UCEDD and IL Networks. The Institutional Theory would support the projects/programming which demonstrate innovations and the dissemination of best practices. It would also provide a basis for failure of the networks to collaborate. The Resource Dependent Theory would explain lack of network collaborations attributable to the different federal funding streams but would also explain collaborations in which funding existed to support collaborative efforts. Finally, the
Theory of Change will be utilized to map out shared goals between both the IL and DD Networks (identified through the surveys) and process map the activities that would be necessary in order to complete the goals and identify the potential barriers as well.

**Study Design, Data Collection, Sample Size (Power), and Data Sources**

This quantitative study will solicit responses from a cross-section of leadership within the UCEDD and IL Networks. Questions about their knowledge of the two Networks, past collaborations, their organization’s priorities and opportunities for future collaborations will be asked. Survey questions will be developed with leadership from both networks and disability leaders. The survey will be piloted by a minimum of seven individuals to help identify any technical difficulties and to ensure fidelity within the questions. Next, the survey will be electronically disseminated using the Qualtrics survey system. If possible, the surveys will be ‘tagged’ in order to track survey respondents to their respective network. Using the online, Qualtrics survey system will allow the survey to be delivered through email, tracked with reminders sent prior to non-respondents before the survey’s close. To achieve a 95% Confidence Level, a minimum of 29 respondents is needed from the 67 UCEDD Directors and 26 responses from the 55 Statewide Independent Living Councils (SILCs). In order to achieve the same 95% Confidence Level, responses from a minimum of 43 Center for Independent Living (CIL) Directors will be needed from the 395 Part C-funded Centers. (Creative Research Systems, 2018) Email address and other contact information will be sought from AUCD, NCIL, APRIL, ILRU or the federal Administration for Community Living (ACL). Other individuals including but not limited to individuals with disabilities, families and others interested/involved with disabilities will also be allowed to partake in the survey. Respondents outside UCEDD and IL leadership will be permitted to identify if there is a difference between individual respondents versus leadership responses, though this is not the primary purpose of this study.

**Data collection methods and Limitations:**

Upon completion of the quantitative data collection, it will be analyzed and interpreted. Software such as SPSS may be utilized to help with the analysis and the creation of applicable graphs. The data is limited by the number of respondents who respond to the online survey and the amount of time available to contact non-respondents.
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**Policy analysis, interventions and program development**

The responses to the survey will be analyzed and graphically displayed. The survey results will be used to develop a “Theory of Change” model for the two networks. A process-map will be developed to identify the common goals, recommendations and the necessary activities required in order to achieve shared goals and objectives. This information will be collected and disseminated throughout the two networks in hopes that it will be used to drive collaborative projects in states and across states.

**Administrative Resources**

Anticipated resources needed to successfully complete this project include: computer, use of survey software (Qualtrics), use of SPSS, paper, projector, access to internet, use of library and library tools, use of phone and long distance fees (if applicable). Travel expenses have also been discussed if opportunities present themselves for meetings with influential leaders that are working in the healthcare field.

**Ethics**

There is no known or anticipated ethical concerns. UNMC IRB was contacted and provided that since this research does not deal with human subjects, IRB is not needed.

**Results**

Qualitative interviews were conducted with individuals within both the UCEDD and IL Networks to help develop the survey questions. Questions related to the knowledge individuals had about each respective network was asked as well as the barriers to collaboration. Many individuals indicated that there were historical barriers to collaboration. For example, many leaders within the IL Network felt that the UCEDDs were driven by the parent movement and had not moved towards fully empowering individuals with disabilities to make their own decisions and be allowed to take risks—core tenants of the Independent Living philosophy. Several individuals reported that they associated each respective network with their historical funding source. A few interviewees indicated that they while they knew
that UCEDDs were required to support individuals with intellectual and developmental disabilities, they likely provided support to a broader pool. Additionally, a couple of the interviewees felt that while CILs and SILCs said that they served individuals with all types of disabilities, they felt that they weren’t supporting individuals with intellectual disabilities at a level that could be and work was needed to do more to be fully inclusive. Leadership within the IL Network felt that there were UCEDDs that stood out for specific things such as conducting research and many associated the UCEDDs with higher academia. It is likely important to note that a few individuals who have been involved with both the UCEDD and IL Networks expressed much interest and delight in this project as they felt that there were silos between the two networks, much overlap and many opportunities to enhance collaborations.

Initially, the survey was drafted and piloted by a few individuals. They provided feedback on the overall content and ease of use. With their suggestions, changes were incorporated. The survey was then piloted again to ensure overall function. The survey totaled nineteen questions and contained questions that utilized a likert scale, matching and a sliding scale. Many of the individuals who piloted the survey stated that they liked the interactive questions as opposed to questions that simply asked them to mark boxes. The survey was disseminated by email to sixty-five UCEDD Directors, four hundred and sixty-three CIL Directors, and forty-nine SILC Directors.

<table>
<thead>
<tr>
<th>Role:</th>
<th>Total Disseminated</th>
<th>Yielded</th>
</tr>
</thead>
<tbody>
<tr>
<td>UCEDD Directors:</td>
<td>65</td>
<td>48%</td>
</tr>
<tr>
<td>SILC Directors:</td>
<td>49</td>
<td>39%</td>
</tr>
<tr>
<td>CIL Directors:</td>
<td>463</td>
<td>21%</td>
</tr>
<tr>
<td>Others:</td>
<td>Unknown</td>
<td></td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td><strong>Unknown</strong></td>
<td><strong>238</strong></td>
</tr>
</tbody>
</table>

An email reminder was disseminated approximately two weeks after the initial launch. An anonymous link was also created and specific ‘key influencers’ were asked if they would help disseminate the survey. Embedded into the *Qualtrics system* was a data code that would link the number of responses back to each key influencer who helped to disseminate the survey. A total of two hundred and thirty-eight responses were obtained during a period of three weeks. Responses consisted of 31 UCEDD Directors (48% of total surveyed), 19 SILC...
Directors (39% of total surveyed), 99 CIL Directors (21% of those surveyed) and finally 89 responses from individuals with other roles outside of those previously named.

The survey included many different types of questions that attempted to ascertain the level of collaborations which existed between the IL Networks and UCEDD programs across all states and U.S. territories. Respondents were asked to answer their beliefs on whether they agreed that the IL Networks and UCEDDs should work together to make policy change, if there were systems issues that prevented collaborations, if the two entities shared the same philosophies and if they competed for the same funding. These questions were pertinent as in many of the qualitative interviews conducted, many individuals felt that while there were many common themes/projects that both the IL and UCEDD programs were likely working and that each held similar beliefs that overall there were few collaborative projects occurring.

The following chart indicates initiatives or projects that CILS, UCEDDs and SILCs are working as reported by each respective organization’s director. You will note that in almost every topic area each organization has involvement and at very similar levels in many areas.

However, collaborations on these initiatives aren’t happening to the extent they could. For example, when respondents were asked to rank the current level of collaborations which exist between UCEDDs
and IL Programs, UCEDD Directors indicated that currently collaborations “exist somewhat” with the mean response at 51.5 on a 100 point scale. IL Program Directors indicated less collaboration with CIL Director’s mean response at 27.87 and SILC Director’s mean responses at 26.47. The level of current collaborations is much less than all of the Directors believe should exist.

Overwhelmingly, respondents indicated that they believed that UCEDDs and IL programs should work together to make policy changes. Specifically, 92% of UCEDD Directors, 93% of SILC Directors and 77% of CIL Directors either agreed or strongly agreed to the statement, “UCEDD and IL programs should work together to make policy changes.”

Responses were mixed to the statement UCEDDs and IL Programs do not share the same philosophies. A total of 77% of UCEDD Directors disagreed or strongly disagreed with this statement, while individuals in the IL Network had a more moderate response. Forty-seven percent of SILC Directors and 48% of CIL Directors disagreed or...
strongly disagreed with the statement. Individuals with disabilities scored lower with 33% disagreeing or strongly disagreeing.

The majority of responses to the statement, “There are systems issues to collaboration between UCEDDs and Independent Living programs” agreed. A total of 67% of SILC Directors, 54% of UCEDD Directors, 35% of CIL Directors and 50% of Individuals with a disability either agreed or strongly agreed. Additionally, 42% of CIL Directors agreed somewhat, which when combining their total level of agreement is 72%. It’s safe to conclude that over 50% of the respondents indicated they agreed at least somewhat that there are systems issues preventing collaboration between the two networks.

Finally, respondents were asked to respond to the statement, “UCEDDs and IL programs compete for the same funding.” Seventy percent of UCEDD Directors either disagreed or strongly disagreed with this statement. However, leadership within the IL Network responded more moderately to this question with 47% of SILC Directors who either disagreed or strongly disagreed but also with 47% agreeing somewhat. Additionally, 50% of both CIL Directors and Individuals with disabilities either disagreed or strongly disagreed with the statement while 41% of CIL Directors and 39% of Individuals with disabilities agreed somewhat.

Additional tables are available for analysis in the appendix.
Service learning activities performed: The service learning completed included the development of a policy brief about innovations and best practices in Medicaid Managed Long-term Services and Supports (MLTSS). It consists of an in-depth brief, a more condensed brief and finally a guide for stakeholders.

Discussion/Recommendations
In the next decade, many of the very programs that are lifelines for individuals with disabilities and their families will very likely be under attack. As our population ages and our baby-boomers begin to need long-term services and supports, there will be increased demand for these programs. At the same time, current projections are showing that there won’t be a large enough population base to ‘pay in’ to support these programs. It will likely become necessary for state and federal disability networks and other advocacy organizations to collaborate to push against these efforts simply to maintain current funding or retain programs.

Systems change usually takes the combination of both data and personal stories. The UCEDDs are situated to collect the data and the IL Networks are tasked to provide advocacy at both an individual and systems level. The collaboration between the two networks could allow each to ‘play to their strengths’.

Since UCEDDs are located within University systems, they frequently are constrained against the priorities of the University system and cannot ‘advocate’ for specific issues. However, UCEDD programs could provide their research to partners with the IL system who are required to do advocacy. Yet, this is only possible when there are collaborations and existing relationships which exist. This research shows that leadership within both the IL and UCEDD networks believe they should be working together to influence policy and systems change and there are many current initiatives that are areas of focus across each network. However, this research also indicates that UCEDDs and the IL Network may not share the same philosophies and that the majority of respondents indicated that there are systems issue to collaboration.
Additional research is needed to delve more deeply to understand what specific systems issues exist and why UCEDD Directors rank both the level of collaborations and the belief that networks share the same philosophies much higher than Directors of CILs or SILCs. These beliefs could be a root cause as to why there is not more robust collaboration between the two networks across states. If additional federal funding was made available in each state in efforts to bring the federally-funded disability networks together or if there were requirements in existing grants, this may help to break down some of these issues.

Conclusions

There are many parallels between the Independent Living Network programs and the UCEDDs and many opportunities for collaboration. With the reorganization of the Administration for Community Living bringing both the Independent Living Administration and the Administration for Intellectual and Developmental Disabilities together to form the Office on Disability, this may also help to bring the respective networks together across states.

The appendix also contains graphs which depict the projects which the leadership within the two networks believes each organization is working. While it was not the priority of this research project to analyze these activities in depth, the graphs clearly indicate that the UCEDD programs stand out across all programs for research. Additionally, leadership within each organization indicate they believe all of the organizations are working within each area provided. Ironically, it seems that overall each leader marks their own organization as having the highest involvement in activities and the other respective network as not having as high of involvement as their own organization. This begs the question if there needs to be more training provided to leadership in both the IL and UCEDD networks on the function of each, their program requirements and highlight focus areas that each network is working. As the graphs in the appendix clearly indicate there are overlaps.
References:


Service Learning/Capstone Experience Reflection:

One direct result of my Service Learning/Capstone is the knowledge that I gained researching innovations and best practices in Medicaid Managed Long-Term Services and Supports. I developed a short brief, a very detailed brief and a guide for stakeholders which I hope to disseminate and publish. It is my intent that these become tools which stakeholders and disability advocates can use to help ensure that the implementation of MLTSS is done with fidelity and with protections in place. Since momentum for MLTSS is growing and the service delivery is changing, I believe that I obtained very practical knowledge about what is effective. I was able to reach out to leaders in this arena who were very willing to provide their knowledge and share insights. I also reached out to individuals who are being impacted by this change. It was interesting to see the difference in responses between policy experts and individuals who have seen significant changes to their services by this policy shift. Individuals who depend on LTSS programs frequently expressed fear and cynicism, while policy specialists discussed the opportunities and concerns. This reminds me of the need to always involve stakeholders at different levels as they likely have different perspectives.

Nebraska is moving toward MLTSS. This research is directly applicable and I plan to disseminate these briefs through the state disability networks. Additionally, the Association of University Centers on Disability (AUCD) plans to post these briefs on their website and disseminate through their network. Receiving mentorship from Denise Rozell and the policy team at AUCD was incredibly empowering. I loved to hear what was going on in Washington D.C. and also learn of their priorities. At some point in my career, it is my hope that I will be able to do a Fellowship in Washington D.C. I love policy because it offers the opportunity to make the biggest impacts.

When my research project was launched, I wanted to obtain a baseline of data on collaborations between the UCEDD and IL Networks and also have the leadership within each, identify priority areas in which they have involvement. Having served as the chair to the Nebraska Statewide Independent Living
Council (NESILC) and also working at the UCEDD, I saw significant overlaps. Anecdotally, it was reported that there may be systems issues to collaboration. I hoped that my survey could help quantify these. Upon the launch of my survey, there were several individuals within both the UCEDD and IL Networks who asked for the results and also indicated interest in conducting future studies on this topic. While the focus of this research was specifically targeted to the leadership within the IL and UCEDD Networks, it was open to anyone who was willing to take the survey. There is much further data which was collected and could be used for future research or provide the basis for a grant application. It is likely that targeted qualitative surveys will be conducted to learn more about the systems issues that exist between the two networks. It is my hope that collaborations between the UCEDD and IL Networks can be improved and that this research could provide the basis for such activities.
Acknowledgements:

First of all, I would like to extend my thanks to Bob Williams. Without his support and backing, I would not have had the opportunity to do a Fellowship at AUCD. For that, I will be forever grateful. Next, I would like to thank Denise Rozell, my preceptor at AUCD. She was always willing to provide mentorship and guidance as I developed the policy briefs and also the survey questions for my research project. She patiently answered questions and helped to connect me to individuals who could further assist me in my quest for knowledge. I also need to thank my Committee members who offered their support throughout my Service/Learning Capstone experience. Additionally, I’d also like to thank Dr. Wayne Stuberg, my Director who served as an ‘ex-officio’ member of my Committee and Kathy Hoell, Executive Director of the Nebraska Statewide Independent Living Council who is my colleague and dear friend. Both offered encouragement, mentorship, and support for me to complete the Service Learning Capstone project and my Masters in Public Health. Finally, and most importantly, I would like to thank my family for their patience and support as I completed my Master’s program. There were many late nights and weekends spent in front of my computer. I hope that my work will help my children see that ‘anything is possible’.
Appendix:

University Center for Excellence in Developmental Disabilities (UCEDD) Director/Associate Director

Organization that is currently working on or supports the topic.

Center for Independent Living (CIL) Director

Organization that is currently working on or supports the topic.
UCEDDs Support Other Types of Disabilities Beside Those With Intellectual and Developmental

CILs Support Those with Intellectual Disabilities

UCEDD Director | SILC Director | CIL Director | Individual with disability
---|---|---|---
Yes | No | Uncertain

CIL Director | Individual with disability
---|---
Yes | No | Uncertain

82.14% | 93.75% | 97.8% | 85.71%
Collaboration between University Centers for Excellence in Developmental Disabilities (UCEDDs) and Independent Living Networks

UCEDDs and Independent Living Programs Compete for the Same Funding

- UCEDD Director
- SILC Director
- CIL Director
- Individuals with Disability

UCEDDs and Independent Living Programs Collaborate on Grant Applications

- CIL Directors
- SILC Directors
- UCEDD Directors
Independent Living Programs and UCEDDs Collaborate at the State Level

Independent Living Programs and UCEDDs Collaborate at the Federal Level