

## **Appendix IV. University Centers for Excellence in Developmental Disabilities Education, Research, and Service**

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### ***Administration on Disabilities (AoD) Disability Employment Technical Assistance (TA) Center Landscape Assessment Appendices***

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As described in the methodology within the main section of the landscape assessment, the Center's project team conducted quantitative and qualitative analysis to identify current University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) initiatives and areas of further development. Appendix IV details findings from the quantitative data reviewed as well the qualitative interviews conducted with UCEDD staff and self-advocates.

### **Trends in Provision of Employment and Economic Advancement Supports and Systems Change Efforts**



Since 1963, UCEDDs have worked to accomplish a shared vision that foresees a nation in which all Americans, including Americans with disabilities, participate fully in their communities. Independence, productivity, and community inclusion are key components of this vision. Currently, all 67 UCEDDs in every state and territory are in a university setting.

Each of the 67 UCEDDs are distinct in terms of structure, focus, and areas of concentration. Interviewees noted that the

UCEDD's affiliation and location within a university system has a significant impact on the identification and implementation of priorities. For example, some UCEDDs are woven into a university children's hospital or a medical school that includes a strong research focus on intellectual and developmental disabilities (I/DD) while other UCEDDs are more autonomous and operate with greater independence.

Another difference that interviewees noted is that some UCEDDs have significant autonomy and flexibility to apply entrepreneurial strategies with respect to partnership building, fundraising, and project development. In contrast, other UCEDDs are restricted to following a bureaucratic internal process to identify projects, secure funding, and establish partnerships with outside entities. As a result, the structure of UCEDDs in relationship to other components of a university system and of their own staff often guide the priorities and areas of concentration. This impacts the extent to

which UCEDDs can focus on improving competitive, integrated employment (CIE) outcomes and economic advancement of individuals with I/DD.

For example, Exhibit 1 presents a case study of the differences among the three UCEDDs in California.

**Exhibit 1. Case Study of California’s Three UCEDDs**

	<b>Tarjan Center at University of California, Los Angeles (UCLA)</b>	<b>University of Southern California (USC) UCEDD at the Children’s Hospital Los Angeles</b>	<b>Center for Excellence in Developmental Disabilities at the University of California, Davis (UC Davis) Medical Investigation of Neurodevelopmental Disorders (MIND) Institute</b>
<b>Location within University</b>	Semel Institute for Neuroscience & Human Behavior	The USC University Center for Excellence in Developmental Disabilities, based at Children’s Hospital Los Angeles and the USC Keck School of Medicine	UC Davis MIND Institute
<b>Center Description</b>	A catalyst for collaboration, innovation, and systems change to advance the self-determination and inclusion of all individuals with disabilities.	<ul style="list-style-type: none"> <li>Provides clinical services to over 5,000 individuals each year and interdisciplinary training programs to over 16,000 parents, students, and professionals.</li> <li>Collaborates in research and policy projects to develop more responsive systems of care and increase access for children with I/DD.</li> </ul>	Serves as a resource in the areas of education, research, and service, and provides a link between the university and the community to improve the quality of life and community inclusion of individuals with I/DD and their families.

***Core Strengths of UCEDDs in Supporting Competitive, Integrated Employment and Economic Advancement***

UCEDDs often deploy entrepreneurial strategies when building a program based on a new or existing area of focus, as well as when identifying collaborative opportunities on state policy reform efforts; leading research, evaluation, and data collection efforts; and providing training and professional development to build the capacity of one or more state systems. Interviewees noted that UCEDDs are well-respected as a subject matter expert on various areas related to supporting the inclusion and advancement of individuals with I/DD.

***Pilots, Evaluations, and Validations of New Models and Promising Practices***

Some UCEDDs also serve in a dual role as grantees under the Administration for Community Living’s (ACL) National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR) as Rehabilitation Research and Training Centers (RRTC). RRTCs conduct coordinated, integrated, and advanced programs of research, training, and information



dissemination in NIDILRR-specified topical areas. Several UCEDDs with RRTCs promote employment, independent living, family support, and economic and social self-sufficiency for individuals with disabilities. UCEDDs that have won awards to become RRTCs to focus on employment and economic self-sufficiency shared that they have had opportunity to pilot new provider transformation models as well as validate and evaluate the implementation of specific promising practices related to advancing CIE for individuals with I/DD, traumatic brain injury, and serious mental illness. For example, the [Institute for Community Inclusion \(ICI\) at the University of Massachusetts-Boston](https://beta.communityinclusion.org)<sup>1</sup> leads the [RRTC on Advancing Employment](https://www.thinkwork.org/rrtc)<sup>2</sup>. One of the goals of ICI at University of Massachusetts-Boston includes developing a model framework and toolkit to support community rehabilitation providers in implementing an Employment First focus. A key feature of this research is the demonstration of an efficient, scalable strategy that enables Community Rehabilitation Programs (CRPs) to create change within their own organizations.

### ***Policy Analysis and Reform***

States often leverage the expertise of UCEDDs to address systemic issues. In a review of state Employment First initiatives, 32 initiatives indicated participation of at least one UCEDD. The role of UCEDDs is typically related to data collection and analysis, program implementation and evaluation, or policy analysis and research. Several UCEDDs interviewed noted involvement with state Employment First systems change efforts and attributed such involvement in these efforts as an opportunity to showcase their entity's strengths. Their participation also created strong and trusting partnerships with state Vocational Rehabilitation (VR), Medicaid, and State Council on Developmental Disabilities (Council) systems. For example, the [University of Iowa's Center for Disabilities and Development's \(CDD\)](https://uihc.org/locations/center-disabilities-and-development)<sup>3</sup> provided ongoing technical assistance (TA) on the realignment of the Medicaid service definitions and reimbursement methodology for employment services to the Iowa Coalition for Integrated Employment that included representatives from the Iowa Department of Human Services, VR, and state Council. The TA from the University of Iowa's CDD led to the update of state employment service definitions, reimbursement rates and methodology, and provider and staff qualifications ensuring consistency between Medicaid and VR.

### ***Capacity Building through Professional Development and Certification***

Although many UCEDDs do not focus on the provision of professional development, several UCEDDs and subject matter experts (SMEs) interviewed indicated this as an emerging opportunity for UCEDDs. In particular, interviewees noted opportunities to provide TA and professional development to direct support professionals (DSPs) and CRPs to strengthen their capacity to support individuals with disabilities to pursue and secure CIE outcomes. UCEDDs that are willing to invest in partnership with employment SMEs and build their own team of SMEs among staff, have the potential to become their state's leading conduit for TA and the credentialing of the front-line support force for individuals with disabilities pursuing CIE. Several UCEDDs have already

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<sup>1</sup> The ICI at the University of Massachusetts-Boston's website is located at: <https://beta.communityinclusion.org>.

<sup>2</sup> The University of Massachusetts-Boston ICI's RRTC on Advancing Employment page is located at: <https://www.thinkwork.org/rrtc>.

<sup>3</sup> The University of Iowa's CDD's website is located at: <https://uihc.org/locations/center-disabilities-and-development>.



played a leading strategic role in their state's TA and capacity building efforts related to CIE. For example:

- The [Center of Excellence in Developmental Disabilities at the University of Connecticut](#)<sup>4</sup> has worked in partnership with the state Council and P&A on a Customized Employment Initiative since the passage of the federal Workforce Innovations and Opportunities (WIOA) Act of 2014. The UCEDD has collected and analyzed data from this initiative, as well as supported training funded by the state Council. To date, approximately 150 employment staff statewide have participated in three-day intensive trainings. An additional 25 staff have received national certification in one of the three initiative components as well as attained significant positive changes between training pre- and post-test scores. The UCEDD continues to support trainings and provide follow-up TA to trainees and the DD network.
- The [North Dakota's Center for People with Disabilities at Minot State University](#)<sup>5</sup> partnered with the state of ND to design and implement the [Statewide Customized Employment Specialist Training Project \(ND CREATE\)](#)<sup>6</sup>. ND CREATE coordinates and provides TA to disability service providers to explore and implement innovative customized employment strategies (CES) to provide CIE for individuals who are currently receiving day and/or work supports in facility-based, segregated environments. Outcomes include training and TA on discovery, marketing and job development, and systematic instruction. CRPs acquire increased skills to deliver CES for individuals with I/DD that lead to CIE. The ND UCEDD is making efforts to align the ND CREATE training curriculum with the Association of Community Rehabilitation Educators (ACRE) Competencies with an Emphasis on Customized Employment. This will raise the service delivery standard in the state of North Dakota while offering participants the nationally recognized ACRE Certificate of Achievement in Employment Services.

### ***Data Collection and Research Activities***

Several UCEDDs interviewed commented on their leadership role related to data collection to inform the development of the state's foundational knowledge regarding the experiences and impact of individuals with disabilities in pursuing employment. Some UCEDDs reported developing and conducting surveys of CRPs, families, and self-advocates regarding the provision of day services and their impact on helping individuals pursue and maintain employment. The outcomes data of this research is often stratified by type of setting where the individual is receiving supports (e.g., as an individual in the community, as part of a group receiving supported employment, as a participant in facility-based programming such as sheltered workshops or day habilitation, and as a self-employed individual or individual receiving job development services). Few if any entities outside a UCEDD would possess both the subject matter expertise related to disability plus the technical skills to complete robust data collection and research activities.

In 2016, the University of Iowa's CDD completed an Individual Employment Outcomes Data Collection Pilot on behalf of the Iowa Coalition for Integrated Employment (ICIE). The survey

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<sup>4</sup> The University of Connecticut UCEDD site is located at: <https://uconnucedd.org/resourcecenter/collaboration-2/>.

<sup>5</sup> The Minot State University UCEDD site is located at: <http://ndcpd.org/>.

<sup>6</sup> The ND CREATE program site is located at: <https://www.ndcpd.org/statewide.html>.



report<sup>7</sup> summarizes the feedback and the individual outcomes data collected from 19 employment service providers. The providers surveyed reported an unduplicated total of 2,104 persons who work in various settings. The survey findings confirmed that individuals with I/DD and other significant disabilities receiving ongoing supports to work in CIE had better employment and economic outcomes than individuals working in group supported employment or sheltered work. For instance:<sup>8</sup>

- Individuals in CIE worked longer hours (~27/week) compared to group supported employment services (SES) (~17/week) and sheltered work (~23.5/week).
- Individuals in CIE received significantly higher hourly wages (\$8.67/hour) than individuals working in group supported employment (\$5.60/hour) or sheltered work (\$3.23/hour).
- Individuals in CIE also received higher monthly wages (\$432) than individuals working in group supported employment (\$194) or sheltered work (\$152).

### Success Story Theme: Collaboration

#### University of Iowa's CDD as a Leader in the State's Employment First Efforts

The University of Iowa's CDD has taken a comprehensive approach to its leadership in advancing the state of Iowa's Employment First agenda. CDD served as Iowa's contracting partner in implementing the federally-funded ten-year Medicaid Infrastructure Grant (MIG) which focused on improving the employment outcomes of individuals receiving Medicaid-funded home and community-based services (HCBS). Additionally, in partnership with the ICIE, CDD focuses on capacity-building and systems change efforts to foster improved CIE outcomes for individuals with disabilities. These activities include spearheading data collection efforts, analyzing trends in Medicaid HCBS provision, offering in-depth training and curriculum to both provider leaders and their staff, and engaging in public awareness campaigns (e.g., "If Everybody Works – Success Stories"). The culmination of CDD's leadership role resulted in a collaborative publication entitled, [The Great Debate](#), which has served as a useful educational tool and model for other state DD networks.

The report from the University of Iowa's CDD was a valuable tool for disability stakeholders to use in educating state agencies and legislatures. State agencies and legislatures have learned about the benefits of investing in building provider capacity for supporting individuals to move into CIE while simultaneously decreasing investments and the state's reliance on group SES and sheltered work.

### Key Challenges and Considerations

#### Relationships with Academia, the DD Network, and State Agencies

The Center's focus groups and interviews with various representatives of the DD network identified several challenges. Often, the roles of the state Council, P&A, and UCEDD are unclear or duplicative. One DD partner could have entirely different priorities and areas of concentration

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<sup>7</sup> Amsbaugh, T. (April 2017). Iowa Coalition for Integrated Employment Outcomes Data Collection Pilot. Center for Disabilities and Development University of Iowa Children's Hospital.

[https://uihc.org/ucedd/sites/uihc.org.ucedd/files/icie\\_outcomes\\_pilot\\_report\\_4-27-2016\\_6-3-16.pdf](https://uihc.org/ucedd/sites/uihc.org.ucedd/files/icie_outcomes_pilot_report_4-27-2016_6-3-16.pdf)

<sup>8</sup> Ibid, #14, p. 5.





from the other two. Thus, developing strong, connective collaborations among the DD network that are focused on improving CIE outcomes for individuals with significant disabilities at the individual and systems level requires time, commitment, and determination on the part of all three DD partners.

These challenges are in addition to the complexity that UCEDDs uniquely encounter in navigating the “strange and territorial waters of academia.” During the project team’s interviews with UCEDD representatives, there was a range of leadership support for employment initiatives from full support to opposition. There was a consensus among UCEDD interviewees that due to the distinct nature of UCEDDs, it was “impractical” to hold an expectation that every UCEDD would focus on employment, even minimally. Some UCEDD interviewees felt strongly that while geography within a university’s biostructure could make it more difficult for some UCEDDs to focus on employment, geography alone was not a sufficient reason for a UCEDD not to explore prioritizing employment as an area of concentration.

With regards to state agency partnerships, some UCEDDs expressed a fear that if they advocate or push state agencies too hard on systems change goals, they may jeopardize their ability to secure future funding and contractual opportunities to partner with state VR, education, Medicaid, and workforce investment agencies on initiatives related to CIE and economic advancement.

Overall, interviewees conveyed that while all UCEDDs *could* conceivably work to build a strong focus and concentration around CIE and economic advancement among its priority areas, it does not necessarily mean that all UCEDDs *should* focus on this area. Particularly in states with multiple UCEDDs or other members of the DD network taking on strong roles related to employment systems change, interviewees noted that it “may be too difficult of an uphill battle” for a UCEDD that has engaged minimally on employment work in the past to invest in building it into the organization’s existing priority areas.

**Success Story Theme: Collaboration  
Tennessee UCEDD & Council**

When it comes to collaboration, the Vanderbilt Kennedy Center UCEDD and the Tennessee Council on Developmental Disabilities have become integral partners in the state’s Employment First initiative. Through the Employment First Task Force collaboration, both the Council and UCEDD have active roles in the Task Force and the leadership committees. The Council is the lead convening agency for the Memorandum of Understanding (MOU) focused on transitioning youth that also includes partnerships with the state Education, Mental Health, Department of Labor, I/DD, and VR agencies. Additionally, the Vanderbilt Kennedy Center UCEDD and Council were integral in advancing the signing of Executive Order No. 28 which mandated the creation of the Employment First Task Force and the prioritization of CIE for Tennesseans with disabilities. Through this partnership, transitioning youth with disabilities are receiving services in a more streamlined and coordinated approach.

## Emerging Themes and Opportunities

Based on these findings, the Center will approach its technical support to UCEDDs much differently than with some of the other AoD grantee types. The Center’s program team will (a) target TA to UCEDDs that are already prioritizing employment and economic advancement projects, particularly those that have only engaged at an elementary or intermediate level and wish to expand their work in this area; and (b) develop and provide basic informational resources that



other UCEDDs can disseminate to self-advocates, families, and relevant programs and schools within the University system to promote the importance of CIE and economic advancement of individuals with disabilities. The project team also intends to work with the Association of University Centers on Disabilities (AUCD) to survey interested UCEDDs on their needs and employment-specific TA activities and topics of interest.

### ***Leading Efforts to Scale and Sustain Innovative Models focused on Competitive, Integrated Employment and Socioeconomic Advancement of Individuals with Disabilities***

UCEDDs can help states, providers, and stakeholders “scale up” and expand evidence-based cases for bringing promising practices and innovative models that promote CIE and improve the financial capability of individuals with disabilities. Often, members of the DD network will use short-term state or federal funding through a grant or contract to create, test, and validate models related to capacity building, provider transformation, and self-advocate training and career exploration. When the initial funding concludes, however, the work often ends with no plan in place to sustain or expand the models. By playing a role in collecting data and evaluating the impact of new models, innovations, and promising practices, UCEDDs can provide the evidence needed to educate policymakers and funders about the importance of continuing to invest in these efforts after the initial grant or program has concluded.

### ***Fostering Greater Focus on Diversity, Equity, and Inclusion Challenges***

National UCEDD partners and individual UCEDD interviewees admitted that the DD network at-large needed to deepen their focus collectively to address the network’s actions to promote ongoing systemic disparities that reinforce racial inequalities for individuals of color with disabilities. Given that employment is driver of economic equity for people with disabilities **and** people of color and an essential conduit to unlocking other components of community inclusion and engagement, the Center could provide a strong vehicle for UCEDDs to work together with other UCEDDs as well as with other partners across the AoD grantee network to implement internal changes and pilot new external models promoting CIE and economic advancement of individuals of color with disabilities. It is critical that UCEDDs receive TA to adopt culturally competent practices and embed principles related to diversity, equity, and inclusion into all aspects of UCEDDs’ work in CIE and economic advancement, such as data collection and research, policy reform, TA, and stakeholder outreach and education.

### ***Drawing upon the Connection of Employment as a Key Social Determinant of Health to Expand Awareness across Disciplines within an Academic Environment***

During the Center’s qualitative research activities, UCEDDs expressed disagreement about potential engagement with other disciplines within their university structure responsible for instructing future professionals in areas that will impact the lives of individuals with disabilities (e.g., schools of education, business, medicine, social work, or law). Some interviewees proposed that because of UCEDDs’ unique positions within university systems, they could access faculty who are teaching the future generation of teachers, social workers, employers, lawyers, doctors, and other health care professionals. With this access, UCEDD representatives could help educate faculty on the importance of teaching their students about employment and economic advancement



of individuals with disabilities to ensure true diversity, equity, and inclusion in society. Most UCEDD interviewees expressed that it would be “a heavy lift” on their part to build any interest and eventual buy-in among faculty members of another school within the university system. However, despite the complexity to connect with other disciplines in the university system, several interviewees suggested that UCEDD staff with joint-faculty positions may have a unique opportunity to pursue this strategy.

Additionally, most interviewees agreed that UCEDDs could be a strong vehicle for disseminating informational resources to other parts of the university describing the intersection between disability, employment and economic advancement, and other disciplines with graduates who will be interfacing with individuals with disabilities throughout their careers. Thus, the Center may attempt over time to develop resources in collaboration with interested UCEDDs and coach joint-faculty with how to foster dialogue with other disciplines around these issues.

