

## **Appendix II. State Councils on Developmental Disabilities**

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

May 2021

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 State Councils on Developmental Disabilities (Council) initiatives and areas of further development. Appendix II details findings from the quantitative data reviewed as well the qualitative interviews conducted with Council staff and self-advocates.

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

Councils are federally-funded, self-governing organizations charged with identifying the most pressing needs of individuals with intellectual and developmental disabilities (I/DD) in their state or territory. Councils are committed to advancing public policy and systems change to help individuals with I/DD gain more control over their lives. The 56 Councils across the United States and its territories work to address identified needs by advancing advocacy, systems change, and capacity building efforts that promote self-determination, integration, and inclusion.



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

Key Council activities include conducting outreach, providing technical assistance (TA), removing barriers, developing coalitions, encouraging citizen participation, and influencing and informing public policy. Several Councils have leveraged these activities to promote improvements in competitive, integrated employment (CIE) outcomes and economic advancement of individuals with I/DD at primarily a systems-level.

#### ***Outreach, Education, and Advocacy***

One of the Council’s key responsibilities – and strongest characteristics – is their focus on reaching out to individuals with I/DD and their families to ensure they have the resources, information, and

education needed to become strong self-advocates for themselves and others with I/DD. With respect to employment and economic advancement goals, Councils have implemented several strategies related to outreach, education, and advocacy, including but not limited to:

- Hosting town hall meetings for individuals with I/DD to ask questions about finding a job and hear examples of workers with I/DD who have achieved CIE.
- Sponsoring job fairs with employers and other members of the DD network.
- Offering individuals with I/DD opportunities to attend state and regional trainings related to the application of self-determination and self-advocacy skills to the pursuit of employment and negotiation of accommodations in the workplace.
- Reaching out to families to promote the benefits of employment of individuals with I/DD in the general workforce, and to provide education about supporting employment and sustaining benefits.
- Offering educational resources regarding the availability and advantages of Achieving a Better Life Experience (ABLE) accounts for individuals with disabilities.
- Developing outreach and educational materials for state partner dissemination to educate individuals with I/DD about how to explore CIE and financial capability.

### **Provision of Technical Assistance and Investments in Innovative Models**

Councils offer and invest in a variety of TA to advance the employment goals of individuals with I/DD. Several examples mentioned in external sources and by interviewees include:

- Supporting providers of facility-based pre-vocational services to transition their models to support individuals with I/DD to achieve CIE.
- Developing pathways for individuals with I/DD to transition out of segregated work and day settings and into CIE.
- Working with schools, Vocational Rehabilitation (VR) entities, employers, and non-traditional partners to help youth and young adults with I/DD transition into the general workforce or post-secondary

#### **Success Story Theme: Innovation**

#### **Rhode Island Developmental Disabilities Council**

In Rhode Island (RI), individuals with disabilities who want to become entrepreneurs can participate in a program that equips them with the skills needed to manage a successful business. The funds are generated by an annual grant from the State Department of Labor and Training (DLT) Real Pathways Initiative with additional funding from the Coronavirus Aid, Relief, and Economic Security (CARES) Act. The program receives additional support through in-kind funding from the RI Council and through long-term job development support for individuals with I/DD from the VR and the state DD Department. This partnership is unique in that many of the partners involved do not focus on serving individuals with disabilities. Because the mission of the non-disability focused partners is related to employment for all regardless of disability, the RI Council took the opportunity to build upon common synergies. The collaboration includes numerous partners such as: RI Department of Labor and Training, RI Small Business Administration, RI Center for Women and Enterprise, RI Small Business Development Center, RI Cross Disability Coalition, Office of Rehabilitative Services, and Northern RI Chamber of Commerce. As a result of the RI Self-Employment Initiative, individuals with disabilities can achieve their goal of self-employment.



education upon completion of high school.

- Investing in the design and expansion of innovative models for apprenticeships, work-based learning, access to skilled jobs, and development of natural supports to strengthen the chances for success in securing and sustaining employment.
- Advising state agencies and financial service institutions administering ABLE accounts on how to educate, recruit, and assist individuals with I/DD and their families to open accounts.

### **Coalition Building and Collaboration**

Councils often serve in a leadership role in building coalitions and strategic collaborations among a host of partners to improved employment and economic advancement outcomes of individuals with disabilities. Others have built effective collaborations bridging the gaps among self-advocates, providers, and families to promote the pathway to employment for individuals with I/DD. Among the Councils interviewed as part of the landscape assessment, several noted their organizations' ability as state agencies to facilitate strong collaborations that involve one or more state partners (e.g., special education, VR, DD services, or Medicaid) and the entire DD network. For example, several Councils have served as the key conveners and leaders of their state's Employment First coalition to promote CIE as the preferred outcome of publicly-funded supports and services.

### **Promoting Diversity**

By law, state governors appoint Council members and must ensure that more than 60% of a Council's membership consists of individuals with I/DD or their family members. In addition to individuals with I/DD and their family members, advocates and state agency representatives also serve as members. Additionally, Councils are encouraged to ensure that members reflect the racial, ethnic, geographic, gender, age, and economic diversity that exists among individuals with I/DD. This diversity enables Councils to better analyze and improve systems and services within a state and ensure representation of the voices of all individuals with I/DD. The Center's project team views these requirements as a potential starting point for more intentional work to enhance diversity, equity, and inclusion among DD network.

### **Influencing and Informing Public Policy**

One of the strongest attributes of Councils is their ability to influence and inform shifts in public policy to advance the best interests of individuals with I/DD. Councils have positively impacted key state level issues such as phasing out subminimum wage, identifying financial incentives for businesses, defining systems of accountability, designing training and certification in customized employment, and establishing policy parameters for becoming an Employment First state.<sup>1</sup>

In the area of employment and economic advancement of individuals with I/DD, many Councils have demonstrated leadership in advancing strong policy reforms. Several examples documented by the National Association of Councils on Developmental Disabilities (NACDD) and the

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<sup>1</sup> Cox, B. and Mattingly, S. (October 2019). Topical Report: ABLE Accounts and Employment. Councils on Developmental Disabilities. <https://nacdd.org/wp-content/uploads/2019/11/ABLE-and-Employment-Report-Oct.-2019.pdf>.



Information & Technical Assistance Center for Councils on Developmental Disabilities (ITAC) include:<sup>2</sup>

- Serving on advisory and decision-making committees or task forces to address a wide array of employment issues, barriers, and opportunities.
- Advising and advocating for change with state policymakers based on established relationships and informed by Council-supported initiatives that have implemented successful practices.
- Facilitating communication and collaboration with state agencies and other employment partners.
- Submitting written comments and recommendations on policies, regulations, and waiver applications under consideration.
- Working with governments to become a model employer, per the National Conference on State Legislators' State as Model Employer initiative.
- Providing feedback on the effective implementation of federal policy at the state level.
- Developing policy briefs, analyses, and reports with recommendations for change.
- Supporting the expansion and sustainability of activities begun under the Office of Disability Employment Policy (ODEP) Employment First State Leadership Mentoring Program.

### ***Key Challenges of Councils in Effectuating Improved CIE Outcomes and Economic Advancement***

While many Councils have achieved success in pushing for greater education, advocacy, TA, policy reform, and strategic partnerships, several Councils have experienced challenges in advancing efforts to improve CIE and financial capability outcomes of individuals with I/DD.

#### ***Lack of Understanding among External Entities about the Role and Contributions of Councils***

Like the experiences of other AoD grantee types, Councils often experience challenges in educating members of the public, external stakeholder organizations, and even self-advocates and families about the role Councils have in increasing CIE and financial capability options for individuals with I/DD in their states. Additionally, while some Councils are “front-and-center” in convening, leading, and participating in state-level policy and programmatic areas, some interviewees commented that Councils are seldom engaged by other state agencies or external partners on these issues. Thus, a major aspect of the Center's TA offerings will include promoting the past and current work and contributions of Councils as well as Councils' ability to facilitate further employment-related systems change.

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<sup>2</sup> Ibid, 12.



### ***Prioritizing Employment and Economic Advancement of Individuals with I/DD***

While NACDD reports that all Councils across the country and in the territories have included goals related to employment in their previous five-year strategic plans, the Center heard that the depth, breadth, and quality of the goals, objectives, performance metrics, and outcomes vary greatly across states. Several Council leaders interviewed reported challenges in making progress on employment and financial capability goals if they had not carefully considered how to embed this area of work into other active goals of importance. Interviewees noted that while Councils include employment and economic advancement as important components of self-advocacy training and support, many Councils have not focused energy or investments in TA or policy reform related to these areas due to competing priorities.

### ***Influencing the Adoption of Major Policy Reforms***

While Councils have successfully influenced gubernatorial proclamations, executive orders, and the introduction of state legislation related to efforts to improve CIE and economic outcomes of individuals with I/DD, several Councils expressed frustrations with their inability thus far to overcome barriers related to more substantive policy reforms. Council interviewees noted have experiencing challenges in securing more specific reforms related to transition services within educational systems, VR services, and Medicaid Home and Community-Based Services (HCBS) provision. Interviewees noted reasons such as a lack of engagement, knowledge expertise, or influence over other partners. Examples of challenges that Council interviewees cited included:

- Developing action-oriented memoranda of understanding (MOU) that reflect partner accountability;
- Engaging with and impacting educational systems to advance scalable transition strategies that promote CIE, especially given that local educational agencies are largely autonomous in their policies and approach to transition;
- Advocating for changes to VR services, reimbursement rates, and provider requirements intended to strengthen the focus and performance of VR agencies relative to CIE; and
- Influencing state Medicaid and DD agencies to implement the federal HCBS settings criteria with fidelity, particularly with respect to congregate day and work settings.
  - Council interviewees noted that despite their input during written comment and public testimonial opportunities, many of their recommendations related to proposed changes to state Medicaid HCBS waivers that would prioritize supported employment and customized employment services over facility-based pre-vocational services are largely ignored.

Councils interviewed stated they would like additional TA on strategies to increase their influence over specific policy reforms related to employment and would like increased opportunities to learn from their peer group about strategies that other Councils have successfully implemented.



## Emerging Themes and Opportunities

### ***Creating a “Niche” Area for Promoting ABLE Accounts***

Councils have demonstrated their unique strength in educating and assisting self-advocates and their families in considering and opening ABLE accounts. These efforts from Councils have led to great success in increasing the number of ABLE accounts across the nation and may serve as a model of successful practices to other AoD grantees. Given this success, helping Councils offer other financial capability trainings and resources as well as expand and sustain their significant impact on ABLE account adoption could be a potential topic of Center/Council collaboration.

### ***Elevate the Voice of Workers and Job-Seekers with I/DD to Influence State and Federal Policy***

A unique feature of Councils is their ability to bring together self-advocates and families for the sole purpose of elevating their voices among state agencies and policymakers. Given the frequent turnover among state and federal leaders, ongoing education of policymakers is central to creating champions for change and systems transformation. Council interviewees noted that major policy discussions occurring at the state or federal level often do not include the perspectives of self-advocates and families. Some interviewees expressed concerns about ongoing “token engagement”<sup>3</sup> of these stakeholders. Interviewees noted a need for “more than simply token engagement” by embedding the stories and experiences of individuals with I/DD and family members into discussions around CIE and economic advancement. These stories are critically important to dismantling low expectations and negative assumptions about what individuals with I/DD can contribute to their communities and the workforce. Particularly as American society shifts to an ever-virtual paradigm, Councils can collaborate with self-advocates and their families to produce low-cost, low-technology virtual videos and testimonials to share with both state and federal policymakers.

### ***Influence the Design, Planning, and Emphasis of State-led TA Efforts Focused on Provider Transformation and Capacity Building***

Several Councils have participated in ODEP’s Employment First State Leadership Mentoring Program and AoD’s Partnerships in Employment Systems Change Grants. Their participation led to successfully piloted and validated models of high-impact, results-oriented investments in provider transformation and capacity building efforts to reduce the reliance on segregated day and work activities and increase CIE options for individuals with I/DD. These models are replicable both within and across states, and serve as an important opportunity for Councils to have a more formidable role in the state efforts to build the capacity of their provider base through using of promising practices related to CIE.

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<sup>3</sup> This refers to the concept of “tokenism.” Merriam-Webster defines this as: “the practice of doing something (such as hiring a person who belongs to a minority group) only to prevent criticism and give the appearance that people are being treated fairly.”



**Success Story Theme: Systems Change**  
**Michigan Developmental Disabilities Council**

Like many state Councils, the Michigan Council facilitates an array of trainings to the community about the benefits of including individuals with disabilities into society. Part of the Council's work has previously focused on co-funding provider transformation efforts in partnership with the state's provider trade association, and negotiating Employment First policy guidance through consensus-building. Additionally, recognizing the critical importance of addressing the longstanding challenges imposed on individuals of color, including those with disabilities, the Michigan Council incorporated diversity and equity training for all organizations receiving funding from the Council. The incorporation of diversity and equity in the training raised education and awareness while also effectively executing the Council's mission.

***Promoting Diversity, Equity, and Inclusion through Areas of Potential Intersection  
Related to Employment, Race, and Disability***

As previously mentioned, federal requirements around the composition of Councils ensure that individuals with I/DD and family members are prominently included in Council membership. However, there are still many opportunities for Councils to bridge the intersection among race, ethnicity, and disability, particularly in areas related to inclusive education, transition to employment and post-secondary education, CIE, and financial independence. Ensuring diversity in not only the composition of membership but also in educational programming, advocacy activities, policy reforms, and TA is timely for Councils to prioritize. While there are a few strong examples across the country of Councils spearheading equity efforts as a part of promoting CIE, there is a tremendous opportunity for the Center to assist Councils in fostering connections with entities representing underserved communities, developing strategies for increasing diversity, equity, and inclusion in the provision of DD services, and improving access for individuals with I/DD to CIE opportunities and financial capability.

