



# **SWTCIE** Practice Brief

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# Engaging People with Disabilities and Lived Experience

#### **About the Subminimum Wage to Competitive Integrated Employment (SWTCIE)**

**National Evaluation.** In September 2022, the Rehabilitation Services Administration awarded five-year grants for Disability Innovation Fund demonstration projects. As part of the Subminimum Wage to Competitive Integrated Employment program, these federal fiscal year 2022 grants provided funding to 14 state vocational rehabilitation agencies to implement Innovative Model Demonstration projects. These projects aim to decrease subminimum wage employment and increase competitive integrated employment for people with disabilities currently employed in or contemplating subminimum wage employment. To achieve these goals, the projects will create innovative models for dissemination and replication that (1) identify strategies to address barriers to accessing competitive integrated employment, (2) provide integrated services that support competitive employment, (3) support participants' integration into the community through competitive employment, (4) identify and coordinate wraparound services for participants who obtain competitive employment, (5) develop and disseminate evidence-based practices, and (6) provide readily accessible and transformative business models that entities with section 14(c) certificates can adopt.

#### Introduction

This practice brief explores how Subminimum Wage to Competitive Integrated Employment (SWTCIE) projects engage people with disabilities and lived experience through communities of practice, stakeholder groups, and mentoring programs. The findings come from interviews with staff from three SWTCIE projects (Connecticut, New York, and Pennsylvania) held in November 2023. Lessons learned could help other grantees effectively engage people with lived experience in the design and implementation phases of their SWTCIE projects. The descriptions presented here represent early engagement efforts and plans, and they do not represent all SWTCIE projects or vocational rehabilitation agencies.

This brief uses the phrase "people with lived experience" as a catch-all term to reflect people with disabilities, families of people with disabilities, people with experience in subminimum wage employment, and people with experience in competitive integrated employment. During interviews, SWTCIE staff used several terms to describe groups that convene to gather input and include people with lived experience, such as communities of practice, work groups, and advisory councils. Generally, communities of practice refers to groups of people with shared expertise or passion who meet regularly to discuss insights and knowledge. Work groups or advisory councils often mean more formal groups with specific responsibilities in managing or directing a project (or some aspect of it), but these definitions might not

February 2024

apply to the specific grantee programs described below. Despite the terminology used, all groups described by interviewed SWTCIE staff convene regularly to gather feedback and include people who attend as part of their jobs and those with an interest in the topic, including people with lived experience.

**Exhibit 1.** Promising practices for recruiting and engaging people with lived experience

<b>Promising practice</b>	Examples
	• <b>Leverage existing partnerships</b> with state agencies and departments to introduce and recruit people with lived experience.
	Involve partners and external organizations with expertise to provide technical
Leverage	assistance and training for mentorship programs.
relationships	Leverage the lived experience of contractors and project staff to increase trust.
	Allow mentors and family members to attend meetings to maximize comfort and support.
Provide	• Schedule meetings at times most convenient for people with lived experience (for example, in evenings or around lunchtime).
accommodations	Offer <b>separate private meetings</b> as a less overwhelming option when onboarding people with lived experience into a new community of practice or advisory group.
	Ensure the availability of assistive technology when needed.
	Offer hybrid meetings to accommodate busy schedules.
\mathrew \frac{1}{2} -	Provide <b>monetary compensation</b> for participation in work groups, communities of practice, and mentorship programs.
	Allow opportunities for participants to coauthor or present feedback to recognize
Recognize participation	their unique contributions.
555V	• Engage <b>family members with varying viewpoints</b> , including those who express support for competitive integrated employment and those with concerns about it.
	Involve underrepresented voices, such as members of the LGBTQ+ community and
Include diverse perspectives	those from non-English speaking communities.

# **Findings**

#### Below are summaries of the three projects discussed in this brief.

#### **Spotlight on Connecticut**



The Connecticut Pathways to Integrated Employment (CT/PIE) project began engaging people with lived experience during the design phase via four subgroups that branched off from an initial Partner Workgroup. Along with staff delegated by state agency commissioners and representatives from independent living centers, Workforce Boards, Community Rehabilitation Providers, 14(c) certificate holders, the Council on Developmental Disabilities, University Centers for Excellence in Developmental

Disabilities Education, and State Rehabilitation Council, each subgroup contains one or more people with intellectual and developmental disabilities and one or more family members. Each subgroup meets monthly and has a specific focus: business pathways, training and technical assistance, outreach and messaging, and individualized supports. As the project moves into its implementation phase (beginning November 2023), these subgroups will transition to regional communities of practice. CT/PIE has successfully recruited people with lived experience to participate in the subgroups and community of practice through CT/PIE's connections with partner agencies, such as the Department of Developmental Services and its ombudsperson office. The project hopes this community of practice will continue the duration of the project and beyond. The state also plans to revamp its existing peer and family mentoring programs, which will be individualized and may include one-to-one and group mentoring services and will introduce compensation for peer mentors. CT/PIE's partners at University of Maryland will provide technical assistance for the mentoring programs.

#### **Spotlight on New York**



The Promoting Advancement of Competitive Integrated Employment (PACIE) project uses a peer-facilitated model through Centers for Independent Living (CILs) to offer an array of comprehensive supports leading to competitive integrated employment. PACIE will engage people with lived experience during its implementation phase through a community of practice. The state's CIL partners, whose staff are primarily people with disabilities and peer mentors, will participate in the communities

of practice. PACIE will also offer peer mentoring services operated by the CILs. Overseen by the New York State Association of Independent Living, CIL staff will recruit and compensate the peer mentors. The PACIE team anticipates that mentors and mentees will be paired based on the types of services provided. Mentors will undergo formal training on customized employment from San Diego State University.

#### **Spotlight on Pennsylvania**



The Integrated Vocational Engagement and Supports (InVEST) project engages people with lived experience through communities of practice, an advisory council, and contracted grant services. The state of Pennsylvania has several statewide and regional communities of practice that involve people with lived experience, including the Supporting Families Community of Practice, Transition Community of Practice, and Regional Employment Collaboratives with the Department of Labor & Industry,

Department of Human Services, and Department of Education. These communities of practice operate externally from the SWTCIE project but will inform its implementation. The InVEST project convenes an advisory panel made of agency partners, provider organizations, disability advocacy organizations, and people with lived experience to inform project design and implementation, individual and family engagement, and person-driven planning using the Charting the Life Course Framework. The InVEST team also makes efforts to involve underrepresented populations, such as people from the LGBTQ+ community and those from non-English speaking communities. Participation in the communities of practice and advisory panel is voluntary, but InVEST plans to offer compensation to people receiving project services who complete feedback surveys. In addition, the project will offer a family mentorship program. InVEST will rely on paid project contractors with lived experience from the PA Family Network, referred to as InVEST Family Advisors, to conduct outreach to project participants and their families. InVEST Family Advisors will mentor participants and their families using Charting the LifeCourse Framework for person-driven planning on their path to competitive integrated employment.



## Methods to solicit input from people with lived experience

SWTCIE projects use many approaches and avenues for including people with lived experience as critical partners in project design, implementation, and evaluation. Some projects created new work groups or advisory panels to provide continuous input on project implementation. For example, New York has a project steering committee of state agencies and the Office for People with Developmental Disabilities, along with providers. In Pennsylvania, project leaders formed an advisory panel including people with lived experience. Some projects, such as Connecticut, engaged people with lived experience early to inform project design components. Connecticut project leaders convened a partner work group with state agency commissioners and directors, who recommended other staff to serve on subgroups. People with lived experience also participated in these subgroups. Connecticut built on this important work by incorporating members from subgroups into local communities of practice in the project implementation phase to create a feedback loop and shape the project. Staff from the Connecticut project plan to intentionally engage family members with differing viewpoints on competitive integrated employment at this phase. Engaging family members who are more skeptical of competitive integrated employment allows project staff to better understand their concerns and develop communication plans based on these perspectives. Additionally, to include more people with lived experience in the communities of practice moving forward, project leaders have asked vocational rehabilitation counselors to encourage participants to join and share their experiences and feedback on project services.

"I think we're going to learn a lot about how to communicate, how to engage, how to develop that relationship. You can't just have a meeting once a year with the person and say, "Do you want to leave what you're doing now, with all your friends?" We're going to learn a lot from the individuals and their families about what's going to motivate them to try something different."

—SWTCIE project leader

Projects also leverage existing groups to learn from and incorporate the perspectives of people with lived experience. Pennsylvania project staff contribute to several external communities of practice that include people with lived experience, such as the PA Family Network. In addition, the New York project is engaging Centers for Independent Living in a community of practice. Centers for Independent Living are directed and operated by the people they serve: the disability community. Therefore, their staff have lived experience and expertise delivering services to support independent living and employment.



### Equitable and meaningful engagement of people with lived experience

Project staff shared strategies to engage people equitably and meaningfully, humanizing the process and ensuring empowering and impactful involvement. These efforts involve relationship building, empathy, and transparency. Staff from the New York project shared that building relationships is an important project goal. In Pennsylvania, project leaders explained that they know they need to also engage groups within the disability community who have not been as included in past efforts, such as those whose primary language is not English.

Inclusive and equitable engagement uses facilitation strategies that support maximum and convenient participation, empowering everyone to provide input. Project staff discussed the need to offer multiple modes for participation. For example, Pennsylvania meetings occur in person together with a virtual option to enable different ways to participate. Offering one-on-one meetings can orient people with lived experience who are joining advisory groups or communities of practice, so they feel more comfortable when they attend meetings. Project staff shared ways they intentionally create comfortable spaces that do not exclude or privilege certain experiences and roles. For example, in Connecticut, smaller subgroups make sharing less intimidating and minimize a potential power imbalance between people with lived experience and agency commissioners. Similarly, staff from the developmental disability agency attend meetings with self-advocates to offer them needed support. Project email communications about meetings also include a contact person for requesting accommodations. Recognizing that people with lived experience have many responsibilities, projects offer flexible meeting times, including around lunchtime or in evenings, to accommodate different schedules.

Insights from people with lived experience are integral to informing project decisions; shared decision-making builds trust and demonstrates equity. As one project staff member described it, "'Nothing about us without us' is a strong sentiment." In Connecticut, one concrete example of meaningful engagement shaped outreach and messaging material. Initially, the project planned to provide messaging at different reading levels for different audiences (such as providers, agencies, people with disabilities, and families). Based on feedback from a self-advocate, the project opted instead to universally incorporate plain language and use the same messaging for all materials so that "everybody was on the same page,

everybody was on the same level." In Connecticut, people with lived experience will help shape a survey for participants, to ensure the survey collects information people with lived experience deem important and relevant.

"We're going to need the feedback from both the person receiving the service and the mentor themselves about what's working, what's not working, and where we need to shift."

—SWTCIE project leader

As an acknowledgement of their time, insight, and contribution as important partners, project staff were exploring ways to provide financial compensation for people with lived experience. Arranging compensation can pose logistical hurdles initially related to getting agency approvals and establishing mechanisms to process and disseminate payments. Ways to offer other benefits in addition to (not instead of) compensation for people with lived experience include skills and professional development opportunities (such as training, conferences, and networking) or meaningful recognition, such as authorship credit and collaboration on presentations. For example, Pennsylvania plans to invite Year 2 participants to co-present at outreach events for Year 3, in addition to creating a social media campaign for participants to share their success stories. In Connecticut, a self-advocate involved in the subgroups created a project video encouraging students and families to consider competitive integrated employment. Pennsylvania also created three "success story" outreach videos featuring individuals who transitioned from subminimum wage to competitive integrated employment. This type of video is consistent with the Rehabilitation Services Administration's latest technical assistance directive to share success stories.



# Use of peer and family mentoring to leverage others' lived experience with pursuing competitive integrated employment

At least 11 of the SWTCIE projects plan to offer peer mentoring. In Connecticut, the subgroup members are discussing how to transform existing mentoring models to support the SWTCIE project. They intend to offer peer and family mentoring as part of the project's interventions, but those elements are not yet fully developed. The project team plans to seek feedback to make the mentoring component successful, including how to compensate mentors and how to offer flexible individualized models. Staff from the University of Maryland will provide training and technical assistance for mentors, which will include "being in the field with the mentors, modeling behavior, and troubleshooting on the spot." In New York, the Centers for Independent Living will recruit, coordinate, compensate, and oversee peer mentors for the project. They would like to see people who transition into competitive integrated employment integrate into the peer mentorship program over time. In Pennsylvania, the PA Family Network identifies individuals and family members with lived experience to serve as InVEST Family Advisors. As paid contractors, InVEST Family Advisors will conduct group outreach to individuals currently in subminimum wage employment and families to share their personal experiences in transitioning to competitive integrated employment. InVEST Family Advisors will then offer individual mentoring sessions based upon expressed interests and needs.

"We want to get [family members'] perspectives out on the table because we know that it is the crux of the issue: education around [competitive integrated employment], building supports and services that can match day habilitation programs in terms of supports, and the ability for them to feel comfortable with that as the long-term plan for their family member. It allows us to understand what kind of messaging and communication we need."

—SWTCIE project leader

Meaningful engagement considers and includes people indirectly affected by an issue, such as the parents and caregivers of people directly impacted by subminimum wage or competitive integrated employment. SWTCIE project staff recognize that buy-in from and engagement of family members is instrumental to designing and implementing an effective project and competitive integrated employment services. In Pennsylvania, project staff realize that family mentors build trust. Family mentors can support families by saying, "I hear you. I understand what you're feeling. I had the same experiences, and here's how I dealt with them. Here's what we did to support my loved one to reach their goals and here is how it benefited them."

#### This project is part of the 84.421D Disability Innovation Fund.

The contents of this brief were developed under grant number 91990020A0018/91990022F0347 from the Department of Education. However, these contents do not necessarily represent the policy of the Department of Education, and you should not assume endorsement by the Federal Government. (Authority: 20 U.S.C §§ 1221e-3 and 3474).