Demonstration Services

What is Addressed in this Tip Sheet?

This tip sheet will provide guidance on the planning and implementation of demonstration services. According to the UCEDD logic model, the definition of demonstration services is as follows: “Services that field test promising or exemplary practices and may be integrated with training, research and/or dissemination functions.”

Why is this Important?

Demonstration Services are a UCEDD core function, according to the DD Act Section 153(a)(2)(B):

Provision of community services – (i) That provide training or technical assistance for individuals with developmental disabilities, their families, professionals, paraprofessionals, policymakers, students, and other members of the community (ii) that may provide services, supports, and assistance for the persons described in clause (i) through demonstration and model activities.

Further, the Office of Intellectual and Developmental Disabilities (OIDD) issued a final rule in 2015 providing guidance on implementing the DD Act (45 C.F.R § 1328.6 2015). In this guidance, OIDD specifically mentions the need for each UCEDD to have a written plan for how their program will implement the core functions as outlined in the DD Act. This is echoed in the UCEDD funding opportunity, in which each applicant must provide a five-
year plan for carrying out the core functions within the context of their settings (HHS-2018-ACL-AOD-DDUC-0251, p. 14, in the section Content and Form of Application Submission).

How have other UCEDDs structured their demonstration services?

The Parent Partner Training Academy
University of Southern California (USC) UCEDD at the Children’s Hospital Los Angeles

The Los Angeles County Department of Mental Health launched the Parent Partner Training Academy in 2016, in partnership with USC. Its purpose was to establish local professional standards of support for parent partners by developing a certification within the Los Angeles County Department of Mental Health. Mental health parent partners are paraprofessionals drawing from lived experience. At USC, parent partners participate as part of the mental health services team and help represent family voices. There are no university-level courses of study for being a parent partner. They learn by doing, which means that much of their training is on-the-job or situation-based. While there are state-level certifications available in states like Iowa and Texas, in California there is currently no state-level certification for parent partners.

L.A. County’s program is parent partner-driven and parent partner-informed. The project is funded by the Workforce Education and Training Programs, through California's Office of Statewide Health Planning and Development. There was a strong desire on the part of parent partners to offer a certification, and to provide training on pertinent topics as well as specialty areas for those working with select populations. This training and certification is mandatory for all wraparound parent partners who provide active, hand-on peer support to parents and caregivers of youths receiving services.

The parent partner originally offered four programs: 1) Specialty skills, which is a three-day continuing education symposium, 2) General skills, which covers parent partner training or essential skills training 3) Supervision and program integration, for people who supervise and train parent partners and 4) Program evaluation and review. The original objective was to develop and conduct three levels of training for parent partners, with an approximate length of five days for each. Each level was skills-based, in the hopes that it could be tied to the requirements for certification through the National Federation of Families for Children's Mental Health.

Based on feedback from the evaluations from Department of Mental Health staff, trainers, participants and evaluators during USC’s pilot program, implementers discovered that there was no clear definition of who needed foundation skills and who needed direct service. The Trainings were combined into one 12-day course, called Essential Skills Training. It supports preparation for the Los Angeles County Department of Mental Health Parent Partner Certification Exam and is now required of all parent partners entering a wraparound program. The training covers 21 essential skills that any parent partner or parent advocate needs, regardless of the agency they work for or type of program they’re conducting. The content includes in-depth discussion of topics such as systems navigation, trauma informed care, crisis management and dispute resolution. USC also developed a two-day “train the trainers” course to ensure Each level was skills-based, in the hopes that it could be tied to the requirements for certification through the National Federation of Families for Children’s Mental Health.
that there are enough trainers to meet the needs of parent partners.

Building the Capacity of the Vietnamese Parents of Disabled Children Association (VPDCA) to Increase their Parent Members’ Access to Regional Center Services for their Children with DD

According to the 2010 census, Orange County and Los Angeles County have the largest Vietnamese population of any metropolitan area in the US, with over 270,000 Vietnamese residents. Among all Asian-language speaking adults, the Vietnamese group has the highest percentage of persons receiving no purchase of services (34.2%).

Three major barriers to services were identified:

- Parents have low expectations of their child because they do not fully understand their child’s disability and possibilities for independence, productivity, and community involvement when appropriate services and supports are accessed.
- Parents continue to have difficulty actively participating in the Individualized Program Plan (IPP) process.
- Aging Caregivers are deeply concerned about what will happen when they are no longer able to care for their adult and aging child(ren) with a disability.

To address the needs of Vietnamese parents with disabled children, the USC UCEDD teamed up with the Vietnamese Parents of Disabled Children Association. Their demonstration service had three objectives: 1) To expand the expectations of Vietnamese parents, 2) To strengthen individual advocacy through person-centered individual program planning, and 3) To provide assistance in planning for the transition of aging caregivers. Activities included planned field trips to see services in action, introducing families to supported living settings, exploring employment placements for family members with disabilities, and advocacy training sessions for parents and caregivers. USC also teamed up with an existing program, Pacific Bridge, to offer culturally responsive independent living alternatives for Asians with DD.

Lessons Learned

- Close collaboration with trainers, parent partners and other stakeholders is time consuming but essential to ensure the relevance, fit, and quality of the final product. It also increases community buy-in. Be open to feedback, and willing to scrap initial plans in order to build a program that is more responsive to the needs of your audience.
- Be culturally responsive. Use plain language to communicate objectives and make sure that the content is accessible to different audiences.
- Plan for sustainability. Develop a process to administer the exam and score it. Think through what happens for those who do not pass, and plan on providing insightful feedback. Provide ongoing training for test administrators.

Latino Community of Practice: Supporting Families with Children and Youth with Disabilities

The Center for Leadership in Disability Georgia State University at Georgia State University

In 2015-2016 and 2016-2017 The Center for Leadership in Disability (CLD), School of Public Health at Georgia State University was awarded Diversity Fellowship grants to co-create and scale-up the Latino Community of Practice in response to the growing numbers of Spanish-speaking and limited English proficiency families with children and youth with intellectual and developmental disabilities.
in the state of Georgia. The Latino Community of Practice (LCPR) is network of professionals, families, and allies. LCPR co-leads bilingual community education and engagement for and with Spanish-speaking and limited English proficient families through a partnership with the Center for Disease Control and Prevention (CDC) and the Learn the Signs Act Early (LTSAE) campaign. LCPR also provides technical assistance to partners on how to best serve the Latino population of Georgia.

LCPR’s organizational model includes three focus areas: 1) Professional capacity building and collective impact, 2) Parent education and leadership development, and 3) Formal and informal advocacy in public policy and systems of care. LCPR provides up-to-date resources and information relevant to Latino families, connects them with organizations that provide services, and advocates for better access to these services for the Latino community.

Leasons Learned

- Multisector collaboration is key. LCPR works with local government, the Georgia Department of Public Health, the Latin American Association, autism centers and parent organizations to make sure that services are culturally responsive and accessible to Latino families.
- It’s important to make sure that content is delivered in the language of the community you serve. Many families in the LCPR umbrella did not know that essential services existed, simply because the information about those services was only available in English.
- Remember to take into account social determinants of health- access to medical insurance, affordable housing, nutritional testing, etc. All of these factors impact the families you serve.

What are the Relevant resources?

- [Webinar: Demonstration Services by UCEDDs](#)
- [UCEDD Logic Model](#)
- [USC UCEDD](#)
- [Center for Leadership in Disability](#)
- [Latino Community of Practice](#)

For More Information

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