New State Plan Project: Executive Summary

Accessible and Effective Treatment for Substance Use Disorders for People with Developmental Disabilities

February 2022

Background

People who have intellectual and developmental disabilities (IDD) can also experience substance use disorder (SUD), mental Illness (MI), and neurological and behavioral symptoms that are the result of trauma. The co-occurrence of SUD, MI, and trauma in a patient who has IDD can present diagnostic and treatment challenges. Community systems of care for each of these conditions are separate (e.g., LIDDAs v. LMHAs v. OSARs) and providers in these systems do not routinely share the same education or experience. Providing accessible and effective treatment requires collaboration and person-centered systems of care that are currently not available using system-to-system referrals alone.

In general medicine, a similar discontinuity of care exists. The occurrence of multiple disorders in individual patients also presents unique diagnostic and treatment challenges. This is especially true for individual patients whose symptoms may require the in-depth consultation and collaboration of providers from different specialties. As with behavioral, developmental, and neurological health services, sequential multiple referrals are not an acceptable default for accessible and effective care. Resource-sparing managed care health systems that rely on volume and shortcuts also factor in as barriers and are a source of ongoing anguish for patients and families.

As a result of these difficulties in general medical practice, in recent years a *consultative medicine specialty* has evolved that is showing that better outcomes for patients can be achieved when health systems do not rely on broad referrals from one area of medicine to another without significant collaboration among providers (*New England Journal of Medicine*, December 23, 2021). Centers for pediatric and adult consultative medicine now exist at many leading healthcare institutions. These centers are proving effective because they provide processes for medical generalists and experts to focus on the patient and share knowledge and insights with one another, effectively sidestepping nonproductive referrals. This model may hold promise for building viable connections between behavioral,

developmental, and neurological providers in Texas. It relies on direct professional communications, focus on the individual, and an allocation of sufficient time and opportunity by generalists and experts to educate each other and brainstorm linkages that may be elusive working independently.

TCDD advocates for the right of people who have IDD to have access to the best available care for all medical conditions, including psychiatric illness, substance use disorders, and trauma. For the best available care to be provided, an infusion of factual information is needed. Stigmatizing and erroneous beliefs about IDD can be overcome with a baseline knowledge and understanding of developmental medicine among all providers.

TCDD-supported researchers on SUD treatment services for people with IDD at the University of North Texas recently conducted a literature review, analyzed hospital and emergency room data, surveyed treatment providers and facilities, and held focus groups and interviews with employees at treatment facilities. The grantee reported that SUD treatment providers often have difficulty knowing how to diagnose, treat, and support people with IDD.

SUD treatment providers also report a desire for more training about IDD, which is often outside their focal area of practice and expertise. Providers whose principal patient group is people with SUD can sometimes recognize MI as a co-occurring disorder or as a sequelae of substance use. However, many report that they do not recognize and may hesitate to identify IDD as a co-occurring disorder unless it has been previously diagnosed by others. In this regard especially, co-occurring SUD in the pediatric population is of great concern because opportunities for a clinical assessment of IDD and trauma during the developmental period can be missed. It is critically important that SUD, psychiatric disorders, and trauma experienced by people with IDD are recognized and effectively treated as soon as possible, and before a crisis arises.

The Texas Council for Developmental Disabilities recognizes that systems improvements in multiple areas are needed to help individuals with IDD who are also experiencing SUD, psychiatric disorders, or trauma. Currently three TCDD grants are focused on co-occurring IDD and MI in the training of community practitioners and public school teachers. The Council now seeks to demonstrate ways in which people with IDD who have SUD can be identified, treated, and supported throughout at any stage of life. The need to support this significant

additional work is perhaps best illustrated by discrimination by health practitioners based on the common and incorrect belief that people with IDD don't get SUD.

State Plan Goal

The Accessible and Effective Treatment for Substance Use Disorders for People with Developmental Disabilities projects will address the following State Plan goal:

> ***Goal 2: Inclusive Community Based Systems***
> *The Council will lead in partnership with family/self-advocates and other stakeholders to improve community-based systems to be more fully inclusive and supportive of Texans with IDD and their families.*
>
> ***Objective 2.4: Health Care***
> *Expand opportunities for Texans with IDD to engage in healthy behaviors and access IDD-informed health care services and supports.*

Project Description & Milestones

The Council seeks to promote statewide capacity buildingand systems change improvements in the prevention, identification, and treatment of substance use disorders among individuals with intellectual and developmental disabilities. The Council may choose to fund one or multiple projects across the following areas of need. The Council may also choose not to fund any specific project, but to direct action through staff activities.

1. **Test Models To Improve the Quality of SUD Services for People with IDD**
   To effectively serve people with IDD, providers need to identify or develop, implement, and test health care models such as assessment teams and consultative centers comprising providers from all relevant specialties, including general medicine, developmental medicine, psychiatry, neurology, and others. For example, projects may include those that integrate SUD, pediatric, and developmental medicine into assessment teams and centers to enhance wellness, early treatment and intervention, and crisis prevention.

   These demonstrations could develop an effective means to connect providers across specialties for collaboration on an individual patient basis. An important foundation for these interactions could be the joint

development of universal clinical assessment guidelines with representation by all relevant specialties. Such a project could include one or more topical consensus development conferences including both experts and practitioners to build relationships as well as identify and propose guidelines concerning frequently challenging co-occurring diagnoses from relevant varied perspectives.

Project Outcomes would be related to improved communication and collaboration among providers and the creation of a framework for sharing expertise and considerations both broadly and specific to individual patients, with measurable improvedquality of care received by individuals with developmental disabilities.

Project Duration would be up to five years for development of consensus guidelines and demonstration of a new model of consultative medicine across a range of clinical practices.

2. **Test Models to Expand Access to SUD Health Services**

More than 50% of respondents with IDD (the National Core Indicators survey) report a gap in access to enough services and enough staff to stay healthy and participate in the community. Specifically, respondents identified gaps in access to services for complex medical needs, access to services for complex behavioral needs, and enough staff for effective service delivery.

Projects may expand access through the use of telemedicine or telehealth in care and treatment of people with co-occurring SUD and IDD. Projects may also involve policy analysis and systems change advocacy to address state support structures for expansion of SUD community-based services that take into account co-occurring IDD and other conditions.

Projects should include the development of training modules on SUD for the use of providers specializing in IDD, as well as modules on IDD for the training of substance use professionals.

Project Outcomes would be related to a greater number of individuals with developmental disabilities receiving community-based SUD services and supports from providers with expertise in this field.

Project Duration would be up to five years for new model development and demonstration in a community-based clinical practice.

Funding and Duration

Up to $150,000 per project, per year, for up to 3 projects. Specific project duration is cited with options above.

Other Considerations

The Council could post one comprehensive RFP that seeks innovative proposals to address one or both proposed options above -- similar to past health and wellness and new initiative programs. The Council could also develop multiple RFPs to align with one or more individual items identified.