Supporting Families Community of Practice Evaluation

Changes in Practice: Ty’s Story

“The Charting the LifeCourse Framework makes it easy for me to see how to get to my goals or be taken down a not so happy path. It is something I am able to complete all by myself and keep with me for reassurance, like a diary to show me I have control of my life. I am able to share it with others or keep it to myself. The Community of Practice is helping people be more aware of ways people can make a difference in their own life and the lives of others.”—Ty

Overview

In 2012 the Administration for Community Living (ACL) funded the development of a National Community of Practice for Supporting Families (CoP) to help state agencies and stakeholders, such as families, make systemic changes that positively impacts individuals with intellectual and developmental disabilities (I/DD) and their families. The CoP is driven by a set of principles that comprise the Charting the LifeCourse (CtLC) framework designed by and for families through the University of Missouri-Kansas City (UMKC)-Institute for Human Development. The core belief of the CtLC framework is that all people have the right to live, love, work, play and pursue their life aspirations in their community.

In 2017, ACL funded an evaluation of the CoP to identify measurable outcomes achieved by the sixteen participating states. The evaluation uses five categories to evaluate the benefits of the CoP and CtLC: sharing information and creating partnerships, increasing knowledge, changing practice, improving performance, and redefining success. This document highlights themes observed across states that relate to the third category: changing practice.

Themes across States

Several themes in the area of changing practice emerged across all sixteen states participating in the evaluation. Many states report policy changes that led to improved support services for families, crediting the Centers for Medicare & Medicaid Services (CMS) home and community-based services (HCBS) settings final rule for influencing these advances. States cited implementing new waivers that embed CtLC principles and language, as well as revising eligibility guidelines for services, as additional changes in practice. States changed existing programs and services, including employment and assistive technology. States revised ISP forms, administrative procedures, and hiring processes to align with the CtLC framework.
Ty’s Story

Ty Lyn Ferguson is a self-advocate from Ohio who uses the CtLC tools and framework to help her achieve her goals. Ty learned about CtLC through Project STIR, a training program that provides self-advocates with knowledge to empower them and other individuals with I/DD. Barb Sapharas and Dana Charlton, members of Ohio’s CoP, are responsible for embedding CtLC principles into Project STIR’s curriculum.

The state of Ohio dedicates time and resource to help reframe the conversations around support options for individuals with disabilities and their families. One organization of note is the Ohio Self-Determination Association (OSDA), which fosters change throughout the state by helping individuals with I/DD and their families self-direct their lives. In pursuit of this goal, OSDA brought Project STIR to Ohio. Project STIR is a training program designed to support self-advocates by providing them the tools to empower themselves, mobilize others, and gain leadership experiences. Dana Charlton, Executive Director of OSDA and Barb Sapharas, Ambassador for Ohio, National CoP team member, and board member of OSDA, joined forces to integrate CtLC tools and principles into Project STIR. During the spring of 2019, Statewide Trainers and Coaches from Project STIR were trained using the updated curriculum.

Members of Ohio’s Community of Practice recognize the benefits of embedding CtLC tools and principles into existing programs, like Project STIR. Instead of developing new avenues for diffusion, the CoP focused on building upon existing structures. Barb and Dana attended a Project STIR training and deliberated where the CtLC tools could offer value to the existing curriculum. The final decision included incorporating the One-Page Portfolio, the Trajectory Worksheet, and the Integrated Supports Star.

Project STIR leaders, with the support of OSDA and the CoP, hosted an event for a select group of coaches and trainers to evaluate changes made to the program. Participants were incredibly enthusiastic about the new tools. The coaches cited how concise and effective the training was, while trainers emphasized the skills it gave them to use in their daily lives. To date, 30 statewide trainers and 27 coaches have had exposure to CtLC.

Ty Lyn Ferguson is a statewide trainer. She credits many of her life’s successes to Project STIR, highlighting how the addition of CtLC tools into the training materials enhance her ability to empower herself and others. Ty uses the tools like a diary, allowing her to think about her trajectory on a daily basis. She constantly writes down what she learns from those around her and keeps track of interventions that have worked and ones that have not. Ty regularly sets new goals for herself and is able to achieve them with the support of the tools. She is just one of the many individuals who have benefited from using the CtLC tools and framework.

In summary, embedding CtLC into existing programs, such as Project STIR helps promote the diffusion of the tools and framework. These changes in practice can lead to better experiences navigating services and supports for individuals like Ty, and their families.