Supporting Families Community of Practice Evaluation
Improvements in Performance: Crystal's Story

> "Charting the LifeCourse has opened up a life full of possibilities allowing us to dream about what our good life can look like." –Crystal

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 fourth category: *improving performance*.

Category Four Activities: Improving Performance
- Less reliance on formal supports
- Reduction in waiting list or process times
- New skills for using services and supports
- Changed behavior (e.g., greater advocacy)
- Better experience with services and navigation
- Increased access/efficiency
- Increased satisfaction and better lives

Themes across States

Several themes in the area of *improving performance* emerged across all sixteen states participating in the evaluation. States noted that increased involvement from families, communities, and state leadership in the CoP leads to behavior changes, including how families and persons with I/DD are supported. Increased efficiency of state service systems was also cited as an area of improvement. States revealed that people are accessing community-based services more often and with greater ease. Instances of policy change have often led to reduced waiting lists and processing times for individuals that receive services.

Crystal's Story

Crystal's story provides an example of how the CoP and CtLC promotes less reliance on formal supports. Crystal used CtLC tools, including the Integrated Supports Star and Life Trajectory worksheet, to help her re-imagine the types of supports that work best for her family.

Like many parents, Crystal envisions a colorful life for her two sons, Conner and Peyton that includes opportunities to make friends and experience inclusion and independence. In the past, they relied heavily on formal supports, separating them from their peers and community. Crystal was often frustrated with the gap between traditional support services offered to her and what her family actually wanted and needed for her sons to live their best lives.

Crystal heard of CtLC, but did not recognize its benefit until she witnessed firsthand through her work on the Family Partnership Program the value it generated for other individuals and their families. She decided to complete the Life Trajectory worksheet and Supports Star with her children and found that it helped her to construct a clear vision. She was able to communicate her family's needs more clearly during service planning meetings, challenging the school's conventional support model. The CtLC tools supported both parties in re-imagining possibilities.

In particular, CtLC supported Crystal in two ways. The first was **making the case for inclusion**. Initially, a one-on-one aide accompanied Peyton throughout the day. Using the CtLC tools, Crystal and the school came up with an alternative solution to support inclusion. Peers throughout the school now assist Peyton during the day eliminating the support strategy that isolated him from his peers. The second was **making the case for independence**. Conner's vision for a good life includes living on his own someday. Instead of having an at-home aide monitor him after school, Crystal used the supports star to brainstorm ways to increase his independence while also keeping him safe. She found an iPad application that Conner now uses to stay in touch while she is away from home, giving Conner the opportunity to develop self-management skills required to live on his own someday.

In summary, Crystal would not have considered these options for her sons without exposure to the CtLC framework. The framework helped her to organize her thoughts and more effectively communicate her wishes when navigating service options for her sons. Now, both Peyton and Conner rely less on formal supports to help them achieve their goals.