



SUPPORTING FAMILIES

of individuals with intellectual & developmental disabilities

THE NATIONAL COMMUNITY OF PRACTICE • FUNDED BY THE ADMINISTRATION ON INTELLECTUAL & DEVELOPMENTAL DISABILITIES

Project Overview

Why are we focusing on families, and why now?

Families are the core unit in our society, serving as a source of support for all its members. For people with intellectual and developmental disabilities (I/DD) the role of family is unique, and often central in the support and care provided across the lifespan. Family members play key roles in identifying and securing opportunities for their family members to participate within their community in meaningful ways and ensuring access to self-determined lives. Parents and other family members of people with I/DD often provide medical, behavioral, financial, and other daily supports beyond what most families provide. Yet, the vital role of families is not fully recognized and supported in disability policy and practice.

Today, there are more than 4.7 million American citizens with an intellectual or developmental disability. Most, 75%, of these individuals live in their communities without any formal disability services. They rely on their families for varying levels of support to have the lives they want to have. Of the 25% that are receiving services, over half live with their families, and in some states, that number is as high as 80%.

In 2011, a group of national and state leaders in the disability field came together at Wingspread Conference Center to provide direction and guidance for the shift to focus on families. One of the recommendations was to develop and fund a National Supporting the Family Initiative. The initiative is to gain consensus on issues related to supporting families at both the national and state level, that would inform practices and identify policies for advancing family supports. This initiative would also focus on working together to further define and build collaborations within and outside the disability system for supporting families across the lifespan, ensuring that community integration is the standard of all the work. This initiative is our Community of Practice.

Project Goal

To build capacity through a community of practice across and within States to create policies, practices and systems to better assist and support families that include a member with I/DD across the lifespan.

Project Outcome

- State and national consensus on a national framework and agenda for improving support for families with members with I/DD.
- Enhanced national and state policies, practices, and sustainable systems that result in improved supports to families.
- Enhanced capacity of states to replicate and sustain exemplary practices to support families and systems. ©

Project Leadership



The Goal of Supporting Families

The overall goal of supporting families, with all of their complexity, strengths and unique abilities is so they can best support, nurture, love and facilitate opportunities for the achievement of self-determination, interdependence, productivity, integration, and inclusion in all facets of community life for their family members.

Supporting people with disabilities to live and fully participate in their communities throughout their lives has emerged as a fundamental right and consideration in disability policy and practices. Because of the role that families continue to play in the lives of their family members, future policies and practices must reflect the family as part of the system of support.

Supporting the family is defined as a set of strategies targeting the family unit but that ultimately benefit the individual with I/DD. Supporting the family strategies are intended to assist family members who have a key role in the provision of support and guidance of their family member with I/DD to address the emotional, physical and material well-being of the entire family. Strategies must be designed, implemented and funded in a manner directed by the family unit. They should be flexible, comprehensive, and coordinated. ©

From the National Agenda on Supports to Families, 2011

Discovery & Navigation: Knowledge & Skills
<ul style="list-style-type: none"> • Information on disability • Knowledge about best practices and values • Skills to navigate and access services • Ability to advocate for services and policy change
Connecting & Networking: Mental Health & Self-efficacy
<ul style="list-style-type: none"> • Parent-to-Parent Support • Self-Advocacy Organizations • Family Organizations • Sib-shops • Support Groups • Professional Counseling • Non-disability community support
Day-to-Day Services: Instrumental Supports
<ul style="list-style-type: none"> • Self/Family-Directed services • Transportation • Respite/Childcare • Adaptive equipment • Home modifications • Financial assistance • Cash Subsidies • Short/Long term planning • Caregiver supports & training

GOAL



Individual

Will achieve self-determination, interdependence, productivity, integration, and inclusion in all facets of community life

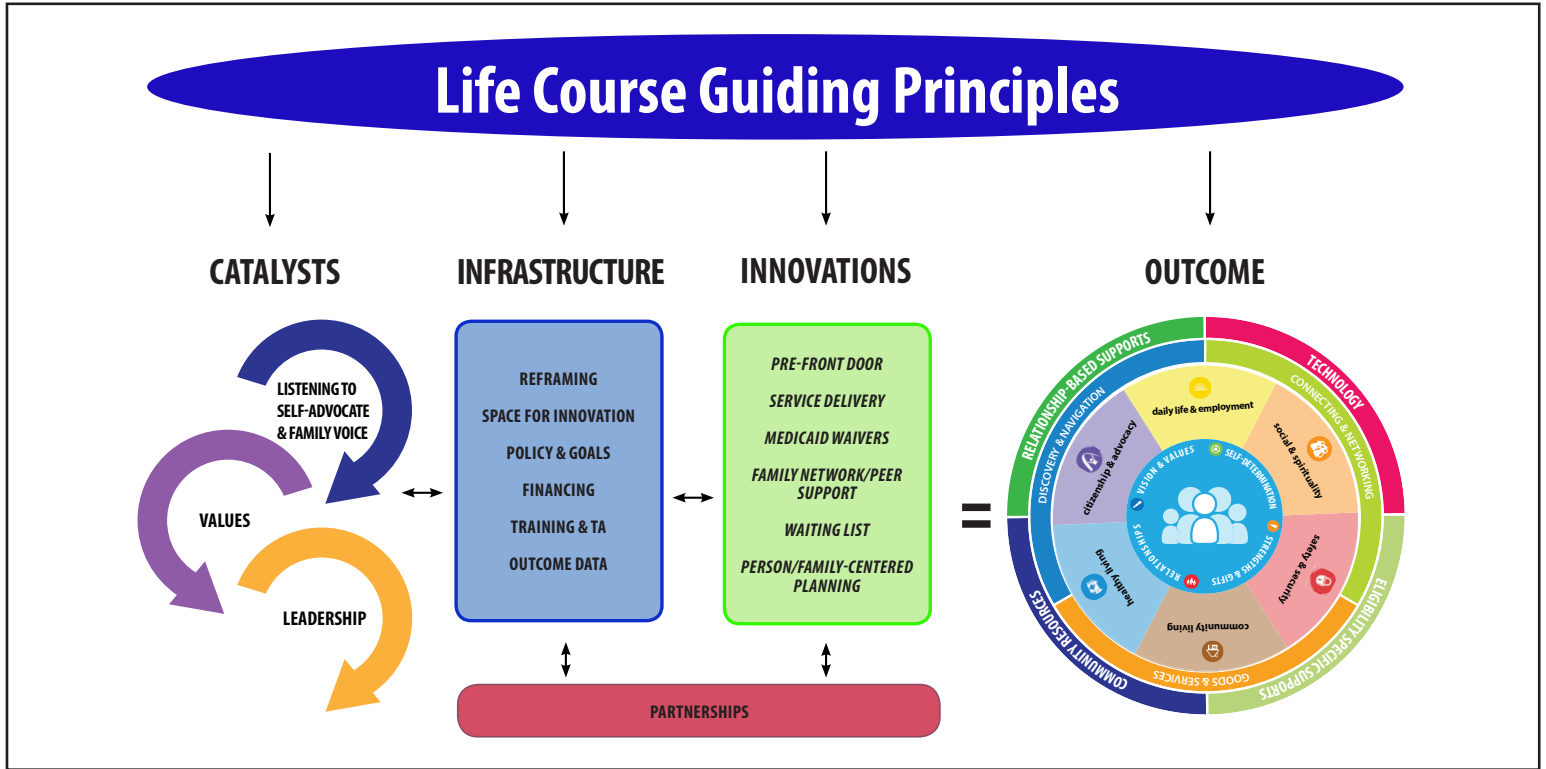


Families

Will be supported in ways that maximize their capacity, strengths, and unique abilities to best nurture, love, and support the individual to achieve their goal

Recognizing that individuals exist within a family system

Framework for Systems Change



The service delivery system for people with disabilities has a history of discrimination and segregation, denying access to many opportunities for individuals with I/DD. Based on this historical discrimination, a change in the culture is necessary for system reform. As societal perception changes about people with disabilities so must the systems and policies designed to support them. The main catalyst for this change is listening to the self-advocate and family voice. Secondary catalysts include leadership and the value that segregation and discrimination is no longer acceptable. These catalysts nudge the system towards change.

Key to system reform is systems efficiency. Disability service systems, through both state and federal programs, furnish a wide array of services and supports to individuals with I/DD. These services and supports provide opportunities for individuals with I/DD to maximize their full potential and participate in their families and community. The state disability system must drive forward innovative services, such as family specific strategies and family- and person-driven services.

Another consideration for system reform is the fact that the new system must effectively facilitate collaboration and use of community assets. There are three strategies in family support that emphasize collaboration and use of current assets the family and community possess, these strategies are: discovery and navigation, connecting and networking, and goods and services.

The interplay of all these aspects come together in the community, and form the outcome of supporting families with a member with a disability across the lifecycle. ©

State Teams in the Community of Practice

A community of practice is a learning environment for an intensive exploration into current policy, practices, trends and barriers. Specifically for this project, five states will be the focus of the Community of Practice with the learning being shared with the entire nation. In addition to these five states, Missouri will collaborate as the demonstration state for the project. Each state will form a team that is facilitated jointly by the state I/DD service system office and the state Council on Developmental Disabilities with additional membership from self-advocacy and family organizations, university, education, aging and other organizations interested in this topic.

Funded By



National Partners



States in the Community of Practice



Why a Community of Practice?

The key to a community of practice is understanding that the sum of the community knowledge is greater than the sum of individual knowledge.

Below are reasons to use a community of practice.

- Connects people who may have never had contact
- Provides a shared context for people to communicate and to share information
- Enables dialogue between people wishing to solve the same types of problems
- Stimulates learning by serving as a vehicle for communication, mentoring, coaching, or self-reflection
- Captures and diffuses existing knowledge
- Introduces collaborative process and encourages the free flow of ideas and information
- Helps people organize around purposeful actions
- Generates knowledge

Learn about policies and practices for supporting families, connect with the Community of Practice, and share your ideas about supporting families:



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