



SUPPORTING FAMILIES

of individuals with intellectual & developmental disabilities

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

Sharing Our Learning at a National Level

On the fifth of February, 2014, leadership organizations; National Association of State Directors of Developmental Disabilities Services, Human Services Research Institute, and University of Missouri Kansas City Institute for Human Development, from the National Community of Practice on Supporting Families of Individuals with Intellectual and Developmental Disabilities brought together a group of influential leaders in the field. There was representation from the National Association of Councils on Developmental Disabilities, Supported Employment Leadership Network, Support Development Associates, University Centers on Excellence on Developmental Disability, National Core Indicators, Family Information Systems Project, the Administration for Community Living, and the Administration on Intellectual and Developmental Disabilities.

Goal of the day: *Share the learning of the National Community of Practice. Unite initiatives. Use the Community of Practice as a safe space to think creatively, try new things, and be ok with failing.*

Message of the Day: *we believe in a future where people with disabilities receive the supports they need to live, love, work, play, and pursue their life aspirations just as others do in the community. Likewise, their families receive the assistance they need to support their loved one while maintaining their family well-being.*

Major Themes

- Think about the 100%- Every citizen with a disability deserves a good life; not just those known to the service system. Only 25% of people with disabilities known to the service system. There must be a recognition and acceptance that we work for the 100%. “We must own it all, we don’t have to deliver or fund it all, but we must own it all”
- Trajectory- What direction is an individual and family headed? A trajectory is the path the family or person is taking. It is important to have a vision for where the trajectory is headed, and to consistently do things and make choices that support the trajectory, instead of ones that push the trajectory in a different direction. People should have opportunities across the lifecourse to participate in activities that enhance their lives and participate in tier community.
- Public health model- In the public health model, the work that is done is trying to prevent crisis. Currently, the service delivery system is very crisis reactive. We must work to move the system to one that supports individuals in ways that prevent them and their families from entering a crisis situation. If crisis is avoided, individuals are able to be supported in their community, as any other citizen. Support must be offered in the community, in a reciprocal way, that enhances the well-being of all
- Anticipatory guidance- Anticipatory guidance can be thought of as planting the seeds for a positive life. It is when a professional points and individual or family in a direction that will take them to a good life in the community. It is about not only offering services for where someone is now, but also supports that affect their life trajectory in a positive way.



- Life experiences- What happens through the life span that moves you along the trajectory toward your vision? People with disabilities and their families should do things any other family or person would do. Attend community events, birthday parties, etc. These experiences are where people grow and become valued members of their community.
- Change our social promise- The implicit promise of the current system, that people will be supported 24 hours, is no longer the vision of the field. People with disabilities and their families are being supported in whole new ways. The general public needs to be educated on the new expectations for the lives of people with disabilities. People should be in charge of the support they receive, to the maximum extent they are able. There is a responsibility of professionals and policymakers to use public dollars wisely, in order to assure the diverse needs of all families and individuals can be met now, and in the future
- Recognize that people live in the context of the family- This is a shift from the current cultural frame the field holds. Have to factor in every member of the family's wellbeing in order for the person with a disability to have a good quality of life.
- Evaluation/Data- It is imperative that we define what supporting families/family support is. Once it is defined, then we can do good evaluation and collect good data. We must always adhere to the cultural frame.

What does this mean for you?

- Employment- The idea of framing around anticipatory guidance is key. Use the skill of pushing the exploration, don't just rely on traditional service avenue. Be creative.
- Data- We must work toward finding and asking the right indicators, when there is a gap; where is the information, and what really did happen? Must agree on a definition so that data can be useful and meaningful.
- Developmental Disability- Disability is part of diversity, not a deficit. Teach kids the value of people with disabilities. Inclusion.
- Family Networks- Family networks must be intentional. They thrive outside the system.

What are the next steps for participants of the sharing and learning meeting?

- Engage multiple initiatives with the Community of Practice.
- Utilize each other's tools. Scale them up.
- Money does not have to be Medicaid. What can we do or utilize differently.
- Caregiver assessment can't replace what we are trying to do with supporting families.
- Think about data in a way that is about supporting families across the lifespan, but also show why this is a good approach.