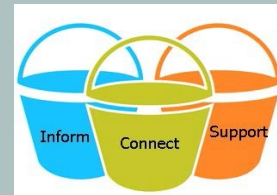


PENNSYLVANIA COMMUNITY OF PRACTICE FOR SUPPORTING FAMILIES

Created by: Family & Self Advocate Engagement Innovation Area Work-group
MAY 2022



Supports Coordinator's Guide to Engaging People with Disabilities and their Families in County Collaboratives

WHY?

“Families are the core unit in our society, serving as a source of support for all of its members. For individuals 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 in meaningful ways within their community and ensuring access to self-determined lives. Parents and other family members of individuals 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 practices.

Supporting individuals with intellectual and developmental 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 with intellectual and developmental disabilities, future policies and practices must reflect the family as part of the system of support and the needs of all the members.”

Wingspread Report 2011

What is a Collaborative?

A Regional Collaborative is an opportunity to bring people together in their communities in ways that discover strategies to truly support families. In this way, all people can best nurture and support their loved one to have full, meaningful Everyday Lives in their communities. *The voices of individuals with disabilities and their families is essential to this endeavor.*

What Can Families Expect?

- ❖ Discussion around the needs of families and people living with disabilities in the region.
- ❖ A mix of "stakeholders"- people who want to make sure that people's needs are being met. Ideally, this would include professionals and community members, as well as people with disabilities and their families.
- ❖ Most collaboratives offer different ways to connect – flexible times, a mix of days and nights, virtual and in-person. Families and people with disabilities often work - and their time is important - but they need the opportunity to participate.

What Will Be Expected of Them?

- ❖ To be present and willing to both learn and share
- ❖ Knowledge of the System is not required
- ❖ To be engaged at their comfort level! If they wish to attend a meeting to see what is involved, they will be asked to participate as they feel comfortable. No pressure!
- ❖ Experience! *Families are the experts in their own lives.* They need to help others understand that lived experience. In this way, they can make a difference.

What can you do next?

TIP: Personal invitation is always best. A person is more willing to participate if they know they're presence was sought out and their input is valued.

TIP: Reach out to Families! SCs know their families the best! Who is creative? Who is passionate? Who is helpful? How do they prefer to receive information?