

PENNSYLVANIA COMMUNITY OF PRACTICE FOR SUPPORTING FAMILIES

Created by: Family & Self Advocate Engagement Innovation Area Work-group
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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. e needs of all the members. It is crucial that programs and policies recognize both the individual within the context of the family and the needs of all the members”

Wingspread Report 2011

HOW? Clearly define your collaborative’s vision and why you need the input of people with disabilities and their families.

Tip: Location– Use community locations around your region. This is especially important for rural areas and joiners

Tip: Flexible times – Mix of days and nights. Families and people w/ disabilities often work, but need the opportunity to participate.

Tip: Accessibility/phone/zoom/in person—It’s not always possible for us to join in-person. A caregivers life is hectic and our responsibilities change often

Tip: Define what the role means/Expectations—participation is less intimidating when the roles and responsibilities are clear

Tip: Minimize systems jargon—make everyone feel comfortable

Tip: Personal invitations by Supports Coordinators, committee members, providers—a personal invitation is always best. A person is more willing to participate if they know they’re presence was sought out

Tip: Identify family members and people w/disabilities who are collaborative—

Tip: Avoid an “all professional” committee—it’s easy for a collaborative to be dominated by AE’s, SCOs, and providers. People who are paid to be there. It’s important to have families, people with disabilities, and community members involved. This is truly the only way we will know what families need to be supported.

Tip: Create a welcoming environment—people will come back, if they feel welcomed and made a part of the group

Tip: Do the work of the collaborative during the meeting, or in sub-committee meetings—People need to feel valued. Having meaningful engagement with the collaborative will achieve that vision

What can you do next?

- ⇒ **Develop a VISION for your Collaborative**
- ⇒ Create a Collaborative Profile, Trajectory & Supports Star
- ⇒ Reach out to Local support groups & committees for members
- ⇒ Ask Supports Coordinators about people who might be interested
- ⇒ Invite the broader community (ie. Faith based, medical, civic)