

PENNSYLVANIA COMMUNITY OF PRACTICE FOR SUPPORTING FAMILIES

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

May 2023



Engaging People with Disabilities and their Families in County Collaboratives to Share their Voices

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. 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

What is a Collaborative? “With counties initiating the lead in bringing stakeholders together in their naturally-connected communities where families live, Pennsylvania has established Regional Collaboratives that allow people to come together in their communities in ways that discovery strategies to truly support families emerge.” (From MyODP*) Essentially, a meeting where family and self-advocate voice and lived experience is necessary for creating an open dialogue with professionals.

WHY Participate?

- Every Collaborative needs to know what Families and Individuals with Lived experience need to be supported.
- Collaborative members need to have real-life stories and examples.
- Your voice and ideas are essential to making the system more responsive.

HOW to Get Started and What to Expect (or ask for if it isn't there!):

Tip: Ask your Supports Coordinator about getting involved, or look on MyODP for the Collaborative Lead. Ask if you can sit in on one meeting if you aren't sure.

Tip: Ask for flexible times if that works better for you. 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 caregiver's 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: Ask everyone to minimize systems jargon

Tip: Establish ground rules ahead of time so there is open communication

Tip: Request an Agenda ahead of time

Tip: Invite other Families and Community members to participate!

Knowledge is Power!

- Join the PA Family Network at [PA Family Network - Vision For Equality](#)
- Join SAU1 at [Self Advocates United as 1 \(sau1.org\)](#)
- Follow the Office of Developmental Programs at
*[My ODP: Log in to the site](#) (sign-up is easy and free)
- <https://www.myodp.org/mod/page/view.php?id=25547> to check out your Regional Collaborative and get started!

If you're interested in joining the Engaging Families and Self-Advocates Innovation Area Work group, please contact the Pa Family Network at 1-844-PAFAMILY or email pafn@visionforequality.org. Everyone is welcome!