



**COMMUNITY OF PRACTICE  
FOR SUPPORTING FAMILIES**  
PENNSYLVANIA STATE TEAM

## **Guidelines for PA's Regional Collaboratives for Supporting Families**

### **Supporting Families throughout the Lifespan**

A Partnership with Pennsylvania's Office of Developmental Programs



#### **ISAC Recommendation 4: Support Families throughout the Lifespan**

The vast majority of people with disabilities in Pennsylvania live with their families. Families need support in order to make an everyday life possible throughout the person's lifetime. Families need information, resources, and training. They need connections with other families and support services. Listening to people with disabilities and their families is key to providing supports that help them achieve an everyday life.

**Strategy 3** Support the continued growth of regional collaboratives, through the Community of Practice (CoP), so that communities and all stakeholders experience genuine direction and ownership in local approaches to ensure equal access and support of individuals and families.



## A Note from the Deputy Secretary

We are very excited to share the updated guidelines for Regional Collaboratives for Supporting Families which are part of Pennsylvania's approach in the National Community of Practice: Supporting Families throughout the Lifespan. This movement offers all of us an opportunity to partner in bringing about powerful change for people with intellectual and developmental disabilities and their families.

Since establishing Regional Collaboratives in 2016, it has been encouraging to see the engagement and activities across the state as Regional Collaboratives connect diverse individuals, families, and community partners, identify what people and families need to be supported, develop and implement strategies to meet these needs through local collaboration and partnerships, and participate in the planning and conversation to improve systems.

ODP has also expanded support to families through policy, practice, and culture change. The Information Sharing and Advisory Committee (ISAC) added Recommendation 4: Support Families Throughout the Lifespan with Strategy 3 "envisioning communities and all stakeholders experience genuine direction and ownership in local approaches to ensure equal access and support of individuals and families through Regional Collaboratives." ODP has also widely adopted the LifeCourse Framework in advancing policies and practices to support families.

Strengthening support to families in their communities must serve as the north star for all of us in our work every day. Today, we have resources developed from the National CoP for Supporting Families including principles for supporting families, the LifeCourse framework, and a *2022 National Agenda: Continuing the Conversation*. Additionally, there is work to be done at all levels toward fulfilling the [RAISE](#) recommendations to improve support to all caregivers, including those caring for a loved one with an intellectual, developmental disability and/or autism.

I look forward to our continued partnerships as we support families, with all of their complexity, strengths, and unique abilities 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.

Sincerely, Kristin Ahrens

Deputy Secretary

## Overview

### Why is ODP focusing on families?

Families are a core unit in our society, serving as a source of support for all its members. For people with intellectual and developmental disabilities and autism (ID/A), the role of family is unique, and often central in the support and care provided across the lifespan. Families play a key role in identifying and securing opportunities for their loved ones to participate in meaningful ways in their communities while ensuring self-determination, and an everyday life. Parents and other family members of people with IDD/A often provide medical, behavioral, financial, and other daily supports beyond what most families provide. Yet, the vital role of the family is not fully recognized and supported in disability policy and practice.

### Transformational Change

The disability movement over the decades has made progress toward overcoming discrimination, segregation, low expectations and social stigma. As societal perceptions about people with disabilities continue to change, the systems, policies and practices to support them must transform. The catalyst for this transformational change is leadership and a collective commitment to the belief that all people and their families should be able to live, love, work, play and pursue their dreams and aspirations in their communities.

Transformational change happens when:

- There is a collective commitment to the belief that all people and their families should be able to live, love, work, play and pursue their dreams and aspirations in their communities.
- Community partners understand that people with disabilities are community citizens and recognize the importance of their role in supporting families so they can then best support, nurture, love, and facilitate opportunities for their family members to live their everyday lives.
- At every level, the state disability system drives forward innovative services, such as family-specific strategies and person-directed services.

### Achieving transformational change through PA's Community of Practice (CoP) for Supporting Families

A CoP is a learning environment for an intensive exploration of current societal and governmental practices, trends, and barriers. The key to a CoP is understanding that the sum of the community knowledge is greater than the sum of individual knowledge. A CoP can:

- **Connect** people who may have never had contact with those living similar lives.
- Provide a context for people to **communicate** and share information.
- Enable dialogue between people wishing to address **similar** issues.
- Stimulate **learning** by serving as a vehicle for communication, mentoring, coaching, or self-reflection.
- Capture and diffuse existing **knowledge**.
- Introduce a **collaborative** process and encourage the free flow of ideas and information.
- Help people **organize** around purposeful actions.
- Generate **new** knowledge.
- Engage with **all** stakeholders to make improvements.

The overarching goal of the National CoP for Supporting Families is to support and strengthen families in ways that strengthen their capacity to best support, nurture, love, and facilitate the achievement of self-determination, interdependence, productivity, integration, and inclusion in all facets of community life for their family members. A major underlying shift that is driving this transformational change is the encouragement of

families to have high expectations for their loved ones' lives -- lives rich with all the possibilities that everyone else is encouraged to imagine for themselves. The LifeCourse Framework, developed by and continually expanding through the National CoP, serves as a platform or roadmap that brings together families and all who touch their lives in supporting that vision of an everyday life for all.

### **Achieving transformational change through PA's Regional Collaboratives for Supporting Families**

One of PA's transformational strategies is to encourage and support planning and collaboration at the local and regional level, thus embracing the broad and rich diversity that defines Pennsylvania's character: diversity in geography, demographics, cultures and ethnicity, history and traditions, and local identity. With counties leading local efforts, the expectation is that all stakeholders in the "Regional Collaboratives" collectively discover and implement strategies, practices, and policies that truly support and strengthen families. Local leadership, commitment, development, broad representation, and ownership of each Regional Collaborative will be essential as the foundations of change within their communities to identify what people and families need to be supported, develop and implement strategies to meet these needs through local collaboration and partnerships and participate in the conversation to improve systems.

# **REGIONAL COLLABORATIVES for SUPPORTING FAMILIES GUIDELINES**

While counties will take the lead in bringing together and guiding a Regional Collaborative for Supporting Families, a broad mix of stakeholders should be at the table with a common vision for supporting families differently, a commitment to listen to and learn from one another, and a shared expectation that everyone can have an everyday life.

**As counties reaffirm their commitment as partners in PA's CoP for Supporting Families through Regional Collaboratives with a common vision for supporting families differently, the agreed-upon guidelines include:**



## **1. Structure of the Collaborative**

The following strategies create a structure that defines who and how Regional Collaboratives function.

- a. Regional Collaboratives are made up of
  - i. Individual counties or joinders,
  - ii. Or a few counties and/or joinders whose communities naturally blend within a particular area of the state.
- b. Leadership in Regional Collaboratives includes
  - i. Coordinators
    1. Each Regional Collaborative will name two or three Coordinators who will be the key contacts with ODP's Supporting Families Director.
    2. At least one Coordinator is a county administrative staff with the ability to modify policy and practices in the county
    3. Functions of the Coordinators include:
      - a. Engage appropriate stakeholders,
      - b. Ensure interaction and communication among stakeholders,
      - c. Establish efficient and effective information-sharing plans,
      - d. Foster relationships and collaboration,
      - e. And keep the focus on the learning that guides the next steps for the Regional Collaborative.
  - ii. The PA Family Network as partners for outreach to families.
- c. Regional collaboratives focus on a common vision for supporting families through
  - i. Welcoming meetings in accessible spaces with accessible materials so that all members can participate fully
  - ii. Collaboration among members to
    1. Define a vision to support local families that is aligned with the Supporting Families Principles and Values
    2. Share resources and information to reach the defined vision
    3. Identify gaps and strategies to fill them by accessing integrated supports

## **2. Membership of the Collaborative**

Including diverse membership from a broad mix of stakeholders such as the suggested partners below provides an array of perspectives as well as resources to define local needs and strategies to meet those needs. Members vary based on those needs.

- a. People with lived experience including individuals and their families
- b. System Partners such as
  - County IDD/A staff
  - ASERT (Autism Services, Education, Resources, and Training)
  - Health Care Quality Unit (HCQU)
  - SCO
  - Provider agency staff
  - Regional ODP Supporting Families lead(s)
- c. Cross System Partners such as
  - Early Intervention (EI)
  - Office of Mental Health and Substance Abuse Services (OMHSAS)
  - Children and Youth Services (CYS)
  - Aging Services
- d. Developmental Disability Council grantees
- e. Community partners across life domains
  - Education
  - Faith groups
  - Clubs and organizations
  - Parks and recreation

### **3. Outcomes of the Collaborative**

Regional Collaboratives identify a collective vision and achieve goals toward that vision. The experiences and opportunities of the collaborative lead in a positive direction toward that vision. Outcomes could address any of the “3 buckets” of Discovery and Navigation, Connecting and Networking, or Goods and Services

- a. This can be filling the family’s buckets
- b. Or filling the community’s buckets
- c. Gaps are identified and strategies are implemented collaboratively to fill them
  - i. Strategies to fill gaps include identifying and accessing, or creating new integrated supports options

### **4. Evaluation of the Collaborative**

Self-evaluation helps to keep a focus on the collective vision or identify the need to redefine the collective vision and strategies.

- a. Complete a trajectory at least annually and submit to the ODP Regional Leads
- b. Complete Progress Tools required by ODP
  - i. Evaluate Structure
  - ii. Evaluate Stakeholder inclusion
  - iii. Evaluate goals achieved

### **5. Participation in the broader PA CoP for Supporting Families**

There are many activities hosted by PA’s CoP for Supporting Families. The activities below are specific to Regional Collaboratives.

- a. Maintain current information on the Regional Collaborative’s landing page with ODP [Community of Practice – Regional Collaboratives – MyODP](#)

- b. Participate in ODP hosted regional meetings for Regional Collaboratives
- c. Participate in ODP's Regional Collaboratives for Supporting Families Summit

Additional information and resources be found at:

[Community of Practice – MyODP](#), [www.supportstofamilies.org](http://www.supportstofamilies.org),  
and [www.lifecoursetools.com](http://www.lifecoursetools.com).

## Appendix A

### Regional Collaboratives for Supporting Families Progress Tool

|                                     |  |
|-------------------------------------|--|
| Date                                |  |
| Collaborative Name                  |  |
| Person Completing the Progress Tool |  |

**DIRECTIONS:**

The Regional Collaborative Progress Tool is used as a self-evaluation tool to help you determine your next steps. It also provides a way to inform and influence the service system.

The information provided is used for a variety of processes including:

- ISAC reporting for Recommendation #4 Supporting Families Across the Life Span,
- updating the Regional Collaboratives’ landing pages at [Community of Practice – Regional Collaboratives – MyODP](#),
- and informing the National Community of Practice (CoP) for Supporting Families on local efforts in PA’s CoP for Supporting Families.

**Activities to Support the Regional Collaborative:**

**Self-Assessment: Rate the Regional Collaborative on the following using this rating scale -**

- 5 Completely Agree
- 4 Mostly Agree
- 3 Slightly Agree
- 2 Slightly Disagree
- 1 Mostly Disagree
- 0 Completely Disagree

|  |   |
|--|---|
|  | <b>The structure of the Collaborative</b> includes identified lead/co-leads, engagement, accessible meetings/materials, relationship with PA Family Network, collaboration, work towards a common vision aligned with the Supporting Families Principles and Values |
|  | <b>Diverse Membership reflects a broad mix of stakeholders</b> including self-advocates and family members, ID/A system partners and cross-system partners, DD council grantees, and/or community partners across all life stages                                   |
|  | <b>Achieve goals</b> as you work toward your vision   |
|  | <b>Participate in the broader CoP for Supporting Families</b> (including regional meetings, PA and/or National Innovation calls, and/or Regional Collaboratives Summit)   |

**Trajectory Creation and Review:**

Does the trajectory remain reflective of current goals?      YES                      NO

*Please attach the current trajectory for the Regional Collaborative when submitting this report.*

What support is needed from ODP?



**Maintain current information on MyODP**

Review the information in each county in your Collaborative at [Community of Practice – Regional Collaboratives – MyODP](#)

The information you provide below will be used to populate the “landing page” for each county in PA’s CoP for Supporting Families. Please review the information for each of the counties in your collaborative and provide updates below **exactly** as you would like it to appear on the website.

Add lines as needed in the chart below.

| County | Updates needed on MyODP   |             |
|--------|---|-------------|
|        | Section Header  | New wording |
|        | Contact Information   |             |
|        | Website/Social Media Links  |             |
|        | Communication and Meetings Structure  |             |
|        | Goals, next steps or actions plans  |             |
|        | AE/SCO/Provider/DHS/Broad Community Partners Represented within Collaborative |             |
|        | Contact Information   |             |
|        | Website/Social Media Links  |             |
|        | Communication and Meetings Structure  |             |
|        | Goals, next steps or actions plans  |             |
|        | AE/SCO/Provider/DHS/Broad Community Partners Represented within Collaborative |             |