



ISAC Recommendation #4 – Support Families Throughout the LifeSpan

April 2026





Overview

- Performance-Based Contacting – Family Engagement Survey Results
- Strategy 5 – Supporting families across the lifespan
- Strategy 8 – Building capacity across systems
- Strategy 9 – Supporting parents with disabilities

Measure Review: QI.03.3



- Attest to assist in efforts, beginning January 1, 2025, to support ODP data collection on family satisfaction with provider engagement
 - ODP will survey individuals and families to measure their satisfaction with family engagement. Measure will not be implemented until January 2025. Providers will fail this measure if there is no evidence of support.
- Ways to meet the measure
 - Response rate > 0%
 - Other evidence of distributed survey
- Results of the survey



157 out of 363 providers had a **response rate higher than 20%**

95 out of 363 providers had a **response rate lower than 10%**

35 providers distributed the survey but had **no response rate**

Results	Met/Unmet	# of Providers
Response Rate > 0%	Met	363
Distributed Survey	Met	35
No Available Respondents	Met	2
Confirmed Receipt*	Unmet	22
No Response	Unmet	11
Total		433

*This means that the provider confirmed they got the request to distribute the survey, yet there is no evidence they did so.



Does the provider build and maintain a relationship with you?

Response	Count	Percent
Yes	1,616	86%
No	272	14%
Total	1,888	100%



How satisfied are you with the level of involvement you have in the individual's planning and decision-making?

Response	Count	Percent
Very satisfied	995	53%
Satisfied	571	30%
Neutral	173	9%
Dissatisfied	80	4%
Very dissatisfied	30	2%
I am not involved in planning and decision-making	39	2%
Total	1,888	100%



How satisfied are you with the **overall communication** from the provider?

Response	Count	Percent
Very satisfied	933	49%
Satisfied	556	29%
Neutral	191	10%
Dissatisfied	141	7%
Very dissatisfied	67	4%
Total	1,888	100%



Do you have any **concerns about how the provider communicates** with you and/or your family?

Response	Count	Percent
Yes	403	21%
No	1,468	78%
Not Applicable	17	1%
Total	1,888	100%



Strategy 5

With most individuals living with their families, whether they receive formal services or not, Family Caregivers are supported to plan across life transitions, from birth throughout the arc of life. This includes financial planning, benefits planning, better planning tools, and SCs assisting in planning. Family caregivers need information, connection, and services and supports.

Recognize, Assist, Include, Support, & Engage (RAISE) Family Caregivers Act



- The RAISE Family Caregivers Act
 - Law on Jan. 22, 2018
 - directs the Sec of HHS to develop a national family caregiving strategy
 - Act - [PUBL119.PS](#)
 - [National Strategy to Support Family Caregivers](#)
- Supporting Families Leadership Team led by ODP & the PA Developmental Disabilities Council remain active and attend webinars and national calls
- PA shares information about our community of practice for supporting families.



Strategy 8

Focus on the engagement of cross-systems partners to build capacity across fields (e.g., medical, hospital social workers, etc.) in the CoP for

Supporting Families to recognize their roles in supporting families to have strong visions and high expectations. The value their roles play in improving access for families to needed information, connection to other families, simplifying the processes of accessing supports, and services throughout the lifespan is essential.



Family Support Research & Training Center

Strive to Thrive: Supporting Families across the Aging and Disability Networks

Future Planning for Adults with Developmental Disabilities and Aging Families

WAVE Program: Wellness Action Via Engagement for Older Family Caregivers

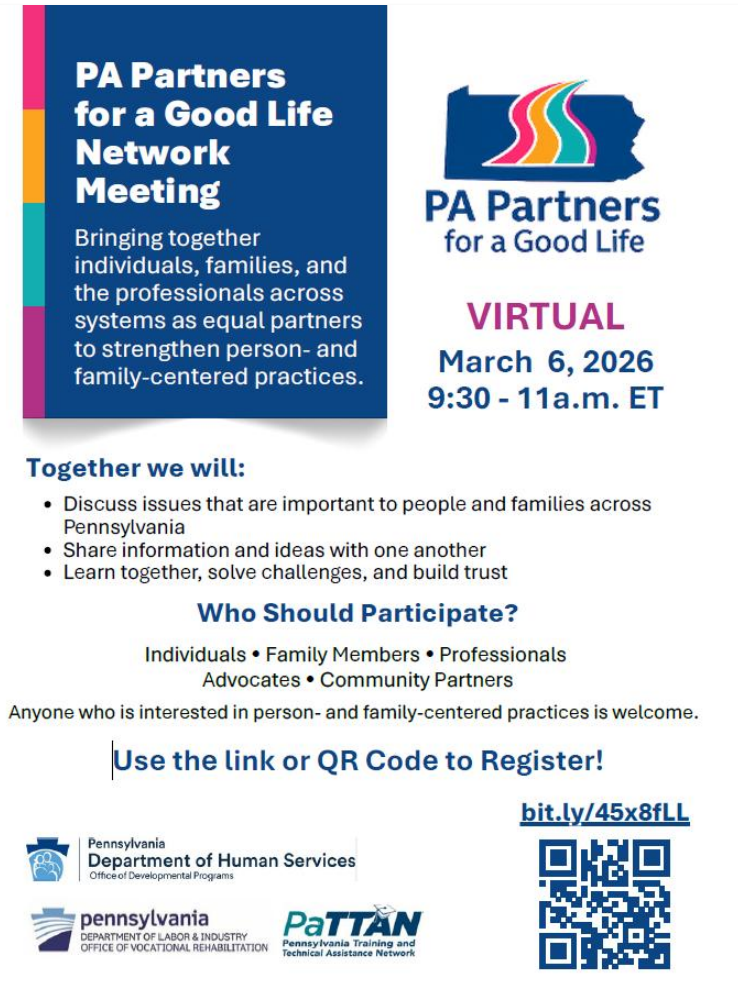
Analysis of National Datasets on Family Support

Policy Analysis and Development to Improve Family Support



Strategy 8: All People - Activities to Help Reach This Vision

Bringing together individuals, families, and the professionals across systems as equal partners to strengthen person- and family-centered practices.



PA Partners for a Good Life Network Meeting

Bringing together individuals, families, and the professionals across systems as equal partners to strengthen person- and family-centered practices.

PA Partners for a Good Life

VIRTUAL
March 6, 2026
9:30 - 11a.m. ET

Together we will:

- Discuss issues that are important to people and families across Pennsylvania
- Share information and ideas with one another
- Learn together, solve challenges, and build trust


Who Should Participate?

Individuals • Family Members • Professionals
Advocates • Community Partners

Anyone who is interested in person- and family-centered practices is welcome.

Use the link or QR Code to Register!

bit.ly/45x8fLL



Pennsylvania Department of Human Services
Office of Developmental Programs

pennsylvania DEPARTMENT OF LABOR & INDUSTRY OFFICE OF VOCATIONAL REHABILITATION

PaTTAN Pennsylvania Training and Technical Assistance Network

Strategy 8: Aging - Activities to Help Reach This Vision



First Steps

Where do I get started?



Caregiving Resources

How do I take better care of the person I'm caring for?



Self-care Resources

How do I take better care of myself?





PA CareKit Coaching Project

Evaluation Plan for PA CareKit Coaching Project

- The University of Pittsburgh is collaborating with the PA Department of Aging to conduct an evaluation of the PA CareKit. This project is supported by a 2-year grant to PDA from the Administration for Community Living (ACL).
- The project will include training providers to become “CareKit Coaches”.

Outcomes of Interest

(5) Pa CareKit Refinement

- The PA CareKit’s design, tools, language, and delivery model will be improved based on provider and consumer feedback.
- These refinements will include specific recommendations for kinship caregivers and older adults caring for adult/grown children with disabilities.



Strategy 9

People with disabilities who are parents, or who are planning to become parents, should be supported to plan for their needs as a family. Support should include planning with the SC. ODP will develop concrete expectations for how to support parents with disabilities and those who plan to become parents. Individuals will have the support they need to explore family planning.



Learning Collaborative: Supporting People with Disabilities who are Parents

Series Goals

- Identify core competencies/best practices for supporting people with disabilities in parenting roles
- Provide meaningful, practical, implementable ideas and strategies
- Provide tools, resources and information
- Facilitate lasting networking and connection among participants

Informational Webinar:

- Learning Collaborative for People with Disabilities who are Parents - June 4th from 10-10:45am





Family Medical Support Assistance: Webinar for Individuals and Families

- In 2022, ODP created a new waiver service, Family Medical Support Assistance (FMSA).
- Webinar to explain FMSA service, how it works, and who it applies to. ODP is encouraging individuals and families to attend this webinar to learn about this waiver service. There will be time during the webinar for questions to be asked directly to ODP.
- **Who should attend?**
 - Individuals and Families
- **Date:**
 - May 29, 2026, 10:00 AM – 11:30 AM
- **Register:**
 - [Family Medical Support Assistance \(FMSA\) Webinar for Individuals and Families](#)

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