

IM4Q Steering Committee Recommendations to the ISAC
from NCI Adult Family Surveys (AFS) and
Family Guardian Survey (FGS)
2022-2023 and 2023-2024
July 2025

This is a report from the IM4Q Steering Committee providing the ISAC recommendations from its review of the 2022-2023 and 2023-2024 National Core Indicators (NCI) **Adult Family Survey (AFS individuals living at home)** for Pennsylvania, as well as some comments from the 2022-2023 NCI **Family Guardian Survey (FGS not living with their family)**.

The report is organized by ISAC Recommendations, followed by the Steering Committee recommendations, and then by data first from 2022-2023 and then 2023-2204 from the NCI reports with percentages highlighted.

ISAC Recommendation 1: Assure Effective Communication

Table 54. Does your family member use technology in their everyday life to help them do things on their own?

State	Yes	No	N
PA	28%	72%	624
Weighted NCI-IDD Average	32%	68%	17341

Technology usage is not very high, yet most people have computers and iPads. For the FGS staff at group homes are not using devices and some will not engage with communication specialists.

Table 55. Is there a computer, tablet (for example an iPad), or smartphone that your family can use in your home? 88% 12% 4757

State	Yes	No	N
PA	92%	8%	648
Weighted NCI-IDD Average	91%	9%	18136

Recommendations:

- Increase awareness of staff and families of communication specialists at ODP. Find out how it works positively for other families.
- Share that Andrew's Gift has an application for free laptops and training for those who reside in Dauphin, Cumberland, Perry, Lancaster or Lebanon Counties. (<https://www.andrewsgift26.com/>).
- ODP gives only 40 hours a year to communication needs, which may not be enough. Provide demonstrations for families (e.g. YouTube, etc.)

Technology Data and Preferred Communication Data: For both living arrangements, only 1% use a device even though it shows people use gestures to communicate.

- **Recommendation:** Continue to Increase training for families, DSPs and others on Technology and Communication Devices and Services.
- **Recommendation:** Increase of hours past 40 to meet communication needs a person has.
- **Recommendation:** Share communication resources with families and service providers such as the Lifeline assistance service for free cell phones

ISAC Recommendation 2: Promote Self-Direction, Choice, and Control

Table 10. Family Member Has Legal Court Appointed Guardian or Conservator

State	No Guardianship or Conservatorship	Limited Full Guardianship Guardianship or or Conservatorship Conservatorship		Has Guardianship or Conservatorship but Level is Unknown	N
PA	48%	12%	35%	5%	596
Weighted NCI-IDD Average	35%	19%	42%	4%	17332

Table 33. Has your family learned about
alternatives to guardianship/conservatorship?

State	Yes	No	N
PA	52%	48%	551
Weighted NCI-IDD Average	51%	49%	14984

Recommendation

Levels of **guardianship** seem high. People who reside in a group home have a higher instance of having a Guardian. Also, the percentage that learned about alternatives is low regardless of which living arrangement. Is there more we can do in this area?

Provide information and training to families on alternatives to Guardianship, especially young families, such as supported decision making and about other decision-making supports like health-care proxies, advance directives, powers of attorney, notarized statements, representation agreements, etc.

Comment on guardianship from Disability Rights PA: Disability Rights Pennsylvania provides information on substitute decision making and has worked with APS on lowering the number of families seeking guardianship. SC's/ODP may need a refresher as we get calls from SC's and parents seeking information on guardianship. It is an expensive process and a family decision, but most times people can help their loved ones without it.

ISAC Recommendation 3: Increase Employment

Table 46. Does your family member have enough supports to work or volunteer in the community?

State	Yes	No	N
PA ↑	70%	30%	484
Weighted NCI-IDD Average	55%	45%	12095

- **Recommendation:** Families need more support and training on employment-related topics for their child to become employed and/or to volunteer.

Suggestions: Families need to understand the rules of work as to how it impacts income, so a person does not lose their benefits. Help individuals explore areas that can lead to employment such as volunteering. Barriers include employers not always being receptive to people with disabilities as workers and some families are fearful of their child working. Look at the path of employment (how it occurs). Share good stories. Does everyone have a benefit query from social security as the first step to benefit counseling? Utilize employer mentors.

ISAC Recommendation 4: Support Families throughout the Lifespan

Table 14. Family Member's Level of Help Needed with Personal Care Activities (for example, bathing, dressing, eating)

Weighted

State	No Support Needed; No Issues with Personal Care Activities	Some Support Needed; Requires Only Occasional Assistance or Monitoring	Extensive Support Needed; Frequent or Severe Enough to Require Regular Assistance	N
PA	32%	41%	28%	651

NCI-IDD

25%

37%

18212

38%

Average

- **Recommendation:** Address the family member's level of help needed with personal care activities (for example, bathing, dressing, eating).

Table 15. Family Member's Need for Help with Other Daily Activities (for example, scheduling, managing money, or shopping)

State	No Support Needed; No Issues with Other Daily Activities	Some Support Needed; Requires Only Occasional Assistance or Monitoring	Extensive Support Needed; Frequent or Severe Enough to Require Regular Assistance	N
PA	3%	24%	73%	648
Weighted NCI-IDD Average	5%	22%	73%	18248

- **Recommendation:** Assist families in finding help with other daily activities (for example, scheduling, managing money, or shopping).

Table 71. Does your family take part in any family-to-family networks in your community?

State	Yes	No	N
PA	15%	85%	560
Weighted NCI-IDD Average	18%	82%	15563

Connection to Family-to-Family networks while above the average is still very low so people are not connected through family groups.

- **Recommendation:** Provide information and promote families taking part in local family-to-family networks (e.g. PA Family Network, Arcs, Autism groups, others).
- **Recommendation:** Explore virtual/on-line/AI as another way to connect with families. HIPPA requirements have not been helpful in connecting people (example is to use WhatsApp and/or SLACK).

Table 90. Have services and supports reduced your family's out-of-pocket expenses for your family member's care?

State	Yes	No	N
PA ↓	64%	36%	562
Weighted NCI-IDD Average	69%	31%	15649

- **Recommendation:** Explore what out of pocket expenses are still being paid by families and suggest resources that may help.

ISAC Recommendation 5: Promote Health, Wellness, and Safety

Table 80. If you asked for crisis or emergency services during the past 12 months, were services provided when needed?

State	Yes	No	N
PA	59%	41%	110
Weighted NCI-IDD Average	57%	43%	4376

Table 82. Have you talked about how to handle emergencies (such as a medical emergency, pandemic or natural disaster) with your family member's case manager/service coordinator?

State	Yes	No	N
PA ↑	60%	40%	597
Weighted NCI-IDD Average	54%	46%	16420

- **Recommendation:** Better respond to crisis/emergency service requests.
- **Recommendation:** Ensure support coordinators have the necessary information to talk about how to handle emergencies (such as a medical emergency, pandemic or natural disaster) with families.

Table 83. Do you know how to file a complaint or grievance about provider agencies or staff?

State	Yes	No or Don't Know	N
PA ↑	70%	30%	637
Weighted NCI-IDD Average	50%	50%	18077

Table 84. If a complaint or grievance was filed or resolved in the past 12 months, are you satisfied with the way it was handled?

State	Yes	No	N
PA ↑	53%	47%	66
Weighted NCI-IDD Average	35%	65%	2508

- **Recommendation: Inform families about how to file a complaint or grievance about provider agencies or staff.**

ISAC Recommendation 6: Support People with Complex Needs

Table 13. Family Member’s Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors

State	No Support Needed; No Issues with Managing Behavior	Some Support Needed; Requires Only Occasional Assistance or Monitoring	Extensive Support Needed; Frequent or Severe Enough to Require Regular Assistance	N
PA	57%	31%	12%	646
Weighted NCI-IDD Average	51%	30%	18%	17749

- **Recommendation:** Support families with information and services to address self-injurious, disruptive, and/or destructive behavior.

ISAC Recommendation 7: Develop and Support Qualified Staff

Table 61. Do your family member’s support workers change too often? Is there too much “turnover” of support workers?

State	Yes	No	N
PA	35%	65%	557
Weighted NCI-IDD Average	35%	65%	12750

Table 62. Is there always a staff person available to support your family member when support is needed?

State	Yes	No	N
PA	77%	23%	546
Weighted NCI-IDD Average	75%	25%	12645

Table 65. Can someone in your family directly manage support staff?

State	Always	Usually	Sometimes	Seldom or Never	N
PA	63%	18%	7%	12%	413
Weighted NCI-IDD Average	59%	21%	7%	13%	941 7

- **Recommendation:** Support increased staff salaries/benefits so turnover/staff change remains low.
- **Recommendation:** ODP to provide resources to find staff/vetting group to assist/way to advertise to get people for staff. For those using Participant Directed Services make sure everyone is connected to a supports broker.
- **Recommendation:** Continue to foster workforce development so staff availability is high.

ISAC Recommendation 8: Simplify the System

Table 27. Do you get enough information to take part in planning services for your family member?

State	Always	Usually	Sometimes	Seldom or Never	N
PA	38%	38%	19%	5%	620
Weighted NCI-IDD Average	33%	36%	21%	9%	1674 2

Table 28. Is the information you get about services and supports easy to understand?

State	Always	Usually	Sometimes	Seldom or Never	N
PA	25%	51%	20%	4%	620
Weighted NCI-IDD Average	29%	44%	21%	5%	1680 7

- **Recommendation:** Develop and/or provide easy to read/comprehend information for families about other public services for which your family is eligible (for example, food stamps, SSI, housing subsidies, etc.)?

Table 31. Do you have enough information about other public services for which your family is eligible (for example, food stamps, SSI, housing subsidies, etc.)?

State	Always	Usually	Sometimes	Seldom or Never	N
PA	27%	35%	23%	15%	546
Weighted NCI-IDD Average	25%	30%	23%	22%	1505 5

- **Recommendation:** Assist families in finding help in planning their family members future, especially in the areas of medical, social and recreational/fun.

Table 32b. Do you need help planning for your family member's future in any of the following areas? (continued)

State	Medical	Social or Relationships	Transition from School	Recreation or Having Fun Other
PA	27%	34%	7%	40% 9%
Weighted NCI-IDD Average	32%	37%	11%	41% 11%

- **Recommendation:** Address why families are not getting all the supports they need.
- **Recommendation:** Utilize this data to invest in what families say they are needing - respite, regularly scheduled support for family members, homemaker services, and home or vehicle modifications.

Table 43. Does your family get the supports and services it needs?

State	Yes	No	N
PA	76%	24%	568
Weighted NCI-IDD Average	73%	27%	14789

Table 44a. If your family does not get the support and services needed, what additional services does your family need?

State	Respite	Regularly Scheduled Support for Family Member	Homemaker Services	Home Vehicle and/or Modifications
PA	65%	35%	15%	13%
Weighted NCI-IDD Average	52%	34%	18%	12%

ISAC Recommendation 10: Expand Options for Community Living

Table 48. If you need respite services, how often are you able to get them when needed?

State	Always	Usually	Sometimes	Seldom or Never	N
PA ↓	23%	28%	17%	33%	332
Weighted NCI-IDD Average	32%	28%	15%	25%	1069 2

- **Recommendation:** There is a need for more respite options for families. Explore why respite options are limited or not available.

ISAC Recommendation 11: Increase Community Participation

Table 69. Does your family member have friends other than paid support workers or family?

State (names abbreviated)		Yes	No	N
PA		67%	33%	628

Weighted NCI-IDD Average

64%

36%

4632

- **Recommendation:** Provide training for families, support coordinators, and provider staff on the value of and ways to increase friendships and relationships for people beyond staff.
- **Recommendation:** Encourage providers to share ideas on ways to support community engagement and the development of natural (non-staff) relationships for the people they serve based on their interests and preferences.
- **Recommendation:** Learn how some families have been successful in connecting their children to other non-disabled people in the community.
- **Recommendation:** Educate community groups and social clubs on benefits of including people with disabilities as members.
- **Recommendation:** Support the creation of Community Brokers to use community resources to connect people.

ISAC Recommendation 14 – Promote Racial Equity

- **Recommendation:** When sending out the AFS and FGS make sure ODP has a targeted/representative sample of non-white and other groups and non-English speaking groups.