

The Office of Developmental Programs (ODP) to Mail National Core Indicators® (NCI®) Family Surveys

ODP Announcement 24-022

AUDIENCE:

All families and legal guardians of adults receiving intellectual disability and autism services through ODP

PURPOSE:

To inform of ODP's participation in the 2023 NCI® family surveys.

BACKGROUND

In 1997, Pennsylvania joined with the Human Services Research Institute (HSRI) and 14 other states to identify the major areas and sub-areas of performance, indicators, measures, and data sources for service system improvement. This effort, called National Core Indicators® (NCI®), provides states with valid and reliable tools to help improve system performance and better serve people with intellectual and developmental disabilities (age 18 and older) and their families. Since then, Pennsylvania has participated annually in the NCI® Project.

These indicators were intended to provide a system-level “snapshot” of how well each state was performing. The states were guided by a set of criteria that was designed to select indicators that were:

- Measurable,
- Related to issues the states had some ability to influence, and
- Important to all individuals they served, regardless of level of disability or residential setting.

Along with an Adult In-Person Survey (IPS) for individuals with intellectual disabilities and autism, two surveys were developed for states to mail to the families and guardians of these individuals. The Adult Family Survey (AFS) measures the experiences of families who have an adult family member living at home. The Family Guardian Survey (FGS), for families whose adult family member does not live at home, measures whether these families had the support they needed to be involved, and whether they were satisfied with the service system that was intended to meet their family member’s needs.

DISCUSSION:

In order to determine participants for the surveys each year, ODP generates a random list of all eligible individuals receiving services from the Home and Community Services Information System (HCSIS) for each survey. To be eligible, each person must:

- Be 18 or older,
- Receive supports coordination plus one other service **or** reside in an Intermediate Care Facility for People with Intellectual Disabilities (ICF/ID) (private or state-operated),

- Live at home with families (for the AFS) **or** live in another setting (for the FGS),
and
- Be listed as having active status in HCSIS.

A random sample list of eligible individuals is created for each survey, meaning that only a portion of individuals will be selected. ODP uses each individual's contact list in HCSIS to determine the appropriate person to whom to send the survey. This is generally a family member who is designated as the primary or additional contact or the legal guardian. The surveys are then mailed out with a request for participation. The surveys are not mandatory, but ODP highly encourages families and legal guardians to provide feedback so that it can improve services for everyone it serves statewide. There is also an opportunity to provide comments and the respondent will be asked if the comments can be shared with others. If the answer is yes, they are shared with the county for follow-up. If the question is left blank, then ODP **will not** automatically share the comments unless a significant concern is noted.

Both surveys are scheduled to be mailed and should be received within the next two weeks. Beginning this year, families and guardians may choose one of two ways to complete the survey they receive. They may either fill out the hard copy and return it to ODP via the self-addressed stamped envelope provided or they may enter their responses directly into a secure online database using the link and instructions contained in the cover letter accompanying the survey. The recorded responses will only be used to complete a collective report and will not be used to identify specific individuals. The deadline for responding to either option is **April 30, 2024**.

CONTACT:

Ms. Lee Stephens, ODP IM4Q/NCI Statewide Lead

ra-pwodpim4qnci@pa.gov

ATTACHMENT:

NCI-IDD 2021-22 DATA AT A GLANCE: FAMILY SURVEYS