

# New York National Core Indicators 2024-25

## Frequently Asked Questions

### What is the National Core Indicator-IDD In-Person Survey?

- A voluntary effort by the New York State Office for People with Developmental Disabilities (OPWDD) to gather the opinions and experiences of individuals who have intellectual and developmental disabilities and receive services.
- “Face-to-face surveys” via Zoom video conference with these individuals.

### What is the purpose of the NCI-IDD In-Person Survey?

- **The survey is not an assessment or review of facilities.**
- **The survey only asks for individuals’ opinions about their quality of life and the services they receive** (e.g. choices of activities, employment, health and safety, and direct care workers).
- OPWDD uses participant feedback to continue making the services and supports meet the needs of people with intellectual or developmental disabilities.

### How did Vital Research get residents’ names?

- Vital Research received a list of randomly selected people who receive services through OPWDD.
- These people live in a variety of places, which may include a residential program.

### Who is funding this project?

- The New York State Office for People with Developmental Disabilities (OPWDD).
- Vital Research is subcontracted to manage the project and hire field interviewers to conduct the survey.

### Who makes up the interviewer team?

- Vital Research’s interviewer team is comprised of a diverse group of individuals from across the United States.
  - Many come from teaching, direct service, human service, social work, and other similar backgrounds, including those who have experience working with people with intellectual and developmental disabilities.
  - **All interviewers must pass a background check, as well as complete HIPAA training on a yearly basis.**

- The interviewer team goes through extensive training to ensure all protocols are adhered to and to ensure that data is gathered according to best practices.
- Many interviewers return year after year and carry valuable experience with them throughout each project.
  - Over half of the interviewers in the 2023-2024 survey cycle are returning from last year.

### Is survey participation required?

- **No, participation is completely voluntary.**
- **An individual's decision whether to participate or not participate will have no impact on the services he/she receives currently.**
- However, we encourage individuals to participate because their feedback is important.

### Can anyone (guardians, family/friends/caregivers, staff) refuse to participate on behalf of the person receiving services?

- Only **legal guardians** may refuse on behalf of the participant.
- Staff members and others cannot refuse.

### What if an individual cannot answer the survey because of their disability (e.g. TBI, age-related dementia, etc.)?

- If the person is not able to answer the questions, a proxy respondent may answer some questions on their behalf.
- A proxy can be a family member, friend, caregiver, or staff person at the facility. It is anyone who knows this person's living situation and services the best.
- During the scheduled phone call, the interviewer will ask two screening questions with the person receiving services to determine if a proxy survey should be used. If a proxy is available, it is preferred to schedule a video conference appointment with both the participant and proxy. The Proxy Survey should take around 20-30 minutes.

### What if facility staff members do not have time to be Proxy?

- We understand that facility staff members' workload might be significant. We certainly appreciate any help you may provide in the project since it helps OPWDD better understand the services individuals receive. The survey for proxies is different from the participant survey. The Proxy survey only asks questions about services the individual receives.
- This project will extend into May, so interviewers will have the flexibility of time to schedule a date/time that works for you during this period.

### **What is the Interviewer outreach process like in this project?**

- Interviewers will receive digital Call Sheets with the participants' information and attempt to contact them by phone.
- Should an individual consent to do the survey, interviewers will schedule a Zoom video conference appointment at a time and date convenient to the person.
- If a participant needs additional support from staff, interviewers will contact the residence or program to let them know about the upcoming appointment and confirm Zoom capabilities.
- Interviewers will be using an OPWDD email account (e.g., [John.X.Doe@opwdd.ny.gov](mailto:John.X.Doe@opwdd.ny.gov))

### **How is the survey conducted and how long is it?**

- The survey is conducted over a HIPAA-compliant Zoom video conference.
- The Participant Survey takes 45 minutes - one hour depending on the individual. The Proxy Survey takes 20-30 minutes.

### **Does the interview need to be completed in one session? What about breaks?**

- No, the interview can be completed over multiple sessions if that is the participant's preference.
- Breaks are permitted and welcomed throughout the interview! The participant would just let the interviewer know they would like to take a break.
- At any point during the interview, the participant can choose to stop, and the interviewer will end the video conference meeting.

### **Do you have to be on a computer? What about Wi-Fi?**

- No, survey respondents may use a computer, laptop, tablet, or smartphone for the video conference.
- Survey respondents must be able to access the Internet (either via Wi-Fi or cellular data) for the entire video conference. Zoom operates on many different devices, but there must be an internet connection to run the application.

### **In what ways can we help a participant prepare for the video conference?**

- Establish a private place where the video conference can take place.
- Download the Zoom application to whatever device will be used for the survey or connect to Zoom via a web browser.
- Test the audio and video connection prior to the meeting time.
- Make sure the person's device is fully charged.

## **Can a copy of the survey be provided? What is the survey going to ask the individual?**

- Unfortunately, printed copies of the survey are not available. The survey asks for an individual's opinions about their quality of life and the services they receive. For example, there will be questions about choices of activities, employment, health and safety, daily activities, and direct care staff.
- Surveys are conducted remotely on HIPAA-compliant Zoom accounts and answers are recorded on secure survey platforms. Interviewers will read the questions out loud and input the responses on their computer or tablet.
- Example questions include: "What long-term services and supports do you receive (Interviewers will read out option responses)?", "Do you have transportation to get to medical appointments?", "Do you do any of these activities at least once a week (Interviewers will read out option responses)?" "How involved are you in your service plan/plan of care and the goals you want for your life?"
- If any questions do not apply or a respondent prefers not to answer them, they will be skipped.

## **Is the survey confidential (private)?**

- All survey responses are confidential and will not affect the services an individual will receive in any way.
- The answers an individual provides will not be shared with any of the people who are paid to help him/her.
- Vital Research will protect privacy by keeping all information confidential. The survey data entry will not collect any Protected Health Information (PHI) such as participants' name, date of birth, etc.
- However: If an interviewer sees or learns something of concern regarding a participant's health or safety, they are required to let OPWDD Incident Management Unit (IMU) know so they can help.

## **How do you interview a person with disabilities?**

- The survey is specially designed to obtain perceptions about experiences from people with varying abilities.
- Interviewers are trained on how to interview persons with disabilities.
- Interviewers will also follow-up with any recommended accommodations.

## **What does training for the Interviewer entail?**

- Each Interviewer has completed over 10 hours of training on how to interact with and survey persons with disabilities.
- In addition to survey administration, interviewer training covers abuse/neglect/exploitation reporting, cultural humility, data security, guardianship, HIPAA, and Zoom protocols.

- OPWDD presents on the I/DD service delivery system and how NCI-IDD data is used to improve services and supports in the state of New York.

### **Where else can I get information about this project?**

- Participants, guardians, caregivers, friends/families, facility staff, or others are more than welcome to review the website for more information:
  - The New York NCI-IDD In-Person Survey project website:  
[www.Vitalresearch.com/newyork/nci](http://www.Vitalresearch.com/newyork/nci)
- The National Core Indicators (NCI) website, which provides a national/state overview of the surveys: <https://www.nationalcoreindicators.org/>
- Contact Vital Research at 888-351-4147 (toll free) or email anytime
  - NY Project Contact: Sandra Verdugo, [sverdugo@vitalresearch.com](mailto:sverdugo@vitalresearch.com)

### **New York State Office for People With Developmental Disabilities (OPWDD)**

#### **Primary contact:**

Olivia Popiel

NCI State Coordinator

NYS Office for People With Developmental Disabilities (OPWDD)

Office: (518) 473-9313

[NCIAdultInPerson@opwdd.ny.gov](mailto:NCIAdultInPerson@opwdd.ny.gov)