



NASDDDS & HSRI

2015-16 Adult Consumer Survey Revisions: An Overview

Pre-Survey

- As an option, the Pre-Survey section can be made available for entry into ODESA
 - Developed in response to request from some states to have ability to capture Pre-Survey directly in ODESA (for use by surveyors)
 - Will fill-in bell symbols throughout the survey
 - The data will not be downloaded by HSRI or included in any data analysis.
 - Secure, encrypted.
 - Because it includes PII, additional data agreement / Business Associates Agreement may be necessary.
- Contact Steph for more info sgiordano@hsri.org



Demographic and Background Info

Race and Guardianship

- Combined race and ethnicity question into one “check all that apply”
- Refined response options
 - Added a response for those in guardianship relationships who do not differentiate between “full guardianship” and “limited guardianship”
 - Added a question on the guardian’s relationship to the individual receiving services



BI-7 Does this person have a legal appointed guardian/conservator (a person who is legally granted authority to make decisions on behalf of the individual)?

Check ONE.

- 1 No, person does not have a guardian/conservator (legally competent or presumed competent) → code BI-8 as 'Not Applicable'
- 2 Yes, **limited** guardianship (a person has authority over certain decisions, such as entering into contracts, medical procedures, etc.)
- 3 Yes, **full** guardianship
- 4 Yes, **unable to distinguish** between limited or full guardianship
- 99 Don't know

BI-8 If this person has a legal/court-appointed guardian, what is the guardian's relationship to the individual?

Check ONE.

- 98 Not Applicable
- 1 Family
- 2 Friend
- 3 Employee of state or guardianship agency
- 4 Other: _____
- 99 Don't know



Demographic and Background Info

Parenthood

- Added a series of questions on parenthood

BI-1 Is this person a parent? (This includes adult children.)

Check ALL THAT APPLY.

- 1 No, does not have a child
- 2 Yes, parent of a child or children *under 18*
- 3 Yes, parent of a child or children *over 18*
- 99 Don't know

BI-10 a. If the person has children under 18 years of age, does the child or children live with the person?

- 98 Not Applicable – no child or child is an adult
- 1 No
- 2 Yes
- 99 Don't know



Demographic and Background Info

Residence

- Categorized and defined residence settings

Intermediate care facility for persons with I/DD (ICF/ID) or other institutional setting

- 1 ICF/ID, **4-6** residents with disabilities
- 2 ICF/ID, **7-15** residents with disabilities
- 3 ICF/ID, **16 or more** residents with disabilities
- 4 Nursing facility
- 5 Other specialized institutional facility

Group residential setting (e.g., group home)

- 6 Group living setting, **2-3** people with disabilities
- 7 Group living setting, **4-6** people with disabilities
- 8 Group living setting, **7-15** people with disabilities

Own home or apartment

- 9 Lives in own home or apartment; may be owned or rented, or may be sharing with roommate(s)
- 10 Parent/relative's home (may include paid services to family for residential supports)

Foster or host home

- 11 Foster care or host home (round-the-clock services provided in a single-family residence where **2 or more people with a disability** live with a person or family who furnishes services)
- 12 Foster care or host home (round-the-clock services provided in a single-family residence where only **one person with a disability** lives with a person or family who furnishes services—sometimes called shared living.)

Other

- 13 Homeless
- 14 Other (specify): _____
- 99 Don't know



Demographic and Background Info

Residence

- Added questions for HCBS Regs and additional information on individuals living in institutions or group homes:
 - Is this person's residence owned or controlled by a provider agency? ('Controlled' means the agency providing services is also connected to the property by lease or ownership. This includes foster care or host home settings as defined in BI-33.)
 - If this person lives in an Intermediate Care Facility for persons with IDD/DD (ICF/IF), a specialized institutional facility or group home, is it publicly or privately operated?
 - Is the person named on the lease?
 - Does the person own his or her own home?
 - Has this person ever lived (longer than a year) in an institutional setting such as a nursing home or ICF?



Demographic and Background Info

Employment

- Separated individual job and small-group to capture if people work in both settings
 - Paid individual job in a community-based setting (A person working at an individual job in a local business alongside peers who do not have disabilities. Job is part of the typical labor market (e.g., competitive employment))
 - Paid small-group job in a community-based setting (The activity is done in an integrated setting, as part of a group of not more than 8 people with disabilities (e.g., enclave, work crew))



Section I

Home and Day Activity

- Begin Section I with 'Home' questions then move to 'Employment'
 - Home questions tend to be easier to answer and applicable to more people (starts on a more positive note)
- Introduced more questions about employment and participation in workshops.
 - Do you go to a program or workshop (program or center where other people with disabilities work)?
 - Would you like to go more or less to the workshop (program or center)?
 - Do you take classes, training or do something to help you get a job or a better job?



Section I

Relationships

- Added several questions about communication with friends and family and staying in contact.
 - Can you see your friends when you want to? (Can you make plans with your friends when you want to?)
 - If no, why can't you see your friends when you want to?
 - Do you have other ways of communicating with your friends when you cannot see them? (like over the phone and through email?)
 - Can you see and/or communicate with your family when you want to? (Can you pick the times you see them? Does someone help you make plans to see them?)



Section I

Community Participation

- Added a “Community Participation and Leisure” section in Section I to get at whether people get to do the things they like to do as much as they’d like.
 - Are you able to go out and do the things you like to do?
 - Do you get to do the things you like to do as much as you like?
 - When you are at home, do you have enough things you like to do? (do you have things to do so you are not bored at home?)



Section I

Service Coordination

- Added more specific questions about service planning
 - Did you take part in the last service planning meeting
 - At the service planning meeting, did you know what was being talked about? (Did they use words you understood? Did they have the meeting in your preferred language?)
 - Did the service planning meeting include the people you wanted to be there?



Section I

Rights

- Moved some Rights questions from Section II to Section I
 - Do people read your mail or email without asking you first?
 - Can you be alone with friends or visitors at your home?
 - Are there rules about having friends or visitors in your home?
 - Can you use the phone or internet when you want to?



Section II

Community Inclusion

- Changed format of Community Inclusion questions
- Deleted question about sports/exercise
- Added question about community group participation in community



47. How often did you go out to a restaurant or coffee shop in the past month?

Other respondent: *In the past month, how many times did this person go out to a restaurant or coffee shop?*

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- 1 0
- 2 1-2 times
- 3 3-4 times
- 4 More than 5 times
- 99 Don't know, no response, unclear response

47a. Who did you usually go with?

Check ALL THAT APPLY.

- 98 Not Applicable – person didn't go out to eat
- 1 Alone
- 2 Friends or family
- 3 Housemates or coworkers
- 4 Staff
- 5 Others not listed
- 99 Don't know, no response, unclear response

49. Do you participate in community groups or other activities in your community? (This includes church groups or any other formal or informal community group.)

Other respondent: *Does this person participate in community groups or other activities in the community??*

Respondent: () 1-individual () 2-family/friend () 3-staff () 4-other

- 2 Yes
- 1 No
- 99 Don't know, no response, unclear response

49a. Who did you go with?

Check ALL THAT APPLY.

- 98 Not Applicable – person didn't participate in a community group
- 1 Alone
- 2 Friends or family
- 3 Housemates or coworkers
- 4 Staff
- 5 Others not listed
- 99 Don't know, no response, unclear response



Section II

- Questions added to Rights section in Section II:
 - Do you have a key to your home?
 - Can you lock your bedroom if you want to?
 - Have you voted in a local, state or federal election?
- Moved Question about physical activity from BI section to Section II



Self-direction Module

- Moved to Section II
- Expanded to include people in “self-directed” or “participant-directed” services (not just those on self-direction waiver)



Self-direction Module

- Do you participate in decisions about how to use your supports budget, hiring staff, or managing the services you get? (Do you self direct your supports?)
- Who makes decisions about how your budget for services is used?
- Do you hire and manage your staff? (Managing staff includes telling them what time to come to work, what their duties are, giving feedback about whether they're doing a good job, firing staff.)
- Do you have enough help deciding how to use your budget/services?



2015-16 Survey Changes

Family Surveys

Demographics of Family Member

- Guardianship:
 - Refined response options and added a question on the guardian's relationship to the individual receiving services
- Level of Education
 - Added response options
- Family Member's Daily Activities
 - Added response and response options
- Help with Daily Activities
 - Separated support needed for personal care and support for daily living



- N. If your family member needs help (support) with personal care activities (for example, bathing, dressing, eating), please indicate how much. (Check ONE)
- 1 No support needed (no help needed with other daily activities)
 - 2 Some support needed; requires only occasional assistance or monitoring
 - 3 Extensive support needed
- O. If your family member needs help (support) with other daily activities (for example, scheduling, managing money, or shopping), please indicate how much. (Check ONE)
- 1 No support needed (no help needed with other daily activities)
 - 2 Some support needed; requires only occasional assistance or monitoring
 - 3 Extensive support needed



Demographics of Respondent and Services and Supports Received

- Respondent Demographics
 - Added question whether anyone in the family is paid to support the family member
 - Added question whether the family (or family member) lives in an urban or rural area
- Services and Supports Received
 - Added response option for self-direction *or* fiscal intermediary services
 - Added question whether the family receives services from non-state entity (e.g., school)



Information and Planning

- Added question on future planning
- Added question on emergency preparedness
- Added questions on transition planning



Transition Planning

AFS and FGS

If your family member transitioned out of school services during the past year, did he/she have a transition plan?

If yes to Q14, did the transition plan include getting or continuing work in a community job?

CFS

Does your child have a transition plan (as part of an IEP or Section 504 plan through his/her high school, usually starting at age 14)?

If yes to Q14, did you help make the transition plan?



Access and Delivery of Services and Supports

- Revised section on to health services
 - Ask whether health professional understand the needs of the family member
 - Ask whether the family understands why medications were prescribed and how to use medication safely
 - Added follow-up to determine what, if any, additional services are needed



Can your family member see health professionals (for example, doctor, dentist, psychologist) when needed?

Does your family member's primary care doctor understand his/her needs related to his/her disability?

Do you have access to dental services for your family member?

If yes to Q28, does your family member's dentist understand his/her needs related to his/her disability?

If your family member takes medications, do you know what they're for?

If your family member takes medications, do you, your family member or someone else in your family know what is needed to safely take the medications (*when it should be taken, how much to take, potential side effects*)?

If your family member uses mental health services, does the mental health professional (for example, psychologist, psychiatrist, counselor) understand your family member's needs related to his/her disability?



Choice and Control and Community Involvement

- Added question as to whether provider agencies work together to support the individual
- Added question about use of family-to-family networks



Questions?

