

Measuring Quality in Home and Community-Based Services



Selected Inventory of Consumer and Caregiver Survey Questions Related to the National Quality Forum HCBS Domains

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Surveys of consumers or their families and caregivers are an essential means of assessing quality in the delivery of home and community-based services (HCBS). A substantial number of such surveys have been fielded for the purpose either of measuring HCBS quality generally or of specific aspects of HCBS quality. Other surveys not developed for HCBS nevertheless measure concepts that are important in HCBS quality, such as life satisfaction or community participation. As the need for implementation of quality metrics in HCBS becomes ever more urgent, it is important to understand which quality-related concepts have been addressed in some form by existing surveys, and how well, and which concepts are generally lacking in relevant survey content.

With funding from the U.S. Department of Health and Human Services, the National Quality Forum (NQF) recently convened a committee of stakeholders to identify and prioritize the domains of quality in HCBS. This ongoing work is expected to be completed by September 2016. A draft interim report was issued in July 2015, containing an initial set of 11 domains of HCBS quality as identified by the committee. Also included were a list of characteristics of a high-quality HCBS system (“characteristics”), which correspond closely to the domains; the characteristics have since been refined and a revised set is included in the second interim report, released in December 2015.

An initial set of proposed subdomains was also included in the first report; these are to be further refined during 2016. As noted in this report, some of the proposed subdomains

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appear in more than one domain, and in other instances very similar subdomains appear in multiple domains. This poses a problem for classification, but it is likely that the committee will clarify the domains and reduce some of this overlap before the final report is issued.

This report represents an attempt to classify questions in the more relevant consumer, family, and caregiver survey instruments that address the NQF HCBS quality domains. Both the corresponding characteristics and the proposed subdomains have been used to guide the process. Although the author attempted to be judicious in the selection and classification of items, it must be acknowledged that many decisions in this process are subjective and somewhat arbitrary, including which instruments to inspect, which items to include from each instrument, into which of multiple, semi-overlapping domains to classify each item, how to group items within each domain, and when to exclude similarly worded items because of overkill in a particular concept. In general, surveys and questions that could apply broadly, across disability type or age group, were given higher priority for inclusion than those that were more narrowly focused. When there are self-response and proxy-response versions of a question, the self-response version is shown.

Note that surveys developed for respondents other than consumers, families, and caregivers have not been included in the inventory. Surveys of providers and program administrators are beyond the scope of this report, as is use of administrative data or encounter data, such as that obtained from provider visits or claims submissions.

Although the main purpose of the report is to illustrate the extent to which surveys have been used to assess the different domains of HCBS quality, some survey developers may want to put together an instrument by selecting items from this inventory. Please proceed with caution. First, some of the instruments included here are under copyright, meaning that the developer's permission might be required before items can legally be borrowed wholesale. This caution especially applies to developers of surveys for commercial use.

Second, a survey instrument is—or at least, ought to be—more than the sum of the questions it contains. It is important to make sure that the items are generally consistent with one another, in that they use the same terminology, for example, and do not constantly shift format, from a yes/no question to a true/false statement to agree/disagree. Furthermore, despite any assurance from the developer of the original survey that the instrument was thoroughly tested, there is no substitute for performing at least some rudimentary cognitive and simple validity testing (e.g., face and content validity) of any new use of items in a different context or on a different population.

NQF Domain: Choice and Control

Description: The level to which individuals who use HCBS are able to choose their services and control how those services are delivered.

Corresponding characteristic: Provides for a person-driven system that optimizes individual choice and control in the pursuit of self-identified goals and life preferences.

Proposed subdomains: Choice of program delivery models and provider(s) including self-direction, agency, particular worker(s), and setting(s);¹ personal freedoms and dignity of risk;² achieving individual goals and preferences (i.e., individuality, person-centered planning);³ self-direction; shared accountability

Survey questions

Choice in living arrangement

Additional items related to residential settings are classified under Community Inclusion.

- Did you help pick this place to live? [PES-DD, MFPQOL]
- Thinking about the decision to move here, would you say: I made the decision all by myself, I made the decision with help from others, someone else made the decision for me. [MNCES]
- Who chose (or picked) the place where you live? (Did you help pick the place where you live?) [NCI-ACS]
- Who picked this place for you to live in? Others made the choice, person had little input, person had some input, person had a major say, person chose [PLQ]
- Does the person have options about where and with whom to live? [POMs]
- Before I moved to where I live now, I was told about or able to visit other places to live. Yes/no [ORIES]
- I was offered the choice to live in a place that is not only for people who have disabilities. Yes/no [ORIES]
- Who chose (or picked) the people you live with (or did you choose to live by yourself)? [NCI-ACS]
- Did you pick who you live with? Others made the choice, person had little input, person had some input, person had a major say, person chose [PLQ]
- I have a choice in who my roommate is. Yes/no [ORIES]
- Did you choose to live in the community instead of living in an institution? [NYPSS]

Satisfaction with living arrangement

- In general, do you like where you're living now? [MNCES]
- Do you like where you live? [PES-DD, MFPQOL]
- All things considered, how satisfied are you with the place in which you are living? Would you say that you are very satisfied, satisfied, or not satisfied? [NLTCs]
- In general, do you like where you are living right now? [NCI-AD]
- Would you prefer to live somewhere else? [NCI-AD]
- Do you like your home or where you live? Would you like to live somewhere else? [NCI-ACS]
- In general, is your room/apartment/home how you like it to be? [MNCES]
- Tell me whether you agree a lot, a little, or not at all with the following statement about your life: I like my living situation very much. [NHATS]

¹ Choice of setting is also included in subdomains of Community Inclusion and Service Delivery.

² Dignity of risk is also a subdomain of Health & Well-Being

² Dignity of risk is also a subdomain of Health & Well-Being

³ Elements of person-centered planning (e.g., goal assessment) are also included in a subdomain of Service Delivery.

- How satisfied are you with the conditions of your living place? Very dissatisfied, dissatisfied, neither satisfied nor dissatisfied, satisfied, very satisfied. [WHOQOL-BREF]
- Do you like the people you live with? [PES-DD]
- My housing situation is satisfactory. Strongly disagree, disagree, undecided, agree, strongly agree [CLMDP]

Control over living arrangement

Items specifically related to privacy are classified under Human and Legal Rights.

- Do you get to decide who comes in and out of your home? [TXPES]
- Are you able to lock the doors to your room if you want to? [NCI-AD]
- Do you have a key to your home? [NCI-ACS]
- Are your visitors able to come at any time, or are there only certain times of day that visitors are allowed? [NCI-AD]

Consumer direction: general

- Can you choose or change what kind of services you get and determine how often and when you get them? [NCI-AD]
- I'm given enough opportunity to arrange and organize the provided care myself. Totally disagree, disagree, don't know/no opinion, agree, totally agree [CCCQ]
- Do you choose where you receive your attendant services? [EAZI]
- Do you decide when you receive your attendant services? [EAZI]
- Are you able to schedule your attendant services during times that you need them most? [EAZI]
- Does your attendant provider pay attention to your choices, such as what you like to eat, where you want to go or what you want to do? [EAZI]
- Caregivers encourage and help me direct my own care. Strongly agree, agree, disagree, strongly disagree [PC-PAL]
- Can your family choose or change the agency that provides your family member's services? [NCI-AFS, NCI-FGS]

Consumer direction: budget authority

- Can you make changes to your budget/services if you need to? {Can you decide to buy something different?} [NCI-ACS]
- Some people get an allowance from the state to pay for the help or equipment they need. Do you get an allowance like this? [MFPQOL]
- In what ways does this person (with unpaid supports if needed) control his/her individual budget? (A) Took part in the original development of the budget. (B) Keeps track of how budget is being spent. (C) Decides how much personal assistance s/he wants each week. (D) Signs and/or authorizes payments to providers of supports. (E) Decides how their individual budget will be modified, with or without assistance. (F) Selects and/or directs a fiscal intermediary to distribute pay or other resources [PLQ]
- Did the person choose whether or not he/she would control the individual budget? [PLQ]
- Does the person have a fiscal intermediary to assist in handling all or some of the individual budget? *If yes:* Did the person choose his/her fiscal intermediary? [PLQ]

Consumer direction: hiring & firing

- Do you help pick the people who are paid to help you? *If no:* Would you like to help pick the people who are paid to help you? [PES-E/D]
- Do you help pick your support staff? *If no:* Would you like to help pick your support staff? [PES-DD]
- Did you help choose the people who are paid to help you? [MNCES]
- Did you choose (or pick) your staff? [NCI-ACS]
- Do you choose your attendant provider? [EAZI]
- Can you choose or change who provides your services if you want to? [NCI-AD]

- Can your family choose or change your family member's support workers? [NCI-AFS]
- Did you know you can change the people who are paid to help you if you want to? [PES-E/D]
- Did you know you can change your support staff if you want to? [PES-DD]
- Do you know you can ask someone to change [workers]? [HCBSEOC]
- Did you hire your *{job coach}* yourself? [HCBSEOC]

Consumer direction: tasks

- Thinking again about the people who are paid to help you, do you tell them what to help you with? [PES-E/D]
- Do you tell your support staff what to help you with? *If no:* Would you like to tell them the things you want help with? [PES-DD]
- Thinking again about the people who are paid to help you, do you tell them what to help you with? *If no:* Would you like to tell them the things you want help with? [PES-E/D]
- Do the people who are paid to help you do things the way you want them done? [NCI-AD]
- Do the people paid to help you listen carefully to what you ask them to do [in your home]? [PES-E/D]
- Do the people who help you listen carefully to what you ask them to do? [MFPQOL]
- How often do [workers] listen carefully to you? Would you say never, sometimes, usually, or always? [HCBSEOC]
- Do [workers] listen carefully to you? Would you say mostly yes or mostly no? [HCBSEOC]
- Do the support staff who come to your home listen carefully to what you ask them to do? [PES-DD]
- I can tell that the carers take my personal wishes into account. Totally disagree, disagree, don't know/no opinion, agree, totally agree [CCCQ]
- I can tell that the carers really listen to me. Totally disagree, disagree, don't know/no opinion, agree, totally agree [CCCQ]

Consumer direction: unwanted help

- In the past year, did staff do things that you didn't want them to do? [MNCES]
- About how often have people who were paid helped you do something when you did not want help? Very often, often, sometimes, or never. [C&C9MO]
- I am given enough opportunity to do what I am capable of doing myself. Totally disagree, disagree, don't know/no opinion, agree, totally agree [CCCQ]
- Are you getting any services or help that you'd rather not have? [MNCES]

Broad measures of control & decision-making

- Do you feel in control of your life? [NCI-AD]
- I am able to control my own life. Strongly disagree, disagree, undecided, agree, strongly agree [CLMDP]
- Which of these statements best describes your present situation? (1) I have as much control over my daily life as I want. (2) Sometimes I don't feel I have as much control over my daily life as I want. (3) I have no control over my daily life [ASCOT]
- Check the answer that best describes you: (1) I can make my own decisions. (2) Other people make decisions for me. [ASDS]
- Check the answer that best describes you: (1) My choices will not be honored. (2) I will be able to make choices that are important to me. [ASDS]
- I have a lot of control over the important things in my life. Strongly agree, agree, neither agree nor disagree, disagree, strongly disagree [OPQOL]
- I have control over what I do and how I spend my time. Would you say that statement is true, mostly true, mostly false, or false? [PART-E]

- I have the freedom to make my own decisions. Would you say that statement is true, mostly true, mostly false, or false? [PART-E]
- Does the person choose personal goals? *If yes:* Are these the goals the person is working toward? [POMs]

Autonomy

- I take responsibility for my own life. Would you say that statement is true, mostly true, mostly false, or false? [PART-E]
- Staff encouraged me to take responsibility for how I live my life. Strongly disagree, disagree, undecided, agree, strongly agree [MHSIP-ACS, CLMDP]
- Tell me whether you agree a lot, a little, or not at all with the following statement: Other people determine most of what I can and cannot do. [NHATS]

Control over transportation & leaving the house

- Do you have control over your transportation? (Can you plan a trip or decide when to go out?) [TXPES]
- I get out of my house to do the activities that I choose. Would you say that statement is true, mostly true, mostly false, or false? [PART-E]
- I can get out and about whenever I choose. Would you say that statement is true, mostly true, mostly false, or false? [PART-E]
- Can you get to the places you need to go, like work, shopping, or the doctor's office? [MFPQOL]
- Can you usually get to the places where you want or need to go, like shopping, for a visit, to church, to get your hair done, to play cards, or to a ball game? [MNCES]
- When you want to go somewhere, can you just go, do you have to make some arrangements, or do you have to plan many days ahead and ask people for help? [MFPQOL]

Control over participation: general

- I have choices about the activities I want to do. Would you say that statement is true, mostly true, mostly false, or false? [PART-E]
- Who decides how you spend your free time (when you are not working, in school, or at the day program)? Individual, family/friend, staff, other. [NCI-ACS]
- I do free time activities based on my interests. I do not even if I have the chance, I do sometimes when I have the chance, I do most of the time I have the chance, I do every time I have the chance [ASDS]
- Does your attendant provider help you go places or do errands in your community such as shopping, movies, sport events, religious services or other community events? *If yes:* Do you choose where you want to go? [EAZI]
- My friends and I choose activities that we want to do. I do not even if I have the chance, I do sometimes when I have the chance, I do most of the time I have the chance, I do every time I have the chance [ASDS]
- When you go out places (field trips, shopping, movies, parks, walks, or any other outings), who picks where you go? [PLQ]

Control over participation: specific activities

- I can get together with people when and where I want. Would you say that statement is true, mostly true, mostly false, or false? [PART-E]
- Can you see your friends when you want to? [NCI-ACS]
- Can you see your family when you want to? [NCI-ACS]
- Can you see your friends and family when you want to see them? [MFPQOL]
- Can you go on a date if you want to? [NCI-ACS]
- I go to restaurants I like. I do not even if I have the chance, I do sometimes when I have the chance, I do most of the time I have the chance, I do every time I have the chance [ASDS]

- I go to movies, concerts, and dances. I do not even if I have the chance, I do sometimes when I have the chance, I do most of the time I have the chance, I do every time I have the chance [ASDS]
- I go shopping or spend time at shopping centers or malls. I do not even if I have the chance, I do sometimes when I have the chance, I do most of the time I have the chance, I do every time I have the chance [ASDS]
- Can you watch TV when you want to? [PES-DD, MFPQOL]

Control over communication

- Are you allowed to use the phone and internet when you want to? [NCI-ACS]
- I have access to a phone or to other methods of communicating with others outside of where I live. I can talk to anyone I want at any time. Always, usually, sometimes, never [ORIES]

Control over employment

- Did you help to choose the job you have now? [HCBSEOC]
- Who chose (or picked) the place where you work? (Did you help make the choice?) [NCI-ACS]
- Who chose (or picked) where you go during the day? (Did you help make that choice?) [NCI-ACS]
- Does the person decide where to work or what to do (e.g., type of job/employer or daytime activity)? [POMs]

Control over other daily activities

- Who decides your daily schedule (like when to get up, when to eat, when to go to sleep)? Individual, family/friend, staff, other. [NCI-ACS]
- I create my own schedule. Always, usually, sometimes, never [ORIES]
- Do you take part in deciding what you do with your time each day? [HCBSEOC]
- Do you take part in deciding when you do things each day—for example, deciding when you get up, eat, or go to bed? [HCBSEOC]
- Can you eat your meals when you want to? (No one else decides for you when you eat.) [NCI-AD]
- When you are at home, can you eat when you want to? [PES-DD]
- Can you go to bed when you want to? [PES-DD, MFPQOL]
- Do you get up and go to bed at the time when you want to? (No one else decides for you when you get up or go to bed, and you get the help you need to get up and go to bed when you want to?) [NCI-AD]
- Can you be by yourself when you want to? [PES-DD, MFPQOL]
- When you are at home, can you eat when you want to? [PES-DD, MFPQOL]
- Can you choose the foods that you eat? [MFPQOL]
- I choose my clothes and the personal items I use every day. I do not even if I have the chance, I do sometimes when I have the chance, I do most of the time I have the chance, I do every time I have the chance [ASDS]

Control over finances

- I choose how to spend my personal money. I do not even if I have the chance, I do sometimes when I have the chance, I do most of the time I have the chance, I do every time I have the chance [ASDS]
- Do you choose what to buy with your spending money? [NCI-ACS]
- I can easily get my money and spend my money as I wish. Always, usually, sometimes, never [ORIES]

Involvement in & control over service planning and decisions

See also "Service coordination/planning" under Community Inclusion.

- Do you know what is in your service plan? [NYPSS]
- Did you work with someone to develop your [care/service plan]? [HCBSEOC]

- Did you help make your service plan? [NCI-ACS]
- I am involved in planning my care and services. Strongly agree, agree, disagree, strongly disagree [PC-PAL]
- I helped to choose my child's services. Strongly disagree, disagree, undecided, agree, strongly agree. [YSSF]
- Were you able to choose the services that you get as part of your service plan? [NCI-ACS]
- Does the person select the services and/or supports that he or she receives? [POMs]
- Does your case manager involve you in discussing and planning your services? Always, usually, sometimes, rarely, never [POMP-CMS]
- Does your case manager/service coordinator ask you what you want? (Does your case manager/service coordinator ask what is important to you?) [NCI-ACS]
- Does the person have ultimate authority? (Could he or she overrule the entire group on an issue, within safety limits?) [PLQ]
- Do the unpaid group members have the real power? (As opposed to paid staff and professionals.) [PLQ]
- I get enough opportunity to say what kind of care I need. Totally disagree, disagree, don't know/no opinion, agree, totally agree [CCCQ]
- I am given enough opportunity to help decide on the kind of care I receive. Totally disagree, disagree, don't know/no opinion, agree, totally agree [CCCQ]
- Does the agency providing residential services to your family member involve him/her in important decisions? [NCI-FGS]
- I am given enough opportunity to help decide on how the care is given. Totally disagree, disagree, don't know/no opinion, agree, totally agree [CCCQ]
- I am given enough opportunity to use my own expertise and experience with respect to the care I need. Totally disagree, disagree, don't know/no opinion, agree, totally agree [CCCQ]
- In the last 12 months, how often were you involved as much as you wanted in these decisions about your health care? Never, sometimes, usually, always [CAHPS-HP]
- In the last 12 months, how often was it easy to get your doctors or other health providers to agree with you on the best way to manage your health conditions or problems? [CAHPS-HP]
- In the last 12 months, did a doctor or other health provider talk with you about the pros and cons of each choice for your treatment or health care? [CAHPS-HP]
- Is the person supported to self-manage their personal health? [POMs]

Service planning according to individual goals

- Does your [care/service plan] include none of the things that are important to you, some of the things that are important to you, most of the things that are important to you, or all of the things that are important to you? [HCBSEOC]
- I, not staff, decided my treatment goals. Strongly disagree, disagree, undecided, agree, strongly agree [MHSIP-ACS, CLMDP]
- I helped to choose my child's treatment goals. Strongly disagree, disagree, undecided, agree, strongly agree. [YSSF]
- Does the planning process make strong efforts to understand the focus person's long term dreams? (As opposed to short term goals set by others.) [PLQ]
- I receive care and services according to my life history, personal preferences, and goals. Strongly agree, agree, disagree, strongly disagree [PC-PAL]
- Do the services and/or supports focus on the person's goals? [POMs]
- Does the organization provide supports and services to assist the person in pursuing personal goals? [POMs]
- Does the organization provide support for the person to do the things he or she wants to do? [POMs]

Other aspects of person-centered planning:

- Do you consider this plan to be “person-centered”? [PLQ]
- How do you feel about what’s in your person-centered plan? Very poor, poor, fair, good, very good [PLQ]
- Does the planning process emphasize building a network of supports from informal, unpaid, or general community sources? [PLQ]
- Did the planning process emphasize cooperation among all participants? (As opposed to professional authority.) [PLQ]
- Do you feel [workers] know what’s on your[care/service plan], including the things that are important to you? [HCBSEOC]
- Does your attendant provider understand what is important to you? [EAZI]

NQF Domain: Human and Legal Rights

Description: The level to which the human and legal rights of individuals who use HCBS are promoted and protected.

Corresponding characteristic: Promotes privacy, dignity, respect, and independence; freedom from abuse, neglect, exploitation, coercion, and restraint; and other human and legal rights.

Proposed subdomains: Delivery system promotes dignity and respect; privacy;⁴ informed consent; freedom from abuse and neglect;⁵ optimizing the preservation of legal and human rights; sense of safety;⁶ system responsiveness

Survey questions

Broad measures of abuse/neglect

- In the past 12 months, have you suspected that you've been abused, neglected, or exploited? [NMPQR]
- In the past 30 days, how often have you been hit, kicked, slapped, or otherwise physically hurt? Never, once, a few times, more than a few times [CLMDP]
- Do you feel that your care was ever neglected by the people who were paid to help? [C&C9MO]

Coercion/restraint

- Where I live now, my provider/staff has never threatened me with physical harm, or used restraints, or punished me, to force me to make a decision I did not want to make. True/False [ORIES]
- Where I live now, I have never been given a medication against my will to control my behavior. True/False [ORIES]
- Where I live now, I have never been held or tied down by a person or object against my will. True/False [ORIES]
- Where I live now, I have never been kept or locked in a room against my will. True/False [ORIES]

Mistreatment by paid helpers

For items related to safety, see also Health & Well-Being; for additional items related to worker treatment of the consumer, see under Workforce.

- Are any of the people paid to help you now mean to you, or do they yell at you? [PES-E/D, MFPQOL]
- Do any [workers] that you have now yell, swear, or curse at you? [HCBSEOC]
- Do the people who help you with your services ever do mean things to you? [NYPSS]
- Have any of the people paid to help you said mean things to you or yelled at you? [MNCES]
- Have you ever been physically hurt by any of the people who help you now? [MFPQOL]
- Have you ever been injured by any of the people paid to help you now? [PES-E/D]
- Do any [workers] that you have now hit you or hurt you? [HCBSEOC]
- Have you ever been hit or hurt by any of the people paid to help you? [MNCES]
- Have you ever felt unsafe or disrespected by any of the people involved with your services? [NYPSS]
- Do you feel safe around the people who are paid to help you? [NCI-AD]
- Do you feel safe with the people that come into your house to provide your services? [NMPQR]
- Do you feel safe with your attendant provider? [EAZI]

⁴ Privacy and respect are also included in subdomains of Workforce.

⁵ "Freedom from abuse, neglect, and exploitation" is also a subdomain of Health and Well-Being.

⁶ Safety is also a subdomain of Health & Well-Being

- Do you think you can trust your attendant provider? [EAZI]

Mistreatment in general

- In the last year, has anyone said mean things to you, yelled at you, or threatened you? [MNCES]
- Does anyone ever do mean things to you, such as yell at you? [PES-DD]
- In the last year, have you been hit or hurt by anyone? [MNCES]
- Does anyone ever hit you or hurt your body? [PES-DD]
- Is there a person you can talk to if someone hurts you or does something to you that you don't like? [HCBSEOC]

Financial exploitation, theft

- In the last year, has anyone taken (or stolen) money from you or put pressure on you to give them money? [MNCES]
- Have any of the people who help you now ever taken your money or things without asking first? [MFPQOL]
- Have any of the people paid to help you now ever taken your things without asking? [PES-E/D]
- Thinking back over the past nine months, did someone who was paid to help you take any money or belongings from the household without letting someone know? [C&C9MO]
- Does anyone take your things without asking first? [PES-DD]
- Do any of the [workers] that you have now take your money or your things without asking you first? [HCBSEOC]
- Has anyone used or taken your money without your permission? [NCI-AD]

Respect from workers

For additional items related to worker treatment of the consumer, see under Workforce.

- Do the people paid to help you treat you respectfully [in your home]? [PES-E/D]
- Do the support staff who come to your home respect you? [PES-DD]
- In the past year, did the people who are paid to help you treat you respectfully? Always, usually, sometimes, never [MNCES]
- Do you feel that the people who are paid to help you treat you with respect? [NCI-AD]
- Do your staff treat you with respect? [NCI-ACS]
- Does your attendant provider treat you with respect? [EAZI]
- Which of the following statements best describes your present situation? I am treated by other people with the dignity and respect that I want. Sometimes I am not treated by other people with the dignity and respect that I want. I am never treated with the dignity and respect that I want. [ASCOT]
- Do interactions with others reflect concern for the person's opinions, feelings and preferences? [POMs]

Equality

- I am treated equally. Would you say that statement is true, mostly true, mostly false, or false? [PART-E]

Privacy

For additional items related to worker respect for privacy, see under Workforce.

- Do you have enough privacy in your home? (Can you have time to yourself?) [NCI-AD]
- Do you have enough privacy at home? [NCI-ACS]
- I may lock my bedroom or living unit door for privacy. Always, usually, sometimes, never [ORIES]
- Do people let you know before they come into your home? [NCI-ACS]
- Do people ask your permission before coming into your home/room? [NCI-AD]
- Do people let you know before they come into your bedroom? [NCI-ACS]
- Do people ever come into your room when you don't want them to? [PED-DD]

- Are you able to be alone at home with visitors if you want to? [NCI-AD]
- Can you be alone with friends or visitors at home, or does someone have to be with you? (Are there rules about having friends or visitors in your home?) [NCI-ACS]
- Can you talk on the telephone without someone listening in? [MFPQOL]
- Can you use the phone privately whenever you want to? [NCI-AD]
- Do people read your mail or email without asking you first? [NCI-AD, NCI-ACS]
- Staff respected my wishes about who is and who is not to be given information about my treatment. [MHSIP-ACS, CLMDP]
- Is personal information shared with others only at the request of, or with the consent of, the person or his/her legally authorized representative? [POMs]

Rights, general

- To what extent do you believe your rights are respected here? Never, rarely, sometimes, usually, always [PLQ]
- I was given information about my rights. Strongly disagree, disagree, undecided, agree, strongly agree [MHSIP-ACS, CLMDP]
- In the last 12 months, were you given information about your rights as a patient? [ECHO]
- Indicate whether the person exercises their rights as a citizen... (1) Right to voice their opinion, (2) right to vote, (3) right to move about the community, (4) right to associate with others, (5) right to practice their religion, (6) right to privacy, (7) right to access their possessions, (8) right to access food/refrigerator, (9) right to have visitors at any time, (10) right to access their money, (11) right for personal decision making, (12) right to fair wages, (13) right to non-discrimination at work, (14) right to dignity and respect, (15) right to freedom from coercion and restraint, (16) right to file complaints about services, (17) other rights that are important to the person. [POMs]
- Is the person provided with the support needed to exercise his or her rights? [POMs]

NQF Domain: Community Inclusion

Description: The level to which HCBS integrates individuals into their communities and fosters social connectedness.

Corresponding characteristic: Promotes social connectedness and inclusion of people who use HCBS in accordance with individual preferences.

Proposed subdomains: Enjoyment or fun; employment, education, or productivity; social connectedness and relationships; social participation; resources to facilitate inclusion; choice of setting;⁷ accessibly built environment

Survey questions

Social contact: family

- Generally, are you satisfied with the amount of contact you have with your family? [MNCES]
- Would you like to see or talk to your relatives more often, less often, or as often as you do now? [NLTCS]
- When you want to, how often can you get together with these family members who live nearby? Would you say never, sometimes, often, or always? [HCBSEOC]
- When you want to, can you get together with these family members who live nearby? Would you say mostly yes or mostly no? [HCBSEOC]
- I am satisfied with my current level of family activities. Not at all, a little bit, somewhat, quite a bit, or very much. [PROMIS-SSRA]

Social contact: friends

- Generally, are you satisfied with the amount of contact you have with friends? [MNCES]
- Would you like to see or talk to your friends more often, less often, or as often as you do now? [NLTCS]
- When you want to, how often can you get together with these friends who live nearby? Would you say never, sometimes, often, or always? [HCBSEOC]
- When you want to, can you get together with these friends who live nearby? Would you say mostly yes or mostly no? [HCBSEOC]
- Can you see or talk to your friends and family (who do not live with you) when you want to? [NCI-AD]
- I am satisfied with my current level of activities with my friends. Not at all, a little bit, somewhat, quite a bit, or very much. [PROMIS-SPDSA, PROMIS-SSRA]
- I am satisfied with the amount of time I spend visiting friends. Not at all, a little bit, somewhat, quite a bit, or very much. [PROMIS-SPDSA]
- Are there people you like to visit with? *If yes:* Can you see this person/these people when you want? [PES-DD]
- Is the person satisfied with the number of friends s/he has? [POMs]
- Is the person satisfied with this amount of contact with his/her friends? [POMs]

Social network

- I would like more companionship or contact with other people. Strongly agree, agree, neither agree nor disagree, disagree, strongly disagree [OPQOL]
- In general, how would you rate your satisfaction with your social activities and relationships? Excellent, very good, good, fair or poor? [PROMIS-GH, NHIS-10]
- How satisfied are you with your personal relationships? Very dissatisfied, dissatisfied, neither satisfied nor dissatisfied, satisfied, very satisfied. [WHOQOL-BREF]

⁷ Choice of setting is also included in subdomains of Choice and Control and Service Delivery.

- Which of the following statements best describes your social situation? My social situation and relationships are as good as I want. Sometimes I feel my social situation and relationships are not as good as I want. I feel socially isolated and often feel lonely. [ASCOT]
- [Satisfaction with:] Relationships with parents, siblings & other relatives—communicating, visiting, helping. Delighted, pleased, mostly satisfied, mixed, mostly dissatisfied, unhappy, terrible. [QOLS]
- Do you have friends you like to talk to or do things with? [NCI-ACS]
- I am happy with the friendships I have. Strongly disagree, disagree, undecided, agree, strongly agree [CLMDP]
- [Satisfaction with:] Close friends. Delighted, pleased, mostly satisfied, mixed, mostly dissatisfied, unhappy, terrible. [QOLS]
- I'd like more people to enjoy life with. Strongly agree, agree, neither agree nor disagree, disagree, strongly disagree [OPQOL]
- I have people with whom I can do enjoyable things. Strongly disagree, disagree, undecided, agree, strongly agree [CLMDP]
- When you participate in leisure activities do you usually do this alone or with others? Mostly alone, mostly with friends who have head injuries, mostly with family members, mostly with friends who do not have head injuries, with a combination of family and friends [CCCQ]

Social support

- Is there someone you can count on in an emergency? [MNCES]
- In a crisis, I would have the support I need from family or friends. Strongly disagree, disagree, undecided, agree, strongly agree [CLMDP]
- My family, friends, and neighbors would help me if needed. Strongly agree, agree, neither agree nor disagree, disagree, strongly disagree [OPQOL]
- People in this community are willing to help each other. Do you agree a lot, a little, or do you not agree? [NHATS]
- I have someone who will listen to me when I need to talk. Never, rarely, sometimes, usually, always [PROMIS-ES]
- I have someone to confide in or talk to about myself or my problems. Never, rarely, sometimes, usually, always [PROMIS-ES]
- There are people I can talk to. Never, rarely, sometimes, usually, always [PROMIS-ES]
- Do you have a best friend, or someone you are really close to? [NCI-ACS]
- Do you have a best friend with whom you confide? [CIQ]
- Sometimes people feel that they have nobody to tell their troubles to. Would you say you feel this way most of the time, some of the time, hardly ever, or never? [NLTCS]
- I have someone who understands my problems. Never, rarely, sometimes, usually, always [PROMIS-ES]
- How often do you get the social and emotional support you need? Would you say always, usually, rarely, or never? [NHIS-01]
- How satisfied are you with the support you get from friends? Very dissatisfied, dissatisfied, neither satisfied nor dissatisfied, satisfied, very satisfied. [WHOQOL-BREF]
- I feel close to my friends. Never, rarely, sometimes, usually, always [PROMIS-ES]
- I get emotional support from my family. Never, rarely, sometimes, usually, always [PROMIS-ES]
- I have people who care about what happens to me. Never, rarely, sometimes, usually, always [PROMIS-ES]
- Does the person have a natural support network? If yes, does the individual feel s/he has enough contact with each group of people in their network? (1) Family, (2) friends, (3) neighbors, (4) co-workers, (5) others in community. [POMs]

Love and affection

- I have someone who gives me love and affection. Strongly agree, agree, neither agree nor disagree, disagree, strongly disagree [OPQOL]
- I get love and affection. Never, rarely, sometimes, usually, always [PROMIS-ES]
- [Satisfaction with:] Close relationship with spouse or significant other. Delighted, pleased, mostly satisfied, mixed, mostly dissatisfied, unhappy, terrible. [QOLS]
- Can you have a close relationship if you want one? (Can you have a boyfriend or girlfriend?) [TXPES]
- Can you go on a date if you want to? [NCI-ACS]
- Does the person have intimate relationships? If yes, how satisfied are they with type and scope of these relationships? Very satisfied, somewhat satisfied, somewhat unsatisfied, very unsatisfied. [POMs]

Satisfaction with use of time

- In general, how satisfying do you find the way you're spending your life these days? Would you call it completely satisfying, pretty satisfying, or not very satisfying? [Channeling]
- Overall, are you satisfied or dissatisfied with the way you are spending your life these days? [C&C9MO]
- Are you satisfied with how you spend your free time? Generally no/generally yes. [MNCES]
- Do you like how you usually spend your time during the day? [NCI-AD]
- Thinking about your usual activities including leisure, doing things for others and paid or unpaid employment, which of the following statements best describes your present situation? (1) I do the activities I want to do. (2) I do some of the activities I want to do. (3) I don't do any of the activities I want to do. [ASCOT]

Roles, fulfillment, meaning

- I do paid or unpaid work or activities that give me a role in life. Strongly agree, agree, neither agree nor disagree, disagree, strongly disagree [OPQOL]
- I am able to pursue my dreams and desires. Would you say that statement is true, mostly true, mostly false, or false? [PART-E]
- Tell me whether you agree a lot, a little, or not at all with the following statement about your life: My life has meaning and purpose. [NHATS]
- To what extent do you feel your life to be meaningful? Not at all, a little, a moderate amount, very much, extremely. [WHOQOL-BREF]
- I spend time helping others. Would you say that statement is true, mostly true, mostly false, or false? [PART-E]
- Can you help other people if you want to? [NCI-ACS]
- [Satisfaction with:] Helping and encouraging others, volunteering, giving advice. Delighted, pleased, mostly satisfied, mixed, mostly dissatisfied, unhappy, terrible. [QOLS]
- I am happy with how much I do for my family. Not at all, a little bit, somewhat, quite a bit, very much. [PROMIS-SSRA]
- I am happy with how much I do for my friends. Not at all, a little bit, somewhat, quite a bit, very much. [PROMIS-SPDSA, PROMIS-SSRA]
- Other people count on me. Would you say that statement is true, mostly true, mostly false, or false? [PART-E]

Extent of participation

- I am satisfied with my current level of social activity. Not at all, a little bit, somewhat, quite a bit, or very much. [PROMIS-SPDSA, PROMIS-SSRA]
- I am satisfied with the extent of my social activities outside my home. Not at all, a little bit, somewhat, quite a bit, or very much. [PROMIS-SSRA]

- Do you feel your social needs are being met (such as participating in community events, visiting friends/family, going to church)? [NDPES]
- Are you as socially active as you'd like to be—like participating in community activities? [MNCES]
- How often do you socialize with other people (talk for visit with friends or relatives)? None, some, a lot [Duke]
- Do you go out to do fun things in your community? *Probe:* These are things that you enjoy such as going to church, the movies or shopping? [MFPQOL]
- Does the person participate in the life of the community? If yes, is the individual satisfied with the type of his/her participation? If yes, is the individual satisfied with the frequency of his/her participation? [POMs]
- I am satisfied with the amount of time I spend doing leisure activities [with others]. Not at all, a little bit, somewhat, quite a bit, or very much. [PROMIS-SPDSA, PROMIS-SSRA]
- I am satisfied with my ability to do all of the community activities that are really important to me. Not at all, a little bit, somewhat, quite a bit, or very much. [PROMIS-SPDSA, PROMIS-SSRA]
- How often do you take part in social, religious, or recreation activities (meetings, church, movies, sports, parties)? None, some, a lot [Duke]
- Is there anything you want to do outside your home that you don't do now? [PES-E/D, MFPQOL]
- When you want to, how often can you do things in the community that you like? Never, sometimes, usually, always [HCBSEOC]
- When you want to, can you do things in the community that you like? Would you say mostly yes or most no? [HCBSEOC]
- Are you able to do things you enjoy outside of your home when and with whom you want to? (For example, visit with friends or neighbors, go shopping, go to a movie or a show or out to eat, to religious functions, to volunteer in the community)? [NCI-AD]
- Does your family member take part in activities in the community (for example, going out to a restaurant, movie, or sporting event)? [NCI-AFS, NCI-FGS]

Participation in specific activities

- Can you tell me approximately how many times a month you now usually participate in the following activities outside your home? (1) Shopping (2) Leisure activities such as movies, sports, restaurants, etc. (3) Visiting friends or relatives [CIQ]
- Do you like to go shopping, for things like clothes, books, or music? *If yes:* Do you go shopping? [PES-DD]
- In the past month, did you go shopping? If yes, how many times in the past month? [NCI-ACS]
- In the past month, did you go out on errands or appointments? If yes, how many times in the past month? [NCI-ACS]
- In the past month, did you go out for entertainment? If yes, how many times in the past month? [NCI-ACS]
- I am satisfied with how often I go out for entertainment. Not at all, a little bit, somewhat, quite a bit, or very much. [PROMIS-SSRA]
- Do you like to go out to eat? *If yes:* Do you go out to eat? [PES-DD]
- In the past month, did you go out to a restaurant or coffee shop? If yes, how many times in the past month? [NCI-ACS]
- In the past month, did you go out to a religious service or spiritual practice? If yes, how many times in the past month? [NCI-ACS]
- In the past month, did you go out for exercise? If yes, how many times in the past month? [NCI-ACS]
- In the past year, did you go away on vacation? If yes, how many times in the past year? [NCI-ACS]

Membership in community

- I feel that I am a part of my community. Would you say that statement is true, mostly true, mostly false, or false? [PART-E]
- I feel I belong in my community. Strongly disagree, disagree, undecided, agree, strongly agree [CLMDP]
- I contribute to the general well-being of my community. Would you say that statement is true, mostly true, mostly false, or false? [PART-E]
- I have a say on decisions in my community. Would you say that statement is true, mostly true, mostly false, or false? [PART-E]
- I feel valued as a member of society. Would you say that statement is true, mostly true, mostly false, or false? [PART-E]

Employment & volunteering

- Are you working for pay right now? *If no:* Do you want to work for pay? [MFPQOL]
- Do you have a paid job in the community? *If no:* Would you like to have a job in the community? [NCI-ACS]
- Do you work for pay at a job? *If no:* Do you want to work for pay at a job? [HCBSEOC]
- *If doesn't have job:* Would you like a job? [NCI-AD]
- *If doesn't have job:* Do you want to work? [PES-E/D]
- Did you help pick the job you have now? [PES-E/D]
- Do you volunteer? [NCI-ACS]
- Are you doing volunteer work or working without getting paid? *If no:* Would you like to do volunteer work or work without getting paid? [MFPQOL]
- *If doesn't do activity:* Do you want to work/go to a day activity program/volunteer? [PES-DD]
- Do you like your (job/day program/volunteer work)? [PES-DD]
- Did you help pick the (job/day program/volunteer work) you go to now? [PES-DD]

Impact of living arrangement on community inclusion

For other items related to residential settings, see under Choice and Control.

- Where I live makes it easy for me to participate in community activities. Always, usually, sometimes, never [ORIES]
- Where I live makes it easy for me to get around in the community as I desire. Always, usually, sometimes, never [ORIES]
- Please choose the description that best describes how the location of your home or residential setting supports your access to the community: Where I live makes it EASY for me to be part of the community where I am located. Where I live makes it HARD for me to be part of the community where I am located. [ORIES]
- Where I live makes it easy for me to look for a job in the community where I can make at least minimum wage, if I want to work. Always, usually, sometimes, never [ORIES]
- My provider/setting supports me with my daily needs in order for me to work. Always, usually, sometimes, never [ORIES]
- I have regular opportunities to be part of the community. Always, usually, sometimes, never [ORIES]

NQF Domain: Service Delivery

Description: Aspects of services that enable a positive consumer experience (e.g., accessibility, respect, dependability, well-coordinated).

Corresponding characteristics:

- Includes a flexible range of services that are sufficient, accessible, appropriate, effective, dependable, and timely to respond to individuals' strengths, needs, and preferences and are provided in a setting of the individual's choosing.
- Integrates healthcare and social services to promote well-being.

Proposed subdomains: Accessibility (e.g., geographic, economic, physical, and public and private awareness or linkage); appropriate (e.g., services aligned with needs and preferences, whether goals are assessed);⁸ sufficiency (e.g., scope of services, capacity to meet existing and future demands); dependable (e.g., coverage, timeliness, workforce continuity, knowledge of needs and preferences, and competency);⁹ timely initiation of services; coordination (e.g., comprehensive assessment, development of a plan, information exchange between all members of the care team, implementation of the plan, and evaluation of the plan)

Survey questions

Met/unmet need for services generally

- Do the services you receive meet your needs and goals? *If no:* What additional services might help you? [NCI-AD]
- Do you get the services you need? [NCI-ACS]
- Did you ever go without any of the services when you needed them? [NDPES]
- I was able to get all the services I thought I needed. Strongly disagree, disagree, undecided, agree, strongly agree [MHSIP-ACS]
- My family got as much help as we needed for my child. Strongly disagree, disagree, neutral, agree, strongly agree [YSSF]
- In general, did you receive the care or help you needed during the past 12 months? Please think of both professional care, and care from family and friends. [GSS-CCR]
- Is there anything else you need help with? [MNCES]
- Does the plan include all the services and supports your family member needs? Does your family member receive all of the services listed in the plan? [NCI-AFS, NCI-FGS]
- Do you believe that the result of your "level of care assessment" identifies your real needs? [NMPQR]
- Are you receiving the services that are in your service plan? [NYPSS]
- Do you believe that you are receiving all of the services and supports that are specified on your plan? [NMPQR]

Met/unmet need for help with activities of daily living (ADL)

Items specifically about worker dependability are classified under Workforce.

- How much assistance with self-care do you generally need? (Things like bathing, dressing, going to the bathroom, eating or moving around your home) *If a lot or some:* Do you always get enough assistance for self-care when you need it? [NCI-AD]
- Do you need more help than you are receiving with personal care, such as eating or bathing? [C&C9MO; *if person doesn't get help, substitute "help" for "more help than you are receiving"*]

⁸ "Achieving individual goals and preferences" is a subdomain of Choice and Control.

⁹ Worker dependability is also a subdomain of Workforce.

- Do you ever go without a bath or shower when you need one? *If yes:* Is this because there is no one there to help you? [MFPQOL, PES-DD, PES-E/D]
- In the last month, did you ever go without [showering/taking a bath/washing up] because no one was there to help? [NHATS]
- Have there been times in the last year when you couldn't take a bath or shower when you wanted to because there was no one to help you? [MNCES]
- Do you always get dressed, take a shower, or bathe when you need to? *If no:* Is this because there are no [workers] to help you? [HCBSEOC]
- Do you ever go without getting dressed when you need to? *If yes:* Is this because there is no one there to help you? [PES-DD, PES-E/D]
- In the last month, did you ever go without getting dressed because there was no one there to help? [NHATS]
- Have there been times in the last year when you didn't get dressed when you wanted to because there was no one to help you? [MNCES]
- Do you ever go without getting out of bed when you need to? *If yes:* Is this because there is no one there to help you? [PES-DD, PES-E/D]
- In the last month, did you ever have to stay in bed because no one was there to help you? [NHATS]
- Have there been times in the last year when you couldn't get out of bed when you wanted to because there was no one to help you? [MNCES]
- Do you ever go without eating when you need to? *If yes:* Is this because there is no one there to help you? [PES-DD, PES-E/D]
- In the last month, did you ever go without eating because no one was there to help? [NHATS]
- Have there been times in the last year when you couldn't eat when you wanted to because there was no one to help you? [MNCES]
- Are you ever unable to use the bathroom when you need to? *If yes:* Is this because there is no one there to help you? [MFPQOL]
- Are you ever unable to get to or use the bathroom when you need to? *If yes:* Is this because there is no one there to help you? [PES-DD, PES-E/D]
- Do you get all the help you need with toileting from [workers] when you need it? [HCBSEOC]
- Have there been times in the last year when you couldn't use the bathroom when you needed to because there was no one to help you? [MNCES]
- In the last month, did you ever accidentally wet or soil your clothes because no one was there to help you get to or use the toilet? [NHATS]

Met/unmet need for help with instrumental activities of daily living (IADL)

- How much assistance with everyday activities do you generally need? (Things like preparing meals, housework, shopping or taking your medications) *If a lot or some:* Do you always get enough assistance with your everyday activities when you need it? [NCI-AD]
- Do you need more help than you are receiving with doing things around the house such as preparing meals, laundry, and housework? [C&C9MO; *if person doesn't get help, substitute "help" for "more help than you are receiving"*]
- Do you ever go without a meal when you need one? *If yes:* Is this because there is no one there to help you? [MFPQOL, PES-DD, PES-E/D]
- In the last month, did you ever go without a hot meal because no one was there to help or make one for you? [NHATS]
- Are you always able to get something to eat when you are hungry? *If no:* Is this because there are no [workers] to help you? [HCBSEOC]
- Are you sometimes unable to get groceries when you need them? *If yes:* Is this because there is no one there to help you? [PES-DD, PES-E/D]

- In the last month, did you ever go without groceries or personal items because no one was there to help or shop for you? [NHATS]
- Do you ever go without taking your medicine when you need it? *If yes:* Is this because there is no one there to help you? [MFPQOL, PES-DD, PES-E/D]
- Do you always take your medicine when you are supposed to? *If no:* Is this because there are no [workers] to help you? [HCBSEOC]
- Do you need more help than you are receiving with medications, including reminders to take it, or with routine health care at home, such as checking blood pressure or doing exercises? [C&C9MO; *if person doesn't get help, substitute "help" for "more help than you are receiving"*]
- In the last month, did you ever make a mistake in taking your prescribed medicines because no one was there to help or keep track of them for you? [NHATS]
- Please think about all the help you received during the last week around the house like cooking or cleaning. Do you need *more* help with things around the house than you are now receiving? [MFPQOL]
- Do your household tasks, like cleaning and laundry, always get done when you need them to? *If no:* Is this because there are no [workers] to help you? [HCBSEOC]
- Does the housework not get done sometimes? *If yes:* Is this because there is no one there to help you? [PES-DD, PES-E/D]
- Have there been times in the last year when you didn't get housework done that you would have liked to have done because there was no one to help you? [MNCES]
- Does the laundry not get done sometimes? *If yes:* Is this because there is no one there to help you? [PES-DD, PES-E/D]
- In the last month, did you ever go without clean laundry because no one was there to help or do that for you? [NHATS]
- Please think about *all* the help you received during the last week with getting around the community, such as shopping and going to a doctor's appointment. Do you need more help getting around than you are receiving? [MFPQOL]
- Do you need more help than you get now from [workers] to do things in your community? [HCBSEOC]
- In the last month, did you ever have to stay in your home because no one was there to help you go out? [NHATS]

Met/unmet need for transportation

- When you want to go somewhere, do you always have a way to get there? [NCI-ACS]
- Can you always get to the places you need to go, like work, shopping, the doctor's office, or a friend's house? [PES-DD, PES-E/D]
- Do you have transportation when you want to do things outside of your home, like visit a friend, go for entertainment, or do something for fun? [NCI-AD]
- Do you need more help than you are receiving with transportation? [C&C9MO; *if person doesn't get help, substitute "help" for "more help than you are receiving"*]
- Are you satisfied or dissatisfied with your ability to get help with transportation when you need it? [C&C9MO]
- In the last month, did a transportation problem ever keep you from [visiting friends and family/attending religious services/participating in clubs, classes, and other organized activities/going out for enjoyment]? [NHATS]
- Do you miss things or have to change plans because you don't have a way to get around easily? [MFPQOL]
- Do you have transportation to get to medical appointments when you need to? [NCI-AD]
- How often do you have a way to get to your medical appointments? Would you say never, sometimes, often, or always? [HCBSEOC]

Met/unmet need for employment supports

- Are you getting all the help you need to find a job? [HCBSEOC]
- Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community? [NCI-AFS, NCI-FGS]
- How often does your [job coach] give you all the help you need? Would you say never, sometimes, often, always? [HCBSEOC]
- Does your [job coach] give you all the help you need? Would you say mostly yes or mostly no? [HCBSEOC]

Met/unmet need for technology

- Many people need assistive devices like a cane, a walker, a scooter, or a wheelchair to help them get around or to help with their everyday lives like hearing aids, communication devices, etc. Do you need one of these devices (or an upgrade to the one you have)? [NCI-AD]
- Many people need to make changes to their homes, for example adding grab bars, ramps, bathroom modifications, remote monitoring, personal emergency response system, or other things to make it easier to live at home. Do you need one of these devices (or an upgrade to the one you have)? [NCI-AD]
- Does your family member have the special equipment or accommodations that s/he needs (some examples include wheelchair, ramp, communication board)? [NCI-AFS, NCI-FGS]

Transitions from institution to community

- When leaving the hospital or the rehab/nursing facility, did you feel comfortable going home/ready to go home? [NCI-AD]
- After leaving the hospital or rehab/nursing facility and going home, did someone follow-up with you to make sure you had the services, supports and help you needed? [NCI-AD]

Satisfaction with services

There are many such measures; hear are some examples:

- Overall, are you satisfied or dissatisfied with the arrangements for your care? [C&C9MO]
- Taking everything into consideration, during the past week have you been happy or unhappy with the help you get with things around the house or getting around your community? [MFPQOL]
- Overall, are you satisfied with the services and supports your family member currently receives? [NCI-FGS]
- My family got the help we wanted for our child. Strongly disagree, disagree, neutral, agree, strongly agree [YSSF]

Service coordination/planning

See also "Involvement in & control over service planning and decisions" under Choice and Control.

- In the last 12 months, did anyone from your health plan, doctor's office, or clinic help coordinate your care among these doctors or other health providers? [CAHPS-HP]
- In the last 12 months, who helped to coordinate your care? Someone from your health plan, someone from your doctor's office or clinic, someone from another organization, a friend of family member, you [CAHPS-HP]
- Does your case manager help coordinate all the services you receive? [POMP-CMS]
- Does your case manager help you get services that you did not have before? [POMP-CMS]
- How satisfied are you with the help you received to coordinate your care in the last 12 months? [CAHPS-HP]
- During the past 12 months, have you felt that you could have used extra help arranging or coordinating [child's] care among these different health care providers or services? [NS-CSHCN]

- Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied with the communication among [child's] doctors and other health care providers? [NS-CSHCN]
- Is your attendant provider an active member of the service planning team? [EAZI]
- Do you feel your provider should be more active in planning for your services or attending their annual planning meeting? [EAZI]

Cultural competence¹⁰

- Are services delivered in a way that is respectful of your family's culture? [NCI-AFS, NCI-FGS]
- My [worker] is sensitive and responsive to customs and traditions of my culture or background. [MAHCSS]
- Staff were sensitive to my cultural background (race, religion, language, etc.). Strongly disagree, disagree, undecided, agree, strongly agree [MHSIP-ACS, CLMDP]
- Staff were sensitive to my cultural/ethnic background. Strongly disagree, disagree, neutral, agree, strongly agree [YSSF]
- Staff respected my family's religious/spiritual beliefs. Strongly disagree, disagree, neutral, agree, strongly agree [YSSF]
- When [child] is seen by doctors or other health care providers, how often are they sensitive to your family's values and customs? Would you say never, sometimes, usually, or always? [NS-CSHCN]
- Does your language, race, religion, ethnic background or culture make any difference in the kind of counseling or treatment you need? *If yes:* In the last 12 months, was the care you received responsive to those needs? [ECHO]
- Do you communicate with your attendant provider in the language that you prefer? [EAZI]
- Do you receive information about your services in the language you prefer? [NCI-AD]
- If your family member does not communicate verbally (for example, uses gestures or sign language), are there support workers who can communicate with him/her? [NCI-AFS, NCI-FGS]

Information needs

- Do you know how to manage that chronic condition or conditions? [NCI-AD]
- Do you understand why you take your medications and what they are for? [NCI-AD]
- 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)? [NCI-AFS, NCI-FGS]
- Do you get enough information to take part in planning services for your family member? [NCI-AFS, NCI-FGS]
- 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?) [NCI-ACS]
- Staff told me what side effects to watch out for. Strongly disagree, disagree, undecided, agree, strongly agree [MHSIP-ACS, CLMDP]
- Staff helped me obtain the information I needed so that I could take charge of managing my illness. Strongly disagree, disagree, undecided, agree, strongly agree [MHSIP-ACS, CLMDP]
- I felt comfortable asking questions about my treatment and medication. Strongly disagree, disagree, undecided, agree, strongly agree [MHSIP-ACS, CLMDP]

¹⁰ Although not explicitly mentioned, cultural competence would seem to belong under the "appropriate" subdomain of Service Delivery. It is also listed as a subdomain of Workforce.

NQF Domain: Health and Well-Being

Description: The level of integration between healthcare and other supportive services to promote holistic wellness.

Corresponding characteristic: Ensures each individual can achieve the balance of personal safety and dignity of risk that he or she desires.

Proposed subdomains:

Physical, emotional, and cognitive functioning; social well-being; spirituality; safety and risk as defined by the consumer;¹¹ freedom from abuse, neglect, and exploitation;¹² health status and wellness (e.g., prevention, management of multiple chronic conditions); behavioral health

Survey questions

General health

Examples of the many similar measures of self-assessed health status:

- In general, how would you rate your overall health? Would you say excellent, very good, good, fair or poor? [HCBSEOC]
- How would you describe your overall health? Excellent, very good, good, fair, poor [NCI-AD]
- Relative to other people your age, how would you rate your health now? Would you say it's excellent, very good, good, fair, poor? [C&C9MO]
- How satisfied are you with your health? Very dissatisfied, dissatisfied, neither satisfied nor dissatisfied, satisfied, very satisfied. [WHOQOL-BREF]
- How often has your health been a worry for you this past month? Would you say never, a few times, or more than that? [Channeling]
- I am healthy enough to get out and about. Strongly agree, agree, neither agree nor disagree, disagree, strongly disagree [OPQOL]

Pain

- During the past week have you had aches and pains? [MFPQOL]
- In the past 7 days, how would you rate your pain on average? Use a scale of 0-10 with 0 being no pain and 10 being the worst imaginable pain. [PROMIS-GH, NHIS-10]
- In the last month, have you been bothered by pain? *If yes:* In the last month, has pain ever limited your activities? [NHATS]
- Pain affects my well-being. Strongly agree, agree, neither agree nor disagree, disagree, strongly disagree [OPQOL]
- To what extent do you feel that physical pain prevents you from doing what you need to do? Not at all, a little, a moderate amount, very much, an extreme amount [WHOQOL-BREF]
- In the past 7 days, how much did pain interfere with your enjoyment of life? Not at all, a little bit, somewhat, quite a bit, very much [PROMIS-PI]

Energy, fatigue, sleep

- I have a lot of physical energy. Strongly agree, agree, neither agree nor disagree, disagree, strongly disagree [OPQOL]
- Do you have enough energy for everyday life? Not at all, a little, a moderate amount, very much, extremely. [WHOQOL-BREF]

¹¹ "Sense of safety" is also a subdomain of Human and Legal Rights. "Dignity of risk" is also a subdomain of Choice and Control.

¹² "Freedom from abuse and neglect" is also a subdomain of Human and Legal Rights. See that domain for relevant items.

- In the past 7 days, how would you rate your fatigue on average? None, mild, moderate, severe, very severe. [PROMIS-GH, NHIS-10]
- In the last month, did you have low energy or were you easily exhausted? *If yes:* In the last month did your low energy or exhaustion ever limit your activities? [NHATS]
- Can you get the sleep you need without noises or other disturbances where you live? [MFPQOL]
- How satisfied are you with your sleep? Very dissatisfied, dissatisfied, neither satisfied nor dissatisfied, satisfied, very satisfied. [WHOQOL-BREF]
- In the last month how often did it take you more than 30 minutes to fall asleep? Would you say every night, most nights, some nights, rarely, or never? [NHATS]
- On nights when you woke up before you wanted to get up, how often did you have trouble falling back asleep? Would you say every night, most nights, some nights, rarely, or never? [NHATS]

Mental health

Mental health status is often measured using a multi-item instrument. The following are examples of more general measures:

- In general, how would you rate your overall mental or emotional health? Would you say excellent, very good, good, fair or poor? [HCBSEOC]
- In general, how would you rate your mental health, including your mood and your ability to think? [PROMIS-GH]
- In the past 7 days, how often have you been bothered by emotional problems such as feeling anxious, depressed, or irritable? Rarely, sometimes, often, or always [PROMIS-GH]
- During the past week have you felt sad or blue? [MFPQOL]
- How often do you feel lonely, sad, or depressed? Often, sometimes, not often, never or almost never [NCI-AD]
- During the past week have you felt irritable? [MFPQOL]

Cognitive ability

- How would you rate your memory at the present time? Would you say it is excellent, very good, good, fair, or poor? [NHATS]
- Do you have trouble remembering basic things (*like where you are, what date it is, what you did earlier*)? [NCI-AD]
- In the last month, how often did memory problems interfere with your daily activities? Would you say every day, most days, some days, rarely, or never? [NHATS]
- Compared to 1 year ago, would you say your memory is much better now, better now, about the same, worse now, or much worse now than it was then? [NHATS]

Loneliness

- Do you find yourself feeling lonely quite often, sometimes, or almost never? [Channeling]
- How often do you feel lonely? (*Or feel like you don't have anyone to talk to*) [NCI-AD]
- Do you ever feel lonely? [NCI-ACS]
- Do you ever get lonely? [PLQ]

Feels safe at home

See also "Mistreatment by paid helpers" under Service Delivery.

- Do you feel safe [here] in your home? [MNCES, NMPQR]
- Do you feel safe living here? [MFPQOL]
- Do you feel safe at home/where you live? [NCI-AD]
- Are you ever afraid or scared when you are at home? [NCI-ACS]
- I feel safe where I live. Strongly agree, agree, neither agree nor disagree, disagree, strongly disagree [OPQOL]
- Do you feel like your belongings are safe here? [MNCES]
- Are you ever worried for the security of your belongings? [NCI-AD]

Feels safe in neighborhood

- Do you feel safe when you go out? [MNCES]
- Do you feel safe when you are out in your community or neighborhood? [NMPQR]
- Are you ever afraid or scared when you are in your neighborhood? [NCI-ACS]

Feels safe in general

- Which of the following statements best describes how safe you feel? (1) I feel as safe as I want. (2) Sometimes I do not feel as safe as I want. (3) I never feel as safe as I want. [ASCOT]
- How safe do you feel in your daily life? Not at all, a little, a moderate amount, very much, extremely. [WHOQOL-BREF]
- Does the person live, work and recreate in environments that are safe? [POMs]
- Are all of the person's safety concerns addressed? [POMs]

Dignity of risk

See also under Choice and Control.

- Are you free to take risks when you want to? (Do you feel like it's okay if you make mistakes or try new things?) [TXPES]
- Does your attendant provider allow you to make your own mistakes? [EAZI]

Risk of falling

- Do you or somebody else have concerns about you falling or being unstable? [NCI-AD]
- In the last month, did you worry about falling down? [NHATS]
- In the last month, have you fallen down? [NHATS]
- Has somebody talked to you or worked with you to reduce your risk of falling or being unstable? [NCI-AD]

Life satisfaction, self-rated quality of life

- Your quality of life as a whole is: Very good, good, all right, bad, very bad [OPQOL]
- In general, would you say your quality of life is excellent, very good, good, fair or poor? [PROMIS-GH, NHIS-10]
- How would you rate your quality of life? Very poor, poor, neither poor nor good, good, very good. [WHOQOL-BREF]
- In general, how would you rate the quality of your life at the present time? Very poor, poor, neither poor nor good, good, very good [MHSIP-ACS]
- In general, how satisfied are you with your life today? Would you say satisfied, partly satisfied, dissatisfied? [Channeling]
- In general, how satisfied are you with your life? Would you say very satisfied, satisfied, dissatisfied, or very dissatisfied? [NHIS-01]
- Generally speaking, how satisfied are you with your life as a whole? Would you say you are very satisfied, satisfied, or not satisfied? [NLTCS]
- Using a scale of 0 to 10, where 0 means "Very dissatisfied" and 10 means "Very satisfied", how do you feel about your life as a whole right now? [GSS-CRR]
- I enjoy my life overall. Strongly agree, agree, neither agree nor disagree, disagree, strongly disagree [OPQOL]
- How much do you enjoy your life? Not at all, a little, a moderate amount, very much, an extreme amount. [WHOQOL-BREF]

Happiness

- Would you say you have been very happy, happy, or unhappy this past month? [Channeling]
- Taking everything into consideration, during the past week have you been happy or unhappy with the way you live your life? [MFPQOL]
- Taken all together, how would you say things are these days? Would you say that you are very happy, pretty happy, or not too happy? [NLTCS]

NQF Domain: Workforce

Description: The adequacy and appropriateness of the provider network and HCBS workforce.

Corresponding characteristic: Supplies and supports an appropriately skilled workforce that is stable and adequate to meet demand.

Proposed subdomains: Sufficient numbers and appropriately dispersed; dependability;¹³ respect for boundaries, privacy,¹⁴ consumer preferences, and values; skilled; demonstrated competencies when appropriate; culturally competent,¹⁵ sensitive, and mindful; adequately compensated, with benefits; safety of the worker; teamwork, good communications, and value-based leadership

Survey questions¹⁶

Worker dependability/reliability (assessed by consumer)

- How often do [workers] come to work on time? Never, sometimes, usually, always [HCBSEOC]
- Do [workers] come to work on time? [HCBSEOC]
- Do your staff come when they are supposed to? [NCI-ACS]
- Is your attendant provider on time? [EAZI]
- How often do [workers] work as long as they are supposed to? Never, sometimes, usually, always [HCBSEOC]
- Do [workers] work as long as they are supposed to? [HCBSEOC]
- Do these [workers] spend all the time with you that they are supposed to? [PES-DD, PES-E/D]
- Do the people who are paid to help you come and leave when they are supposed to? [NCI-AD]
- About how often have people who were paid left early or arrived late? [C&C9MO]
- When staff cannot come to work on a day that they are scheduled, does someone let you know if [workers] cannot come that day? [HCBSEOC]
- Does your attendant provider let you know if they are running late? [EAZI]
- During those two weeks, did [worker] ever not come to help when he/she was scheduled to come? [C&C9MO]
- Was there a time when someone who was hired did not come when expected and you had a serious problem finding someone else to help you? [C&C9MO]

Worker availability & turnover

- Is it difficult for you to find attendant providers for your care? [EAZI]
- How hard was it, *overall*, for you to find someone to help that you were satisfied with? Was it very hard, somewhat hard, or not very hard? [C&C9MO]
- Do the people who are paid to help you change too often? [NCI-AD]
- How often do you need to find a new attendant provider? [EAZI]
- Do you go for long periods of time without the attendant services that you need? [EAZI]
- *If no paid help:* Sometimes people try to get help with personal care, things around the house or community, or routine health care, but none is available. During the last nine months, did you try to get help like that from someone who was paid? [C&C9MO]

¹³ Dependability is also a subdomain of Service Delivery.

¹⁴ Privacy is also a subdomain of Human and Legal Rights.

¹⁵ Cultural competence could perhaps better be subsumed by the “appropriate” subdomain of Service Delivery. Questions related to cultural competence have been classified there.

¹⁶ Questions listed are from consumer, family, and caregiver surveys only. Surveys of workers and other providers are not included.

Treatment of consumer

- How often do [workers] treat you the way you want them to? Would you say never, sometimes, usually, or always? [HCBSEOC]
- Do [workers] treat you the way you want them to? Would you say mostly yes or mostly no? [HCBSEOC]
- You said that you have people who help you. Do the people who help you treat you the way you want them to? [MFPQOL]
- About how often were the people who were paid rude or disrespectful? Very often, often, sometimes, or never. [C&C9MO]
- How often are [workers] nice and polite to you? Would you say never, sometimes, usually, or always? [HCBSEOC]
- Are [workers] nice and polite to you? Would you say mostly yes or mostly no? [HCBSEOC]
- Is your attendant provider courteous and polite to you? [EAZI]
- Do the support staff who come to your home say "please" and "thank you" when they ask you for something? [PES-DD]
- Does your attendant provider listen to what you have to say? [EAZI]

Respect for privacy

For more general questions about privacy, see under Human and Legal Rights.

- In the past year, did the people who are paid to help you respect your privacy? Always, usually, sometimes, never [MNCES]
- Does your attendant provider respect your privacy; like your personal belongings, your personal space, and your private life? [EAZI]
- How often do [workers] make sure you have enough personal privacy when you dress, take a shower, or bathe? Would you say never, sometimes, usually, or always? [HCBSEOC]
- Do [workers] make sure you have enough personal privacy when you dress, take a shower, or bathe? Would you say mostly yes or mostly no? [HCBSEOC]
- Does your attendant provider keep personal information about you such as files, health information, progress notes, or incident reports confidential so that it is not shared without your permission? [EAZI]

Worker competence/training

- Do you feel [workers] know what kind of help you need with everyday activities, like getting ready in the morning, getting groceries, or going places in your community? [HCBSEOC]
- Do you feel your staff have the right training to meet your needs? [NCI-ACS]
- Do support workers have the right information and skills to meet your family's needs? [NCI-AFS, NCI-FGS]
- Do you think your attendant provider is properly trained? [EAZI]

Worker performance

- How would you rate the help you get from [workers]? Would you say excellent, very good, good, fair, or poor? [HCBSEOC]
- Are you satisfied or dissatisfied with the way [worker] carries out their duties in helping you with personal care? [C&C9MO]
- Are you satisfied or dissatisfied with the way [worker] helps with doing things around the house or community? [C&C9MO]
- Using any number from 0 to 10, where 0 is the worst help from [workers] possible and 10 is the best help from [workers] possible, what number would you use to rate the help you get from [workers]? [HCBSEOC]
- Do the people who are paid to help you do things for you the way you want them done? [NCI-AD]
- Does your attendant provider complete tasks the way that you ask them to? [EAZI]

- Caregivers provide the help I need to do what I want to do when I want to do it. Strongly agree, agree, disagree, strongly disagree [PC-PAL]
- Has a case manager helped you solve a problem that you have told them about? [MNCES]

NQF Domain: Caregiver Support

Description: The level of support (e.g., financial, emotional, technical) available for the paid and unpaid caregivers of individuals who use HCBS.

Corresponding characteristic: Supports family caregivers.

Proposed subdomains: Training and skill-building; access to resources (e.g., respite, crisis support); caregiver well-being (e.g., stress reduction, coping); caregiver and/or family assessment and planning; compensation

Survey questions

Support from family/friends/community

- Do you have friends or family that help you care for [person]? [NSOC]
- To accommodate your caregiving duties, has your spouse or partner modified their life and work arrangements? [GSS-CRR]
- To accommodate your caregiving duties, have your children provided you with help (such as helping with household chores)? [GSS-CRR]
- To accommodate your caregiving duties, have your extended family members provided you with help? [GSS-CRR]
- To accommodate your caregiving duties, have your close friends or neighbors provided you with help? [GSS-CRR]
- To accommodate your caregiving duties, have your community, spiritual community, or cultural or ethnic groups provided you with help? [GSS-CRR]

Support from providers

- In your experience as a caregiver, have you ever had a doctor, nurse, or social worker ask you about what you needed to help care for [person]? [CGUS]
- In your experience as a caregiver, have you ever had a doctor, nurse, or social worker ask you about what you needed to take care of yourself? [CGUS]
- During the past 12 months, how often did [child]'s doctors or other health care providers help you feel like a partner in [his/her] care? Would you say never, sometimes, usually, or always? [NS-CSHCN]
- When [person] was in the hospital, were you included by health care workers, like nurses, doctors, or social workers, in discussions about [person's] care? [CGUS]

Respite care

- To accommodate your caregiving duties, have you had occasional relief or respite care? [GSS-CRR]
- Have you received respite care, which allows you a brief break while temporary care is provided to [person], either in your home or someplace else? [POMP-CSS]
- In the last year, have you used any service that took care of [person] so that you could take some time away from helping? [NSOC]
- In your experience as a caregiver, have you ever used respite services where someone would take care of [person] to give you a break? [CGUS]
- Did you or your family receive *all* the respite care that was needed? *If no:* Did you or your family get *any* respite care during the past 12 months? [NS-CSHCN]
- If you need respite services, do you have access to them? (Respite is support for family or other care-providers to allow them to take a break from providing care for a time-limited period). [NCI-AFS]

Training and support groups

- In the last year, have you received any training to help you take care of [person]? [NSOC]

- Have you received caregiver training or education, including participation in support groups, to help you make decisions and solve problems in your role as a caregiver? [POMP-CSS]
- Did anyone prepare you to do these [medical/nursing] tasks? *If yes:* How well do you feel that person prepared you to take on these medical/nursing tasks? [CGUS]
- Before [person] left the hospital or was discharged, did you receive clear instructions about any medical/nursing tasks you would need to perform for [person]? [CGUS]
- In the last year, have you gone to a support group for people who give care? [NSOC]
- Does your family take part in any family-to-family networks in your community? (For example, Parent to Parent, sibling networks, etc.) [NCI-AFS, NCI-FGS]

Financial support

- To accommodate your caregiving duties, have your family or friends provided you with financial support? [GSS-CRR]
- To accommodate your caregiving duties, have you received money from government programs? [GSS-CRR]
- Have you received any Federal tax credits for which caregivers may be eligible (e.g., caregiver tax credit, infirm dependent tax credit, medical expense tax credit)? [GSS-CRR]
- In your experience as a caregiver, have you ever requested information about how to get financial help for [person]? [CGUS]

Unmet need for support

- In addition to the kinds and amounts of services you are receiving (and the services that [person] is receiving), what additional or new kinds of help would be valuable to you as a caregiver: (a) housekeeping assistance for [person], (b) shopping assistance for [person], (c) transportation assistance for [person], (d) assistance in making meals for [person], (e) assistance in...personal care for [person], (f) adult daycare for [person], (g) assistance in getting other family members involved in caring for [person], (h) assistance in administering and monitoring side effects of medicine for [person], (i) in-home respite care, (j) help with money management and financial advice? [POMP-CSS]
- In addition to what you currently have or use now, what additional medical-related support would help you as a caregiver? (1) Mental health services, supports or therapy for me; (2) medical equipment and supplies such as nebulizers, hospital beds and wheelchairs for [person]; (3) home medication and adaptive equipment such as hand rails, ramp and bath chairs for [person]; (4) nutritional supplements such as Ensure, Boost, etc. for [person]; (5) stress relief exercise such as yoga for me. [SCSPWD]
- In addition to what you currently have or use now, what additional caregiving-related services would help you as a caregiver? (1) Caregiver education or training; including medication management; (2) caregiver support group or advocacy group; (3) in-home respite care or a temporary break from providing [person's] care; (4) other in-home services, such as home health aide, personal care assistant, housekeeper, companion, etc.; (5) temporary out-of-home respite care; (6) child care. [SCSPWD]
- In addition to what you currently have or use now, what additional programs or services would help you as a caregiver? (1) Legal assistance; (2) transportation; (3) financial planning and assistance; (4) programs or services geared to [person's] social and emotional needs; (5) transition services. [SCSPWD]
- Did you or your family receive *all* the mental health care or counseling that was needed? *If no:* Did you or your family get *any* mental health care or counseling during the past 12 months? [NS-CSHCN]

- What additional or new kinds of information would be valuable to you as a consumer: (a) help line..., (b) ...counseling services or support groups, (c) info on...condition or disability, (d) info on changes in laws..., (e) info on how to select nursing home, group home..., (f) info on how to pay for nursing homes..., (g) info on how to deal with agencies..., (h) info on health insurance or long-term care insurance? [POMP-CSS]
- How difficult is it to get affordable services in [person's] local area or community that could help you care for [person], like delivered meals, transportation, or in-home health services? 5-point scale from "not at all difficult" to "very difficult." [CGUS]

Impact of support received

- In general, would you say that the caregiver service has helped you? [POMP-CSS]
- Have the caregiver services enabled you to provide care for a longer period of time than would have been possible without these services? [POMP-CSS]
- Would [person] have been able to continue home if caregiver services had not been provided? [POMP-CSS]
- Have services and supports reduced your family's out-of-pocket expenses for your family member's care? [NCI-AFS]
- As a result of the caregiver services, do you (a) have more time for personal activities, (b) feel less stress, (c) have a clearer understanding of how to get the services you and [person] need, (d) know more about [consumer's] condition or illness, (e) feel more confident in providing care to [person]? [POMP-CSS]

Impact of caregiving: stress & coping

- In your experience as a caregiver, how often do you feel that caregiving causes you stress? Always, usually, sometimes, rarely, never [POMP-CSS]
- How stressful have your caregiving responsibilities been during the past 12 months? Were they very stressful, stressful, somewhat stressful, not at all stressful? [GSS-CRR]
- How emotionally stressful would you say that caring for [person] is for you? 5-point scale from "not a strain at all" to "very much a strain." [CGUS]
- Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work? Never, rarely, sometimes, quite frequently, always [ZBI]
- In general, how have you been coping with your caregiving responsibilities? Would you say: very well, generally well, not very well, not well at all? [GSS-CRR]
- People manage their caregiving responsibilities in different ways. Which of these describes your approach? (1) Shared responsibilities with spouse or other family member; (2) asked a family member for help; (3) asked a friend for help; (4) stopped working; (5) worked less but did not stop working; (6) hired help; (7) applied for government assistance; (8) sought other resources; (9) prayed.
- My life satisfaction has suffered because of the care. Strongly agree, agree, disagree, strongly disagree [BSFC]

Impact of caregiving: rewards

- How rewarding have your caregiving experiences been during the past 12 months? Were they very rewarding, rewarding, somewhat rewarding, not at all rewarding? [GSS-CRR]
- My caregiving responsibilities have given my life more meaning. Not at all, a little, moderately, a lot, a great deal [TCARE]
- My caregiving responsibilities have given me a sense of fulfillment. Not at all, a little, moderately, a lot, a great deal [TCARE]
- How often does being a caregiver for [person] give you the joy of spending time with someone you care about? Always, usually, sometimes, rarely, never [POMP-CSS]
- How often does being a caregiver provide you with a sense of accomplishment? Always, usually, sometimes, rarely, never [POMP-CSS]

- Please tell me whether this describes your situation very much, somewhat, or not so much: Helping [person] has made you more confident about your abilities. [NSOC]
- Please tell me whether this describes your situation very much, somewhat, or not so much: Helping [person] has taught you to deal with difficult situations. [NSOC]

Impact of caregiving: alone time, privacy

- In your experience as a caregiver, how often do you feel that caregiving does not leave you enough time for yourself? Always, usually, sometimes, rarely, never [POMP-CSS]
- My caregiving responsibilities have decreased time I have to myself. Not at all, a little, moderately, a lot, a great deal [TCARE]
- Do you feel that, because of the time you spend with your relative, you don't have enough time for yourself? Never, rarely, sometimes, quite frequently, nearly always [ZBI]
- Please tell me whether this describes your situation very much, somewhat, or not so much: You don't have time for yourself. [NSOC]
- In the past 12 months, have your caregiving responsibilities caused you to spend less time on relaxing or taking care of yourself? [GSS-CRR]
- Do you feel that you don't have as much privacy as you would like, because of your relative? Never, rarely, sometimes, quite frequently, nearly always [ZBI]

Impact of caregiving: relationships

- In the past 12 months, have your caregiving responsibilities caused you to spend less time with [your spouse or partner/your children/other family members/friends]? [GSS-CRR]
- Do you feel that your relative currently affects your relationship with other family members? Never, rarely, sometimes, quite frequently, always [ZBI]
- In the past 12 months, have your caregiving responsibilities caused strain in your relationship with family members or friends? [GSS-CRR]
- My relationships with other family members, relatives, friends and acquaintances are suffering as a result of the care. Strongly agree, agree, disagree, strongly disagree [BSFC]
- I feel torn between the demands of my environment (such as family) and the demands of the care. Strongly agree, agree, disagree, strongly disagree [BSFC]
- My caregiving responsibilities have caused conflicts with my care receiver. Not at all, a little, moderately, a lot, a great deal [TCARE]
- Please tell me whether this describes your situation very much, somewhat, or not so much: Helping [person] has brought you closer to [person]. [NSOC]
- Has your relationship with the person or persons you have been caring for strengthened during this time? [GSS-CRR]
- My caregiving responsibilities have made me more satisfied with my relationship with the care receiver. Not at all, a little, moderately, a lot, a great deal [TCARE]

Impact of caregiving: employment/education

- In your experience as a caregiver, how often do you feel that caregiving interferes with your work? Always, usually, sometimes, rarely, never [POMP-CSS]
- Has providing care for [person] ever interfered with your work? [POMP-CSS]
- In the last month, did helping [person] make it harder for you to get your work done? [NSOC]
- How often have you had too little time for work because of your caregiving responsibilities? Would you say... never, sometimes, usually, always? [SCSPWD]
- During the past 12 months, did you quit a job because of your caregiving responsibilities? [GSS-CRR]
- Did your caregiving responsibilities cause you to quit work or retire early? [POMP-CSS]
- Have you or other family members stopped working because of [child's] health conditions? [NS-CSHCN]

- Have you ever been fired from any job as a result of being a caregiver for [person] or any other loved one? [CGUS]
- During the past 12 months, were you fired, laid off, or asked to resign from a job because of your caregiving responsibilities? [GSS-CRR]
- How many times during the past 12 months did you go to work late, leave early or take time off during the day because of your caregiving responsibilities? [GSS-CRR]
- How many times during the past 12 months did you take one or more days off from your job because of your caregiving responsibilities? [GSS-CRR]
- Did you reduce your regular weekly hours of work because of your caregiving responsibilities? [GSS-CRR]
- Have you or other family members cut down on the hours you work because of [child's] health conditions? [NS-CSHCN]
- As a result of caregiving, did you ever experience any of these things at work? (a) Went in late, left early, or took time off during the day to provide care. (b) Took a leave of absence. (c) Went from working full-time to part-time, or cut back your hours. (d) Turned down a promotion. (e) Lost any of your job benefits. (f) Gave up working entirely. (g) Retired early. (f) Received a warning about your performance or attendance at work. [CGUS]
- Because of providing care for [person], have you (a) taken a less demanding job, (b) changed from full-time to part-time work, (c) reduced your official working hours, (d) lost some of your employment fringe benefits, (e) had time conflicts between working and caregiving, (f) used your vacation time to provide care, (g) taken a leave of absence to provide care, (h) lost a promotion, (i) worked less than your normal number of hours last month? [POMP-CSS]
- In the past 12 months, have you postponed enrolling in an education or training program because of your caregiving responsibilities? [GSS-CRR]
- In the past 12 months, have your studies been affected because of your caregiving responsibilities? [GSS-CRR]

Impact of caregiving: financial

- During the past 12 months, have you experienced financial hardship because of your caregiving responsibilities? [GSS-CRR]
- Is helping [person] financially difficult for you? [NSOC]
- Do your caregiving responsibilities make it difficult to meet your essential household expenses? [SCSPWD]
- How much of a financial strain would you say that caring for [person] is for you? 5-point scale from "not a strain at all" to "very much a strain." [CGUS]
- In your experience as a caregiver, how often do you feel that caregiving creates a financial burden for you? Always, usually, sometimes, rarely, never [POMP-CSS]
- Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses? Never, rarely, sometimes, quite frequently, nearly always [ZBI]
- Since I have been a caregiver my financial situation has decreased. Strongly agree, agree, disagree, strongly disagree [BSFC]

Impact of caregiving: leisure activities

- My caregiving responsibilities have caused my social life to suffer. Not at all, a little, moderately, a lot, a great deal [TCARE]
- Do you feel that your social life has suffered because you are caring for your relative? Never, rarely, sometimes, quite frequently, nearly always [ZBI]
- In the past 12 months, have your caregiving responsibilities caused you to spend less time participating in social groups? [GSS-CRR]
- My caregiving responsibilities have given me less time for friends and relatives. Not at all, a little, moderately, a lot, a great deal [TCARE]

- In the past 12 months, have your caregiving responsibilities caused you to spend less time on social activities or hobbies? [GSS-CRR]
- In the last month, did helping [person] ever keep you from [visiting in person with friends or family/attending religious services/participating in club meetings or group activities/going out for enjoyment/volunteer work]? [NSOC]
- My caregiving responsibilities have kept me from recreational activities. Not at all, a little, moderately, a lot, a great deal [TCARE]
- In the past 12 months, have your caregiving responsibilities caused you to spend less time volunteering for an organization? [GSS-CRR]
- In the past 12 months, have your caregiving responsibilities caused you to make holiday plans and change or cancel them? [GSS-CRR]
- In the past 12 months, have your caregiving responsibilities caused you to not make holiday plans at all? [GSS-CRR]

Impact of caregiving: physical health

- How would you say taking care of [person] has affected your health? Made it better, not affected it, made it worse. [CGUS]
- During the past 12 months, has your overall health suffered because of your caregiving responsibilities? [GSS-CRR]
- My health is affected by the care situation. Strongly agree, agree, disagree, strongly disagree [BSFC]
- In your experience as a caregiver, how often do you feel that caregiving negatively affects your health? Always, usually, sometimes, rarely, never [POMP-CSS]
- Do you feel that your health has suffered because of your involvement with your relative? Never, rarely, sometimes, quite frequently, always [ZBI]
- Is helping [person] physically difficult for you? [NSOC]
- How much of a physical strain would you say that caring for [person] is for you? 5-point scale from “not a strain at all” to “very much a strain.” [CGUS]
- Please tell me whether this describes your situation very much, somewhat, or not so much: You are exhausted when you go to bed at night. [NSOC]
- During the past 12 months, have you suffered any injuries while performing your caregiving responsibilities? [GSS-CRR]

Impact of caregiving: health behaviors

- In the past 12 months, have your caregiving responsibilities affected the amount of exercise that you usually get? *If yes:* Did the amount of exercise increase or decrease? [GSS-CRR]
- In the past 12 months, have your eating habits changed as a result of your caregiving activities? *If yes:* Did your eating habits become more healthy or less healthy? [GSS-CRR]
- In the past 12 months, have your caregiving responsibilities affected the amount of alcohol you consume? *If yes:* Did you increase your drinking, decrease your drinking, stop drinking, start drinking? [GSS-CRR]
- In the past 12 months, have your smoking habits changed as a result of your caregiving activities? *If yes:* Did you increase the number of cigarettes you smoke, decrease the number of cigarettes you smoke, stop smoking, start smoking? [GSS-CRR]

Impact of caregiving: mental health

- Is helping [person] emotionally difficult for you? [NSOC]
- My caregiving responsibilities have created a feeling of hopelessness. Not at all, a little, moderately, a lot, a great deal [TCARE]
- My caregiving responsibilities have depressed me. Not at all, a little, moderately, a lot, a great deal [TCARE]

- My caregiving responsibilities have made me nervous. Not at all, a little, moderately, a lot, a great deal [TCARE]
- My caregiving responsibilities have made me anxious. Not at all, a little, moderately, a lot, a great deal [TCARE]

Impact of caregiving: other

- In the past 12 months, have your caregiving responsibilities caused you to move residences?
[GSS-CRR]

NQF Domain: Effectiveness/Quality of Services

Description: The level to which HCBS services are able to produce intended outcomes.

Corresponding characteristic: *None*

Proposed subdomains: Goals and needs realized; preferences met;¹⁷ health outcomes achieved; technical skills assessed and monitored; technical services delivered; team performance; rebalancing

Survey questions

Outcomes attributed to services: general

- Would you say your attendant services are improving your life? [EAZI]
- Are services and supports helping you to live a good life? [NCI-ACS]
- Do you feel services and supports have made a positive difference in the life of your family member? [NCI-FGS]
- Do you feel services and supports have made a positive difference in the life of your family? [NCI-AFS]
- Would you say that the help you receive has made your life better, about the same, or worse? [MNCES]
- As a result of the services my child and/or family received, I am satisfied with our family life right now. Strongly disagree, disagree, undecided, agree, strongly agree [YSSF]
- As a direct result of the services I received, I do things that are more meaningful to me. Strongly disagree, disagree, undecided, agree, strongly agree [MHSIP-ACS]
- As a direct result of the services I receive, I feel I belong in my community. Strongly disagree, disagree, undecided, agree, strongly agree [MHSIP-ACS]

Outcomes attributed to services: living situation

- As a direct result of the services I received, my housing situation has improved. Strongly disagree, disagree, undecided, agree, strongly agree [MHSIP-ACS]
- Would you have to live somewhere else if you didn't have the services and help you are receiving? [NCI-AD]

Outcomes attributed to services: control, choice, participation

- As a direct result of services I received, I am better able to control my own life. Strongly disagree, disagree, undecided, agree, strongly agree [MHSIP-ACS]
- As a direct result of the services I received, I am better able to do the things I want to do. Strongly disagree, disagree, undecided, agree, strongly agree [MHSIP-ACS]
- As a result of the services my child and/or family received, my child is better able to do things he or she wants to do. Strongly disagree, disagree, undecided, agree, strongly agree [YSSF]
- As a result of the services my child and/or family received, my child is doing better in school and/or work. Strongly disagree, disagree, undecided, agree, strongly agree [YSSF]

Outcomes attributed to services: relationships, social support

- As a direct result of the services I receive, I am happy with the friendships I have. Strongly disagree, disagree, undecided, agree, strongly agree [MHSIP-ACS]
- As a direct result of the services I receive, I have people with whom I can do enjoyable things. Strongly disagree, disagree, undecided, agree, strongly agree [MHSIP-ACS]
- As a direct result of the services I receive, in a crisis, I would have the support I need from family or friends. Strongly disagree, disagree, undecided, agree, strongly agree [MHSIP-ACS]

¹⁷ Needs realized and preferences met overlap with the “appropriate” subdomain of Service Delivery. See that domain for relevant items.

- As a result of the services my child and/or family received, my child gets along better with family members. Strongly disagree, disagree, undecided, agree, strongly agree [YSSF]
- As a result of the services my child and/or family received, my child gets along better with friends and other people. Strongly disagree, disagree, undecided, agree, strongly agree [YSSF]

Outcomes attributed to services: coping

- As a result of the services my child and/or family received, my child is better at handling daily life. Strongly disagree, disagree, undecided, agree, strongly agree [YSSF]
- As a result of the services my child and/or family received, my child is better able to cope when things go wrong. Strongly disagree, disagree, undecided, agree, strongly agree [YSSF]

NQF Domain: Equity

Description: The level to which HCBS is equitability delivered and made available to a broad array of individuals who need long-term supports.

Corresponding characteristic: Reduces disparities by offering equitable access to and delivery of services that are developed, planned, and provided in a culturally sensitive and linguistically appropriate manner.

Proposed subdomains: Reduction in health and service disparities; transparency of resource allocation; access or waiting list; safe, accessible, and affordable housing; availability; timeliness; consistency across jurisdictions

Survey questions

Items in several other domains, such as Health & Well-Being and Service Delivery, can be combined with responses to other demographic and disability questions to obtain equity measures.

NQF Domain: System Performance

Description: The level of accountability within the HCBS system and the extent to which it operates efficiently, ethically, and is able to achieve desired outcomes.

Corresponding characteristics:

- Coordinates and integrates resources to best meet the needs of the individual and maximize affordability and long-term sustainability.
- Receives adequate funding to deliver accessible, affordable, and cost-effective services to those who need them.
- Supplies valid, meaningful, integrated, aligned, accessible, outcome-oriented data to all stakeholders.
- Fosters accountability through measurement and reporting of quality and outcomes.

Proposed subdomains: Consumer engagement; participatory program design; reliability; publicly available data; appropriate and fair resource allocation based on need; primarily judged by the aggregate of individual outcomes; waiting lists; backlog; financing and service delivery structures; availability of services; efficiency and evidence based practices; data integrity

Survey questions: None

NQF Domain: Consumer Voice

Description: The level of involvement individuals who use HCBS have in the design, implementation, and evaluation of the HCBS system at all levels.

Corresponding characteristics: Engages individuals who use HCBS in the design, implementation, and evaluation of the system and its performance

Proposed subdomains: Meaningful mechanism for input (e.g., design, implementation, evaluation); consumer-driven system; breadth and depth of consumer participation; level of commitment to consumer involvement; diversity of consumer and workforce engagement; and outreach to promote accessible consumer engagement

Survey questions: None

Sources of Survey Questions

- ASCOT: Adult Social Care Outcomes Toolkit, three-level self-completion questionnaire (SCT3), Version 3. <http://www.pssru.ac.uk/ascot/instruments.php> (Registration required)
- ASDS: The Arc's Self-Determination Scale, Adolescent Version, Rev. 2013. <http://www.thearc.org/document.doc?id=3670>
- BSFC: Burden Scale for Family Caregivers, Short Version. <http://www.psychiatrie.uk-erlangen.de/index.php?id=11049/>
- CAHPS-HP: CAHPS Health Plan Survey 4.0, Supplemental items for the Adult Questionnaire. <http://cahps.ahrq.gov/surveys-guidance/hp/instructions/medicaidsurveylist.html>
- CCCQ: Client-Centered Care Questionnaire, English translation. <http://link.springer.com/article/10.1007%2Fs11136-014-0650-7>
- Channeling: National Long Term Care Channeling Evaluation, 1982–1984. Sample Member Follow-up Questionnaire. http://www.icpsr.umich.edu/cgi-bin/file?comp=none&study=8683&ds=5&file_id=142725
- CGUS: Caregiving in the U.S. 2015. <http://www.caregiving.org/caregiving2015/>
- CIQ: Community Integration Questionnaire. <http://tbims.org/combi/ciq/ciqsyl.html>
- CLMDP: SAMHSA's NOMs Client-Level Measures for Discretionary Programs Providing Direct Services, Adult Programs, Version 13 dated Oct. 2015. http://cmhs-gpra.samhsa.gov/TracPRD/View/docs/SVCS_AdultTool_v13_10_2015.pdf
- C&C9MO: Evaluation of the Cash & Counseling Demonstration, Nine-Month Follow-up Instrument. http://www.mathematica-mpr.com/~media/publications/PDFs/health/cashcounseling_9month.pdf
- Duke: Duke Health Profile. <http://healthmeasures.mc.duke.edu/images/DukeForm.pdf>
- EAZI: Empowering Arizona's Individuals (EAZI) with Developmental Disabilities Consumer to Consumer Survey, Attendant Instrument dated June 22, 2007. <http://www.nasuad.org/hcbs/article/quality-improvement-surveys-and-training-materials-arizona>
- ECHO: Experience of Care and Health Outcomes Survey, Adult, Managed Care Organization, Version 3.0. <http://cahps.ahrq.gov/surveys-guidance/echo/about/ECHO-3.0-MCO-Kit.zip>
- GSS-CCR: Statistics Canada's General Social Survey, Cycle 26, Caregiving and Care Receiving, 2012. http://www23.statcan.gc.ca/imdb-bmdi/instrument/4502_Q2_V3-eng.htm
- HCBSEOC: HCBS Experience of Care Survey. Version dated 6/19/13. www.ct.gov/dss/lib/dss/hit/cthcbseocreportv3.pdf
- MAHCSS: Massachusetts Home Care Satisfaction Survey 2008. <http://www.nasuad.org/hcbs/article/participant-experience-survey>
- MFPQOL: Money Follows the Person Quality of Life Survey. http://www.mathematica-mpr.com/~media/publications/PDFs/health/MFP_QoL_Survey.pdf
- MHSIP-ACS: Mental Health Statistics Improvement Project Adult Consumer Survey, 2014 version. <http://depts.washington.edu/pbhjp/sites/default/files/2014%20ACS%20Toolkit.pdf>

- MNCES: 2009 Elderly Waiver Consumer Experience Survey, Minnesota Department of Human Services. <http://www.nasuad.org/hcbs/article/participant-experience-survey>
- NCI-ACS: National Core Indicators Adult Consumer Survey, 2015-16.
- NCI-AD: National Core Indicators — Aging and Disabilities, 2015-16.
- NCI-AFS: National Core Indicators Adult Family Survey, 2015-16.
- NCI-FGS: National Core Indicators Family/Guardian Survey, 2015-16.
- NDPEs: North Dakota Department of Human Services, Home and Community Based Services Participant Experience Survey. <http://www.nasuad.org/hcbs/article/participant-experience-survey>
- NHATS: National Health and Aging Trends Study, Round 1 Questionnaire. <http://www.nhats.org/scripts/dataCollInstr.htm>
- NHIS-01: 2001 National Health Interview Survey Sample Adult Questionnaire. ftp://ftp.cdc.gov/pub/Health_Statistics/NCHS/Survey_Questionnaires/NHIS/2001/qsamadlt.pdf
- NHIS-10: 2010 National Health Interview Survey Sample Adult Questionnaire, Cancer Supplement. ftp://ftp.cdc.gov/pub/Health_Statistics/NCHS/Survey_Questionnaires/NHIS/2010/English/qcancer.pdf
- NLTCs: 2004 National Long Term Care Survey Community Questionnaire. http://www.nltcs.aas.duke.edu/pdf/2004_Community_QUESTIONNAIRE_Beta2.pdf
- NMPQR: New Mexico CoLTS (1915c) Waiver Participant Quality Review. <http://www.nasuad.org/hcbs/article/participant-experience-survey>
- NSOC: National Study of Caregiving. <http://www.nhats.org/scripts/dataCollInstrNSOC.htm>
- NS-CSHCN: National Survey of Children with Special Health Care Needs, 2009–10. <http://www.cdc.gov/nchs/slaits/cshcn.htm>
- NYPSS: New York Traumatic Brain Injury Waiver Program Participant Satisfaction Survey. <http://www.nasuad.org/hcbs/article/participant-experience-survey>
- OPQOL: Older People's Quality of Life Questionnaire (OPQOL-35). http://www.ilcuk.org.uk/files/pdf_pdf_161.pdf
- ORIES: Oregon Individual Experience Survey dated 8/21/15. <http://www.dhs.state.or.us/policy/spd/transmit/im/2015/im15061.pdf>
- PART-E: Participation Assessment with Recombined Tools—Enfranchisement. http://www.ric.org/pdf/Heinemann_Lai_Magasi_2011.pdf
- PC-PAL: Resident Person-Centered Planning in Assisted Living. <http://www.theceal.org/component/k2/item/946>
- PES-DD: Participant Experience Survey, MR/DD Version, 2003. <http://www.nasuad.org/hcbs/article/participant-experience-survey-pes-tools>
- PES-E/D: Participant Experience Survey, Elderly/Disabled Version, 2003. <http://www.nasuad.org/hcbs/article/participant-experience-survey-pes-tools>
- PLQ: Personal Life Quality Protocol. <http://eoutcome.org/default.aspx?pg=327>
- POMP-CSS: Performance Outcome Measurement Project Caregiver Services Survey. http://www.aoa.acl.gov/Program_Results/POMP/Caregiver.aspx

- POMP-CMS: Performance Outcome Measurement Project Case Management Survey. http://www.aoa.acl.gov/Program_Results/POMP/Casemanagement.aspx
- POMs: Council on Leadership and Quality's Personal Outcome Measures Adult Survey, 2015 version.
- PROMIS-ES: PROMIS Item Bank v2.0 - Emotional Support. <http://www.assessmentcenter.net/> (Registration required)
- PROMIS-GH: PROMIS v1.1 Global –Global Health. <http://www.assessmentcenter.net/> (Registration required)
- PROMIS-PI: PROMIS Item Bank v. 1.1 –Pain Interference. <http://www.assessmentcenter.net/> (Registration required)
- PROMIS-SPDSA: PROMIS Item Bank v. 1.0 –Satisfaction with Participation in Discretionary Social Activities. <http://www.assessmentcenter.net/> (Registration required)
- PROMIS-SSRA: PROMIS Item Bank v2.0 - Satisfaction with Social Roles and Activities. <http://www.assessmentcenter.net/> (Registration required)
- QOLS: Flanagan's Quality of Life Scale. <http://hqlo.biomedcentral.com/articles/10.1186/1477-7525-1-60>
- SCSPWD: Survey of Caregivers Supporting a Person with a Disability Outside of the Disability Support Service System. <https://aspe.hhs.gov/basic-report/survey-caregivers-supporting-person-disability-outside-disability-support-service-system>
- TCARE: Tailored Caregiver Assessment and Referral Personal Caregiver Survey. <http://www.dshs.wa.gov/sites/default/files/AL TSA/stakeholders/documents/Personal%20Caregiver%20Survey.pdf>
- TXPES: Texas Participant Experience Survey (Elderly/Disabled), 2010, Version 6.00. <http://www.nasuad.org/hcbs/article/participant-experience-survey>
- WHOQOL-BREF: World Health Organization Quality of Life—BREF module, 2004. http://www.who.int/entity/substance_abuse/research_tools/en/english_whoqol.pdf
- YSSF: Youth Services Survey for Families, version dated 2/17/06. <http://dhs.iowa.gov/sites/default/files/YSSFURS-Version-2006.pdf>
- ZBI. Zarit [Caregiver] Burden Interview. http://www.proqolid.org/content/download/11520/176013/version/1/file/ZBI-22_AU1.0_eng-USori_ReviewCopy.pdf