

- 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.nasud.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