Aging and Disability Resource Center Grant Program Evaluation: Data Collection Materials

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SECTION 1: ORIGINAL PROPOSED DATA COLLECTION TOOLS

Date_____

PROCESS EVALUATION: WEB-BASED SURVEY

INSTRUCTIONS TO WEB SURVEY PROGRAMMER: PREPOPULATE (PP) INFORMATION IN [] BASED ON SITE DIRECTOR TYPE (DT) OR ID NUMBER (ID). THESE PROPOPULATED DATA WILL BE USED THROUGHOUT THE SURVEY TO ORIENT THE RESPONDENT BASED ON TYPE OF SITE. EACH SITE WILL ALSO RECEIVE A UNIQUE ID NUMBER WITH THE NAME OF THE SITE.

[ID Number - ID]

Name of Site

[Director Type - DT]

- □ ADRC1 (State-level)
- □ ADRC2 (Local-level)
- □ AAA

Section A. Baseline Characteristics

[FOR STATE AND LOCAL-LEVEL ADRC DIRECTORS]: The first set of questions focus on characteristics of your organization/network **PRIOR** to receiving an ADRC grant and the influence on your organization/network of the Administration on Aging (AoA) and/or CMS grant(s) (i.e., AoA Title IV grants, AoA title II grants, CMS Real Choice System Change grants, CMS Person-centered hospital discharge planning grants, Patient Protection and Affordable Care Act funds).

[FOR AAA AND CIL DIRECTORS ONLY]: We are interested in how your organization/network has changed over time, therefore, the first set of questions deals with the characteristics of your organization approximately 7 years ago (i.e., in 2004-2005).

- Has your organization or network realized an improvement in ability to provide integrated, comprehensive access to long-term care services and supports (e.g., provide one-stop or streamlined benefits access, increase awareness of LTSS options, provide assistance to consumers such as counseling regarding LTSS choices or transitions from institutions back into the community) [if DT = ADRC1 or ADRC 2 since the start of the ADRC grant ; if DT=AAA or CIL over the past 7 years]
 - Yes

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- □ No [skip to question 3]
- 2. Which have had the most positive impact on your organization/network's ability to provide integrated, comprehensive access to long-term care services and supports (e.g., provide one-stop or streamlined benefits access, increase awareness of LTSS options, provide assistance to consumers such as counseling regarding LTSS choices or transitions from institutions back into the community)? (Select up to two)
 - □ Partnerships developed/expanded
 - Staffing changes
 - Shared data
 - □ Focusing on providing person-centered, self-directed services
 - □ Other, please specify
- 3. [FOR STATE-LEVEL ADRC DIRECTORS ONLY]: Which of the following **BEST** describes the reason your State applied for an ADRC grant (If you have applied for more than one ADRC grant, please think back to reason for applying for the first grant):
 - □ To better integrate service provision systems
 - □ To develop or strengthen agency/organizational partnerships
 - □ To improve data or IT infrastructure
 - To improve marketing or awareness efforts related to Long Term Care Services and Supports (LTSS)
 - □ To expand services to additional populations
 - □ To expand services to additional geographic locations
 - □ Other , please specify
- 4. [FOR STATE-LEVEL ADRC DIRECTORS ONLY]: Please indicate how your State selected local sites to receive ADRC funds.
 - □ Selected sites that were already integrated to help them maintain or expand their efforts
 - □ Selected sites that were partially integrated to support further integration
 - □ Selected sites that were fragmented to encourage integration
 - □ Other, please specify
- 5. [FOR LOCAL-LEVEL ADRC DIRECTORS ONLY]: Which of the following best describes the reason your site became an ADRC:
 - □ To better integrate service provision systems
 - □ To develop or strengthen agency/organizational partnerships
 - □ To improve data or IT infrastructure
 - To improve marketing or awareness efforts related to Long Term Care Services and Supports (LTSS)
 - □ To expand services to additional populations
 - □ To expand services to additional geographic locations
 - □ Other, please specify
- 6. [FOR AAA AND CIL DIRECTORS ONLY]: Is your site interested in becoming an ADRC or becoming part of an ADRC in the future?

Interviewer Initials (or ID) _____

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- Yes; If yes, what is your current stage or status in becoming an ADRC? (Open Response)
- □ No; If no, please explain why you do not plan to become an ADRC? (Open Response)
- □ Other, please specify
- 7. [FOR AAA AND CIL DIRECTORS ONLY]: How would you describe your site's perception of the ADRC program? (Open Response)
- 8. [FOR STATE AND LOCAL-LEVEL ADRC DIRECTORS ONLY]: Please indicate the extent to which Federal (AoA/CMS) grants have enabled your ADRC to realize any of the following outcomes... (Select all that apply)

	(3-point scale: Very much; Somewhat; Very little)
increase the skills of existing staff	
recruit or attract more experienced staff	
increase/expand populations served	
increase the number of consumers served	
increase the number of partnerships	
increase range of services offered	
make other changes (please specify)	

 [FOR STATE AND LOCAL-LEVEL ADRC DIRECTORS ONLY]: How has the ADRC grant(s) affected the resources or resource allocation at your organization/network or within your state? [IF THERE IS MORE THAN ONE ADRC IN THE STATE CHECK THE BOX IF THE ITEM IS TRUE OF AT LEAST ONE ADRC] (Check all that apply)

	At the site or local level	At the State level
Helped us leverage other funds		
Improved staff training opportunities		
Increased service efficiency		
Contributed to the development of a statewide database of LTSS services and/or consumers		
Promoted the development of standard operating procedures		
Increased the level of coordination between organizations serving older individuals and individuals with disabilities		

Interviewer	Initials	(or ID))
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Improved awareness/marketing	
campaigns/activities	

Section B. Populations Served

This second set of questions asks about the populations in your service area as well as consumers that your organization/network serves. For questions about consumers, please focus on those who received services designed to enhance individual choice and support informed decision-making among consumers. This includes empowering individuals to effectively navigate their health and other long-term support options (e.g., Information, referral and awareness services; Consumer-focused decision support; Assistance with planning for future LTSS Needs; Streamlined eligibility determination for public programs Person-centered transition support from institutional setting to community settings; and Independent living skills.) Please answer these questions to the best of your knowledge. In questions asking for percentages, please provide estimates if your organization does not collect the requested data.

NOTE: The data will be used to group like organizations together to allow for more complex data analyses. These data will not be used to evaluate the efforts of your specific organization/network.

For the following items, please indicate the demographic composition of your **service area**. (This question applies to the community that [insert ID] serves)

- 10a. Latino/Hispanic Origin
 - Yes %
 - No %
- 10b. Race
- Caucasian/White %
- Black or African American %
- American Indian or Alaska Native %
- Asian %
- Nation Hawaiian or Other Pacific Islander %

10c. If you have one or more significant racial/ethnic sub-populations in your service area please list it here:

10d. What percentage of your service area is living at or below the poverty line?

- At or below the poverty line %
- □ Not sure, but a significant population lives under the poverty line
- □ Not sure, but the population is small or non existent
- 10e. What percentage of your service area is uninsured/does not have health insurance coverage?
 - Uninsured %
 - □ Not sure, but a significant population is uninsured

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Date_____

□ Not sure, but the population is small or non existent

- 11. [FOR LOCAL-LEVEL ADRC, CIL, AND AAA DIRECTORS ONLY]: Within the last 12 months, has a community LTSS needs assessment been conducted?
 - □ Yes
 - □ No, but we did complete a community needs assessment within the past three years
 - □ No, a community needs assessment was not completed within the past three years

[FOR STATE-LEVEL ADRC DIRECTORS ONLY]:

- □ Yes , we assessed the needs in all ADRC communities in our State
- □ Yes, we assessed the needs in some of the ADRC communities in our State
- No, but we did complete a community needs assessment, for at least some of the ADRC communities in our State within the past three years
- □ No, a community needs assessment was not completed within the past three years
- 12. This next set of questions is designed to gather information about the conditions in your service area. [SPECIAL INSTRUCTIONS FOR THE STATE-LEVEL ADRC DIRECTORS: PLEASE THINK ABOUT THE STATUS OF YOUR STATE AS A WHOLE].

Community Needs		
Barriers to receiving LTSS services (3-point scale: not a barrier; sometimes a barrier; often a barrier)		
To what extent is each of the following a barrier for individuals seeking receiving an ADRC grant [approximately 7 years ago] and currently?	LTSS services bo	oth prior to
	Prior	Currently
Lack of LTSS services-Needed services are not offered		
Lack of available LTSS service slots-(e.g., There are long waitlists)		
Poor service quality		
Lack of health insurance		
Providers not accepting consumers with Medicaid		
Barriers based on consumer disabilities		
Language barriers		
Cultural barriers		
Religious barriers		
Sexual orientation barriers		
People needing services do not have a permanent address		
Consumers lack transportation		
Stigma, discrimination and prejudice against older adults		

Interviewer Initials (or ID)	Date
Stigma, discrimination and prejudice against persons with disabi	lities
Providers have high staff turnover	
Providers lack appropriately trained staff	
Service provider hours/locations are hard to access	
Other Please specify:	

Service Availability/Choice	Please indicate the Current availability of the following services within your service area (Adequate availability; Available but inadequate to meet need; Not available)	For the followin what extent is the choice? Service has (<i>no;</i> <i>adequate</i>) provi Prior to first ADRC grant [7 years prior]	here provider <i>limited;</i>
Safe and affordable housing options			
Peer support services/groups			
HCBS Medicaid Waiver Programs			
Caregiver Support (i.e. respite programs, support groups, or counseling)			
Nutrition Programs			
Employment services			
Education services			
Opportunities to develop advanced directives			
Transportation services			
Opportunities for socialization/recreation			
Mental health services			
Ombudsman services			
Health prevention and screening services			
Services for emergent cases/Crisis intervention			

Interviewer Initials (or ID)	Date		
Service Availability/Choice	Please indicate the Current availability of the following services within your service area (Adequate availability;	For the following what extent is th choice? Service has (<i>no;</i> <i>adequate</i>) provid	nere provider limited;
	Available but inadequate to meet need; Not available)	Prior to first ADRC grant [7 years prior]	Currently
Transition programs (from hospitals, nursing homes etc.)			
Nursing home (institutional) diversion programs			
Nursing home/residential beds			
Income assistance			
Energy assistance			
Personal care services			
Independent Living services (e.g., home modification, attendant care)			
Other, please specify			

13. How many consumers of each type were served in the most recent 6 month period (October 2011-March 2012) NOTE: This question is specific to the consumers who access [insert ID] services such as I&R/I&A, benefits or options counseling, Information and referral services, services to support transitions from residential or institutional facilities to the community.

Characteristics	Currently	
	Consumers under 60	Consumers over 60
Older Adults (60+)		
Individuals with Disabilities		
Physical disabilities		
Cognitive impairment		
Intellectual disabilities		
Developmental disabilities		
Mental Illness		

Date

	Currently		
Characteristics	Consumers under 60	Consumers over 60	
Multiple disabilities			
Caregivers			
Informal/family caregiver			
Paid Caregiver			
Health & Human Service Professional (e.g., physician, hospital discharge planner, nursing home staff)			
Special Subpopulations			
Traumatic Brain Injury (TBI)			
Emergent/Emergency Cases			
Low income			
Limited English proficiency			
Is the [insert ID] making any special efforts to target a particular population not listed above? If yes, please specify.			
Other (Please specify)			
Other (Please specify)			

- 14a. [FOR STATE AND LOCAL LEVEL ADRC DIRECTORS ONLY]: Since the start of the ADRC grant, the number of clients **under** 60 served by [insert ID] has:
 - □ Significantly increased
 - □ Significantly decreased
 - □ Stayed the same
- 14b. [FOR AAA AND CIL DIRECTORS ONLY]: Over the past 7 years, the number of clients **under** 60 served by [insert ID] has:
 - □ Significantly increased
 - □ Significantly decreased
 - □ Stayed the same
- 15a. [FOR STATE AND LOCAL LEVEL ADRC DIRECTORS ONLY]: Since the start of the ADRC grant, the number of consumers **over** 60 served by [insert ID] has:
 - □ Significantly increased
 - □ Significantly decreased
 - □ Stayed the same

Interviewer Initials (or ID) _____

Date_____

- 15b. [FOR AAA AND CIL DIRECTORS ONLY]: Over the past 7 years the number of consumers **over** 60 served by [insert ID] has:
 - □ Significantly increased
 - □ Significantly decreased
 - □ Stayed the same

16a. [FOR STATE AND LOCAL LEVEL ADRC DIRECTORS ONLY]: Since the start of the ADRC grant, the number of consumers with physical disabilities served by [insert ID] has:

- □ Significantly increased
- □ Significantly decreased
- Stayed the same
- 16b. [FOR AAA AND CIL DIRECTORS ONLY]: Over the past 7 years, the number of consumers with physical disabilities served by [insert ID] has:
 - □ Significantly increased
 - □ Significantly decreased
 - □ Stayed the same
- 17a. [FOR STATE AND LOCAL LEVEL ADRC DIRECTORS ONLY]: Since the start of the ADRC grant, the number of consumers with mental/emotional disabilities served by [insert ID] has:
 - □ Significantly increased
 - □ Significantly decreased
 - □ Stayed the same
- 17b. [FOR AAA AND CIL DIRECTORS ONLY]: Over the past 7 years, the number of consumers with mental/emotional disabilities served by [insert ID] has:
 - □ Significantly increased
 - □ Significantly decreased
 - □ Stayed the same
- 18a. [FOR STATE AND LOCAL LEVEL ADRC DIRECTORS ONLY]: Since the start of the ADRC grant, the number of consumers with multiple disabilities served by [insert ID] has:
 - □ Significantly increased
 - □ Significantly decreased
 - □ Stayed the same
- 18b. [FOR AAA AND CIL DIRECTORS ONLY]: Over the last 7 years, the number of consumers with multiple disabilities served by [insert ID] has:
 - □ Significantly increased

Date_____

- □ Significantly decreased
- □ Stayed the same
- 19a. [FOR STATE AND LOCAL LEVEL ADRC DIRECTORS ONLY]: Since the start of the ADRC grant, the number of caregivers served by [insert ID] has:
 - □ Significantly increased
 - □ Significantly decreased
 - □ Stayed the same
- 19b. [FOR AAA AND CIL DIRECTORS ONLY]: Over the past 7 years, the number of caregivers served by [insert ID] has:
 - □ Significantly increased
 - □ Significantly decreased
 - □ Stayed the same

Section C. Service Provision

These questions are about the services provided by your organization/network

- 20. [FOR LOCAL LEVEL ADRC, CIL, AND AA DIRECTORS ONLY] What three topics do consumers most commonly ask about?
 - □ Advanced directives
 - □ Advocacy
 - □ Attendant care services
 - □ Caregiver/respite support
 - □ Chronic health conditions
 - □ Education
 - Employment
 - Energy assistance
 - □ Home modification
 - □ Housing
 - Income assistance
 - □ Medicaid questions (including about HCBC waivers)
 - □ Medicare questions
 - Mental health
 - Nutrition
 - Ombudsman/abuse or neglect issues
 - □ Other Independent living supports or services
 - Personal care
 - Preventative health services
 - □ Recreation opportunities
 - □ Services for emergent cares/crisis intervention
 - □ Support groups
 - □ Transition services

Date_____

- Transportation
- □ Other, please specify
- Do not know
- 21. [FOR LOCAL LEVEL ADRC, CIL, AND AA DIRECTORS ONLY] Does [insert ID] engage in advocacy activities for older adults?
 - Yes
 - No
- 22. [FOR LOCAL LEVEL ADRC, CIL, AND AA DIRECTORS ONLY] Does [insert ID] engage in advocacy activities for persons with disabilities?
 - Yes
 - □ No
- 23a. [FOR LOCAL LEVEL ADRC, CIL AND AAA DIRECTORS ONLY]: Is nursing home diversion is an outcome sought to be achieved?
 - □ Yes
 - □ No [Skip to question 28]
- 23b. [FOR LOCAL LEVEL ADRC, CIL AND AAA DIRECTORS]: Is [insert ID] meeting its program's goals for diverting individuals from nursing homes or other institutional residential settings?
 - □ Yes, completely
 - To a large degree
 - □ To a limited degree
 - □ No
- 23c. [FOR LOCAL LEVEL ADRC, CIL AND AAA DIRECTORS]: How is [insert ID] measuring and tracking this?
 - □ Staff track using a standard electronic system
 - □ Staff track using a standard hardcopy/paper system
 - □ An external group (e.g., an evaluator, auditor) tracks using a standard system
 - □ Staff track using an informal system
 - □ Other, please specify

[FOR SITES WITH CARE COORDINATION/TRANSITION ASSISTANCE PROGRAMS ONLY]

- 24. Does your network/organization provide transition services to consumers discharged from an acute care setting?
 - Yes
 - □ No [If no skip to question 29]

Date_____

25. Care Coordination/Transition Assistance

[insert ID] Clients Provided Care Coordination/Transition	Assistance
What is the number of [insert ID] individuals assisted with hospital discharge following an acute care episode?	
What is the number of [insert ID] individuals assisted with transition from hospital through formal care transitions program (evidence-based CT intervention or innovative model)?	
What is the number of [insert ID] individuals assisted with transition from nursing facility?	
What is the number of [insert ID] individuals assisted with transition from ICF/MR into the community?	
What is the number of [INSERT ID] individuals assisted with transition from other institutional setting (e.g. psychiatric hospital)?	
What is the cumulative number of individuals assisted with transition from hospital through formal care transitions intervention across all participating hospitals in this [INSERT ID] program service area to date?	

- 26. What is the number of individuals who were assisted with transition from hospital through formal care transitions intervention in this [INSERT ID] program service area this reporting period by participating hospital?
 - \Box Name of Hospital 1
 - \Box No. of Individuals for Hospital 1
 - □ Name of Hospital 2
 - \Box No. of Individuals for Hospital 2
 - □ Name of Hospital 3
 - \Box No. of Individuals for Hospital 3
- 27. What is the number of individuals who were assisted with transition from hospital through formal care transitions intervention across all participating hospitals in this [INSERT ID] program service area this reporting period by age group?
 - \Box Aged 60 and Over
 - 🗆 Under Age 60
 - 🗆 Age Unknown

Date_____

- 28. What is the number of individuals who were assisted with transition from hospital through formal care transitions intervention across all participating hospitals in this [INSERT ID] program service area this reporting period by health insurance source?
 - □ Medicare
 - Medicaid
 - □ Dual-Eligible
 - □ Other Unknown
- 29. What is the number of individuals who were assisted with transition from hospital through formal care transitions intervention across all participating hospitals in this [INSERT ID] program service area in this reporting period who were referred to one or more health/prevention programs?

 - □ Exercise Program
 - $\hfill\square$ Mental Health and Substance Misuse
 - □ Falls Management and Prevention
 - □ Alzheimer's Programs
 - □ Medication Management
 - □ Home Injury/Risk Screenings
 - 🗆 Other
- 30. [FOR LOCAL LEVEL ADRC, CIL, AND AAA DIRECTORS ONLY]: Do you have an operational marketing plan?
 - □ Yes, our marketing plan is operational
 - □ No, we have a plan but it is not yet operational
 - □ No, we do not have a plan at this time
 - 30a. [FOR LOCAL LEVEL ADRC, CIL, AND AAA DIRECTORS ONLY]: Does [insert ID] or your network utilize a standard operating procedure to assess consumer need?
 - □ Always
 - □ Sometimes
 - Never
 - 30b. [FOR STATE-LEVEL ADRC DIRECTORS ONLY]: Do the ADRCs in your State utilize standard operating procedures to assess consumer need?
 - □ All or most
 - □ Some
 - Few or none

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- 31. [FOR LOCAL LEVEL ADRC ONLY]: Is the consumer assessment tool and/or basic consumer needs assessment process common across partner organizations?
 - □ Yes, common across all partners
 - □ Yes, common across some partners
 - □ No, each partner organization uses their own assessment tool/process

[FOR SITES WITH OPTIONS COUNSELING OR OTHER ONE ON ONE COUNSELING ONLY]

- 32. Does your organization/network provide "Options Counseling" or other one-on-one counseling designed to support consumers' ability to make informed decisions about their long-term care?
 - Yes
 - □ No [If no skip to question 36]
- 33. Referrals to Public and Private Services this Reporting Period

Referrals to Public and Private Services this Reporting Period	
What is the number of [insert ID] clients referred to or given an application for a public program, including Older Americans Act; Medicare; Medicaid; Food Stamps; TANF; Social Security (SSI or SSDI); LI-HEAP; VDHCBS; Other State-funded and county-funded programs for Medicaid; Other?	
What is the number of [insert ID] clients referred to some other type of service (non- public services, resources or program)?	
What is the number of [insert ID] clients that were not referred to any type of service?	
What is the number of [insert ID] Unknown Clients (remainder of all Clients)?	
Total	

Interviewer Initials (or ID) _____

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[FOR SITES WITH OPTIONS COUNSELING OR OTHER ONE ON ONE COUNSELING ONLY]

34. Clients Provided Options Counseling this Reporting Period

[insert ID] Clients Provided Options Counseling By Age		
[insert ID] Clients Aged 60 and Over		
[insert ID] Clients Under Age 60		
[insert ID] Clients Age Unknown		
Total		

[insert ID] Clients Provided Options Counseling by Method		
In person		
By phone		
Electronic Communication		
(e.g. email or website chat)		
Total		

[insert ID] Clients Provided Options Counseling by Setting		
[insert ID]		
Hospital		
Nursing facility/Institution		
At the client's community residence		
Other		
Total		
Client Feedback About Options	Counseling	
What is the number of [insert ID] Clients who report that options counseling enabled them to make well informed decisions about their long term support services?		
What is the number of [insert ID] Clients surveyed this reporting period?		

Interviewer Initials (or ID) _____

Date_____

- 35. [FOR LOCAL LEVEL ADRC, CIL, AND AAA DIRECTORS ONLY]: Does [insert ID] or network have a standardized tool or process to provide options counseling?
 - Yes
 - No
 - Don't know
 - Not applicable

[FOR SITES THAT REFER CLIENTS TO PUBLIC PROGRAMS ONLY]:

36. Average Monthly Public LTSS Program Enrollment in WHOLE [INSERT ID] SERVICE AREA This set of questions is asking about all current enrollment levels in these programs in the [INSERT ID] service area. Enrollment fluctuates from month to month, so please calculate the average enrollment per month during the reporting period.

What is the average number of individuals enrolled in Medicaid HCBS Waivers in [INSERT ID] Service Area each month (should include [INSERT ID] Clients and might include Non-[INSERT ID] Clients)?	
What is the average number of individuals enrolled in Medicaid residing in institutions in [INSERT ID] Service Area each month (should include [INSERT ID] Clients and might include Non-[INSERT ID] Clients)?	
What is the average number of individuals enrolled in other public LTSS programs in [INSERT ID] Service Area each month (should include [INSERT ID] Clients and might include Non-[INSERT ID] Clients)? Please list LTSS programs and HCBS waivers (e.g. aged and disabled, MR/DD) that individuals are enrolled in.	

Date_____

[FOR SITES THAT REFER CLIENTS TO PUBLIC PROGRAMS ONLY]:

37. Total New Enrollment among [INSERT ID] CLIENTS ONLY in Public LTSS Programs This set of questions is asking about the absolute number of [INSERT ID] clients who were newly enrolled into these programs during the last six months.

Total New Enrollment among [INSERT ID] CLIENTS ONLY in Public LTSS Prog	rams
What is the number of [INSERT ID] Clients who are newly enrolled into a Medicaid HCBS Waiver this reporting period (including individuals enrolled by [INSERT ID] staff and individuals referred for assessment/application by [INSERT ID] staff)?	
What is the number of [INSERT ID] Clients who are newly enrolled into Medicaid institutional services this reporting period (including individuals enrolled by [INSERT ID] staff and individuals referred for assessment/application by [INSERT ID] staff)?	
What is the average number of individuals enrolled in other public LTSS programs in [INSERT ID] Service Area each month (should include [INSERT ID] Clients and might include Non-[INSERT ID] Clients)? Please list LTSS programs and HCBS waivers (e.g. aged and disabled, MR/DD) that individuals are enrolled in.	

- 38. [FOR LOCAL LEVEL ADRC, CIL, AND AAA DIRECTORS ONLY]: For data collected on consumers, are staff required to follow the Alliance of Information and Referral Systems (AIRS) standards¹?
 - □ Yes with all consumers
 - □ Yes, with specific groups of consumers –Please specify:
 - Never
- 39. [FOR LOCAL LEVEL ADRC, CIL, AND AAA DIRECTORS ONLY]: Does [insert ID] have a database/MIS that does any of the following (Select all that apply):
 - □ Track information and referral (I&R) requests
 - □ Track consumers/Maintaining consumer records
 - □ Maintain a list of services/service providers
 - □ Other, please specify
 - □ We do not have an electronic records/tracking system [skip to question 41]

¹ Standard 13: Inquirer Data Collection

Date

- 40. [FOR LOCAL LEVEL ADRC, CIL, AND AAA DIRECTORS ONLY]: Do you have designated internal staff who oversee the quality control of the organization's database?
 - Yes
 - No
- 41. [FOR LOCAL LEVEL ADRC, CIL, AND AAA DIRECTORS ONLY]: Do operational partners update information in your organization's or network's database?
 - □ Yes
 - □ No, but there are plans to develop that capacity
 - □ No, and there are no current plans to do this
- 42. [FOR LOCAL LEVEL ADRC, CIL, AND AAA DIRECTORS ONLY]: Do service providers enter new information or create new records in your organization's or network's database?
 - □ Yes
 - □ No, but there are plans to develop that capacity
 - □ No, and there are no current plans to do this
- 43. [FOR LOCAL LEVEL ADRC, CIL, AND AAA DIRECTORS ONLY]: Can partners and providers access consumer-level information from your organization's or network's database?
 - □ Yes, both partners and providers
 - Only partners
 - Only providers
 - □ No, neither partners or providers
- 44. Does staff follow up with consumers after their initial contact with your organization or network?
 - Always
 - □ Sometimes-Under what circumstances:
 - Never
- 45. When consumers are referred to other agencies or organizations, are those providers contacted as part of the follow up procedure?
 - Always
 - □ Sometimes-Under what circumstances:
 - Never
- 46. Approximately what percentage of consumers who are referred to other organizations receive a "warm transfer" (e.g., Simultaneous transfer of a telephone call and its associated data from one agent to another agent or supervisor)? _____%
- 47. [FOR LOCAL LEVEL ADRC, CIL, AND AAA DIRECTORS ONLY]: Does your organization routinely collect quantitative performance data about its services and consumers?
 - □ Yes
 - □ No (Skip to question 48)

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- 48. [FOR LOCAL LEVEL ADRC, CIL, AND AAA DIRECTORS ONLY]: Indicate any of the ways that your organization uses performance data: [check all that apply]
 - □ To justify funding requests
 - $\hfill\square$ To improve consumer service
 - □ To administer service provider contracts
 - □ To provide information to stakeholders (governing board, advocacy organizations, local government, etc.)
 - □ For program planning
 - Do not use performance data
- 49. [FOR STATE AND LOVAL LEVEL ADRC DIRECTORS] On which topics, if any, would you like to receive additional assistance from the technical assistance provider? (Open Response)

Section D. Organizational Characteristics

These questions are about your organization or network budget, partnerships, and structure.

- 50. What is your total budget for the current fiscal year? (In \$ amounts)
- 51. For the current Fiscal Year, what is the approximate amount of funding from each of the following sources? (In \$ amounts)

Check if you have received funding in prior Fiscal Years	Amount of funding during the current Fiscal Year	Funding source
		Administration on Aging Title IV ADRC Grant
		Administration of Aging Title II Grant
		CMS Real Choice Systems Change Grants
		CMS Person-Centered Hospital Discharge Planning Grant
		Patient protection and Affordable Care Act Grant
		Veteran's Administration
		Money Follows the Person Demonstration
		State Transformation Grant
		Alzheimer's Disease Demonstration

Interviewer Initials (or ID) _____

Date_____

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Check if you have received funding in prior Fiscal Years	Amount of funding during the current Fiscal Year	Funding source
		Grant
		Evidence-Based Disease Prevention Grant
		Program of All-Inclusive Care for the Elderly (PACE)
		Medicare Improvement for Patients and Providers Act (MIPPA)
		Respite Care Act funds
		Rehabilitation Services Administration (RSA)
		Substance Abuse and Mental Health Services Administration (SAMHSA) - Mental Health Transformation Grant
		Agency for Health Care Research and Policy - Chronic Disease Self- Management Grant
		Administration for Children and Families, Office of Community Services - Low Income Home Energy Assistance Program (LIHEAP)
		Health Resources and Services Administration HIV/AIDS Bureau - Ryan White Fund
		State Unit on Aging
		State General Revenue
		County government
		Private entities/grants - Hospitals or other businesses
		Other, please specify

Date_____

- 52. [FOR LOCAL LEVEL ADRC, CIL, AND AAA DIRECTORS ONLY]: Is [insert ID] more of a single-point of entry (centralized) OR a no wrong door (decentralized)?
 - □ Single-point of entry (i.e. one agency knowledgeable about care alternatives which helps people make decisions about the best and most feasible options.)
 - □ No wrong door (i.e., multiple agencies which cooperate to assist consumers in need regardless of which agency the consumer first contacts)
- 53. [FOR AAA DIRECTORS ONLY]: Do you identify your structure as any of the following:
 - □ Independent, non-profit
 - Part of city government
 - □ Part of COG or RPDA
 - □ Other
- 54. [FOR LOCAL LEVEL ADRC DIRECTORS ONLY]: What organizations comprise the core operating organizations?

Organization	Core Operating Organization? (Yes/No)
ААА	
State Unit on Aging	
Veterans Organization	
Alzheimer's Association	
Other Aging Services Organization	
Centers for Independent Living	
Vocational Rehabilitation Departments	
Other Disability Services Organization	
Community Mental Health	
County or Regional Council of Governments	
County Government Office or Agency	
Local Housing Authority	
State or Local Medicaid Agency	
211	
Other Human Services of Social Service Provider (please specify)	

Interviewer Initials (or ID) _____

Date_____

55. With which organizations do [insert ID] have a partnership? What is the strength of the relationship, as well as the type of partnership agreement and shared resources?

				Shared Resources
Organization	Partner* (Check all that apply)	Functionality of the partnership (1=Dysfunctional 2=Moderately functional/ functional in some areas 3=Highly functional	Partnership Agreement (Select from the following list: Funding relationship Formal MOU Contract Cooperative - Informal working relationship Other, please specify)	Select from the following list: Co-located staff Shared monetary resource Information sharing Joint training Joint sponsorship of programs Shared non-monetary resources (i.e. office space) Shared data No shared resources
Area Agency on Aging [row will not show for AAA respondents]				
State Unit on Aging				
Veterans Organization				
Alzheimer's Association				
Other Aging Services Organization				
Centers for Independent Living [row will not show for CIL respondents]				
Vocational Rehabilitation Departments				

Interviewer Initials (or ID)	Date_			
Organization	Partner* (Check all that apply)	Functionality of the partnership (1=Dysfunctional 2=Moderately functional/ functional in some areas 3=Highly functional	Partnership Agreement (Select from the following list: Funding relationship Formal MOU Contract Cooperative - Informal working relationship Other, please specify)	Shared Resources Select from the following list: Co-located staff Shared monetary resource Information sharing Joint training Joint sponsorship of programs Shared non-monetary resources (i.e. office space) No shared resources
AIDS Coalition				
American Council of the Blind				
Schools for the blind				
Deaf Service Centers				
Schools for the Deaf				
State Associations for the Deaf				
Easter Seals (All Disabilities)				
The ARC				
National Autism Association state/regional chapter				
Autism Society state/regional chapter				
Epilepsy Foundation state/regional chapter				

Interviewer Initials (or ID)	Date_			
Organization	Partner* (Check all that apply)	Functionality of the partnership (1=Dysfunctional 2=Moderately functional/ functional in some areas 3=Highly functional	Partnership Agreement (Select from the following list: Funding relationship Formal MOU Contract Cooperative - Informal working relationship Other, please specify)	Shared Resources Select from the following list: Co-located staff Shared monetary resource Information sharing Joint training Joint sponsorship of programs Shared non-monetary resources (i.e. office space) Shared data No shared resources
Easter Seals (All Disabilities)				
United Cerebral Palsy (UCP)				
National Multiple Sclerosis Society state/regional chapter				
National Association of Mental Illness (NAMI) state/regional chapter				
Brain Injury Association (BIA) state/regional chapter				
Community Mental Health				
County or Regional Council of Governments				
County Government Office or Agency				
Local Housing Authority				
State or Local Medicaid Agency				

Interviewer Initials (or ID)	Date_			
Organization	Partner* (Check all that apply)	Functionality of the partnership (1=Dysfunctional 2=Moderately functional/ functional in some areas 3=Highly functional	Partnership Agreement (Select from the following list: Funding relationship Formal MOU Contract Cooperative - Informal working relationship Other, please specify)	Shared Resources Select from the following list: Co-located staff Shared monetary resource Information sharing Joint training Joint sponsorship of programs Shared non-monetary resources (i.e. office space) No shared resources
211 Other Human Services of Social Service Provider (please specify)				
Hospital				
Religious institutions (e.g., church, synagogue, mosque, temple)				
Library				
Other, please specify				

Date_____

- 56. Approximately, how many FTEs (Full-time equivalents) perform each of the following functions?
 - I&R/I&A
 - Options counseling/counseling to provide in-depth person centered decision support
 - Benefits counseling/eligibility determination
 - Care transition services
 - Crisis intervention services
 - Independent Living services
 - Advocacy services
 - Providing administrative or other support for the above functions
- 57. [FOR STATE LEVEL ADRC DIRECTORS ONLY] At the State level, how many FTE are dedicated to working with the ADRC(s) in your State?
- 58. [FOR LOCAL LEVEL ADRC, CIL, AND AAA DIRECTORS ONLY]: How many front line staff are Alliance of Information and Referral Systems (AIRS) certified?
 - Number of AIRS certified staff
 - Total number of front line staff

Section E. LTSS Environment

- 59. Since this [insert ID] started serving consumers, has there been an impact on the LTSS or Home and Community-Based (HCBS) system in your community?
 - □ There has been an **increase in the** <u>**number**</u> of LTSS providers.
 - □ There has been a **decrease in the <u>number</u>** of LTSS providers.
 - □ There has been an **increase in the <u>quality</u>** of LTSS services.
 - There has been a **decrease in the <u>quality</u>** of LTTS services.

Please add any final thoughts about [insert ID] and either its operations and/or its results (Open response).

Date

PARTICIPANT EXPERIENCE SURVEY

INSTRUCTIONS TO ABT SRBI: PREPOPULATE (PP) INFORMATION FROM AGENCY ELIGIBILITY SCREENING (ES) AND DATA COLLECTION (DC) TOOLS. THESE PREPOPULATED DATA WILL BE USED THROUGHOUT THE SURVEY TO ORIENT THE RESPONDENT TO THEIR EXPERIENCE WITH THE AGENCY AT THE TIME OF THE CONTACT IN WHICH THEY WERE SCREENED FOR ELIGIBILITY FOR THE STUDY.

[ID Number – Footer ES/DC] [Agency Type – ES 2] □ ADRC [Need Spanish interpreter – DC 6] □ Yes □ No [Need TTY service - DC 7] □ Yes □ No [Preferred call time – DC 5] PP1. [Agency Name – ES 1] _____ PP2. [Respondent Type – ES 3] □ Self Parent □ Child □ Other relative □ Friend □ Neighbor □ Client/Patient Other: _____ DK

PARTICIPANT EXPERIENCE SURVEY

Interviewer Initials (or ID) _____ Date □ REF PP3. [Study Type – ES 5/ES 6] □ Older Adult (response to $5=\geq 60$) □ Disability (yes to any 6a-6f) PP4. [Result of Contact – ES 7] Options Counseling Benefits Eligibility Determination Information & Referral /Information & Assistance ______ □ Crisis intervention □ Independent living services Transition Assistance ______ PP5. [Date of Contact – DC 1] (month, date, year) __/__/__ PP6. [Reason for contacting the agency (client's need at time of the time of contact) – DC 8]

PP7. [Mode of Contact – DC 10]

- □ In-person (visit)
- □ Telephone (call)
- PP8. [Respondent Name DC 2]
- PP9. [Respondent Age ES 5]

Date

1. Introduction

"Hello, may I speak to ______ **[insert PP8]**? (**IF ASKED:** I am calling on behalf of the United States Administration on Aging about his/her satisfaction with a recent service experience.)

Hello, my name is [insert survey administrator name].

[IF INTRO TO AoA ABOVE IS READ, THEN READ]: I am calling to ask about the quality of your experience with the [insert PP1] on [insert pp5] about [REASON FOR CONTACT PP6].

[IF INTRO TO AoA ABOVE IS NOT READ]: I am calling on behalf of the United States Administration on Aging to ask about the quality of your experience with the **[insert PP1]** on **[insert pp5]**.

During that **[insert PP7]** you talked to staff about service needs for **[insert PP2]**. (At that time you said that you would be willing to participate in an interview about your experience). Can I ask you some questions about that experience? It will only take 20 minutes. Is now a good time for the interview about your experiences?

	Yes [If yes,	skip to	Statement	of Informed	Consent]
--	--------------	---------	-----------	-------------	----------

	No, this is a bad time	[Continue]
--	------------------------	------------

□ No, I don't remember calling agency [Terminate]

□ REF, no I don't want to do an interview **[Terminate]**

When would be a better time to call back to do the interview?

Gives call back time

If REF, can I ask why you are not interested in participating?

Thank you for your time [end the call].

Date_____

2. **Participant Experience Survey**

If you have any questions during the interview, please stop me and ask me. Also, please let me know if you do not understand a question or if you would like me to repeat it.

Section A. Initial Contact

The first set of questions has to do with the experiences that you had when you [insert PP7] the [insert PP1] on [insert PP5].

- 1. When you contacted the **[insert PP1]**, you said that the main reason for your **[insert PP7]** was **[insert PP6]**. Is that correct?
 - □ YES [If yes, skip to qA3, else continue to qA2]
 - □ NO
 - □ DK
 - \Box REF
- 2. I'm sorry; please tell me, what was the **main** reason that you contacted the **[insert PP1]** on **[insert PP5]**? **[RECORD RESPONSE AND CHECK APPRORIATE RESPONSE BELOW]**

- □ Peer support services/groups
- □ HCBS Medicaid Waiver Programs
- □ Caregiver Support (i.e. respite programs, support groups, or counseling)
- □ Nutrition Programs
- Employment services
- □ Education services
- Opportunities to develop advanced directives
- Transportation services
- Opportunities for socialization/recreation
- Mental health services
- Ombudsman services/Services related to abuse or neglect
- □ Health prevention and screening services
- □ Services for emergent cases/Crisis intervention
- □ Transition programs (from hospitals, nursing homes etc.)
- In Nursing home (institutional) diversion programs

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[□] Safe and affordable housing options

Date_____

- □ Nursing home/residential beds
- □ Income assistance
- □ Energy assistance
- □ Personal care services
- □ Independent Living services (e.g., home modification, attendant care)
- □ Independent Living Skills training
- □ Other
- 3. From where did you *first* find out about the [insert PP1]? [CHECK MOST APPROPRIATE RESPONSE]
 - □ Family member, friend or other acquaintance
 - □ Hospital/Clinic/Doctor
 - □ Nursing Home/Assisted Living
 - Phone Book
 - □ Brochure/Flyer
 - Referral from senior center
 - □ Referral from another agency/organization
 - □ Through work
 - □ Internet/Website
 - □ Media/Newspaper/TV/Radio
 - Other _____
- 4. Was [insert PP1] the first organization that you contacted about [insert PP6]?
 - □ Yes
 - \square No
 - □ DK
 - □ REF

Section B. Agency Efficiency

These next questions are about your experience during your contact with [insert PP1].

- 1. [ASK ONLY IF PP7 = IN-PERSON (VISIT); ELSE SKIP TO Qb2] When you contacted the [insert PP1], how long did you wait during the initial call to talk with someone who could help you with [insert PP6]?[DO NOT READ RESPONSES, PLEASE CHECK APPROPRIATE RESPONSE]
 - Minimal wait (less than five minutes)
 - □ Five to 10 minutes

Date

- □ 10 minutes to 20 minutes
- □ Over 20
- □ DK
- □ REF

[Following response, skip to qB4].

- 2. Were you able to talk to a representative during your first contact?
 - □ YES [If yes, skip to qB4, else continue to qB3]
 - \square NO
 - □ DK
 - □ REF
- Do you recall how many additional contacts (including calls where you left a message on a machine) you had to make before you were able to talk with a representative? [DO NOT READ RESPONSES]
 - □ None
 - □ One
 - □ Two
 - □ Three
 - □ Four or more
- 4. Including the contact that you made (the first time you talked with someone) with the [insert PP1] on [insert PP5], how many times have you had to describe your request for services, or explain what you needed? [DO NOT READ RESPONSES]
 - One time
 - Two times
 - □ Three or four times
 - □ Five or more times
- 5. Throughout your contact with **[insert PP1]** did any of the following circumstances reduce or prevent your ability to resolve your issue? **[CHECK ALL THAT APPLY]**
 - □ [insert PP1] hours of operations
 - Difficulty reaching [insert PP1] staff
 - □ Language issues
 - □ Staff professionalism
 - □ Staff knowledge
 - □ Staff follow through

Section C. Effectiveness of Agency Representative

- 1. Did you feel the representative at **[insert PP1]** paid close attention to what you were saying?
 - \Box YES
 - \Box NO
 - □ SOMEWHAT
 - □ DK
 - \Box REF
- 2. In your opinion, how knowledgeable was the representative at [insert PP1]? Were they...
 - □ Very knowledgeable
 - □ Somewhat knowledgeable
 - □ Not very knowledgeable
 - Not at all knowledgeable
 - □ DK
 - □ REF
- 3. Was the information you received from the representative at **[insert PP1]** clear and understandable?
 - Very clear and understandable
 - □ Somewhat clear and understandable
 - □ Not very clear or understandable
 - □ Not at all clear or understandable
 - □ DK
 - □ REF
- 4. Based on your request for [insert PES A2 if answered; else insert PP6] when you contacted [insert PP1], did the representative ask questions that made you feel that your needs were being correctly assessed?
 - □ YES
 - □ NO
 - □ DK
 - □ REF

- 5. If assistance was requested, did the representative at **[insert PP1]** work with you to develop an action plan outlining your next steps in meeting your long terms care needs?
 - □ YES [if yes go to C6; otherwise skip to D1]
 - □ NO
 - □ N/A
 - D DK
 - □ REF
- 6. Does the plan accurately reflect your needs and preferences?
 - □ Yes
 - \square No
 - □ Somewhat
 - □ N/A
 - □ DK
 - □ REF

Section D. Institutional Diversion

- 1. When you contacted the **[insert PP1]**, were you considering a move to a long-term care setting, such as a nursing home, for **[insert PP2]**?
 - \Box YES
 - \square NO
 - □ DK
- 2. Did the representative you talked to at the **[insert PP1]** on **[insert PP5]** help you to understand other choices in addition to a nursing home or other long-term care setting?
 - □ YES
 - \square NO
 - □ N/A
 - □ DK
 - □ REF

Interviewer Initials (or ID)

Date_____

3. On a scale from 0% to 100% [ASK IF PP9 IS < 65 YEARS OLD], what is the percent chance that you, or the person for whom you contacted the agency will ever have to move into a nursing home?

______ % PROMPT 0 10 20 30 40 50 60 70 80 90 100%

OR

[ASK IF PP9 AGE IS EQUAL TO OR GREATER THAN 65], what is the percent chance that you or the person for whom you contacted the agency will move into a nursing home in the next five years?

_____ % PROMPT 0 10 20 30 40 50 60 70 80 90 100%

Section E. Assistance with Services

From the next set of questions, we would like to learn about your experiences in obtaining the services for which you contacted the **[insert PP1]** on **[insert PP5]**.

- 1. Did you receive the service that you needed directly from them or indirectly by a referral to another agency?
 - Directly ([insert PP1] provided the service) [If selected, skip to Section E.1]
 - □ Indirectly (you were referred elsewhere)
 - □ Both/some services provided by [insert PP1] staff and some through referrals
 - □ DK
 - □ REF
- 2. Did the representative of the **[insert PP1]** help you to connect with the services you needed?

PROBE: TRANSFER YOUR CALL, PROVIDE A TELEPHONE NUMBER OR ADDRESS, OR SET UP A CALL BACK FROM AN AGENCY/ORGANIZATION.

- □ YES [If yes, continue to qE3; else skip to Section E1]
- \square NO
- □ DK
- □ REF
- 3. Did the representative of the **[insert PP1]** transfer your call to an agency/organization that provided you with your needed/requested services?
 - □ YES [If yes, skip to qE6; else, continue to qE4]
 - \square NO
 - □ DK
 - □ REF

- 4. Did the representative give you contact information (telephone number, address, web address) of an agency/organization that provided you with needed/requested services?
 - □ YES [If yes, skip to qE6; else continue to qE5]
 - □ NO
 - □ DK
 - □ REF
- 5. Did the representative contact the needed service provider and arrange for them to contact you?
 - □ YES [If yes, continue to qE6; else, skip to Section E.1]
 - \square NO
 - D DK
- 6. When you contacted the needed service provider, did that provider already have the information that you provided to **[insert PP1]** or did you have to start the process again?**[RECORD RESPONSE AND CHECK APPRORIATE RESPONSE BELOW]**
 - Provider had the information
 - Provider had the information but it wasn't correct or it was incomplete had to start the process again
 - □ Provider did not have the information had to start the process again
 - □ DK
 - \Box REF

PARTICIPANT EXPERIENCE SURVEY

Interviewer	Initials	(or ID))
interviewer	in incluing i		/

Date_____

- 7. To what supports and services were you transferred or referred?[RECORD RESPONSE AND CHECK APPRORIATE RESPONSE BELOW]
 - □ Safe and affordable housing options
 - □ Peer support services/groups
 - HCBS Medicaid Waiver Programs
 - □ Caregiver Support (i.e. respite programs, support groups, or counseling)
 - □ Nutrition Programs
 - Employment services
 - □ Education services
 - Opportunities to develop advanced directives
 - □ Transportation services
 - □ Opportunities for socialization/recreation
 - □ Mental health services
 - $\hfill\square$ Ombudsman services/Services related to abuse or neglect
 - □ Health prevention and screening services
 - □ Services for emergent cases/Crisis intervention
 - □ Transition programs (from hospitals, nursing homes etc.)
 - □ Nursing home (institutional) diversion programs
 - Nursing home/residential beds
 - □ Income assistance
 - □ Energy assistance
 - □ Personal care services
 - □ Medicaid waiver assistance
 - □ Independent Living services (e.g., skills training, peer support)
 - Other _____
 - □ None
 - □ DK
 - □ REF

Interviewer Initials (or ID) _____

Date_____

- 8. What was the result of the referral?[READ FROM THE FOLLOWING LIST AND CHECK THE MOST APPROPRIATE RESPONSE]
 - □ [insert PP2] received services [If selected, skip to Section E.1]
 - □ [insert PP2] DID NOT receive services
 - □ It's too soon to tell [If selected, skip to Section E.1]
- 9. You said that **[insert PP2]** did not receive the services through the referral, why do you think that is? **[RECORD RESPONSE AND CHECK APPRORIATE RESPONSE(S) BELOW]**
 - □ The services were not what [insert PP2] wanted/needed
 - □ The service/program is not accepting applications/there is a waitlist
 - □ It is too expensive
 - □ There is no transportation
 - □ The service or program is not available at times needed
 - □ [insert PP2] is not eligible
 - □ I tried to contact the service or program that was referred, but was busy/unavailable
 - □ Line was busy
 - □ Wait time too long
 - Other _____
 - □ Have not yet contacted, but plan to
 - □ Have no plans to contact the service or program
 - Please Specify reason ______
 - □ DK
 - □ REF

Section E.1. Assistance with Medicaid Eligibility Determination

The next set of questions has to do with information and help that you may have received from the **[insert PP1]** on whether or not you are eligible for **[insert name of state Medicaid program]**.

[IF RESPONDENT SAYS THAT THEY ALREADY RECEIVE MEDICAID BENEFITS OR THAT THEY DID NOT TALK ABOUT THIS WITH THE AGENCY REPRESENTATIVE, THEN SKIP TO SECTION E.2].

- 1. Did you receive specific information on applying for [insert name of state Medicaid program]?
 - □ YES
 - □ NO [If no, skip E.1.5; else continue to E.1.2]
 - □ DK
 - \square REF

Interviewer	Initials	(or	ID)	
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- 2. Did you complete a [insert name of state Medicaid program] application through the [insert PP1]?
 - □ YES [If yes, continue to qE1.3; else skip to Section E1.4].
 - □ NO
 - □ DK
 - □ REF

If no, please explain why _____

- 3. Were you provided with help by the agency in completing the **[insert name of state Medicaid program]** application?
 - \Box YES
 - □ NO
 - □ DK
 - □ REF
- 4. How long did you wait to find out if you qualified for [insert name of state Medicaid program]? [DO NOT READ RESPONSES, CHECK APPRORIATE RESPONSE]
 - □ One day or less
 - Two to six days
 - One week
 - □ More than one week, but less than a month
 - Over a month
 - □ Still waiting
 - □ DK
 - □ REF
- 5. Were you given information by the agency about other insurance resources besides [insert name of state Medicaid program]?
 - \Box YES
 - \Box NO
 - □ DK
 - □ REF

If yes,	please specify	
,,		

Section E.2. Assistance with One-on-One Options Counseling

- 1. Did you request, need, or accept a conversation with a counselor (e.g., one-on-one counselor, case management), in other words, someone to talk with about understanding and selecting the long-term services (beyond information and referral)?
 - \Box YES
 - **NO** [If no, skip to Section E3; else continue to qE.2.2]
 - □ DK
 - □ REF
- 2. Did the counselor (e.g., one-on-one counselor, case manager) visit you in your home?
 - \Box YES
 - \square NO
 - □ DK
- 3. Following the first meeting, did the counselor (e.g., one-on-one counselor, case manager) follow-up with you either by phone calls and/or additional in-home visits?
 - \Box YES
 - \Box NO
 - □ DK
 - □ REF
- 4. Did the information and support that the counselor (e.g., one-on-one counselor, case manager)gave you help you to:

	Yes,	Yes,	No,	No,	
	definitely	probably	probably not	definitely not	n/a
a. Better understand your long term service and support options?					
b. Make a decision about long-term support services?					
c. Access (i.e., streamline) public programs?					
d. Access private services including services that you have to pay for yourself?					
e. Obtain long-term support planning or services that fit within your budget?					

Interviewer Initials (or ID)

Date_____

- 5. How satisfied or dissatisfied are you with the service you received from the counselor (e.g., one-on-one counselor, case manager)?
 - Very satisfied
 - Somewhat satisfied
 - Somewhat dissatisfied
 - Very dissatisfied

Section E3. Care Transition Services

- 1. Did you receive services that helped you to transition from a hospital or other acute care facility into the community?
 - □ YES
 - **NO** [If no, skip to Section F; else continue to qE3.2]
 - □ DK
- 2. Did you receive any of the following services?
 - A contact before discharge to assess your discharge needs
 - □ An explanation of your discharge instructions
 - Post discharge services such as transportation to the doctor, help filling prescriptions, household help
 - □ Follow up within 48 hours of discharge
- 3. How satisfied or dissatisfied are you with the transition service you received?
 - □ Very satisfied
 - $\hfill\square$ Somewhat satisfied
 - □ Somewhat dissatisfied
 - □ Very dissatisfied

Section F. Services Received from the [insert PP1]

Now I'd like to ask you some questions about the overall results of your contact with [insert PP1].

- 1. Did you ever receive the service that you were seeking based on your contact with [insert PP1]?
 - □ YES, within one week of contact
 - □ YES, after more than a week
 - □ NO [If no continue to qF2; else, skip to qF3]
 - □ DK
 - □ REF
- 2. Why do you think you have not received the services?[READ FROM THE FOLLOWING LIST, STOP AT THE FIRST YES RESPONSE AND CHECK THAT RESPONSE]
 - □ The services are not available.
 - □ [insert PP2] is on a waitlist.
 - □ I could not get to the services (e.g., hours of operation, transportation barriers)
 - □ The information/help received from **[insert PP1]** was not useful.
 - □ I did not follow-up on the information and/or referral.
 - □ I no longer need the services.
 - Other
- 3. Since contacting the [insert PP1] on [insert PP5], have you been in touch with any other agencies similar to [insert PP1] to receive [insert PES A2 if answered; else insert PP6]?
 - □ YES [If yes, continue to qF4; else, skip to qF5]
 - □ NO
 - □ DK
 - □ REF

If yes, please specify name of agency/organization ______

- 4. Were there any needs that this agency/organization [identified above in qF3] was able to meet that the [insert PP1] was NOT able to meet?
 - YES [If yes, please specify need(s) _____]
 - □ NO
 - □ DK
 - □ REF

Interviewer Initials (or ID) _____

Date_____

- 5. As a result of your conversations with **[insert PP1]** staff, did **YOU** realize that you had a need or concern that you did not know that you had before contacting the **[insert PP1]**?
 - □ YES
 - □ NO
 - □ DK
 - □ REF
- 6. Did the **[insert PP1]** follow up with you to find out how useful the information was or how the referral(s) turned out?
 - □ YES
 - □ NO
 - □ DK
 - \Box REF
- 7. On the following scale, as a result of your contact with **[insert PP1]**, how satisfied are you with...

	Very satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied
a. The services that you received directly from [insert PP1]?				
[If somewhat or very dissatisfied] please explain why				
b. The services that you received from agencies you were referred to by [insert PP1]?				
If somewhat or very dissatisfied, please explain why				
c. Comprehensiveness of the information or services provided?				
If somewhat or very dissatisfied, please explain why				
d. The personalization/individualization of the services offered?				
If somewhat or very dissatisfied, please explain why				
e. The accuracy of the information provided?				
If somewhat or very dissatisfied, please explain why				
f. The support you received related to decision-making?				
If somewhat or very dissatisfied, please explain why				

PARTICIPANT EXPERIENCE SURVEY

Interviewer Initials (or ID) _____

Date_____

	Very satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied
g. The professionalism of the organization/staff?				
If somewhat or very dissatisfied, please explain why				
h. How easy it was to work with [insert PP1] to resolve my issue related to [insert PP6]?				
If somewhat or very dissatisfied, please explain why				

- 8. As a result of your contact with the **[insert PP1]**, would you say that you are.....
 - Much better informed about your long term care options
 - □ A little better informed
 - □ About the same
 - A little more confused
 - $\ \ \, \square \quad Much more confused$
 - □ DK
 - □ REF
- 9. To what degree has the information you received from **[insert PP1]** been useful to you as you select the long term care options that are best for you?
 - □ Very useful
 - Somewhat useful
 - Not useful
 - □ DK
 - □ REF
- 10. Would you tell a friend or relative who needed help to contact the [insert PP1]?
 - \Box YES
 - \square NO
 - □ DK
 - □ REF
- 11. How likely is it that you would contact the [insert PP1] for services in the future?
 - □ Very likely
 - Somewhat likely
 - □ Somewhat unlikely
 - □ Very unlikely

Interviewer Initials (or ID) _____

Date_____

Section G. Heath and Demographic Information

In the next set of questions we would like to learn a little about your health and health insurance.

1. Do you have any of the following types of health insurance? [Record all that apply]

	NO	YES	Don't Know
Medicare			
[insert name of state Medicaid agency]			
Private Health Insurance			
Other, please specify			
Uninsured			

- 2. At the present time, would you say your health is excellent, good, fair, or poor?
 - □ Excellent
 - \Box Good
 - □ Fair
 - □ Poor
 - □ Refused to answer
 - Don't know
- 3. Have you been admitted to a hospital in the past 6 months?
 - Yes
 - □ No
 - □ Refused to answer
 - Don't know
- 4. As part of this study, we would like to follow up on your use of health care over the next few years. To do this we would like to obtain the last four digits of your social security number. We assure you that we will keep this number safe and confidential.
 - □ SS # _____

Interviewer Initials (or ID) _____

Date_____

The last set of questions will tell us a little more about you. This information is to describe the group of persons included in the study and will not be used to identify you as an individual. We will use this information to determine whether not the **[insert PP1]** and other similar agencies are reaching all members of the community.

5. [Ask only if PP2= SELF, else go to 6. What is your date of birth?

month/day/year [After response, go to qG7.

- 6. What is the date of birth of the person for whom you contacted the agency?
- 7. What is your gender?
 - □ Male
 - Female
 - □ DK
 - □ REF
- 8. What is the highest grade or year of school you have completed?
 - No formal schooling
 - □ First through 7th grade
 - □ 8th grade
 - □ Some high school
 - □ High school graduate
 - □ Some college
 - □ Associates degree
 - □ Four-year college graduate
 - □ Some graduate school
 - □ Graduate and professional degrees
 - □ (VOL) REF

- 9. Which of the following racial categories describes you? You may select more than one. **READ LIST AND MULTIPLE RECORD**
 - American Indian or Alaska Native
 - Asian
 - Black or African-American
 - □ Hispanic/Latino
 - Native Hawaiian or Other Pacific Islander
 - □ White
 - □ (VOL) Other (SPECIFY)
 - □ (VOL) Refused
- 10. What was your total household income before taxes in 2011? Your best estimate is fine. [CHECK APPROPRIATE RESPONSE]
 - □ Less than \$5,000
 - □ \$5,000 to \$14,999
 - □ \$15,000 to \$29,999
 - □ \$30,000 to \$49,999
 - □ \$50,000 to \$74,999
 - □ \$75,000 to \$99,999
 - □ \$100,000 or more
 - □ (VOL) Not sure
 - □ (VOL) Refused
- 11. What is you marital status? Are you
 - D Married
 - $\ \ \, \square \quad Widowed$
 - Divorced
 - Separated
 - □ Single, never married
- 12. With whom, if anyone, do you live? [READ LIST; SELECT ONE]
 - □ Alone
 - □ With a spouse
 - □ With one or more other family members
 - □ With one or more friends/people who are not related to me

- 13. Of the following choices, which one most closely describes your living situation? Do you live in...... [READ LIST, COULD BE MORE THAN ONE RESPONSE]
 - My own house or apartment (e.g., free-standing, row house, town house, apartment, etc.)
 - Non-medical custodial housing (e.g., group home, congregate house, half-way house, safe-house, recovery house, board and care house, other residential non-medical adult care facility)
 - □ In an assisted living setting [if yes, skip to qG15]
 - □ In a nursing home
 - □ In a continuing care retirement setting
 - Other [If other, please specify] ______
- 14. Have you ever lived in an assisted living setting?
 - □ Yes
 - □ No
 - □ (VOL) DK
 - □ (VOL) REF

If yes, how long did you live there? ____/__ (months/years)

- 15. Have you ever lived in a nursing home?
 - □ Yes
 - □ No
 - □ (VOL) DK
 - □ (VOL) REF

If yes, how long did you live there? ____ (months/years)

THANK YOU VERY MUCH FOR TAKING THE TIME TO SHARE YOUR EXPERIENCES OF SEEKING INFORMATION ABOUT SERVICES IN YOUR COMMUNITY. IT IS OUR HOPE THAT THE INFORMATION THAT YOU PROVIDED WILL HELP IMPROVE THE ACCESSIBILITY AND QUALITY OF SERVICES IN YOUR COMMUNITY.

I just want to confirm that you consent to our sharing your name, contact information, and Social Security number (if provided) with the Administration on Aging for possible inclusion in a future study about the health care usage of individuals seeking long term services or support. Participation in that study would not involve further contact or any more of your time.

- □ Yes
- □ No

[If no, assure participant that these data will not be provided to AoA.]

COMPLETE THIS FORM AND BE SURE THAT IT IS ATTACHED TO PART 2 AND PART 3. RETURN PARTS 1, 2, AND 3 TO RESEARCH TEAM IN PRE-PAID ENVELOPE. (NOTE – MAILING INSTRUCTIONS WILL BE INCUDED ONLY ON THE PAPER COPY OF THESE DOCUMENTS).

CLIENT SCREENING TOOL

INSTRUCTIONS FOR COMPLETING THIS FORM:

THROUGHOUT THIS DOCUMENT, CLIENT REFERS TO THE PERSON WHO IS MAKING CONTACT WITH YOUR AGENCY. CONSUMER IS THE PERSON FOR WHOM THE LTSS ARE INTENDED.

SOME SCREENING QUESTIONS ARE PREPOPULATED, AND OTHERS MAY BE ANSWERED DURING THE COURSE OF THE ROUTINE DISCUSSION WITH THE CLIENT.

QUESTIONS 1 AND 2 WILL BE PREPOPULATED BY THE RESEARCH TEAM.

QUESTIONS 3-7 SHOULD BE ASKED IF NOT ANSWERED DURING THE ROUTINE CLIENT DISCUSSION.

QUESTIONS 8 AND 9 SHOULD BE FILLED IN BY THE AGENCY

- 1. Agency Name _____ [WILL BE PREPOPULATED BY RESEARCH TEAM]
- 2. Agency Type [WILL BE PREPOPULATED BY RESEACH TEAM]
 - □ ADRC
 - □ AAA
 - CIL
- 3. ASK: "For whom did you contact the agency?"
 - □ Self
 - Parent
 - □ Child
 - □ Other relative
 - □ Friend
 - □ Neighbor
 - □ Client/Patient*
 - Other:

COMPLETE THIS FORM AND BE SURE THAT IT IS ATTACHED TO PART 2 AND PART 3. RETURN PARTS 1, 2, AND 3 TO RESEARCH TEAM IN PRE-PAID ENVELOPE. (NOTE – MAILING INSTRUCTIONS WILL BE INCUDED ONLY ON THE PAPER COPY OF THESE DOCUMENTS).

> □ DK □ REF

IF DK OR REF, CLIENT IS INELIGIBLE FOR THE STUDY. DISCONTINUE SCREENER.

*IF SELF ASK: "Do you have a legal guardian?"

Yes No

IF YES TO LEGAL GUARDIAN, CLIENT IS INELIGIBLE FOR THE STUDY. DISCONTINUE SCREENER.

*IF CLIENT/PATIENT ASK: "Are you a professional caregiver such as a physician, hospital discharge planner, nursing home staff?"

Yes No

IF YES TO PROFESSIONAL CAREGIVER, CLIENT IS INELIGIBLE FOR THE STUDY. DISCONTINUE SCREENER.

[RESPONSE TO THE FOLLOWING QUESTION SHOULD BE MADE FOR THE PERSON IDENTIFIED IN QUESTON 3 ABOVE]

4. Are you proficient in English or Spanish?

Yes No

IF NO, DISCONTINUE SCREENER.

5. ASK," What is your age (OR THE AGE OF THE PERSON FOR WHOM CONTACT WAS MADE, IF NOT SELF)"?

_____Years

PROBE IF UNABLE TO REMEMBER AGE: DO YOU RECALL THE YEAR OF BIRTH?

COMPLETE THIS FORM AND BE SURE THAT IT IS ATTACHED TO PART 2 AND PART 3. RETURN PARTS 1, 2, AND 3 TO RESEARCH TEAM IN PRE-PAID ENVELOPE. (NOTE – MAILING INSTRUCTIONS WILL BE INCUDED ONLY ON THE PAPER COPY OF THESE DOCUMENTS).

[RESPONSE TO THE FOLLOWING QUESTION SHOULD BE MADE FOR THE PERSON IDENTIFIED IN ITEM #3 ABOVE]

 6. IF THE FOLLOWING INFORMATION IS NOT NORMALLY COLLECTED BY YOUR AGENCY, PLEASE READ THE FOLLOWING TO THE CONSUMER: "I'd like to ask you a few additional questions to see if you are eligible to participate in a satisfaction survey. Is it okay if I ask these questions?" Yes No

IF NO, DISCONTINUE SCREENER.

- 7. ASK, "Do you (OR THE PERSON FOR WHOM CONTACT WAS MADE, IF NOT SELF) have a disability...."
 - a. Are you deaf or do you have serious difficulty hearing?
 - □ Yes
 - □ No
 - D DK
 - □ REF
 - b. Are you blind or do you have serious difficulty seeing, even when wearing glasses?
 - \Box Yes
 - □ No
 - D DK
 - □ REF
 - c. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?
 - □ Yes
 - □ No
 - □ DK
 - □ REF
 - d. Do you have serious difficulty walking or climbing stairs?
 - □ Yes
 - □ No
 - D DK
 - □ REF
 - e. Do you have difficulty dressing or bathing?

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COMPLETE THIS FORM AND BE SURE THAT IT IS ATTACHED TO PART 2 AND PART 3. RETURN PARTS 1, 2, AND 3 TO RESEARCH TEAM IN PRE-PAID ENVELOPE. (NOTE – MAILING INSTRUCTIONS WILL BE INCUDED ONLY ON THE PAPER COPY OF THESE DOCUMENTS).

- □ Yes
- \square No
- D DK
- \Box REF
- f. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?
 - \Box Yes
 - \square No
 - \Box DK
 - \Box REF
- g. Do you have a physical, mental, or emotional condition that otherwise significantly disrupts your life?
 - \Box Yes
 - \square No
 - D DK
 - \Box REF

IF AGE IS LESS THAN 60 <u>AND</u> NO TO ALL ITEMS IN QUESTION 5, PARTICIPANT IS INELIGIBLE FOR THE STUDY. DISCONTINUE SCREENING.

INSTRUCTIONS: QUESTIONS 8 AND 9 SHOULD BE ANSWERED BY AGENCY BASED ON OBSERVATIONS OF THE CLIENT.

- 8. As a result of this contact, did/will the client (OR THE RECIPIENT OF LTSS) receive any of the following services?
 - Yes No
 - a.
 Information Assistance and/or Referral(s) (not including options counseling)
 - b. D Options Counseling or Peer Support/Peer Counseling
 - c.
 Benefits Counseling or Eligibility Determination
 - d.
 - e.
 Crisis intervention
 - f.
 Life skills training or support

IF NO TO <u>ALL</u> RESPONSES IN 8 ABOVE, CLIENT IS INELIGIBLE FOR THE STUDY. DISCONTINUE SCREENING.

COMPLETE THIS FORM AND BE SURE THAT IT IS ATTACHED TO PART 2 AND PART 3. RETURN PARTS 1, 2, AND 3 TO RESEARCH TEAM IN PRE-PAID ENVELOPE. (NOTE – MAILING INSTRUCTIONS WILL BE INCUDED ONLY ON THE PAPER COPY OF THESE DOCUMENTS).

NOTE SERVICES RECEIVED OR CLIENT REQUEST

9. Based on your observation, does the client have any apparent physical, cognitive, or mental conditions that would prevent him/her from making an informed decision about taking part in this study and /or participating in a 15-20 minutes telephone survey? Yes No

IF YES TO ITEM 8, CLIENT IS INELIGIBLE FOR THE STUDY.

IF NO, CONTINUE TO SECTION 2. STUDY DESCRIPTION/AGREEMENT TO PARTICIPATE.

For questions regarding how to use the screening tool or complete the form, please contact the project Co-Principal Investigator, Rosanna Bertrand or team member, Louisa Buatti:

Rosanna Bertrand, Ph.D. Abt Associates Inc. (617) 349-2556 Rosanna_Bertrand@ abtassoc.com Louisa Buatti Abt Associates Inc. (301) 634-1711 Louisa_Buatti@abtassoc.com

PART 2. STUDY DESCRIPTION/AGREEMENT TO PARTICIPATE

COMPLETE THIS FORM AND BE SURE THAT IT IS ATTACHED TO PART 2 AND PART 3. RETURN PARTS 1, 2, AND 3 TO ABT SRBI IN PRE-PAID ENVELOPE. (NOTE – MAILING INSTRUCTIONS WILL BE INCUDED ONLY ON THE PAPER COPY OF THESE DOCUMENTS).

STUDY DESCRIPTION/AGREEMENT TO PARTICIPATE

INSTRUCTIONS: READ THE FOLLOWING STATEMENT TO EACH PERSON WHO IS ELIGIBLE TO PARTICIPATE IN THE STUDY.

The Administration on Aging has contracted with IMPAQ International and Abt Associates, to conduct a study about the experiences of people like you in obtaining community-based support and services. Your opinion is very important, which is why you are being invited to participate in a 15 to 20 minute survey which will ask you about your experiences today. If you agree, someone from Abt SRBI, the company conducting the survey, will contact you by telephone within the next month to tell you more about the study and confirm whether or not you want to participate.

Right now, I am asking your permission to share some information about you with Abt SRBI so that they can call you about participating in the survey. With your permission, I would like to share your name, phone number, the reason you contacted us today, and a few other pieces of information such as information about possible disabilities. Your name or other identifying information will be used only to contact you and will not be stored in the same data file with your responses to the survey or used in any written materials generated in this study. Your decision will not affect your relationship with this agency nor your eligibility to receive their services.

May I share this information so that Abt SRBI can contact you for participation in the survey?"

Yes No

IF NO, SAY "Thank you for your consideration."

IF YES, SAY "Thank you" AND CONTINUE TO PART 3. DATA COLLECTION TOOL

3. DATA COLLECTION TOOL

COMPLETE THIS FORM AND BE SURE THAT IT IS ATTACHED TO PART 2 AND PART 3. RETURN PARTS 1, 2, AND 3 TO ABT SRBI IN PRE-PAID ENVELOPE. (NOTE – MAILING INSTRUCTIONS WILL BE INCUDED ONLY ON THE PAPER COPY OF THESE DOCUMENTS).

CONTACT INFORMATION DATA COLLECTION TOOL

INSTRUCTIONS:

COMPLETE THE INFORMATION BELOW <u>FOR EACH PERSON</u> WHO AGREED TO SHARE CONTACT INFORMATION WITH THE RESEARCH TEAM IN ORDER TO RECEIVE A FOLLOW-UP CALL TO PARTICIPATE IN A TELEPHONE SURVEY.

THROUGHOUT THIS DOCUMENT, THE CLIENT REFERS TO THE PERSON WHO CONTACTED THE AGENCY.

1. Date of Contact with Agency (month, date, year) __/_/__

- 2. ASK: What is your name (First, Middle, Last) _____, ____,
- 3. ASK: "What is the best phone number where you can be reached by the research team?"

Client Phone number (___)__--

4. ASK: "What is the best time for someone to call you about participating in the study?"

Preferred time to call __:__ AM PM Preferred day to call?

- 5. ASK: "Would you like assistance from a Spanish interpreter when the research team calls you to discuss the study?"
 - □ No
 - 2 Yes
- 6. ASK: "Would you like to use TTY service for the study?"
 - □ No
 - 2 Yes

[ID# _____ES (will be pre-filled)]

[Agency Name ______ (will be pre-filled)]

3. DATA COLLECTION TOOL

COMPLETE THIS FORM AND BE SURE THAT IT IS ATTACHED TO PART 2 AND PART 3. RETURN PARTS 1, 2, AND 3 TO ABT SRBI IN PRE-PAID ENVELOPE. (NOTE – MAILING INSTRUCTIONS WILL BE INCUDED ONLY ON THE PAPER COPY OF THESE DOCUMENTS).

ASK: "What was the main reason that you contacted us today?"

- \Box Income assistance
- □ Energy assistance
- \Box Medicare questions
- □ Medicaid questions (including about HCBC waivers)
- □Housing
- □ Personal care
- □ Transportation
- □Nutrition
- \Box Chronic health conditions
- \Box Employment
- □ Support groups
- \Box Recreation opportunities
- □ Caregiver/respite support
- \Box Home modification
- □ Attendant care services
- \Box Advocacy
- Education
- □ Services for emergent cares/crisis intervention
- \Box Preventative health services
- □ Ombudsman/abuse or neglect issues
- \Box Advanced directives
- □ Mental health
- \Box Transition services
- □ Other Independent living supports or services
- \Box Other, please specify
- 7. ASK: "Is this the first time you contacted this agency?"
 - First time contact
 - Repeat contact

QUESTIONS 9-11 SHOULD BE ANSWERED BY THE AGENCY.

- 8. Mode of Contact with Agency
 - □ Visited
 - □ Telephoned

9. IF THE CLIENT STOPPED THE QUESTIONNAIRE BEFORE COMPLETING IT, PLEASE SELECT THE BEST/MOST LIKELY REASON FOR STOPPING:

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3. DATA COLLECTION TOOL

COMPLETE THIS FORM AND BE SURE THAT IT IS ATTACHED TO PART 2 AND PART 3. RETURN PARTS 1, 2, AND 3 TO ABT SRBI IN PRE-PAID ENVELOPE. (NOTE – MAILING INSTRUCTIONS WILL BE INCUDED ONLY ON THE PAPER COPY OF THESE DOCUMENTS).

[ID# _____ES (will be pre-filled)] [Agency Name ______ (will be pre-filled)]

- \Box Client refused to answer
- □ Client's cognitive abilities prevented completion of questionnaire
- □ Client's physical condition prevented completion of the questionnaire
- □ Client's emotional condition prevented completion of the questionnaire
- □ Other, please explain _____
- 10. The signature of the person who administered this questionnaire indicates that he/she has read the above statement to the consumer/consumer representative and that the person has agreed to have his/her personal information released to Abt SRBI for the purpose of the evaluation.

Name_____ Date_____

For questions regarding how to use the screening tool or complete the data collection tool, please contact the project Co-Principal Investigator, Rosanna Bertrand or team member, Louisa Buatti:

Rosanna Bertrand, Ph.D. Abt Associates Inc. (617) 349-2556 Rosanna_Bertrand@ abtassoc.com

Louisa Buatti Abt Associates Inc. (301) 634-1711 Louisa_Buatti@abtassoc.com

[ID# _____ES (will be pre-filled)]

[Agency Name ______ (will be pre-filled)]

PROCESS EVALUATION SURVEY STATEMENT OF INFORMED CONSENT

[The process evaluation survey is intended to be administered as an online survey and the statement of informed consent will appear on page one. Respondents will have received an email invitation prior to opening the survey that will describe the study and provide instructions and a link to the survey.]

Statement of Informed Consent

This online survey funded by the Administration on Aging is part of a larger evaluation project measuring the effect of integrated systems on long-term care service delivery. It is designed to help the Administration on Aging: (1) gain an understanding of long term care support and service programs from State and local perspectives, (2) inform the analysis of consumer outcomes, and (3) collect information that will guide recommendations for continuous quality improvement for the long term service and support field in general and the Aging and Disability Resource Center initiative specifically. Program information collected through this survey will be shared with AoA, however, no direct quotes or individual responses will be attributed to particular respondents or organizations. Your participation in this survey is voluntary and you can refuse to answer any question. No penalty or loss of program benefits or resources will result from refusal to participate. We expect this survey to take approximately one hour to complete; however, it could take longer if it is necessary to collect data from other sources.

If you have questions about this survey you may contact Daver Kahvecioglu, Project Director at IMPAQ International, LLC at (443) 367-0088 ext. 2223, For questions about your rights as a participant in this study, please call Teresa Doksum, Abt Associates Inc. Institutional Review Board Chair, at (617) 349-2896

By completing and submitting this online survey, you are agreeing to the terms stated in this informed consent.

PARTICIPANT EXPERIENCE SURVEY STATEMENT OF INFORMED CONSENT

I will read to you a statement of informed consent that will provide you with information about the survey and inform you of your rights as a survey respondent. The Administration on Aging is sponsoring a national evaluation of the accessibility of community long-term support services. You are receiving this call because you contacted the [name of agency] on [insert date] and gave your permission for a research team to contact you to participate in a brief telephone survey about your experience. The survey is being conducted by Abt SRBI on behalf of the Administration on Aging. Your input about your experiences in obtaining community-based support and services is important to us. Your participation in this 15 – 20 minute survey is completely voluntary and you may choose to discontinue the interview at any time, for any reason.

We will combine the information that we gather from all participants (about 6000), and include the findings in a report that will be prepared for the Administration on Aging for the purpose of improving its services. Your name or any other identifying information will not be used in any report generated in this study. Your confidentiality will be protected to the extent provided by law. There will be no direct benefit to you from participating in the evaluation, nor will your or your family's services be impacted in any way by your responses to this survey. The information you provide will help the Administration on Aging improve its services for both older Americans and individuals with disabilities.

LETTER OF SUPPORT FROM THE ADMINISTRATION ON AGING FOR ORGANIZATIONS PARTICIPATING IN THE PROCESS EVALUATION

Dear [RESPONDENT NAME],

The Administration on Aging (AoA) had contracted IMPAQ International LLC and Abt Associates Inc., to evaluate the Aging and Disability Resource Center (ADRC) Grant Program. The overall purpose of the evaluation is to gather a range of program and consumer information to help AoA better understand how to best support the delivery of long-term services and supports (LTSS). The study will consider the effectiveness of different approaches to the provision of long-term care services and supports from the organizational and individual perspectives. We are writing to encourage you to participate in this study by completing an online survey about the general operational processes of your [ADRC, AAA or CIL].

This online organizational-level survey is designed to (1) provide an understanding of long term care support and service programs from State and local perspectives, (2) inform the analysis of consumer outcomes, and (3) collect information that will guide recommendations for continuous quality improvement for the long term service and support field in general, and the Aging and Disability Resource Center initiative specifically. Program information collected through this survey will be shared with AoA, however, no direct quotes or individual responses will be attributed to particular respondents or organizations. Your participation in this survey is voluntary. **[For respondents who also respond to the SART:** In order to reduce the burden to you, this data collection replaces part of your semi-annual Reporting Tool (SART) reporting requirement. There will be several questions that ask you to confirm existing data from your organization, reported through previous SART submissions.]

We ask that you participate in this survey and provide us with honest feedback about your program so that we can better understand how services are actually provided and gain needed insight into the consumer experience.

We expect this survey to take approximately one hour to complete; however, it could take longer if it is necessary for you to consult with other staff or program records.

If you have any questions about your participation in this evaluation, please e-mail the AoA Project Officer for this project Susan Jenkins at Susan.Jenkins@AoA.HHS.gov.

Thank you in advance for your support of this effort,

PROCESS EVALUATION SURVEY INVITATION FOR SITE DIRECTORS/MANAGERS OR OTHER STAFF

Your organization has been selected to participate in an online survey sponsored by the Administration on Aging as part of a larger evaluation to help AoA better understand how to best support the delivery of long-term services and supports (LTSS). The study considers the effectiveness of different approaches to the provision of long-term care services and supports from the organizational and consumer perspectives.

This survey is designed to collect information about your program including program goals, daily operations, partnerships, and the availability of services in your community. Your opinions and experiences are extremely important. The information that you and others provide will be aggregated and used to make improvements to current and future Administration on Aging grant programs. The data will be used to (1) provide an improved understanding of long term care service and support programs from the State and local perspectives, (2) inform the analysis of consumer-level outcomes, and (3) guide recommendations for continuous quality improvement for the long term service and support field in general, and the Aging and Disability Resource Center initiative specifically.

Your responses will be held in confidence and will only be used in combination with those of other respondents; neither you nor your organization or network will be individually identified when the data are shared with Administration on Aging, staff within your organization, or any other agency except as required by law.

Once you have accessed the survey, proceed through it by clicking on the navigation buttons. You will be able to exit and return to the survey at any time between [month day, 2012] and [month day, 2012]. The program will automatically bring you back to the last page on which you were working. Use the "Back" navigation button to review and/or edit earlier responses.

Please note that the dial found in the lower left corner on each page of the survey is an indication of your progress toward completion of the survey.

Thank you in advance for your support!

Susan Jenkins, PhD, Social Science Analyst Office of Performance and Evaluation US Administration on Aging, US Department of Health and Human Services Washington, DC 20201 Telephone-202.357.3591; Fax-202.357.3549; E-mail- <u>Susan.Jenkins@AoA.HHS.Gov</u>

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LETTER OF SUPPORT FROM THE ADMINISTRATION ON AGING TO POTENTIAL ORGANIZATIONS SELECTED FOR THE OUTCOME EVALUATION

Dear [DIRECTOR NAME],

The Administration on Aging (AoA) had contracted IMPAQ International, LLC and Abt Associates Inc., to evaluate the Aging and Disability Resource Center (ADRC) Grant Program. The overall purpose of the evaluation is to gather a range of program and consumer information to help AoA better understand how to best support the delivery of long-term services and supports (LTSS). The study will consider the effectiveness of different approaches to the provision of long-term care services and supports from the organizational and individual perspectives. We are contacting your organization to ask you to participate in the consumer-level data collection effort. The data supplied by your organization or network and its consumers will be combined with data from other organizations or networks to determine which approaches to service provision work best for different types of consumers and under what circumstances.

[ORGANIZATION NAME] has been selected to participate in the study based on its geographic location and other community-level attributes. We are asking for assistance from the I&R / I&A specialists in your organization or network to screen and recruit consumers to participate in a survey to be administered by the research team. We expect that screening and recruiting participants will take less than five minutes and can be done during the course of routine interaction with consumers. In fact, much of the needed information is likely already collected by your staff. Training and ongoing support will be provided to I&R/ I&A specialists by the researchers. To provide you with more information, we have included a one-page fact sheet about the evaluation with this letter.

In approximately one week, you will receive a phone call from the evaluators at Abt Associates who will provide you with more information concerning the study and formally request your organization's participation.

If you have any questions about your participation in this evaluation, please email Susan Jenkins at Susan.Jenkins@AoA.HHS.GOV.

Thank you for your participation,

ADRC EVALUTION FACT SHEET

[Will be sent with Letter of Support from the Administration on Aging to potential organizations selected for the outcome evaluation]

Sponsor: This study is being sponsored by the Administration on Aging (AoA) an operating division of the US Department of Health and Human Services

Purpose: To help AoA better understand how to support the delivery of long-term services and supports (LTSS). The study will consider the effectiveness of different approaches to the provision of long-term care services and supports from the organizational and consumer perspectives.

Benefits to your organization: While there are no direct benefits to your organization, the information that you collect will provide important insight into the provision of long-term services and supports (LTSS). This will help organizations, such as yours, and Agencies, such as AoA, improve LTSS policies and practices. The ultimate benefit is for consumers.

Your role: If your organization is able to participate in this important research, your organization will be asked to:

- 1. Provide contact information for the frontline staff (I&R/I&A) with whom consumers first come into contact. Estimated time required: varies by organization
- 2. Allow the research team to contact these staff and provide them with training and technical support regarding their role in the research study. <u>Estimated time required: 30 minutes per staff member</u>
- 3. Over a 3-6 month period, as I&R/I&A staff are contacted by consumers they will ask them a few screening questions and gather contact information. Estimated time required: 5 minutes per <u>consumer.</u>
- 4. Send the screening and contact information to the research team approximately monthly. <u>Estimated</u> <u>time required: 15 minutes per month.</u>

OUTCOMES EVALUATION RECRUITMENT TELEPHONE SCRIPT

Recruitment calls are made to the directors at local-ADRC, AAA, and CIL sites that have been selected to participate in the outcome evaluation. This call is made approximately one week following the expected date that the agency director receives the AoA letter of support.

Step 1: Describe main parts of study and informed consent, answer any questions

Hello/ Good morning/ Good afternoon. My name is []. I am calling from Abt Associates about a study we are conducting for the Administration on Aging (AoA). You should have received a letter from AoA alerting you to the study within the past week or two. Did you receive the letter?

1. [If no, skip to # 2] If YES, Did you have a chance to look it over [if no, skip to #2]? To remind you, the study involves a telephone survey that will be administered to some of your consumers. It is designed to help AoA better understand the experiences of older adults and persons with disabilities in obtaining community-based support and services through organizations like yours. I am calling to answer any questions that you might have about the study and to confirm your organization's involvement. But, first let me tell you a bit about the study. Participation in this study by your organization is voluntary so you may choose not to join and will not be penalized for your decision. If you agree to participate, we will ask that your key I&R/I&A specialists participate in a 40 minute webinar training program, screen consumers who contact them over a 3-6 month period for eligibility in the study, and collect and forward this information to the research team. The eligibility screener gathers information about whether the consumer contacted you for themselves or someone else (e.g., the primary consumer), the primary consumer's age, whether the primary consumer has any of a range of physical or mental disabilities, and the type of services the consumer received or was referred to. The data collection portion requests the consumer's contact information (so that the research team can contact them to conduct the interview); whether they need any accommodations for the interview, such as a Spanish speaking interviewer or if they will be using a TTY service; the main reason for their contact with your organization; and the mode of contact (e.g., telephone, walk in). Because you likely already collect much of this is information, it is expected that the eligibility screening and data collection will take less than five additional minutes. I&R/I&A specialists will also be asked to forward the data to the research team according to a schedule we jointly determine, most likely monthly.

Say, "Is your organization able to participate in the study?"

If NO, say "Can I ask why?" "Thank you for your time."

If YES, say "Great. You will be receiving follow-up email from the research team confirming your participation, and asking for contact information for the organization's I&R/I&A specialists. With your permission, we will follow-up with them directly regarding their participation and to provide information about the training."

2. If NO (did not receive the letter) or if did not have a chance to look over study materials, let me tell you about the study.

The study involves a telephone survey that will be administered to some of your consumers. It is designed to help AoA better understand the experiences of older adults and persons with disabilities in obtaining community-based support and services through organizations like yours. Your participation in this study is voluntary so you may choose not to join and will not be penalized for your decision.

If you agree to participate, we will ask that your key I&R/I&A specialists participate in a **40 minute** webinar training program, screen consumers who contact them over a 3-6 month period for eligibility in the study, and collect and forward this information to the The eligibility screener gathers information about whether the research team. consumer contacted you for themselves or someone else (e.g., the primary consumer), the primary consumer's age, whether the primary consumer has any of a range of physical or mental disabilities, and the type of services the consumer received or was referred to. The data collection portion requests the consumer's contact information (so that the research team can contact them to conduct the interview); whether they need any accommodations for the interview, such as a Spanish speaking interviewer or if they will be using a TTY service; the main reason for their contact with your organization; and the mode of contact (e.g., telephone, walk in). Because you likely already collect much of this is information, it is expected that the eligibility screening and data collection will take less than five additional minutes. I&R/I&A specialists will also be asked to forward the data to the research team according to a schedule we jointly determine, most likely monthly.

Say, "Is your organization able to participate in the study?"

If NO, say "Thank you for your time."

If YES, say "Great. You will be receiving follow-up email from the research team confirming your participation, and asking for contact information for the organization's I&R/I&A specialists.

With your permission, we will follow-up with them directly regarding their participation and to provide information about the training. "

SECTION 2: COMMENTS TO ORIGINAL 60-DAY NOTICE, RESPONSES TO COMMENTS RECEIVED, AND REVISED DATA COLLECTION TOOLS

COMMENTS RECEIVED IN RESPONSE TO THE 60-DAY FEDERAL REGISTER NOTICE AND RESPONSES

Aging and Disability Resource Center Grant Program Evaluation

Comments by the National Council on Independent Living (NCIL) ADRC Task Force

Submitted to AoA (Now ACL²) on December 13, 2011

The National Council on Independent Living (NCIL) considers the Evaluation of Aging and Disability Resource (ADRC) Grant Program participants to be an important opportunity to measure and evaluate the impact of ADRCs. NCIL believes that the process of ADRC Grant Program Evaluation is a chance to identify strategies to increase access to programs and long-term services and supports for seniors and people with disabilities. If the primary goal of the ADRCs is to create a single, coordinated system of information and access for all persons seeking long-term services and supports, regardless of age, disability or income, we do not believe that this process and evaluation will result in those findings. NCIL suggests that the following issues be addressed:

1) We find it problematic that Centers for Independent Living and the disability community were not involved in the design of the ADRC evaluation from the beginning.

<u>Response:</u> Centers for Independent Living and members of the disability community have been involved in the evaluation design in a meaningful way from the beginning of the process. For example, several members of disability organizations are members of the technical advisory group for this evaluation. These include:

- a. K. Charlie Lakin, PhD Center on Community Living Director University of Minnesota
- b. Henry Claypool, Director of the Office on Disability, US Health and Human Services
- c. Melissa Hulbert, MA, Acting Director, Division of Community Systems Transformation, CMS
- d. Louis Frick, Executive Director, Access to Independence
- e. Sue Swenson, Deputy Assistant Secretary, Office of Special Education and Rehabilitative Services

In addition, the research team includes a disability services expert and made multiple attempts via phone and email to collaborate with key NCIL staff throughout the design phase. In June 2011, staff from seven Centers for Independent Living participated in a discussion on the feasibility of Centers for Independent Living participating in the evaluation as designed.

² As of April 2012 the Administration on Aging, the Office on Disability and the Administration on Developmental Disabilities were combined into a single agency, the Administration for Community Living (ACL) that supports both cross-cutting initiatives and efforts focused on the unique needs of individual groups, such as children with developmental disabilities or seniors with dementia. For more information see: https://federalregister.gov/a/2012-9238 or http://hhs.gov/acl

2) NCIL is concerned with AoA's evaluation of Options Counseling when AoA standards for Options Counseling are not yet finalized.

<u>Response:</u> This evaluation is an evaluation of ADRCs which include Options Counseling. To that end there are four questions in the Process Evaluation survey (numbers 32-35) ask about whether Options Counseling or a similar service is provided and the Participant Experience Survey asks respondents who have received one-on-one counseling about their options (i.e., Options Counseling) to provide feedback on those services through a series of five questions (section E.2.1-5). This is not an evaluation of Options Counseling itself, but rather these questions are to determine the extent to which one-on-one counseling regarding Long term service and support options is provided (process evaluation survey) and whether consumers find it to be helpful (Participant Experience Survey).

3) We find it counterproductive to compare services provided by CILs and AAAs when each are designed drastically different, especially when many of the services that are being measured are offered by other entities such as the State, Housing Authorities, Home Health Agencies, etc.

<u>Response:</u> The evaluation design has been revised and Centers for Independent Living will not be used to identify consumers for participation in the comparison group.

4) While we do understand the need to use an organization that reaches a more diverse age group and a wider range of individuals with disabilities as a comparison group in the evaluation, the mission of Centers for Independent Living is fundamentally different than ADRCs. The current design, which involves use of CILS requesting participation of their consumers in the areas of the country without ADRCs is not acceptable to us.

<u>Response:</u> The evaluation design has been revised and Centers for Independent Living will not be used to identify consumers for participation in the comparison group.

5) The use of a comparison group is not necessarily needed to determine if the ADRCs are indeed providing better access to long-term services and supports to people of all ages, incomes and disabilities. Rather, the evaluation of ADRCs should only be asking the existing ADRCs what they are doing to meet and the extent to which they are meeting the definition and standards stated in the Older Americans Act.

<u>Response:</u> Title II Section 206 of the Older Americans Act of 1965 specifies that the Assistant Secretary for Aging "shall measure and evaluate the impact of all programs authorized by this Act." The ADRC program is authorized under Title II Section 202 Subsection b of the OLDER AMERICANS ACT AMENDMENTS OF 2006 (PUBLIC LAW 109–365—OCT. 17, 2006)³. In order to determine the impact of ADRCs a comparison group is needed for this evaluation. But, the evaluation design has been revised and Centers for Independent Living will not be used to identify consumers for participation in the comparison group.

³ Downloaded from <u>http://www.doleta.gov/reports/pdf/pl 109-365.pdf</u> on 12-5-11

In addition, guidance from the Office of Management and Budget supports the use of a comparison group in this case. According the Guidance from the Office of Management and Budget released on October 7, 2009 "Rigorous, independent program evaluations can be a key resource in determining whether government programs are achieving their intended outcomes as well as possible and at the lowest possible cost."⁴ This initiative focuses on impact evaluations, or evaluations aimed at determining the causal effects of programs.

Previous guidance from the Office and Management and Budget, also supports the use of the most rigorous evaluation design possible. In their January 20, 2006 Memorandum for the President's Management Council⁵ they provided the following guidance regarding evaluation methods:

"When agency research questions involve trying to determine whether there is a causal relationship between two variables or whether a program caused a change for participants, then agencies will need to employ an experimental or quasi-experimental design or demonstrate how their study design will allow them to determine causality. " (page 20)

As an experimental design is not feasible, the next most rigorous evaluation design is a quasi experimental design which compares outcomes from program participants to outcomes for comparison groups that do not receive program services. Therefore, a comparison group is required to determine if the ADRC model is better than the alternatives.

6) Based on our observations NCIL has found that many problems with ADRCs do not lie at the local level, but rather at the state level. Therefore, we believe that this evaluation would yield more useful information if it were focused more towards the state level organizations rather than local.

<u>Response</u>: State and local processes are being assessed through a process evaluation. A representative from every state and local ADRC will be invited to participate in the process evaluation. One of the unique aspects of the ADRC program is the integration of the state and local levels. An evaluation of the program would be incomplete if the local level processes and experiences were not included.

7) NCIL sees the importance for a more stringent evaluation on the state level to hold states accountable for coordinating their efforts with CILs and AAAs. In addition, with only 57% of ADRCs reporting having active CIL involvement, NCIL is concerned with how the other ADRCs will be evaluated.

⁴ http://www.whitehouse.gov/sites/default/files/omb/assets/memoranda_2010/m10-01.pdf

⁵ http://www.whitehouse.gov/sites/default/files/omb/inforeg/pmc_survey_guidance_2006.pdf

<u>Response:</u> All of the ADRCs will be evaluated using the same instruments and analyses. ACL (formerly AoA) has information in its records regarding which ADRCs have formal partnerships with CILs. Therefore, as designed, this evaluation will be able to analyze whether, at the local level, ADRCs with CILs as partners are operate differently from ADRCs without CIL partners as well as whether consumer outcomes are different for ADRCs with CIL partners and those without CIL partners.

8) From our experience, it does not seem likely that many CILs will have the staff time or the resources to complete such an extensive survey. Many CIL's staff and budgets are stretched, and currently there are not funding resources available to assist CILs with staffing this process.

<u>Response:</u> The evaluation design has been revised and Centers for Independent Living will not be used to identify consumers for participation in the comparison group.

9) It was our understanding that the purpose of this evaluation was to understand if ADRCs are making a difference in how services are provided and if they are in fact meeting the standards and definition as defined in the Older Americans Act which is to streamline access to long-term care. However, the Support Letters and Fact Sheet at the end of the evaluation tool states that the purpose it is to help AoA better understand how to support the delivery of long-term services and supports (LTSS). The purpose of this evaluation needs to be clarified.

<u>Response:</u> There is no contradiction between the goal of the evaluation as stated in the justification and the Support Letters and the Fact Sheet. The text used in the Support Letters and Fact Sheet was simplified to be more comprehensible to the recipients.

- 10) Some of our concerns on the tool itself:
 - a. Process Evaluation:
 - State IL Associations should be included in this evaluation. In many states these organizations are involved, especially at the state level. Currently, these organizations have been left out completely
 <u>Response:</u> State Independent Living Associations have not been included in the evaluation because this is not an evaluation of Centers for Independent Living.
 - ii. CILs are required to complete a 704 report, a data collection tool defined by RSA, each year. This evaluation's statistical and demographic data corresponds with SART data collection. SART and 704 reports do not categorically correspond. Therefore, CILs will be unable to respond accurately to statistical and demographic questions.

<u>Response:</u> The evaluation design has been revised and Centers for Independent Living will not be used to identify consumers for participation in the comparison group.

iii. Some of the evaluation questions are requesting responses as to how services were seven years ago, prior to the ADRC grants to present. The responses to these questions will not be accurate if there has been staff turnover at the state or local levels.

<u>Response:</u> In response to this comment, we have added a not applicable option to questions that ask about services and community contact seven years previous.

- iv. According to the AoA website ADRCs were designed to streamline access to long-term care. There are multiple items in the process evaluation that are not necessary to evaluate the streamlining of access to long-term care.
 - A. Page 12 #20. We do not find it necessary to ask about what topics consumers most commonly ask about to evaluate streamlining of access to LTC. For the purpose of this evaluation, the only topics and services that should be covered should be related to LTC.
 <u>Response:</u> The purpose of this question is to gain a sense of how consumers that contact the different organizations (ADRCs and AAAs) may differ in their service needs. The information will be used to inform the interpretation of the data collected.
 - B. Page 14 We do not find it necessary to as what entity at local level does advocacy, nursing home/institution diversion, how it is tracked, or if the entity provides transition services. Advocacy has lots to do with LTC but not with the streamlining access. If you are part of the ADRC or a partner of one, then you have agreed to working on streamlining access to LTC, therefore advocacy should not be necessary to streamline if the state and partners all agree.

<u>Response</u>: All questions in process and outcome evaluation map directly to the functions, mission and goals of the two organizations. More specifically, advocacy questions were added to address long term services that were determined to be more relevant for younger individuals with a disability. During the process evaluation we are also trying to assess the availability of different types of services. We would expect the outcome evaluation results to vary based on the availability of adequate resources in the community. The evaluation was designed to identify where breakdowns exist amongst partners and which could affect client/consumer outcomes.

C. Page 17 - #33. We find it irrelevant to know how many individuals were referred for services unrelated to access to LTC.

<u>Response:</u> The skip pattern for this question has been changed so that it will only be asked of local-level staff.

D. Page 19 - #36. CILs would not know the number of consumers (questions use term clients) enrolled in Medicaid HCBS Waivers outside of their own consumers if they are a HCBS provider. In addition, not all CILs are HCBS providers. CILs would also not know numbers of individuals enrolled in Medicaid residing in institutions in their service area. Centers do not have access to these numbers. This section is to be completed by sites that refer consumers (clients) to public programs only. Because a site makes a referral does not necessarily mean the individual is enrolled. CILs do not have access to this type of data from other providers.

<u>Response:</u> The evaluation design has been revised and Centers for Independent Living will not be used to identify consumers for participation in the comparison group.

E. Page 22 - #48. How organizations use performance data is not relevant to improve consumer access to long-term care. Many of the options provided are also irrelevant to consumer access to long-term care.

<u>Response:</u> The purpose of this question (now #46) is to determine the extent to which the program uses performance-based management as a proxy for program quality and flexibility. The data may be used as a control variable for the analyses of outcome evaluation data.

- F. Page 22 Section D.
 - I. #50. The total budget of a CIL is not relevant to this evaluation. Similarly, #51 should only be concerned with funding related to the ADRC for the purpose of this evaluation.

<u>RESPONSE</u>: The evaluation design has been revised and Centers for Independent Living will not be used to identify consumers for participation in the comparison group.

II. #54. Language should be modified to clarify that the evaluation is asking what organizations comprise the core operating organizations of the ADRC.

<u>Response:</u> The organizations providing respondents for the comparison group will not be part of an ADRC. The evaluation team believes that the diversity of partnerships is an important control variable for the analyses of outcome evaluation data.

> III. #55. This item should refer to partnerships within the ADRC only. Any other partnerships are not relevant to this evaluation.

<u>Response:</u> The organizations providing respondents for the comparison group will not be part of an ADRC. The evaluation team believes that the diversity of partnerships is an important control variable for the analyses of outcome evaluation data.

IV. #56-58. It should be made clear that these items are in regard to staff working on ADRC goal of streamlining access to LTC, not all positions are relevant.

<u>Response:</u> These questions are now #64-66. The evaluation team believes that agency capacity as measured through human resource levels is an important control variable for the analyses of outcome evaluation data.

G. Page 8 & 9 - We find that the lists of services available are focused around aging and that many are irrelevant to evaluate access to LTC. We find it unnecessary to ask about other services such as education, employment, housing, socialization/recreation, etc. which have little to do with streamlining access to LTC. Many of the services on the list are necessary for a consumer to become more independent but are not related to streamlining access to LTC.

<u>Response:</u> As ADRCs are tasked with providing access to the full-range of long term care services, the research team wants to collect information about any services that consumers may seek from an ADRC or AAA. In addition, services such as education, employment, housing, and socialization/recreation are quite relevant to younger audiences' ability to remain in the community, which is an outcome of streamlined LTSS. With regard to CILs, the evaluation design has been revised and Centers for Independent Living will not be used to identify consumers for participation in the comparison group.

> I. This list also includes attendant care in parentheses behind Independent Living Services, HCBS Medicaid Waiver Program, and Personal Care Services which seems to be repetitive. Rather, we suggest listing the Medicaid waivers and Personal Care services separately due to the fact that not all individuals needing personal care services would qualify for Medicaid waivers. We suggest listing the Independent Living Services, but the examples given are home modifications and attendant care, which do not capture the goal of IL services. The four core services of IL are I & R, Peer Support, Independent Living Skills Training (budgeting, cooking, menu planning, cleaning, etc.), and Advocacy (Individual and Systems). That being said IL Services typically go much further than the four core services usually based on consumer needs in the CIL's area. So other services could be housing, education, employment, assistive technology, benefits counseling, etc.

Therefore we suggest modifying the examples of IL services provided.

Response: The examples have been revised as suggested in the comment.

H. Page 16 - Question 29. CDSMP and DSMP should be defined. Similarly, all acronyms and study related language should be defined initially.

Response: The tools have been revised as suggested in the comment.

- I. Page 16 Question 30. This question needs to be clarified. Does the CIL have a marketing plan in general or in regard to accessing LTC? If used, the question should only be concerned with a marketing plan in regard to accessing LTC.
- 11) <u>Response:</u> The evaluation design has been revised and Centers for Independent Living will not be used to identify consumers for participation in the comparison group.
 - a. Participant Survey:
 - i. If a consumer contacts a CIL about services not pertaining to community based services/LTC then these individuals should not be passed on for the evaluation. Again, they have nothing to do with evaluating the purpose of the ADRC.

<u>Response:</u> The evaluation design has been revised and Centers for Independent Living will not be used to identify consumers for participation in the comparison group.

ii. Page 32 - If REF, can I ask why you are not interested in participating? -The IL Philosophy is consumer controlled therefore it is the consumers choice to participate and should not be questioned.

<u>Response</u>: The evaluation design has been revised and Centers for Independent Living will not be used to identify consumers for participation in the comparison group.

iii. The ADRC/CIL/AAA's staff person that does I & R/I & A will go through a training on Eligibility Screening to complete the Client Screening Tool. Then in the next 3-6 months, they screen new consumers coming in for eligibility to do the survey. Finally, the CIL would provide those names with contact information to the surveyors. We have concerns about asking these questions to new consumers who we have not yet built a relationship with.

<u>**RESPONSE</u>**: The evaluation design has been revised and Centers for Independent Living will not be used to identify consumers for participation in the comparison group.</u>

iv. Not all CILs have a designated person doing I & R/I & A. The CIL partnering in a particular area may have a small staff or may be a satellite

office with a small number of staff. Many CIL's staff and budgets are stretched, and currently there are not funding resources available to assist CILs with staffing this process.

<u>**RESPONSE</u>**: The evaluation design has been revised and Centers for Independent Living will not be used to identify consumers for participation in the comparison group.</u>

- v. Again, there are many questions in the Participant Survey that are not related to streamlining access to LTC.
 - A. What type of services, if they received services, what was requested, where they found out about (CIL), etc. are all questions that do not evaluate the ADRC purpose of streamlining services. The questions more relevant to evaluating the purpose of ADRCs are the items related to the process of how and the extent to which they were served i.e. no wrong door, warm transfer, etc.
 - B. Again, the list of services provided goes beyond the scope of streamlining access to LTC as stated above.
 - C. Page 36 #5. This question along with Section C that follows it are evaluating the CIL and/or staff not the process of the ADRC.

<u>RESPONSE</u>: The purpose of the questions referred to in v. A-C above is to get a full picture of the consumer's service experience. Streamlining access to services is not the only charge of the ADRCs and therefore, these questions ask about other important features of consumer service. The data related to each question maps to the evaluation research questions. In addition, the evaluation design has been revised and Centers for Independent Living will not be used to identify consumers for participation in the comparison group.

D. Page 38 - #5. NCIL suggests adding "if assistance was requested." Obviously this would not be offered if they did not need an action plan to meet LTC needs. CILs are required to offer each consumer an Independent Living Plan or they may choose to sign a waiver to not develop a plan. This question jumps quickly into whether the agency/organization developed a plan for LTCSS. Not all customers need LTCSS. It seems this would be better located further into the survey under Options Counseling.

<u>**RESPONSE</u>**: The language of the question will be changed to add "if assistance was requested".</u>

E. Page 38 - Section D - NCIL suggests changing the language of this section and instead use "Institution Diversion". The current

language, Long-term Care Diversion, conveys diverting LTC services completely including community based.

<u>RESPONSE</u>: The title of this section will be changed to "Institutional Diversion"

F. Page 41 - #7. This item asks what agency/organization the customer was referred or transferred to. The options provided are all various types of services, not the types of agencies/organizations. But, the agency/organization list should only be relevant to the ADRC.

<u>RESPONSE</u>: The question will be changed to read "To what supports and services were you...."

G. Page 42 - Section E.1. NCIL suggests a statement be added to make sure the consumer understands the interviewer is talking about Medicaid. The differences between Medicaid and Medicare are very confusing to many consumers and people in general.

<u>Response:</u> Through programming in the CATI system the term "Medicaid" will be replaced with the name of the Medicaid program in the consumer's state.

H. Page 47 - #7. The language of this chart (i.e. professionalism, comprehensiveness, dissatisfied, etc.) tends to be complex and should be worded to be more friendly for consumers. Additionally, we suggest the use of "Not Satisfied" rather than "Dissatisfied" to reduce the opportunity for misinterpretation by consumers. We believe that many individuals with cognitive or intellectual disabilities will have difficulty providing accurate responses with the current language.

<u>**RESPONSE</u>**: This language was taken from a satisfaction survey currently used by several ADRCs which serve individuals with cognitive and intellectual disabilities. For continuity, the language will not be changed unless indicated during the cognitive testing phase of this study.</u>

I. Page 49 - Section G. We find this section, especially Questions 1-4, to be extremely intrusive and irrelevant in a satisfaction survey to evaluate the purpose of ADRCs. We would consider it irresponsible for consumers to allow their insurance numbers and health care information to be tracked for an undefined number of years. Centers advise consumers not to give out personal information such as insurance numbers. In addition, these items do not obtain any information in regards to participant experience.

<u>RESPONSE</u>: These data will inform the interpretation of the data and help the research team to determine what types of consumers tend to contact each type of organization and whether outcomes are dependent on a consumer's current assessment of their health status. With regard to the request for Medicare/Medicaid numbers, these will no longer be requested through this research. Rather, respondents will be asked to provide other information that could be used by the Centers for Medicare and Medicaid Services to access respondents' health care utilization data. These are date of birth, zip code and the last four digits of respondents' social security numbers.

b. Page 42 - Section E.1. This section asks questions about eligibility for Medicaid, Care transitions, etc. CILs have no control over eligibility; that is a state issue. We do not believe obtaining this information will be beneficial to improve access to such services, expedite eligibility, or to encourage "presumed eligibility requirements."

<u>Response:</u> Based on the existing skip patterns, these questions will only be asked if they are relevant to a respondent. In addition, these questions are relevant for understanding the range of services that clients are receiving. The services asked about have been shown, through other research, to promote individuals' ability to live in the community

- c. Client Screening Tool
 - i. While the Client Screening Tool refers to the person who is making contact with a CIL, CILs still consider these individuals to be consumers. Therefore, the language of this section should be modified to "Consumer Screening Tool."

<u>Response:</u> Different organizations refer to clients and consumers using different terms. The term client applies to the largest number of organizations included in this evaluation and, therefore, will be remain in the title of the tool.

ii. Again, if a consumer contacts a CIL about services not pertaining to community based services/LTC then these individuals should not be passed on for the evaluation. These are also irrelevant to evaluating the purpose of the ADRC.

<u>Response:</u> Question #7 on the Client Screening Tool asks if a consumer received any of the types of services that are also offered by an ADRC. Only individuals who received such services would be to be eligible for participation in the study.

iii. Page 57 - #7. Questions referring to specifics of an individual's disability are intrusive. The individual or the person for whom contact was made has a disability or the CIL would not be providing them services and a referral would not be taken.

<u>Response:</u> These questions are pulled from the US Department of Health and Human Services standards and are used by on the American Community Survey and other major surveys to characterize functional disability is proposed as the standard for collecting population survey data on disability. The question set was developed by a Federal interagency committee and reflects how disability is conceptualized consistent with the International Classification of Functioning, Disability, and Health. The question set went through several rounds of cognitive and field testing and has been adopted in most major federal data collection systems. OMB has encouraged the use of this question set when Federal agencies conducting national population studies in order to promote a consistency in measurement and continuity in the dialogue. Disability-specific questions are important to measure variations in services and outcomes based on disability type.

iv. Page 59 - #9. The ability for a CIL consumer to participate in this study is not a determination for staff to make. Rather, the consumer is given the choice to participate and if they feel they need assistance they should be able to make that request and their answers should be considered eligible for the study.

<u>Response:</u> Based on staff expertise in working with their consumer populations, they are asked to make a professional judgment regarding the ability of the consumer to participate in a 20 minute survey. Detailed information about how this judgment should be made will be included in the training materials provided to sites participating in the evaluation.

v. Following item 9 reads "If yes to item 8, Client is ineligible for the study." Item 8 is a multipart question and therefore the statement does not make sense.

<u>Response:</u> The questions were mis-numbered and this has now been fixed so that the skip pattern refers to the correct question.

12) NCIL ADRC Task Force is concerned that this evaluation will not result in information to assess the successes of ADRCs in increasing and streamlining access to information and services and supports for people with disabilities and seniors.

<u>**RESPONSE</u></u>: The IMPAQ/Abt team, which brings together many years of experience in evaluation design, has spent significant time and effort designing an evaluation that can yield the most informative results on the activities of the ADRC. We are confident that this evaluation will provide meaningful insight into the capabilities of the ADRC, consumer experiences, and where there is room for improvement.</u>**

Date

Attachment A: PROCESS EVALUATION: WEB-BASED SURVEY

PROCESS EVALUATION: LOCAL-LEVEL WEB-BASED SURVEY

INSTRUCTIONS TO WEB SURVEY PROGRAMMER: PREPOPULATE (PP) INFORMATION IN [] BASED ON SITE DIRECTOR TYPE (DT) OR ID NUMBER (ID). THESE PROPOPULATED DATA WILL BE USED THROUGHOUT THE SURVEY TO ORIENT THE RESPONDENT BASED ON TYPE OF SITE. EACH SITE WILL ALSO RECEIVE A UNIQUE ID NUMBER WITH THE NAME OF THE SITE.

[ID Number - ID]

Name of Site

[Director Type - DT]

— ADRC (Local-level)

— AAA (Local-level)

Section A. Baseline Characteristics

[FOR LOCAL-LEVEL ADRC DIRECTORS]: The first set of questions focus on characteristics of your organization **PRIOR** to receiving an ADRC grant and the influence on your organization of the Administration on Aging (AoA) and/or CMS grant(s) (i.e., AoA Title IV grants, AoA title II grants, CMS Real Choice System Change grants, CMS Person-centered hospital discharge planning grants, Patient Protection and Affordable Care Act funds).

[FOR LOCAL-LEVEL AAA DIRECTORS]: We are interested in how your organization has changed over time, therefore, the first set of questions deals with the characteristics of your organization approximately 7 years ago (i.e., in 2004-2005).

- Has your organization realized an improvement in ability to provide integrated, comprehensive access to long-term care services and supports (e.g., provide one-stop or streamlined benefits access, increase awareness of LTSS options, provide assistance to consumers such as counseling regarding LTSS choices or transitions from institutions back into the community)? [if DT = ADRC since the start of the ADRC grant; if DT=AAA over the past 7 years]
 - Yes
 - □ No [skip to question 3]
- 2. Which have had the most positive impact on your organization's ability to provide integrated, comprehensive access to long-term care services and supports (e.g., provide one-stop or streamlined benefits access, increase awareness of LTSS options, provide assistance to

Date

consumers such as counseling regarding LTSS choices or transitions from institutions back into the community)? (Select up to two)

- □ Partnerships developed/expanded
- □ Staffing changes
- Shared data
- □ Focus on providing person-centered, self-directed services
- □ Other, please specify
- 3. Which of the following best describes the reason your site became an ADRC?
 - □ To better integrate service provision systems
 - □ To develop or strengthen agency/organizational partnerships
 - □ To improve data or IT infrastructure
 - □ To improve marketing or awareness efforts related to Long Term Care Services and Supports (LTSS)
 - □ To expand services to additional populations
 - □ To expand services to additional geographic locations
 - □ Other, please specify
- 4. [FOR AAA DIRECTORS ONLY]: Is your site interested in becoming an ADRC or becoming part of an ADRC in the future?
 - □ Yes; If yes, what is your current stage or status in becoming an ADRC? (Open Response)
 - □ No; If no, please explain why you do not plan to become an ADRC? (Open Response)
 - □ Other, please specify
- 5. Please indicate the extent to which Federal (AoA/CMS) grants have enabled your ADRC to realize any of the following outcomes... (Select all that apply)

	Very much	Somewhat	Very little
increase the skills of existing staff	0	0	0
recruit or attract more experienced staff	0	0	0
increase/expand populations served	0	0	0
increase the number of consumers served	0	0	0
increase the number of partnerships	0	0	0
increase range of services offered	0	0	0
make other changes (please specify)	0	0	0

Date

 How has the ADRC grant(s) affected the resources or resource allocation at your organization or within your state? [IF THERE IS MORE THAN ONE ADRC IN THE STATE CHECK THE BOX IF THE ITEM IS TRUE OF AT LEAST ONE ADRC] (Check all that apply)

	At the site or local level	At the State level
Helped us leverage other funds		
Improved staff training opportunities		
Increased service efficiency		
Contributed to the development of a statewide database of LTSS services and/or consumers		
Promoted the development of standard operating procedures		
Increased the level of coordination between organizations serving older individuals and individuals with disabilities		
Improved awareness/marketing campaigns/activities		

Section B. Populations Served

This second set of questions asks about the populations in your service area as well as consumers that your organization serves. For questions about consumers, please focus on those who received services designed to enhance individual choice and support informed decision-making among consumers. This includes empowering individuals to effectively navigate their health and other long-term support options (e.g., Information, referral and awareness services; Consumer-focused decision support; Assistance with planning for future LTSS Needs; Streamlined eligibility determination for public programs; Person-centered transition support from institutional setting to community settings; and Independent living skills.) Please answer these questions to the best of your knowledge. In questions asking for percentages, please provide estimates if your organization does not collect the requested data.

NOTE: The data will be used to group like organizations together to allow for more complex data analyses. These data will not be used to evaluate the efforts of your specific organization.

For the following items, please indicate the demographic composition of your **service area**. (This question applies to the community that [insert ID] serves)

- 7. Latino/Hispanic Origin
 - Yes %
 - No %

Interviewer Initials (or ID) _____

Date_____

Race

- Caucasian/White %
- Black or African American %
- American Indian or Alaska Native %
- Asian %
- Nation Hawaiian or Other Pacific Islander %
- 8. If you have one or more significant racial/ethnic sub-populations in your service area please list it here:______
- 9. What percentage of your service area is living at or below the poverty line?
 - At or below the poverty line %
 - □ Not sure, but a significant population lives under the poverty line
 - □ Not sure, but the population is small or negligible
- 10. What percentage of your service area is uninsured/does not have health insurance coverage?
 - Uninsured %
 - □ Not sure, but a significant population is uninsured
 - □ Not sure, but the population is small or negligible
- 12. Within the last 12 months, has a community LTSS needs assessment been conducted?
 - □ Yes
 - □ No, but we did complete a community needs assessment within the past three years
 - □ No, a community needs assessment was not completed within the past three years
- 13. This next set of questions is designed to gather information about the conditions in your service area.

[BLANK RESPONSE BOXES WILL BE POPULATED BY DROP-DOWN BOXES SHOWING OPTIONS EXPLAINED ABOVE 'PRIOR' AND 'CURRENTLY' COLUMNS]

Community Needs

Barriers to receiving Long Term Supports and Service services

To what extent is each of the following a barrier for individuals seeking Long Term Supports and Service services both prior to receiving an ADRC grant [approximately 7 years ago or if you do not have information that goes back that far, as far back as you do have information] and currently?

	Please use dropdown menus to select: not a barrier, sometimes a barrier, often a barrier	
	Prior	Currently
Lack of Long Term Supports and Services-Needed services are not offered		

Community Needs

Date_____

Barriers to receiving Long Term Supports and Service services		
To what extent is each of the following a barrier for individuals seeking services both prior to receiving an ADRC grant [approximately 7 years a information that goes back that far, as far back as you do have information	ago or if you do n	ot have
information that goes back that fail, as failback as you do have informa	-	•
	Please use dropdown menus to select: not a barrier, sometimes a barrier, often a barrier	
	Prior	Currently
Lack of available Long Term Supports and Service slots-(e.g., There are long waitlists)		
Poor service quality		
Lack of health insurance		
Providers not accepting consumers with Medicaid		
Barriers based on consumer disabilities		
Language barriers		
Cultural barriers		
Religious barriers		
Sexual orientation barriers		
People needing services do not have a permanent address		
Consumers lack transportation		
Stigma, discrimination and prejudice against older adults		
Stigma, discrimination and prejudice against persons with disabilities		
Providers have high staff turnover		
Providers lack appropriately trained staff		
Service provider hours/locations are hard to access		
Other Please specify:		

[BLANK RESPONSE BOXES WILL BE POPULATED BY DROP-DOWN BOXES SHOWING OPTIONS EXPLAINED ABOVE 'PRIOR' AND 'CURRENTLY' COLUMNS]

Service Availability/Choice	Please indicate the Current availability of the following	For the following services, to what extent is there provider choice?
	services within your service area	Service has (<i>no; limited; adequate</i>) provider choice

Interviewer Initials (or ID)	Date		
		Prior	Currently
Safe and affordable housing options	Adequate availability/Available but inadequate to meet need/Not available		
Peer support services/groups	Adequate availability/Available but inadequate to meet need/Not available		
HCBS Medicaid Waiver Programs	Adequate availability/Available but inadequate to meet need/Not available		
Caregiver Support (i.e. respite programs, support groups, or counseling)	Adequate availability/Available but inadequate to meet need/Not available		
Nutrition Programs	Adequate availability/Available but inadequate to meet need/Not available		
Employment services	Adequate availability/Available but inadequate to meet need/Not available		
Education services	Adequate availability/Available but inadequate to meet need/Not available		
Opportunities to develop advanced directives	Adequate availability/Available but inadequate to meet need/Not available		
Transportation services	Adequate availability/Available but inadequate to meet need/Not available		
Opportunities for socialization/recreation	Adequate availability/Available but inadequate to meet need/Not available		

Interviewer Initials (or ID)	Date		
Service Availability/Choice	Please indicate the Current availability of the following services within your service area	For the following se extent is there prov Service has (<i>no; lim</i> provider choice	vider choice?
		Prior	Currently
Mental health services	Adequate availability/Available but inadequate to meet need/Not available		
Ombudsman services	Adequate availability/Available but inadequate to meet need/Not available		
Health prevention and screening services	Adequate availability/Available but inadequate to meet need/Not available		
Services for emergent cases/Crisis intervention	Adequate availability/Available but inadequate to meet need/Not available		
Transition programs (from hospitals, nursing homes etc.)	Adequate availability/Available but inadequate to meet need/Not available		
Nursing home (institutional) diversion programs	Adequate availability/Available but inadequate to meet need/Not available		
Nursing home/residential beds	Adequate availability/Available but inadequate to meet need/Not available		
Income assistance	Adequate availability/Available but inadequate to meet need/Not available		
Energy assistance	Adequate availability/Available but inadequate to meet		

Interviewer Initials (or ID)	Date		
Service Availability/Choice	Please indicate the Current availability of the following services within your service area	extent is there	ing services, to what e provider choice? o; limited; adequate) ce
		Prior	Currently
	need/Not available		
Personal care services	Adequate availability/Available but inadequate to meet need/Not available		
Medicaid waivers	Adequate availability/Available but inadequate to meet need/Not available		
Independent Living services (e.g., skills training, peer support)	Adequate availability/Available but inadequate to meet need/Not available		
Other, please specify	Adequate availability/Available but inadequate to meet need/Not available		

14. How many consumers of each type were served in the most recent 6 month period (October 2011-March 2012) NOTE: This question is specific to the consumers who access [insert ID] services such as I&R/I&A, benefits or options counseling, Information and referral services, services to support transitions from residential or institutional facilities to the community.

Characteristics	naracteristics Currently	
	Consumers under 60	Consumers over 60
Older Adults (60+)		
Individuals with Disabilities		
Physical disabilities		
Cognitive impairment		
Intellectual disabilities		
Developmental disabilities		

Process Evaluation Survey: Loca	Il-Level
erviewer Initials (or ID)	Date
Characteristics	Currently
Mental Illness	
Multiple disabilities	
Caregivers	
Informal/family caregiver	
Paid Caregiver	
Health & Human Service Professional (e.g., physician, hospital discharge planner, nursing home staff)	
Special Subpopulations	
Traumatic Brain Injury (TBI)	
Emergent/Emergency Cases	
Low income	
Limited English proficiency	
Is the [insert ID] making any special efforts to target a particular population not listed above? If yes, please specify	у.
Other (Please specify)	
Other (Please specify)	

- 14a. Since the start of the ADRC grant, the number of clients **under** 60 served by [insert ID] has:
 - □ Significantly increased
 - □ Significantly decreased
 - □ Stayed the same
- 14b. [FOR AAA DIRECTORS ONLY]: Over the past 7 years, the number of clients **under** 60 served by [insert ID] has:
 - □ Significantly increased
 - □ Significantly decreased
 - □ Stayed the same
- 15a. Since the start of the ADRC grant, the number of consumers **over** 60 served by [insert ID] has:
 - □ Significantly increased
 - □ Significantly decreased
 - □ Stayed the same
- 15b. [FOR AAA DIRECTORS ONLY]: Over the past 7 years the number of consumers **over** 60 served by [insert ID] has:

Date_____

- □ Significantly increased
- □ Significantly decreased
- □ Stayed the same

16a. Since the start of the ADRC grant, the number of consumers with physical disabilities served by [insert ID] has:

- □ Significantly increased
- □ Significantly decreased
- □ Stayed the same

16b. [FOR AAA DIRECTORS ONLY]: Over the past 7 years, the number of consumers with physical disabilities served by [insert ID] has:

- □ Significantly increased
- □ Significantly decreased
- □ Stayed the same
- 17a. Since the start of the ADRC grant, the number of consumers with mental/emotional disabilities served by [insert ID] has:
 - □ Significantly increased
 - □ Significantly decreased
 - □ Stayed the same
- 17b. [FOR AAA DIRECTORS ONLY]: Over the past 7 years, the number of consumers with mental/emotional disabilities served by [insert ID] has:
 - □ Significantly increased
 - □ Significantly decreased
 - □ Stayed the same
- 18a. Since the start of the ADRC grant, the number of consumers with multiple disabilities served by [insert ID] has:
 - □ Significantly increased
 - □ Significantly decreased
 - □ Stayed the same
- 18b. [FOR AAA DIRECTORS ONLY]: Over the last 7 years, the number of consumers with multiple disabilities served by [insert ID] has:
 - □ Significantly increased
 - □ Significantly decreased
 - □ Stayed the same
- 19a. Since the start of the ADRC grant, the number of caregivers served by [insert ID] has:

Date_____

- □ Significantly increased
- □ Significantly decreased
- □ Stayed the same
- 19b. [FOR AAA DIRECTORS ONLY]: Over the past 7 years, the number of caregivers served by [insert ID] has:
 - □ Significantly increased
 - □ Significantly decreased
 - □ Stayed the same

Section C. Service Provision

These questions are about the services provided by your organization/network

20. How frequently do consumers ask about the following? For each, indicate "frequently," "sometimes," "infrequently", or "never." Advanced directives

Торіс	Frequency of consumer inquiry:
	There will be a drop down menu in each cell with
	the options: "frequently," "sometimes," "infrequently", or "never."
Advanced directives	innequentiy, or never.
Advocacy	
Caregiver support	
Respite services	
Chronic health conditions	
Education	
Employment	
Energy assistance	
Home modification	
Affordable housing	
Income assistance	
Medicaid eligibility and services	
Medicare eligibility and services	
Mental/behavioral health services	
Nutrition services	
Ombudsman/abuse or neglect issues	
Independent living services	
Personal care/attendant care services	
Preventative health services	
Recreation opportunities	
Services for emergent care/crisis intervention	
Support groups	
Transition services	
Transportation	
Other, please specify	

Date_____

- 21. Does [insert ID] engage in advocacy activities for older adults?
 - Yes
 - No
- 22. Does [insert ID] engage in advocacy activities for persons with disabilities?
 - Yes
 - □ No
- 23a. Is diversion form nursing homes or other institutional residential facilities an outcome sought to be achieved? Specific goal...
 - □ Yes
 - □ No [Skip to question 24]
- 23b. How is [insert ID] measuring and tracking this?
 - □ Staff track using a standard electronic system
 - □ Staff track using a standard hardcopy/paper system
 - □ An external group (e.g., an evaluator, auditor) tracks using a standard system
 - □ Staff track using an informal system
 - □ Other, please specify

CARE COORDINATION/TRANSITION ASSISTANCE PROGRAMS

- 24. Does your organization provide transition services to consumers discharged from an acute care setting?
 - 🗌 Yes
 - □ No [If no skip to question 30]

Date

25. Care Coordination/Transition Assistance

[insert ID] Clients Provided Care Coordination/Transition	Assistance
No. individuals assisted with transition from hospital ONLY through formal care transitions program (evidence-based CT intervention or innovative model)	
Number of participants carried over from last reporting period (started program in last reporting period and continued with the intervention into this reporting period)	
Number of participants whose cases were closed during this period (i.e., participants whose transition services were ended either bacause of a readmission or new admission to a care facility or because the transition period ended)	
# of participants that readmitted within 30 days of discharge	
# of participants that readmitted within 30 days and re-entered the care transition program	

- 26. What is the number of individuals who were assisted with transition from hospital through formal care transitions intervention in this [INSERT ID] program service area this reporting period by participating hospital?
 - $\hfill\square$ Name of Hospital 1
 - \Box No. of Individuals for Hospital 1
 - □ Name of Hospital 2
 - \Box No. of Individuals for Hospital 2
 - □ Name of Hospital 3
 - \Box No. of Individuals for Hospital 3
- 27. What is the number of individuals who were assisted with transition from hospital through formal care transitions intervention across all participating hospitals in this [INSERT ID] program service area this reporting period by age group?
 - \Box Aged 60 and Over
 - 🗆 Under Age 60
 - 🗆 Age Unknown
- 28. What is the number of individuals who were assisted with transition from hospital through formal care transitions intervention across all participating hospitals in this [INSERT ID] program service area this reporting period by health insurance source?

_____Medicare _____Medicaid _____Dual-Eligible ______No insurance

Date_____

Private insurance Veterans Administration Services Other Unknown

- 29. What is the number of individuals who were assisted with transition from hospital through formal care transitions intervention across all participating hospitals in this [INSERT ID] program service area in this reporting period who were referred to one or more health/prevention programs?
 - _____Chronic Disease Self Management Program
 - _____Diabetes Self Management Program

_____Exercise Program

_____Mental Health and Substance Misuse

_____Falls Management and Prevention

_____Alzheimer's Programs

_____Medication Management

_____Home Injury/Risk Screenings

____Other

30a.What is the number of individuals who were assisted with transition from hospital through formal care transitions intervention across all participating hospitals in this [INSERT ID] program service area in this reporting period that were referred to one or more of the following long term services or supports?

_____ Additional Options Counseling

_____ Home delivered meals

_____Nutrition services or nutrition counseling

_____ Care giver support

_____Personal care/homemaker/choremaker services

_____Transportation

31a. Do you have a marketing plan?

- □ Yes, our marketing plan is operational
- □ Yes, we have a plan but it is not yet operational
- □ No, we do not have a plan at this time
- 31b. Does [insert ID] utilize a standard operating procedure to assess consumer need?
 - □ Always
 - □ Sometimes
 - Never
 - 32. Is the consumer assessment tool and/or basic consumer needs assessment process common across partner organizations?
 - □ Yes, common across all partners
 - □ Yes, common across some partners
 - □ No, each partner organization uses their own assessment tool/process

Date_____

OPTIONS COUNSELING OR OTHER ONE ON ONE COUNSELING

- 33. Does your organization/network provide "Options Counseling" or other one-on-one counseling designed to support consumers' ability to make informed decisions about their long-term care?
 - □ Yes
 - □ No [If no skip to question 36]
- 34. Referrals to Public and Private Services this Reporting Period

Referrals to Public and Private Services this Reporting Period	
What is the number of [insert ID] clients referred to or given an application for a public program, including Older Americans Act; Medicare; Medicaid; Food Stamps; TANF; Social Security (SSI or SSDI); LI-HEAP; VDHCBS; Other State-funded and county-funded programs for Medicaid; Other?	
What is the number of [insert ID] clients referred to some other type of service (non-public services, resources or program)?	
What is the number of [insert ID] clients that were not referred to any type of service?	
What is the number of [insert ID] Unknown Clients (remainder of all Clients)?	
Total	

Date_____

[FOR SITES WITH OPTIONS COUNSELING OR OTHER ONE ON ONE COUNSELING ONLY]

35. Clients Provided Options Counseling this Reporting Period

[insert ID] Clients Provided Options Counseling By Age		
[insert ID] Clients Aged 60 and Over		
[insert ID] Clients Under Age 60		
[insert ID] Clients Age Unknown		
Total		

[insert ID] Clients Provided Options Counseling by Method	
In person	
By phone	
Electronic Communication (e.g. email or website chat)	
Total	

[insert ID] Clients Provided Options Counseling by Setting		
[insert ID]		
Hospital		
Nursing facility/Institution		
At the client's community residence		
Other		
Total		
Client Feedback About Options Counseling		
What is the number of [insert ID] Clients who report that options counseling enabled them to make well informed decisions about their long term support services?		

Date____

			[insert ID]	
Clients	surveyed	this	reporting	
period?				

- 36. Does [insert ID] or network have a standardized tool or process to provide options counseling?
 - Yes
 - □ No
 - Don't know
 - Not applicable

PUBLIC PROGRAMS

37. Average Monthly Public LTSS Program Enrollment in WHOLE [INSERT ID] SERVICE AREA This set of questions is asking about all current enrollment levels in these programs in the [INSERT ID] service area. Enrollment fluctuates from month to month, so please calculate the average enrollment per month during the reporting period.

Average Monthly Public LTSS Program Enrollment in WHOLE [INSER	RT ID] SERVICE AREA
What is the average number of individuals enrolled in Medicaid HCBS Waivers in [INSERT ID] Service Area each month (should include [INSERT ID] Clients and might include Non-[INSERT ID] Clients)?	
What is the average number of individuals enrolled in Medicaid residing in institutions in [INSERT ID] Service Area each month (should include [INSERT ID] Clients and might include Non-[INSERT ID] Clients)?	
What is the average number of individuals enrolled in other public LTSS programs in [INSERT ID] Service Area each month (should include [INSERT ID] Clients and might include Non-[INSERT ID] Clients)? Please list LTSS programs and HCBS waivers (e.g. aged and disabled, MR/DD) that individuals are enrolled in.	

Date_____

[FOR SITES THAT REFER CLIENTS TO PUBLIC PROGRAMS ONLY]:

38. Total New Enrollment among [INSERT ID] CLIENTS ONLY in Public LTSS Programs This set of questions is asking about the absolute number of [INSERT ID] clients who were newly enrolled into these programs during the last six months.

Total New Enrollment among [INSERT ID] CLIENTS ONLY in Publi	c LTSS Programs
What is the number of [INSERT ID] Clients who are newly enrolled into a Medicaid HCBS Waiver this reporting period (including individuals enrolled by [INSERT ID] staff and individuals referred for assessment/application by [INSERT ID] staff)?	
What is the number of [INSERT ID] Clients who are newly enrolled into Medicaid institutional services this reporting period (including individuals enrolled by [INSERT ID] staff and individuals referred for assessment/application by [INSERT ID] staff)?	
What is the average number of individuals enrolled in other public LTSS programs in [INSERT ID] Service Area each month (should include [INSERT ID] Clients and might include Non-[INSERT ID] Clients)? Please list LTSS programs and HCBS waivers (e.g. aged and disabled, MR/DD) that individuals are enrolled in.	

- 39. For data collected on consumers, are staff required to follow the Alliance of Information and Referral Systems (AIRS) standards⁶?
 - □ Yes with all consumers
 - □ Yes, with specific groups of consumers –Please specify:
 - Never
- 40. Does [insert ID] have a database/MIS that does any of the following (Select all that apply)?:
 - □ Track consumer requests for information and referrals
 - □ Track referrals made to consumers
 - □ Maintain records on individual consumers
 - □ Maintain a list of services/service providers
 - □ Links to other databases (e.g., Medicaid waiver tracking systems, Money Follows the Person tracking system). If yes, specify: _____
 - □ Other, please specify
 - □ We do not have an electronic records/tracking system [skip to question 41]

⁶ Standard 13: Inquirer Data Collection

Date_____

- 41. Do operational partners have access to data they need for their operations such as data about your consumers/services? If yes, for what purpose? (review client information, input client demographic information, input referrals, input service utilization information, review client service utilization, obtain summary reports on clients and/or services)
 - Yes (specify _____
 - □ No, but there are plans to develop that capacity
 - □ No, and there are no current plans to do this
- 42. Do service providers have access to data about our consumers? If yes, for what purpose? (see above)
 - Ves (Specify_____)
 - □ No, but there are plans to develop that capacity
 - □ No, and there are no current plans to do this

42a. Do staff follow up with consumers after their initial contact with your organization?

- Always
- Sometimes-Under what circumstances: ______
- □ Never [skip to question 45]

42b. How many times does staff follow up with consumers after their initial contact with your organization?

- Once
- □ Multiple times

42c. What is the approximate timing of the <u>first</u> follow up with consumers after their initial contact with your organization?

- One to weeks after service
- □ Three weeks after service
- One to two months after service
- □ Three to five months after service
- □ Six months after service
- One year or longer after service

42d. What is the approximate timing of the <u>last</u> follow up with consumers after their initial contact with your organization?

- □ One week after service
- □ Two weeks after service
- □ Three weeks after service
- One to two months after service
- □ Three to five months after service
- □ Six months after service

Date_____

- □ One year or longer after service
- 43. When consumers are referred to other agencies or organizations, are those providers contacted as part of the follow up procedure?
 - Always
 - Sometimes-Under what circumstances:_____
 - Never
- 44. Approximately what percentage of consumers who are referred to other organizations receive a "warm transfer" (e.g., Simultaneous transfer of a telephone call and its associated data from one agent to another agent or supervisor)? _____%
- 45. Does your organization routinely collect quantitative performance data about its services and consumers?
 - Yes
 - □ No [skip to question 49]
- 46. Indicate any of the ways that your organization uses performance data: [check all that apply]
 - □ To justify funding requests
 - □ To improve consumer service
 - □ To administer service provider contracts
 - □ To provide information to stakeholders (governing board, advocacy organizations, local government, etc.)
 - □ For program planning
 - □ Do not use performance data
- 47. On which topics, if any, would you like to receive additional assistance from the technical assistance provider? (Open Response)

Eligibility Screening Module: Initial Screening of ADRC Clients

- 48. When a client contacts the ADRC about long-term services and supports (LTSS), do ADRC staff administer a screening questionnaire to make a preliminary determination of eligibility and need for publicly-funded LTSS?
 - □ Yes
 - □ No
 - Other, please describe _____

49a. If yes, to which of the following populations is the eligibility screening instrument administered ? Check all that apply.

- □ Aged 65 and older
- Physical disability
- □ Intellectual Disability/Developmental Disability
- Brain injury
- □ HIV/AIDS

Date_____

- Medically fragile
- Autism
- Mental illness
- Other (specify _____)

49b. What kind of information is collected? Check all that apply.

- Demographic information (i.e., age, gender, ethnicity, marital status)
- Living arrangements
- □ Caregivers
- Health status
- Activities of daily living (ADL)
- □ Instrumental activities of daily living(IADL)
- Cognitive functions
- □ Troublesome behaviors
- LTSS currently received
- Income
- Assets
- Other, please list _____

Eligibility Screening Module: Financial Eligibility Determination

- 50. How do clients in your state/site complete and file applications for financial eligibility for Medicaid or publicly-funded LTSS? Check all that apply.
 - □ Applications are accessed on-line, printed, completed by hand, and returned to a state or county office.
 - □ Applications are accessed on-line, completed on-line, printed, and returned to a state or county office.
 - □ Applications are accessed on-line, completed on-line, and submitted to the state or county electronically.
 - Paper copy applications are obtained at various locations including _____ [INSERT LOCATIONS], completed by hand, and returned either in person or by mail to a state or county office.
 - □ Other _____
- 51. In what ways do ADRC staff assist clients with financial eligibility applications for Medicaid LTSS Programs? Check all that apply.
 - □ We do not assist clients with financial eligibility applications
 - □ Advise the client where s/he can obtain an application
 - □ Assist the client in completing the application
 - □ Assist the client in collecting the required financial documentation
 - □ Check on the status of the client's application
 - □ Notify the client when the application has been approved/disapproved
 - □ Manage appeals by clients whose applications were not approved
 - Other _____

Date_____

- 52. In what ways do ADRC staff assist clients with financial eligibility applications for publicly-funded LTSS* other than Medicaid LTSS? Check all that apply.
 - □ We do not assist clients with financial eligibility applications
 - □ Advise the client where s/he can obtain an application
 - □ Assist the client in completing the application
 - □ Assist the client in collecting the required financial documentation
 - □ Check on the status of the client's application
 - □ Notify the client when the application has been approved/disapproved
 - □ Manage appeals by clients whose applications were not approved
 - Other ____
 - *Please describe the publicly funded LTSS services in your state. This includes LTSS programs funded solely by state or county ______
- 53. Does your state/site permit presumptive financial eligibility in order to expedite the provision of LTSS to clients while their financial eligibility applications are being processed?
 - □ Yes
 - □ No
 - □ In Progress

Eligibility Screening Module: Functional Assessment

- 54. Does your state/site use a universal, comprehensive assessment instrument for functional (level of care) eligibility determinations for LTSS?
 - Yes
 - No
 - □ No, but in development

55a. If yes, what best describes the kind of instrument your state/site is using? Check one.

- □ A custom-designed instrument developed by state staff
- □ A custom-designed instrument developed by a vendor specifically for our state
- □ An instrument developed by a vendor that is also used by other states
- Other, please list: ______

55b. What best describes the process for how the assessor completes the instrument? Check all that apply.

- □ The assessor completes a paper form while interviewing the client; there is no electronic data entry.
- □ The assessor completes a paper form while interviewing the client and later inputs the data on an electronic form at the office.
- □ The assessor completes an electronic form while interviewing the client, which is later downloaded into an electronic database.
- □ The assessor completes a web-based form while interviewing the client and the client's data is entered "real time" into an electronic database.

Interviewer Initials (or ID) _____ Date_____ Our state/site uses multiple processes, including _____ [SELECT FROM A-D ABOVE]

55c.Do you work with consumers to develop a care plan?

- □ Yes, with all consumers
- □ Yes under certain circumstances (Please specify_____)
- □ No, that is not part of this service

55d.For which of the following populations is the functional assessment used? Check all that apply.

- Aged 65 and older
 Physical disability
 ID/DD
 Brain injury
 HIV/AIDS
 Medically fragile
 Autism
 Mental illness
- 56. The Affordable Care Act requires states to implement Health Insurance Exchanges effective January 1, 2014. States are required to provide a single electronic portal for "real time" financial eligibility determinations for Medicaid and Qualified Health Plans offered through the Exchange.

56als your organization involved in planning for your state's Exchange?

- Yes
- □ No [skip to question57]
- Not Sure.

If Yes, please describe your organization's role role: ______

56b.Is your state/site examining ways to align functional eligibility determination for publiclyfunded LTSS with Medicaid financial eligibility determination carried out through the Exchange website?

- YesNo
- Not Sure.

If Yes, please describe: ______

- 57. Are any of your organization's functions reimbursed under Federal financial participation (FFP) or Federal medical assistance percentage (FMAP)? If so please specify the functions.
 - □ No, none of our functions are reimbursed under FFP or FMAP

Interviewer Initials (or ID) _____

Date_____

□ Yes, the following functions are reimbursed under FFP

□ Yes, the following functions are reimbursed under FMAP

Section D. Organizational Characteristics

These questions are about your organization budget, partnerships, and structure.

58. For the current Fiscal Year, what is the approximate amount of funding from each of the following sources? (In \$ amounts)

Check if you have received funding in prior Fiscal Years	Amount of funding during the current Fiscal Year	Funding source
		Administration on Aging Title IV ADRC Grant
		Administration of Aging Title II Grant
		CMS Real Choice Systems Change Grants
		CMS Person-Centered Hospital Discharge Planning Grant
		Patient protection and Affordable Care Act Grant
		Veteran's Administration
		Money Follows the Person Demonstration
		State Transformation Grant
		Alzheimer's Disease Demonstration Grant
		Evidence-Based Disease Prevention Grant
		Program of All-Inclusive Care for the Elderly (PACE)
		Medicare Improvement for Patients and Providers Act (MIPPA)
		Respite Care Act funds
		Rehabilitation Services Administration (RSA)
		Substance Abuse and Mental Health Services Administration (SAMHSA) - Mental Health Transformation Grant
		Agency for Health Care Research and Policy - Chronic Disease Self-Management Grant
		Administration for Children and Families, Office of Community

Interviewer Initials	; (or ID)	Date
Check if you have received funding in prior Fiscal Years	Amount of funding during the current Fiscal Year	Funding source
		Services - Low Income Home Energy Assistance Program (LIHEAP)
		Health Resources and Services Administration HIV/AIDS Bureau - Ryan White Fund
		State Unit on Aging
		State General Revenue
		County of local government
		Private entities/grants - Hospitals or other businesses
		Medicaid for Direct Services (state and federal)
		Medicaid for Federal Financial Participation
		Care Transitions Income
		Consumer Fees or Cost Sharing
		Charitable Donations
		Other, please specify
		Total Budget for FY 2013

59. What best characterizes the operation of your agency?

- Single-point of entry: one agency maintains a knowledgebase on LTSS options and assists consumers in making decisions about the best and most feasible options for LTSS
- No wrong door: multiple agencies are knowledgeable about LTSS options and cooperate to assist consumers regardless of which agency the consumer first contacts.
- 60. Do you identify your structure as any of the following:
 - □ Independent, non-profit
 - □ Part of city government
 - □ Part of county government
 - □ Part of COG or RPDA
 - Other. Specify: _____
- 61. [ADRCs only] What organizations comprise the core operating organizations? [BLANK RESPONSE BOXES WILL BE POPULATED BY DROP-DOWN BOXES SHOWING YES/NO]

Date_____

Organization	Core Operating Organization? (Yes/No)
ААА	
State Unit on Aging	
Veterans Organization	
Alzheimer's Association	
Other Aging Services Organization	
Centers for Independent Living	
Vocational Rehabilitation Departments	
Other Disability Services Organization	
Community Mental Health	
County or Regional Council of Governments	
County Government Office or Agency	
Local Housing Authority	
State or Local Medicaid Agency	
211	
Other Human Services of Social Service Provider (please specify)	

62. [FOR EACH OF THE CORE OPERATING ORGANIZATIONS]: Please describe your relationship with other core operating organizations at your site and the functionality of the site in meeting the objective of improving and streamlining access to information, assistance, and long-term services and supports for older adults, persons with disabilities, and their families. Would you describe the current status as having a solid working relationship? Please provide as much detail as possible.

Date_____

63. With which organizations do [insert ID] have a partnership? What is the strength of the relationship, as well as the type of partnership agreement and shared resources? [BLANK RESPONSE BOXES WILL BE POPULATED BY DROP-DOWN BOXES SHOWING OPTIONS EXPLAINED IN EACH COLUMN]

			Partnership Agreement	Shared Resources
	Partner (Check all the apply)	Functionality of Partnership (1=Weak functionality; 2=Moderately functional/ functional in some areas; 3=Highly functional)	Select from the following list: •Funding relationship •Formal MOU •Contract •Cooperative •Informal working relationship • Other, please specify	Select from the following list: Co-located staff Shared monetary resource Information sharing Joint training Joint sponsorship of programs Shared non-monetary resources (i.e. office space) Shared data No shared resources
State Departments (with cabinet-level	the apply)	Tunctional)	specify	
secretaries):				
Health				
Human Services				
Aging				
Other (specify):				
State Agencies (located within state				
departments):				
Aging				
Developmental Disabilities				
Acquired or Late-Onset Disabilities				
Mental Health				
Medicaid				
Housing				
Education				
Other (specify):				

Process Evaluation Survey: Local-Level

Interviewer	Initials	(or ID) _	
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Local Government Agencies		
Area Agency on Aging		
County Health Department		
County Medicaid office		
County Department on Aging		
County Department on Disability		
County Housing Office		
Library		
Other (specify):		
Federal Agencies:		
Local Veterans Administration		
Local Indian Health Service		
Other (specify):		
Organizations Providing Direct Services:		
211 or other call center		
Community Health Clinic		
Community Mental Health Clinic		
Deaf Service Center		
Hospital/Medical Center		
School for the Blind		
School for the Deaf		
The ARC		
United Way		
Vocational/Rehabilitation Services		
Other (specify):		
Advocacy/Referral Organizations:		
AIDS Coalition		
Alzheimer's Association		
American Council of the Blind		
Autism Society state/regional chapter		

Process Evaluation Survey: Local-Level

Interviewer Initials (or ID)	Date
Brain Injury Association state/regional chap	oter de la constant d
Centers for Independent Living	
Easter Seals	
Epilepsy Foundation state/regional chapter	
National Association of Mental Illness state/regional chapter	
National Autism Association state/regional chapter	
National Multiple Sclerosis Society state/regional chapter	
State Association for the Deaf	
United Cerebral Palsy	
Other (specify):	

Date_____

- 64. Approximately how many FTEs (Full-time equivalents) perform each of the following functions?
 - I&R/I&A
 - Options counseling/counseling to provide in-depth person centered decision support
 - Benefits counseling/eligibility determination
 - Care transition services
 - Crisis intervention services
 - Independent Living services
 - Advocacy services
 - Providing administrative or other support for the above functions
- 65. How many front line staff are Alliance of Information and Referral Systems (AIRS) certified?
 - Number of AIRS certified staff
 - Total number of front line staff
- 66. Is your organization paid on a fee-for-service or per-unit basis for performing any of the following services for a client? (Please check all that apply)
- □ Information/referral
- Options counseling
- □ Screening
- Assessment
- Application assistance
- Transition support
- □ Other, please specify
 - 67. [if any of the boxes are checked in previous question] What is the source of the fee-forservice or per-unit payments?
- Medicare
- Medicaid waiver
- Medicaid state plan
- Medicaid managed care organization
- □ State-funded program other than Medicaid
- Private health plan
- Provider
- □ Other, please specify

Section E. LTSS Environment

- 68. Since this [insert ID] started serving consumers, has there been an impact on the LTSS or Home and Community-Based (HCBS) system in your community?
 - □ There has been an **increase in the** <u>**number**</u> of LTSS providers.
 - □ There has been a **decrease in the** <u>number</u> of LTSS providers.
 - □ There has been an **increase in the <u>quality</u>** of LTSS services.

- □ There has been a **decrease in the <u>quality</u>** of LTTS services.
- 69. Please add any final thoughts about [insert ID] and either its operations and/or its results (Open response).

Date_____

PROCESS EVALUATION — STATE-LEVEL WEB-BASED SURVEY

INSTRUCTIONS TO WEB SURVEY PROGRAMMER: PREPOPULATE (PP) INFORMATION IN [] BASED ON SITE DIRECTOR TYPE (DT) OR ID NUMBER (ID). THESE PREPOPULATED DATA WILL BE USED THROUGHOUT THE SURVEY TO ORIENT THE RESPONDENT BASED ON NAME OF SITE. EACH SITE WILL ALSO RECEIVE A UNIQUE ID NUMBER WITH THE NAME OF THE SITE.

[ID Number - ID]

Name of State-level Site

[Director Type - DT]

— ADRC (State-level)

Section A. Baseline Characteristics

The first set of questions focus on characteristics of your aging and disability network **PRIOR** to receiving an ADRC grant and the influence on your aging and disability network.

 Click <u>here</u> to review federal funding received by your state since [ENTER YEAR OF RECEIPT OF ADRC GRANT] for the development of ADRCs. On a scale of 1 to 5, how would you rate your state's progress since [YEAR] in improving access to the following services, with 1 being "Poor" and 5 being "Excellent?"

	Po	Poor			Excellent
	1	2	3	4	5
Information, referral, and					
awareness of LTSS options					
Options counseling and					
assistance					
Streamlined eligibility					
determination for public					
programs					
Person-centered transition					
support					

2. States used federal grant funding in a variety of ways to develop their aging and disability networks. On a scale of 1 to 5, indicate the importance of each of the following in improving access to LTSS in your state since YEAR, with 1 being "not important at all" and 5 being "very important."

	Not important at all				Very important
	1	2	3	4	5
Development of					
new partnerships					
Staffing					

Interviewer Initials (or ID) _____

Date____

Advisory council			
Development of shared data systems			
Web-based information and referral			
Other			

- 3. When your state applied for its first ADRC grant in YEAR, what were your goals for the project? Check all that apply.
 - □ To better integrate the delivery of LTSS for the aging and disability populations
 - □ To develop or strengthen agency/organizational partnerships
 - □ To improve data or IT infrastructure
 - □ To improve marketing or awareness efforts related to Long Term Care Services and Supports (LTSS)
 - □ To expand services to additional populations
 - □ To expand services to additional geographic locations
 - Other, please specify _____
- 4. Please indicate how your State initially selected local sites to receive ADRC funds.
 - □ Selected sites that were already integrated to help them maintain or expand their efforts
 - □ Selected sites that were partially integrated to support further integration
 - □ Selected sites that were fragmented to encourage integration
 - □ Selected AAAs already in operation
 - □ Selected organizations that were currently serving the aging community (e.g., senior centers)
 - □ Selected sites that were currently serving the disability community (e.g., CILS)
 - Selected county offices because existing infrastructure was available
 - □ Other, please specify

Indicate the extent to which the grants your state received for ADRC development contributed to the following:

	Very much	Somewhat	Very little
increase the skills of existing staff	0	0	0
recruit or attract more experienced staff	0	0	0
increase/expand populations served	0	0	0
increase the number of consumers served	0	0	0
increase the number of partnerships	0	0	0
increase range of services offered	0	0	0
make other changes (please specify)	0	0	0

5. How has the ADRC grant(s) affected the resources or resource allocation at your organization/network or within your state? If there is more than one ADRC in your state, select the box if the item is true for at least one ADRC. (Select all that apply)

	At the Site or Local Level	At the State Level
Helped us leverage other funds (including reimbursement for specific functions)		
Improved staff training opportunities		
Increased service efficiency		
Contributed to the development of a statewide database of Long Term Supports and Service and/or consumers		
Promoted the development of standard operating procedures		
Increased the level of coordination between organizations serving older individuals and individuals with disabilities		
Improved awareness/marketing campaigns/activities		

- 6. Within the last 12 months, has the state conducted a community long-term service and support needs assessment?
 - □ Yes , we assessed the needs in all [ADRC communities in our State
 - □ Yes, we assessed the needs in some of the [ADRC or communities in our State
 - □ No, but we did complete a community needs assessment, for at least some of the [ADRC or communities in our State within the past three years
 - □ No, a community needs assessment was not completed within the past three years

This next set of questions is designed to gather information about the conditions in the service network for your state. Please think about the status of your state as a whole.

7. Community Needs

Barriers to receiving Long Term Supports and Service services

What barriers do individuals in your state encounter in accessing LTSS? For each barrier listed below, indicate the extent to which this was a barrier in YEAR when the state first began developing its ADRC network and the extent to which it is currently a barrier.

Use drop-down menu to select "not a barrier," "sometimes a barrier," or "often a barrier"

Process Evaluation Survey: State-Lev	ei	
rviewer Initials (or ID) Date		
	YEAR	2012
Non-availability of needed services and supports		
Limits on Medicaid HCBS waiver enrollment		
Limits on enrollment in state-only funded LTSS		
Quality of available LTSS		
Lack of health insurance		
Providers not accepting consumers with Medicaid		
Lack of accommodations for consumers with disabilities		
Language barriers		
Cultural barriers		
Religious barriers		
Sexual orientation barriers		
People needing services do not have a permanent address		
Consumers lack transportation		
Stigma, discrimination and prejudice against older adults		
Stigma, discrimination and prejudice against persons with disabilities		
Providers have high staff turnover		
Providers lack appropriately trained staff		
Service provider hours/locations are hard to access		
Other, Please specify:		

8. Service Availability/Choice	Please indicate the Current availability of the following services within your service	For the following se extent is there prov Service has (<i>no; lim</i> provider choice	vider choice?
	area	Prior to first ADRC grant	Currently
Safe and affordable housing options	Adequate availability/Available but inadequate to meet need/Not available	No/Limited/Adequate	No/Limited/Adequate
Peer support services/groups	Adequate availability/Available but inadequate to meet need/Not available	No/Limited/Adequate	No/Limited/Adequate

8. Service Availability/Choice	Please indicate the Current availability of the following services within your service	For the following services, to what extent is there provider choice? Service has (<i>no; limited; adequate</i>) provider choice		
	area	Prior to first ADRC grant	Currently	
HCBS Medicaid Waiver Programs	Adequate availability/Available but inadequate to meet need/Not available	No/Limited/Adequate	No/Limited/Adequate	
Caregiver Support (i.e. respite programs, support groups, or counseling)	Adequate availability/Available but inadequate to meet need/Not available	No/Limited/Adequate	No/Limited/Adequate	
Nutrition Programs	Adequate availability/Available but inadequate to meet need/Not available	No/Limited/Adequate	No/Limited/Adequate	
Employment services	Adequate availability/Available but inadequate to meet need/Not available	No/Limited/Adequate	No/Limited/Adequate	
Education services	Adequate availability/Available but inadequate to meet need/Not available	No/Limited/Adequate	No/Limited/Adequate	
Legal services	Adequate availability/Available but inadequate to meet need/Not available	No/Limited/Adequate	No/Limited/Adequate	
Transportation services	Adequate availability/Available but inadequate to meet need/Not available	No/Limited/Adequate	No/Limited/Adequate	
Socialization/recreation programs	Adequate availability/Available but inadequate to meet need/Not available	No/Limited/Adequate	No/Limited/Adequate	
Mental/behavioral health services	Adequate availability/Available but inadequate to meet need/Not available	No/Limited/Adequate	No/Limited/Adequate	
Ombudsman services	Adequate availability/Available but inadequate to meet need/Not available	No/Limited/Adequate	No/Limited/Adequate	
Health prevention and screening services	Adequate availability/Available but inadequate to meet need/Not available	No/Limited/Adequate	No/Limited/Adequate	
Emergency services/crisis intervention	Adequate availability/Available but inadequate to meet need/Not available	No/Limited/Adequate	No/Limited/Adequate	
Nursing home transition programs	Adequate availability/Available but inadequate to meet need/Not available	No/Limited/Adequate	No/Limited/Adequate	

8. Service Availability/Choice	Please indicate the Current availability of the following services within your service area	For the following se extent is there prov Service has (<i>no; lim</i> provider choice Prior to first ADRC grant	ider choice?	
Hospital transition programs				
Nursing home (institutional) diversion programs	Adequate availability/Available but inadequate to meet need/Not available	No/Limited/Adequate	No/Limited/Adequate	
Nursing home services	Adequate availability/Available but inadequate to meet need/Not available	No/Limited/Adequate	No/Limited/Adequate	
Assisted living services				
Shared living programs				
Adult day care				
Consumer-directed LTSS				
Income assistance	Adequate availability/Available but inadequate to meet need/Not available	No/Limited/Adequate	No/Limited/Adequate	
Energy assistance	Adequate availability/Available but inadequate to meet need/Not available	No/Limited/Adequate	No/Limited/Adequate	
Personal care/attendant services	Adequate availability/Available but inadequate to meet need/Not available	No/Limited/Adequate	No/Limited/Adequate	
Medicaid HCBS waiver programs	Adequate availability/Available but inadequate to meet need/Not available	No/Limited/Adequate	No/Limited/Adequate	
Independent Living supports (e.g., skills training, vocational programs, peer support)	Adequate availability/Available but inadequate to meet need/Not available	No/Limited/Adequate	No/Limited/Adequate	
Other, please specify	Adequate availability/Available but inadequate to meet need/Not available	No/Limited/Adequate	No/Limited/Adequate	

Date_____

Section B. Organizational Characteristics

These questions are about your organization or network budget, partnerships, and structure.

9. For the current Fiscal Year, what is the approximate amount of funding from each of the following sources? (In \$ amounts)

Check if you have received funding in prior Fiscal Years	Amount of funding during the current Fiscal Year	Funding source
		Administration on Aging Title IV ADRC Grant
		Administration of Aging Title II Grant
		CMS Real Choice Systems Change Grants
		CMS Person-Centered Hospital Discharge Planning Grant
		Patient protection and Affordable Care Act Grant
		Veteran's Administration
		Money Follows the Person Demonstration
		State Transformation Grant
		Alzheimer's Disease Demonstration Grant
		Evidence-Based Disease Prevention Grant
		Program of All-Inclusive Care for the Elderly (PACE)
		Medicare Improvement for Patients and Providers Act (MIPPA)
		Respite Care Act funds
		Rehabilitation Services Administration (RSA)
		Substance Abuse and Mental Health Services Administration (SAMHSA) - Mental Health Transformation Grant
		Agency for Health Care Research and Policy - Chronic Disease Self-Management Grant
		Administration for Children and Families, Office of Community Services - Low Income Home Energy Assistance Program (LIHEAP)
		Health Resources and Services Administration HIV/AIDS Bureau - Ryan White Fund
		State Unit on Aging

Interviewer Initials (or ID)

Date

		Dutc
Check if you have received funding in prior Fiscal Years	Amount of funding during the current Fiscal Year	Funding source
		State General Revenue
		County of local government
		Private entities/grants - Hospitals or other businesses
		Medicaid for Direct Services (state and federal)
		Medicaid for Federal Financial Participation
		Care Transitions Income
		Consumer Fees or Cost Sharing
		Charitable Donations
		Other, please specify
		Total Budget for FY 2013

Interviewer Initials (or ID) _____

Date_____

10. With which organizations do [insert ID] have a partnership? What is the strength of the relationship, as well as the type of partnership agreement and shared resources? [BLANK RESPONSE BOXES WILL BE POPULATED BY DROP-DOWN BOXES SHOWING OPTIONS EXPLAINED IN EACH COLUMN]

				Shared
				Resources
				Select from
				the following
			Partnership	list:
			Agreement	□ Co-located staff
			Select from	Shared
			the following	monetary resource
			list:	□ Information
		Functionality	• Funding	sharing Joint training
		of Partnership	relationship •Formal	☐ Joint training
		runnersnip	MOU	sponsorship of
		(1=Weak functionality;	 Contract Cooperative 	programs Shared non-
		2=Moderately	•Informal	monetary
	Partner	functional/	working	□ resources (i.e.
	(Check	functional in some areas;	relationship • Other,	office space) Shared data
	all the	3=Highly	please	No shared
	apply)	functional)	specify	resources
State Departments (with cabinet-level				
secretaries):				
Health				
Human Services				
Aging				
Other (specify):				
State Agencies (located within state				
departments):				
Aging				

Interviewer Initials	(or ID)	
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Developmental Disabilities			
Acquired or Late-Onset Disabilities			
Mental Health			
Medicaid			
Housing			
Education			
Other (specify):			
Local Government Agencies			
Area Agency on Aging			
County Health Department			
County Medicaid office			
County Department on Aging			
County Department on Disability			
County Housing Office			
Library			
Other (specify):			
Federal Agencies:			
Local Veterans Administration			
Local Indian Health Service			
Other (specify):			
Organizations Providing Direct Servic	es:		
211 or other call center			
Community Health Clinic			
Community Mental Health Clinic			
Deaf Service Center			
Hospital/Medical Center			
School for the Blind			
School for the Deaf			
The ARC			
United Way			

Interviewer Initials (or ID)	Date_		
Voca	ational/Rehabilitation Services		
Othe	er (specify):		
Adv	ocacy/Referral Organizations:		
AIDS	S Coalition		
Alzh	neimer's Association		
Ame	erican Council of the Blind		
Auti	ism Society state/regional chapter		
Brai	n Injury Association state/regional		
char	pter		
Cent	ters for Independent Living		
East	ter Seals		
Epile	epsy Foundation state/regional		
char	pter		
Nati	ional Association of Mental Illness		
state	e/regional chapter		
Nati	ional Autism Association		
state	e/regional chapter		
	ional Multiple Sclerosis Society		
state	e/regional chapter		
Stat	e Association for the Deaf		
Unit	ted Cerebral Palsy		
Othe	er (specify):		

Date_____

- 11. Approximately, how many FTEs (Full-time equivalents) at the state level perform each of the following functions?
 - Information & Referral /Information & Assistance (I&R/I&A)
 - Options counseling/counseling to provide in-depth person centered decision support
 - Benefits counseling/eligibility determination
 - Care transition services
 - Crisis intervention services
 - Independent Living services
 - Advocacy services
 - Providing administrative or other support for the above functions
- 12. At the State level, how many FTE (Full-time equivalents) are dedicated to working with the ADRC(s) in your State?
- 13. Is your organization paid on a fee-for-service or per-unit basis for performing any of the following services for a client? (Please check all that apply)
 - □ Information/referral
 - Options counseling
 - □ Screening
 - Assessment
 - □ Application assistance
 - □ Transition support
 - Other, please specify
 - 14. . [if any of the boxes are checked in previous question] What is the source of the fee-forservice or per-unit payments?
 - Medicare
 - Medicaid waiver
 - Medicaid state plan
 - Medicaid managed care organization
 - □ State-funded program other than Medicaid
 - Private health plan
 - Provider
 - □ Other, please specify

Section D. Long-Term Service and Support Environment

15. Please add any final thoughts about [insert ID] and either its operations and/or its results (Open response) ______

Date

Attachment B: PARTICIPANT EXPERIENCE SURVEY

INSTRUCTIONS TO ABT SRBI: PREPOPULATE (PP) INFORMATION IN [] FROM CLIENT SCREENING TOOL (ES) AND DATA COLLECTION (DC) TOOLS. THESE PREPOPULATED DATA WILL BE USED THROUGHOUT THE SURVEY TO ORIENT THE RESPONDENT TO THEIR EXPERIENCE WITH THE AGENCY AT THE TIME OF THE CONTACT IN WHICH THEY WERE SCREENED FOR ELIGIBILITY FOR THE STUDY.

[ID Number – Footer ES/DC] [Agency Type – ES 2] □ ADRC [Need Spanish interpreter – DC 6] □ Yes □ No [Need TTY service - DC 7] □ Yes □ No [Preferred call time – DC 5] PP1. [Agency Name – ES 1] _____ PP2. [Respondent Type – ES 3] □ Self Parent □ Child □ Other relative □ Friend Neighbor □ Client/Patient Other: _____ DK

PARTICIPANT EXPERIENCE SURVEY

Interviewer Initials (or ID) _____ Date □ REF PP3. [Study Type – ES 5/ES 6] □ Older Adult (response to $5=\geq 60$) □ Disability (yes to any 6a-6f) PP4. [Result of Contact – ES 7] Options Counseling □ Public benefits counseling /eligibility determination Information & Referral /Information & Assistance ______ □ Crisis intervention □ Independent living services Transition Assistance ______ PP5. [Date of Contact – DC 1] (month, date, year) __/__/__ PP6. [Reason for contacting the agency (client's need at time of the time of contact) – DC 8]

PP7. [Mode of Contact – DC 10]

- □ In-person (visit)
- □ Telephone (call)
- PP8. [Respondent Name DC 2]
- PP9. [Respondent Age ES 5]

Date

3. Introduction

"Hello, may I speak to ______ **[insert PP8]**? (**IF ASKED:** I am calling on behalf of the United States Administration on Aging about his/her satisfaction with a recent service experience.)

Hello, my name is [insert survey administrator name].

[IF INTRO TO AoA ABOVE IS READ, THEN READ]: I am calling to ask about the quality of your experience with the [insert PP1] on [insert pp5] about [REASON FOR CONTACT PP6].

[IF INTRO TO AoA ABOVE IS NOT READ]: I am calling on behalf of the United States Administration on Aging to ask about the quality of your experience with the **[insert PP1]** on **[insert pp5]**.

During that **[insert PP7]** you talked to staff about service needs for **[insert PP2]**. (At that time you said that you would be willing to participate in an interview about your experience). Can I ask you some questions about that experience? It will only take 20 minutes. Is now a good time for the interview about your experiences?

	Yes [If yes,	skip to	Statement	of Informed	Consent]
--	--------------	---------	-----------	-------------	----------

	No, this is a bad time	[Continue]
--	------------------------	------------

□ No, I don't remember calling agency [Terminate]

□ REF, no I don't want to do an interview **[Terminate]**

When would be a better time to call back to do the interview?

Gives call back time _____

If REF, can I ask why you are not interested in participating?

Thank you for your time [end the call].

Date_____

4. **Participant Experience Survey**

If you have any questions during the interview, please stop me and ask me. Also, please let me know if you do not understand a question or if you would like me to repeat it.

Section A. Initial Contact

The first set of questions has to do with the experiences that you had when you [insert PP7] the [insert PP1] on [insert PP5].

- 1. When you contacted the **[insert PP1]**, you said that the main reason for your **[insert PP7]** was **[insert PP6]**. Is that correct?
 - □ YES [If yes, skip to qA3, else continue to qA2]
 - □ NO
 - □ DK
 - \Box REF
- 2. I'm sorry; please tell me, what was the **main** reason that you contacted the **[insert PP1]** on **[insert PP5]**? **[RECORD RESPONSE AND CHECK APPRORIATE RESPONSE BELOW]**

- □ Peer support services/groups
- □ HCBS Medicaid Waiver Programs
- □ Caregiver Support (i.e. respite programs, support groups, or counseling)
- □ Nutrition Programs
- Employment services
- □ Education services
- Opportunities to develop advanced directives
- □ Transportation services
- Opportunities for socialization/recreation
- Mental health services
- Ombudsman services/Services related to abuse or neglect
- $\hfill\square$ Health prevention and screening services
- □ Services for emergent cases/Crisis intervention
- □ Transition programs (from hospitals, nursing homes etc.)
- In Nursing home (institutional) diversion programs

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[□] Safe and affordable housing options

Date_____

- □ Nursing home/residential beds
- □ Income assistance
- □ Energy assistance
- □ Personal care services
- □ Independent Living services (e.g., home modification, attendant care)
- □ Independent Living Skills training
- □ Other
- 3. From where did you *first* find out about the [insert PP1]? [CHECK MOST APPROPRIATE RESPONSE]
 - □ Family member, friend or other acquaintance
 - □ Hospital/Clinic/Doctor
 - □ Nursing Home/Assisted Living
 - Phone Book
 - □ Brochure/Flyer
 - Referral from senior center
 - □ Referral from another agency/organization
 - □ Through work
 - □ Internet/Website
 - □ Media/Newspaper/TV/Radio
 - Other _____
- 4. Was [insert PP1] the first organization that you contacted about [insert PP6]?
 - □ Yes
 - \square No
 - □ DK
 - □ REF

Section B. Agency Efficiency

These next questions are about your experience during your contact with [insert PP1].

- 1. [ASK ONLY IF PP7 = IN-PERSON (VISIT); ELSE SKIP TO Qb2] When you contacted the [insert PP1], how long did you wait during the initial call to talk with someone who could help you with [insert PP6]?[DO NOT READ RESPONSES, PLEASE CHECK APPROPRIATE RESPONSE]
 - Minimal wait (less than five minutes)
 - □ Five to 10 minutes

Date

- □ 10 minutes to 20 minutes
- □ Over 20
- □ DK
- □ REF

[Following response, skip to qB4].

- 2. Were you able to talk to a representative during your first contact?
 - □ YES [If yes, skip to qB4, else continue to qB3]
 - □ NO
 - □ DK
 - □ REF
- Do you recall how many additional contacts (including calls where you left a message on a machine) you had to make before you were able to talk with a representative? [DO NOT READ RESPONSES]
 - □ None
 - □ One
 - □ Two
 - □ Three
 - □ Four or more
- 4. Including the contact that you made (the first time you talked with someone) with the [insert PP1] on [insert PP5], how many times have you had to describe your request for services, or explain what you needed? [DO NOT READ RESPONSES]
 - One time
 - Two times
 - □ Three or four times
 - □ Five or more times
- 5. Throughout your contact with **[insert PP1]** did any of the following circumstances reduce or prevent your ability to resolve your issue? **[CHECK ALL THAT APPLY]**
 - □ [insert PP1] inconvenient hours of operations
 - Difficulty reaching [insert PP1] staff
 - □ Language or communication problems
 - Lack of Staff professionalism
 - □ Lack of Staff knowledge
 - □ Lack of Staff follow through

Section C. Effectiveness of Agency Representative

- 1. Did you feel the representative at **[insert PP1]** paid close attention to what you were saying?
 - \Box YES
 - \square NO
 - □ SOMEWHAT
 - □ DK
- 2. In your opinion, how knowledgeable was the representative at [insert PP1]? Were they...
 - □ Very knowledgeable
 - □ Somewhat knowledgeable
 - □ Not very knowledgeable
 - Not at all knowledgeable
 - □ DK
- 3. Was the information you received from the representative at **[insert PP1]** clear and understandable?
 - Very clear and understandable
 - □ Somewhat clear and understandable
 - □ Not very clear or understandable
 - □ Not at all clear or understandable
 - □ DK
 - □ REF
- 4. Based on your request for [insert PES A2 if answered; else insert PP6] when you contacted [insert PP1], did the representative ask questions that made you feel that your needs were being correctly assessed?
 - □ YES
 - □ NO
 - □ DK
 - □ REF

- 5. If assistance was requested, did the representative at **[insert PP1]** work with you to develop an action plan outlining your next steps in meeting your long terms care needs?
 - □ YES [if yes go to C6; otherwise skip to D1]
 - □ NO
 - □ N/A
 - D DK
 - □ REF
- 6. Does the plan accurately reflect your needs and preferences?
 - □ Yes
 - \square No
 - □ Somewhat
 - □ N/A
 - □ DK
 - □ REF

Section D. Institutional Diversion

- 1. When you contacted the **[insert PP1]**, were you considering a move to a long-term care setting, such as a nursing home, for **[insert PP2]**?
 - □ YES
 - \square NO
 - □ DK
- 2. Did the representative you talked to at the **[insert PP1]** on **[insert PP5]** help you to understand other choices in addition to a nursing home or other long-term care setting?
 - □ YES
 - \square NO
 - □ N/A
 - □ DK
 - \Box REF

3. On a scale from 0% to 100% what is the percent chance that you, or the person for whom you contacted the agency will have to move into a nursing home within the next five years?

______ % PROMPT 0 10 20 30 40 50 60 70 80 90 100%

OR

Section E. Assistance with Services

From the next set of questions, we would like to learn about your experiences in obtaining the services for which you contacted the **[insert PP1]** on **[insert PP5]**.

- 1. Did you receive the service that you needed directly from them or indirectly by a referral to another agency?
 - Directly ([insert PP1] provided the service) [If selected, skip to Section E.1]
 - □ Indirectly (you were referred elsewhere)
 - Both/some services provided by **[insert PP1]** staff and some through referrals
 - □ DK
 - □ REF
- 2. Did the representative of the **[insert PP1]** help you to connect with the services you needed?

PROBE: TRANSFER YOUR CALL, PROVIDE A TELEPHONE NUMBER OR ADDRESS, OR SET UP A CALL BACK FROM AN AGENCY/ORGANIZATION.

- YES [If yes, continue to qE3; else skip to Section E1]
- \Box NO
- □ DK
- □ REF
- 3. Did the representative of the **[insert PP1]** transfer your call to an agency/organization that provided you with your needed/requested services?
 - □ YES [If yes, skip to qE6; else, continue to qE4]
 - \Box NO
 - □ **D**K
 - □ REF

- 4. Did the representative give you contact information (telephone number, address, web address) of an agency/organization that provided you with needed/requested services?
 - □ YES [If yes, skip to qE6; else continue to qE5]
 - □ NO
 - □ DK
 - □ REF
- 5. Did the representative contact the needed service provider and arrange for them to contact you?
 - □ YES [If yes, continue to qE6; else, skip to Section E.1]
 - \square NO
 - D DK
- 6. When you contacted the needed service provider, did that provider already have the information that you provided to **[insert PP1]** or did you have to start the process again?**[RECORD RESPONSE AND CHECK APPRORIATE RESPONSE BELOW]**
 - Provider had the information
 - Provider had the information but it wasn't correct or it was incomplete had to start the process again
 - □ Provider did not have the information had to start the process again
 - □ DK
 - □ REF

PARTICIPANT EXPERIENCE SURVEY

	wer Initials (or ID)
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- 7. To what supports and services were you transferred or referred?[RECORD RESPONSE AND CHECK APPRORIATE RESPONSE BELOW]
 - □ Safe and affordable housing options
 - □ Peer support services/groups
 - HCBS Medicaid Waiver Programs
 - □ Caregiver Support (i.e. respite programs, support groups, or counseling)
 - □ Nutrition Programs
 - Employment services
 - □ Education services
 - Opportunities to develop advanced directives
 - □ Transportation services
 - □ Opportunities for socialization/recreation
 - □ Mental health services
 - $\hfill\square$ Ombudsman services/Services related to abuse or neglect
 - □ Health prevention and screening services
 - □ Services for emergent cases/Crisis intervention
 - □ Transition programs (from hospitals, nursing homes etc.)
 - □ Nursing home (institutional) diversion programs
 - Nursing home/residential beds
 - □ Income assistance
 - □ Energy assistance
 - □ Personal care services
 - □ Medicaid waiver assistance
 - □ Independent Living services (e.g., skills training, peer support)
 - Other _____
 - □ None
 - □ DK
 - □ REF

Date_____

- 8. What was the result of the referral?[READ FROM THE FOLLOWING LIST AND CHECK THE MOST APPROPRIATE RESPONSE]
 - □ [insert PP2] received services [If selected, skip to Section E.1]
 - □ [insert PP2] DID NOT receive services
 - □ It's too soon to tell [If selected, skip to Section E.1]
- 9. You said that **[insert PP2]** did not receive the services through the referral, why do you think that is? **[RECORD RESPONSE AND CHECK APPRORIATE RESPONSE(S) BELOW]**
 - □ The services were not what [insert PP2] wanted/needed
 - □ The service/program is not accepting applications/there is a waitlist
 - □ It is too expensive
 - □ There is no transportation
 - □ The service or program is not available at times needed
 - □ [insert PP2] is not eligible
 - □ I tried to contact the service or program that was referred, but was busy/unavailable
 - □ Line was busy
 - □ Wait time too long
 - Other _____
 - □ Have not yet contacted, but plan to
 - □ Have no plans to contact the service or program
 - Please Specify reason _____
 - □ DK
 - □ REF

Section E.1. Assistance with Medicaid Eligibility Determination

The next set of questions has to do with information and help that you may have received from the **[insert PP1]** on whether or not you are eligible for **[insert name of state Medicaid program]**.

[IF RESPONDENT SAYS THAT THEY ALREADY RECEIVE MEDICAID BENEFITS OR THAT THEY DID NOT TALK ABOUT THIS WITH THE AGENCY REPRESENTATIVE, THEN SKIP TO SECTION E.2].

- 1. Did you receive specific information on applying for [insert name of state Medicaid program]?
 - □ YES
 - □ NO [If no, skip E.1.5; else continue to E.1.2]
 - □ DK
 - \Box REF

Interviewer	Initials	(or	ID)	
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- 2. Did you complete a [insert name of state Medicaid program] application through the [insert PP1]?
 - □ YES [If yes, continue to qE1.3; else skip to Section E1.4].
 - □ NO
 - □ DK
 - □ REF

If no, please explain why _____

- 3. Were you provided with help by the agency in completing the **[insert name of state Medicaid program]** application?
 - \Box YES
 - □ NO
 - □ DK
 - □ REF
- 4. How long did you wait to find out if you qualified for [insert name of state Medicaid program]? [DO NOT READ RESPONSES, CHECK APPRORIATE RESPONSE]
 - □ One day or less
 - $\hfill\square$ Two to six days
 - One week
 - D More than one week, but less than a month
 - \Box Over a month
 - □ Still waiting
 - □ DK
 - □ REF
- 5. Were you given information by the agency about other insurance resources besides [insert name of state Medicaid program]?
 - \Box YES
 - □ NO
 - □ DK
 - □ REF

lf \	/es,	please	specif	/		

Section E.2. Assistance with One-on-One Options Counseling

- 6. Did you request, need, or accept a conversation with a counselor (e.g., one-on-one counselor, case management), in other words, someone to talk with about understanding and selecting the long-term services (beyond information and referral)?
 - \Box YES
 - **NO [If no, skip to Section E3; else continue to qE.2.2]**
 - □ DK
 - □ REF
- 7. Did the counselor (e.g., one-on-one counselor, case manager) visit you in your home?
 - □ YES
 - □ NO
 - □ DK
 - □ REF
- 8. Following the first meeting, did the counselor (e.g., one-on-one counselor, case manager) follow-up with you either by phone calls and/or additional in-home visits?
 - \Box YES
 - \square NO
 - □ DK
 - □ REF
- 9. Did the information and support that the counselor (e.g., one-on-one counselor, case manager)gave you help you to:

	Yes,	Yes,	No,	No,	n/a	
	definitely	probably	probably not	definitely not		
a. Better understand your long term service and support options?						
b. Make a decision about long-term support services?						
c. Access (i.e., streamline) public programs?						
d. Access private services including services that you have to pay for yourself?						
e. Obtain long-term support planning or services that fit within your budget?						

- 10. How satisfied or dissatisfied are you with the service you received from the counselor (e.g., one-on-one counselor, case manager)?
 - Very satisfied
 - Somewhat satisfied
 - □ Somewhat dissatisfied
 - Very dissatisfied

Section E3. Care Transition Services

- 1. Did you receive services that helped you to transition from a hospital or other acute care facility into the community?
 - □ YES
 - **NO** [If no, skip to Section F; else continue to qE3.2]
 - □ DK
- 2. Did you receive any of the following services?
 - A contact before discharge to assess your discharge needs
 - □ An explanation of your discharge instructions
 - Post discharge services such as transportation to the doctor, help filling prescriptions, household help
 - □ Follow up within 48 hours of discharge
- 3. How satisfied or dissatisfied are you with the transition service you received?
 - □ Very satisfied
 - $\hfill\square$ Somewhat satisfied
 - □ Somewhat dissatisfied
 - □ Very dissatisfied

Section F. Services Received from the [insert PP1]

Now I'd like to ask you some questions about the overall results of your contact with [insert PP1].

- 1. Did you ever receive the service that you were seeking based on your contact with [insert PP1]?
 - □ YES, within one week of contact
 - □ YES, after more than a week
 - □ NO [If no continue to qF2; else, skip to qF3]
 - □ DK
 - □ REF
- 2. Why do you think you have not received the services?[READ FROM THE FOLLOWING LIST, STOP AT THE FIRST YES RESPONSE AND CHECK THAT RESPONSE]
 - □ The services are not available.
 - □ [insert PP2] is on a waitlist.
 - □ I could not get to the services (e.g., hours of operation, transportation barriers)
 - □ The information/help received from **[insert PP1]** was not useful.
 - □ I did not follow-up on the information and/or referral.
 - □ I no longer need the services.
 - Other
- 3. Since contacting the [insert PP1] on [insert PP5], have you been in touch with any other agencies similar to [insert PP1] to receive [insert PES A2 if answered; else insert PP6]?
 - □ YES [If yes, continue to qF4; else, skip to qF5]
 - □ NO
 - □ **D**K
 - □ REF

If yes, please specify name of agency/organization ______

- 4. Were there any needs that this agency/organization [identified above in qF3] was able to meet that the [insert PP1] was NOT able to meet?
 - YES [If yes, please specify need(s) _____]
 - □ NO
 - □ DK
 - □ REF

- 5. As a result of your conversations with **[insert PP1]** staff, did **YOU** realize that you had a need or concern that you did not know that you had before contacting the **[insert PP1]**?
 - □ YES
 - □ NO
 - □ DK
 - □ REF
- 6. Did the **[insert PP1]** follow up with you to find out how useful the information was or how the referral(s) turned out?
 - □ YES
 - □ NO
 - D DK
 - □ REF
- 7. On the following scale, as a result of your contact with **[insert PP1]**, how satisfied are you with...

	Very satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied	Not applicable
b. The services that you received directly from [insert PP1]?					
[If somewhat or very dissatisfied] please explain why					
b. The services that you received from agencies you were referred to by [insert PP1]?					
If somewhat or very dissatisfied, please explain why					
c. Comprehensiveness of the information or services provided?					
If somewhat or very dissatisfied, please explain why					
d. The personalization/individualization of the services offered?					
If somewhat or very dissatisfied, please explain why					
e. The accuracy of the information provided?					
If somewhat or very dissatisfied, please explain why					
f. The support you received related to decision- making?					

PARTICIPANT EXPERIENCE SURVEY

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	Very satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied	Not applicable
If somewhat or very dissatisfied, please explain why					
g. The professionalism of the organization/staff?					
If somewhat or very dissatisfied, please explain why					
h. How easy it was to work with [insert PP1] to resolve my issue related to [insert PP6]?					
If somewhat or very dissatisfied, please explain why					

- 8. As a result of your contact with the [insert PP1], would you say that you are.....
 - □ Much better informed about your long term care options
 - □ A little better informed
 - □ About the same
 - A little more confused
 - \Box Much more confused
 - □ DK
 - □ REF
- 9. To what degree has the information you received from **[insert PP1]** been useful to you as you select the long term care options that are best for you?
 - □ Very useful
 - □ Somewhat useful
 - Not useful
 - □ DK
 - □ REF
- 10. Would you tell a friend or relative who needed help to contact the [insert PP1]?
 - \Box YES
 - \square NO
 - □ DK
- 11. How likely is it that you would contact the [insert PP1] for services in the future?
 - □ Very likely
 - □ Somewhat likely

Interviewer Initials (or ID) _____

Date_____

- □ Somewhat unlikely
- □ Very unlikely

Section G. Heath and Demographic Information

In the next set of questions we would like to learn a little about your health and health insurance.

1. Do you have any of the following types of health insurance? [Record all that apply]

	NO	YES	Don't Know
Medicare			
[insert name of state Medicaid agency]			
Private Health Insurance			
Other, please specify			
Uninsured			

- 2. At the present time, would you say your health is excellent, good, fair, or poor?
 - □ Excellent
 - □ Good
 - □ Fair
 - \square Poor
 - □ Refused to answer
 - Don't know
- 3. Have you been admitted to a hospital in the past 6 months?
 - □ Yes
 - □ No
 - □ Refused to answer
 - Don't know
- 4. As part of this study, we would like to follow up on your use of health care over the next few years. To do this we would like to obtain the last four digits of your social security number. We assure you that we will keep this number safe and confidential.
 - □ SS # _____

Interviewer Initials (or ID) _____

Date_____

The last set of questions will tell us a little more about you. This information is to describe the group of persons included in the study and will not be used to identify you as an individual. We will use this information to determine whether not the **[insert PP1]** and other similar agencies are reaching all members of the community.

5. [Ask only if PP2= SELF, else go to 6. What is your date of birth?

month/day/year [After response, go to qG7.

- 6. What is the date of birth of the person for whom you contacted the agency?
- 7. What is your gender?
 - □ Male
 - Female
 - □ DK
 - □ REF
- 8. What is the highest grade or year of school you have completed?
 - □ No formal schooling
 - □ First through 7th grade
 - □ 8th grade
 - □ Some high school
 - □ High school graduate
 - Some college
 - Associates degree
 - □ Four-year college graduate
 - □ Some graduate school
 - □ Graduate and professional degrees
 - □ (VOL) REF
- 9. Which of the following racial categories describes you? You may select more than one. **READ LIST AND MULTIPLE RECORD**
 - American Indian or Alaska Native
 - Asian
 - Black or African-American
 - □ Hispanic/Latino
 - Native Hawaiian or Other Pacific Islander
 - □ White
 - □ (VOL) Other (SPECIFY)
 - □ (VOL) Refused

Interviewer Initials (or ID) _____

Date_____

- 10. What was your total household income before taxes in 2011? Your best estimate is fine. [CHECK APPROPRIATE RESPONSE]
 - □ Less than \$5,000
 - □ \$5,000 to \$14,999
 - □ \$15,000 to \$29,999
 - □ \$30,000 to \$49,999
 - □ \$50,000 to \$74,999
 - □ \$75,000 to \$99,999
 - □ \$100,000 or more
 - □ (VOL) Not sure
 - □ (VOL) Refused
- 11. What is you marital status? Are you
 - \square Married
 - \square Widowed
 - \square Divorced
 - □ Separated
 - □ Single, never married
- 12. With whom, if anyone, do you live? [READ LIST; SELECT ONE]
 - □ Alone
 - $\hfill\square$ With a spouse
 - □ With one or more other family members
 - □ With one or more friends/people who are not related to me

Date_____

- 13. Of the following choices, which one most closely describes your living situation? Do you live in..... [READ LIST, COULD BE MORE THAN ONE RESPONSE]
 - My own house or apartment (e.g., free-standing, row house, town house, apartment, etc.)
 - Non-medical custodial housing (e.g., group home, congregate house, half-way house, safe-house, recovery house, board and care house, other residential non-medical adult care facility)
 - □ In an assisted living setting [if yes, skip to qG15]
 - □ In a nursing home
 - □ In a continuing care retirement setting
 - Other [If other, please specify] ______
- 14. Have you ever lived in an assisted living setting?
 - □ Yes
 - □ No
 - □ (VOL) DK
 - □ (VOL) REF

If yes, how long did you live there? ____/__ (months/years)

- 15. Have you ever lived in a nursing home?
 - □ Yes
 - □ No
 - □ (VOL) DK
 - □ (VOL) REF

If yes, how long did you live there? ____ (months/years)

THANK YOU VERY MUCH FOR TAKING THE TIME TO SHARE YOUR EXPERIENCES OF SEEKING INFORMATION ABOUT SERVICES IN YOUR COMMUNITY. IT IS OUR HOPE THAT THE INFORMATION THAT YOU PROVIDED WILL HELP IMPROVE THE ACCESSIBILITY AND QUALITY OF SERVICES IN YOUR COMMUNITY.

I just want to confirm that you consent to our sharing your name, contact information, and the last four digits of your Social Security number (if provided) with the Administration on Aging for possible inclusion in a future study about the health care usage of individuals seeking long term services or support. Participation in that study would not involve further contact or any more of your time.

- □ Yes
- □ No

[If no, assure participant that these data will not be provided to AoA.]

COMPLETE THIS FORM AND BE SURE THAT IT IS ATTACHED TO PART 2 AND PART 3. RETURN PARTS 1, 2, AND 3 TO RESEARCH TEAM IN PRE-PAID ENVELOPE. (NOTE – MAILING INSTRUCTIONS WILL BE INCUDED ONLY ON THE PAPER COPY OF THESE DOCUMENTS).

[ID#_____ES (will be pre-filled)]

[Agency Name ______ (will be pre-filled)]

Attachment C: CLIENT SCREENING TOOL

INSTRUCTIONS FOR COMPLETING THIS FORM:

THROUGHOUT THIS DOCUMENT, CLIENT REFERS TO THE PERSON WHO IS MAKING CONTACT WITH YOUR AGENCY. CONSUMER IS THE PERSON FOR WHOM THE LONG TERM SUPPORTS AND SERVICE ARE INTENDED.

SOME SCREENING QUESTIONS ARE PREPOPULATED, AND OTHERS MAY BE ANSWERED DURING THE COURSE OF THE ROUTINE DISCUSSION WITH THE CLIENT.

QUESTIONS 1 AND 2 WILL BE PREPOPULATED BY THE RESEARCH TEAM.

QUESTIONS 3-6 SHOULD BE ASKED IF NOT ANSWERED DURING THE ROUTINE CLIENT DISCUSSION.

QUESTIONS 7 AND 8 SHOULD BE FILLED IN BY THE AGENCY

- 1. Agency Name _____ [WILL BE PREPOPULATED BY RESEARCH TEAM]
- 2. Agency Type [WILL BE PREPOPULATED BY RESEARCH TEAM]
 - □ ADRC
 - □ AAA
- 3. ASK: "For whom did you contact the agency?"
 - Self*
 - Parent
 - □ Child
 - Other relative
 - □ Friend
 - □ Neighbor
 - □ Client/Patient*

COMPLETE THIS FORM AND BE SURE THAT IT IS ATTACHED TO PART 2 AND PART 3. RETURN PARTS 1, 2, AND 3 TO RESEARCH TEAM IN PRE-PAID ENVELOPE. (NOTE – MAILING INSTRUCTIONS WILL BE INCUDED ONLY ON THE PAPER COPY OF THESE DOCUMENTS).

[ID# _____ES (will be pre-filled)]

 \square

[Agency Name ______ (will be pre-filled)]

Other: ____
 DK

REF

IF DK OR REF, CLIENT IS INELIGIBLE FOR THE STUDY. DISCONTINUE SCREENER.

*IF SELF ASK: "Do you have a legal guardian? That is someone appointed by the court to handle your affairs."

Yes No

IF YES, CLIENT HAS A LEGAL GUARDIAN, CLIENT IS INELIGIBLE FOR THE STUDY. DISCONTINUE SCREENER.

*IF CLIENT, ASK: "Are you a professional caregiver such as a physician, hospital discharge planner, or nursing home staff?"

Yes No

IF YES TO PROFESSIONAL CAREGIVER, CLIENT IS INELIGIBLE FOR THE STUDY. DISCONTINUE SCREENER.

[RESPONSE TO THE FOLLOWING QUESTION SHOULD BE MADE FOR THE PERSON IDENTIFIED IN QUESTON 3 ABOVE]

4. Are you proficient in English or Spanish?

Yes	No

IF NO, DISCONTINUE SCREENER.

5. ASK," What is the age of the consumer (i.e., the person for whom contact was made)?

_____Years

COMPLETE THIS FORM AND BE SURE THAT IT IS ATTACHED TO PART 2 AND PART 3. RETURN PARTS 1, 2, AND 3 TO RESEARCH TEAM IN PRE-PAID ENVELOPE. (NOTE – MAILING INSTRUCTIONS WILL BE INCUDED ONLY ON THE PAPER COPY OF THESE DOCUMENTS).

[ID#_____ES (will be pre-filled)]

[Agency Name ______ (will be pre-filled)]

PROBE IF UNABLE TO REMEMBER AGE: DO YOU RECALL THE YEAR OF BIRTH?

[RESPONSE TO THE FOLLOWING QUESTION SHOULD BE MADE FOR THE PERSON IDENTIFIED IN QUESTION 3 ABOVE]

IF THE FOLLOWING INFORMATION IS NOT NORMALLY COLLECTED BY YOUR AGENCY, PLEASE READ THE FOLLOWING TO THE CLIENT: "I'd like to ask you a few additional questions to see if you are eligible to participate in a satisfaction survey. Is it okay if I ask these questions?"

Yes

IF NO, DISCONTINUE SCREENER.

No

- 6. ASK, "Do you (OR THE PERSON FOR WHOM CONTACT WAS MADE, IF NOT SELF) have a disability...."
 - a. Are you deaf or do you have *serious* difficulty hearing?
 - \Box Yes
 - \square No
 - D DK
 - □ REF
 - b. Are you blind or do you have *serious* difficulty seeing, even when wearing glasses?
 - \Box Yes
 - \square No
 - \Box DK
 - □ REF
 - c. Because of a physical, mental, or emotional condition, do you have *serious* difficulty concentrating, remembering, or making decisions?
 - \Box Yes
 - □ No
 - D DK
 - □ REF

COMPLETE THIS FORM AND BE SURE THAT IT IS ATTACHED TO PART 2 AND PART 3. RETURN PARTS 1, 2, AND 3 TO RESEARCH TEAM IN PRE-PAID ENVELOPE. (NOTE – MAILING INSTRUCTIONS WILL BE INCUDED ONLY ON THE PAPER COPY OF THESE DOCUMENTS).

[ID#_____ES (will be pre-filled)]

[Agency Name ______ (will be pre-filled)]

- d. Do you have serious difficulty walking or climbing stairs?
 - \Box Yes
 - □ No
 - D DK
 - \square REF
- e. Do you have *serious* difficulty dressing or bathing?
 - \Box Yes
 - □ No
 - D DK
 - □ REF
- f. Because of a physical, mental, or emotional condition, do you have *serious* difficulty doing errands alone such as visiting a doctor's office or shopping?
 - □ Yes
 - \square No
 - \Box DK
 - □ REF

IF AGE IS LESS THAN 60 <u>AND</u> NONE OF THE ITEMS IN QUESTION 6 HAD A "YES" RESPONSE, PARTICIPANT IS INELIGIBLE FOR THE STUDY. DISCONTINUE SCREENING.

INSTRUCTIONS: QUESTIONS 7 AND 8 SHOULD BE ANSWERED BY AGENCY BASED ON OBSERVATIONS OF THE CLIENT.

- 7. As a result of this contact, did/will the client (OR THE RECIPIENT OF LTSS) receive any of the following services?
 - Yes No
 - a.
 Information Assistance and/or Referral(s) (not including options counseling)
 - b.
 Options Counseling or Peer Support/Peer Counseling
 - c.
 Benefits Counseling or Eligibility Determination
 - d.
 - e.
 Crisis intervention

COMPLETE THIS FORM AND BE SURE THAT IT IS ATTACHED TO PART 2 AND PART 3. RETURN PARTS 1, 2, AND 3 TO RESEARCH TEAM IN PRE-PAID ENVELOPE. (NOTE – MAILING INSTRUCTIONS WILL BE INCUDED ONLY ON THE PAPER COPY OF THESE DOCUMENTS).

[ID#____ES (will be pre-filled)]

[Agency Name ______ (will be pre-filled)]

f.
Life skills training or support

IF NO TO <u>ALL</u> RESPONSES IN 7 ABOVE, CLIENT IS INELIGIBLE FOR THE STUDY. DISCONTINUE SCREENING.

NOTE SERVICES RECEIVED OR CLIENT REQUEST

8. Based on your observation, does the client have any apparent physical, cognitive, or mental conditions that would prevent him/her from making an informed decision about taking part in this study and /or participating in a 15-20 minute telephone survey?

Yes No

IF YES TO ITEM 8, CLIENT IS INELIGIBLE FOR THE STUDY.

IF NO, CONTINUE TO SECTION 2. STUDY DESCRIPTION/AGREEMENT TO PARTICIPATE.

For questions regarding how to use the screening tool or complete the form, please contact the project Co-Principal Investigator, Rosanna Bertrand or team member, Louisa Buatti:

Rosanna Bertrand, Ph.D. Abt Associates Inc. (617) 349-2556 ADRC_Mailbox@abtassoc.com Louisa Buatti Abt Associates Inc. (301) 634-1711

PART 2. STUDY DESCRIPTION/AGREEMENT TO PARTICIPATE

COMPLETE THIS FORM AND BE SURE THAT IT IS ATTACHED TO PART 2 AND PART 3. RETURN PARTS 1, 2, AND 3 TO ABT SRBI IN PRE-PAID ENVELOPE. (NOTE – MAILING INSTRUCTIONS WILL BE INCUDED ONLY ON THE PAPER COPY OF THESE DOCUMENTS).

[ID#____ES (will be pre-filled)]

[Agency Name ______ (will be pre-filled)]

Attachment D: STUDY DESCRIPTION/AGREEMENT TO PARTICIPATE

INSTRUCTIONS: READ THE FOLLOWING STATEMENT TO EACH PERSON WHO IS ELIGIBLE TO PARTICIPATE IN THE STUDY.

"The Administration on Aging has contracted with IMPAQ International and Abt Associates to conduct a study about the experiences of people like you in obtaining community-based supports and services. Your opinion is very important, which is why you are being invited to participate in a 15 to 20 minute survey which will ask you about your experiences today. If you agree, your name will be added to a list of possible participants, and if randomly selected from the list, someone from Abt SRBI, the company conducting the survey, will contact you by telephone within the next month to tell you more about the study and confirm whether or not you want to participate.

Right now, I am asking your permission to share some information about you with Abt SRBI so that they will be able to call you about participating in the survey. With your permission, I would like to share your name, phone number, the reason you contacted us today, and a few other pieces of information such as information about possible disabilities. Your name or other identifying information will be used only to contact you and will not be stored in the same data file with your responses to the survey or used in any written materials generated in this study. Your decision will not affect your relationship with this agency nor your eligibility to receive their services.

May I share this information so that Abt SRBI can contact you for participation in the survey?"

Yes No

IF NO, SAY "Thank you for your consideration."

3. DATA COLLECTION TOOL

COMPLETE THIS FORM AND BE SURE THAT IT IS ATTACHED TO PART 2 AND PART 3. RETURN PARTS 1, 2, AND 3 TO ABT SRBI IN PRE-PAID ENVELOPE. (NOTE – MAILING INSTRUCTIONS WILL BE INCUDED ONLY ON THE PAPER COPY OF THESE DOCUMENTS).

[ID#____ES (will be pre-filled)]

[Agency Name ______ (will be pre-filled)]

ATTACHMENT E: CONTACT INFORMATION DATA COLLECTION TOOL

INSTRUCTIONS:

COMPLETE THE INFORMATION BELOW <u>FOR EACH PERSON</u> WHO AGREED TO SHARE CONTACT INFORMATION WITH THE RESEARCH TEAM IN ORDER TO RECEIVE A FOLLOW-UP CALL TO PARTICIPATE IN A TELEPHONE SURVEY.

THROUGHOUT THIS DOCUMENT, THE CLIENT REFERS TO THE PERSON WHO CONTACTED THE AGENCY.

1. Date of Contact with Agency (month, date, year) __/__/__

2. ASK: What is your name (First, Middle Initial, Last) _____, ____,

- 3. ASK: What is your home zip code? _____
- 4. ASK: "What is the best phone number where you can be reached by the research team?"

Client Phone number (___) ___-

5. ASK: "What is the best time for someone to call you about participating in the study?"

Preferred time to call __:__ AM PM Preferred day to call? ____

- 6. ASK: "Would you like assistance from a Spanish interpreter when the research team calls you to discuss the study?"
 - □ No
 - □ Yes

3. DATA COLLECTION TOOL

COMPLETE THIS FORM AND BE SURE THAT IT IS ATTACHED TO PART 2 AND PART 3. RETURN PARTS 1, 2, AND 3 TO ABT SRBI IN PRE-PAID ENVELOPE. (NOTE – MAILING INSTRUCTIONS WILL BE INCUDED ONLY ON THE PAPER COPY OF THESE DOCUMENTS).

[ID#____ES (will be pre-filled)]

[Agency Name ______ (will be pre-filled)]

- 7. ASK: "Would you like to use TTY service for the study?"
 - □ No
 - □ Yes

8. ASK: "What was the main reason that you contacted us today?"

- □ Income assistance
- □ Energy assistance
- □ Medicare questions
- □ Medicaid questions (including questions about HCBC waivers)
- □Housing
- \Box Personal care
- □ Transportation
- □ Nutrition
- \Box Chronic health conditions
- □ Employment
- □ Support groups
- □ Recreation opportunities
- □ Caregiver/respite support
- \Box Home modification
- □ Attendant care services
- Advocacy
- □ Education
- □ Services for emergent care/crisis intervention
- □ Preventative health services
- □ Ombudsman/abuse or neglect issues
- \Box Advanced directives
- □ Mental health
- □ Transition services
- □ Other Independent living supports or services
- \Box Other, please specify

3. DATA COLLECTION TOOL

COMPLETE THIS FORM AND BE SURE THAT IT IS ATTACHED TO PART 2 AND PART 3. RETURN PARTS 1, 2, AND 3 TO ABT SRBI IN PRE-PAID ENVELOPE. (NOTE – MAILING INSTRUCTIONS WILL BE INCUDED ONLY ON THE PAPER COPY OF THESE DOCUMENTS).

[ID#____ES (will be pre-filled)]

[Agency Name ______ (will be pre-filled)]

9. ASK: "Is this the first time you contacted this agency?"

- □ First time contact
- Repeat contact

QUESTIONS 10-11 SHOULD BE ANSWERED BY THE AGENCY.

- 10. Mode of Contact with Agency
 - \Box Visited
 - \Box Telephoned

11. IF THE CLIENT STOPPED THE QUESTIONNAIRE BEFORE COMPLETING IT, PLEASE SELECT THE BEST/MOST LIKELY REASON FOR STOPPING:

- \Box Client refused to answer
- □ Client's cognitive abilities prevented completion of questionnaire
- □ Client's physical condition prevented completion of the questionnaire
- □ Client's emotional condition prevented completion of the questionnaire
- □ Other, please explain _____
- 12. The signature of the person who administered this questionnaire indicates that he/she has read the above statement to the consumer/consumer representative and that the person has agreed to have his/her personal information released to Abt SRBI for the purpose of the evaluation.

Name_____ Date_____

For questions regarding how to use the screening tool or complete the data collection tool, please contact the project Co-Principal Investigator, Rosanna Bertrand or team member, Louisa Buatti:

Rosanna Bertrand, Ph.D. Abt Associates Inc. (617) 349-2556 Rosanna_Bertrand@ abtassoc.com Louisa Buatti Abt Associates Inc. (301) 634-1711 Louisa_Buatti@abtassoc.com

ATTACHMENT F: PROCESS EVALUATION SURVEY STATEMENT OF INFORMED CONSENT

[The process evaluation survey is intended to be administered as an online survey and the statement of informed consent will appear on page one. Respondents will have received an email invitation prior to opening the survey that will describe the study and provide instructions and a link to the survey.]

Statement of Informed Consent

This online survey funded by the Administration on Aging is part of a larger evaluation project measuring the effect of integrated systems on long-term care service delivery. It is designed to help the Administration on Aging: (1) gain an understanding of long term care support and service programs from State and local perspectives, (2) inform the analysis of consumer outcomes, and (3) collect information that will guide recommendations for continuous quality improvement for the long term service and support field in general and the Aging and Disability Resource Center initiative specifically. Program information collected through this survey will be shared with AoA, however, no direct quotes or individual responses will be attributed to particular respondents or organizations. Your participation in this survey is voluntary and you can refuse to answer any question. No penalty or loss of program benefits or resources will result from refusal to participate. We expect this survey to take approximately one hour to complete; however, it could take longer if it is necessary to collect data from other sources.

If you have questions about this survey you may contact Daver Kahvecioglu, Project Director at IMPAQ International, LLC at (443) 367-0088 ext. 2223, For questions about your rights as a participant in this study, please call Teresa Doksum, Abt Associates Inc. Institutional Review Board Chair, at (617) 349-2896

By completing and submitting this online survey, you are agreeing to the terms stated in this informed consent.

Attachment G: PARTICIPANT EXPERIENCE SURVEY STATEMENT OF INFORMED CONSENT

I will read to you a statement of informed consent that will provide you with information about the survey and inform you of your rights as a survey respondent. The Administration on Aging is sponsoring a national evaluation of the accessibility of community long-term supports and services. You are receiving this call because you contacted the [name of agency] on [insert date] and gave your permission for a research team to contact you to participate in a brief telephone survey about your experience. The survey is being conducted by Abt SRBI on behalf of the Administration on Aging. Your input about your experiences in obtaining community-based supports and services is important to us. Your participation in this 15 – 20 minute survey is completely voluntary and you may choose to discontinue the interview at any time, for any reason.

We will combine the information that we gather from all participants (about 3,400), and include the findings in a report that will be prepared for the Administration on Aging for the purpose of improving its services. Your name or any other identifying information will not be used in any report generated in this study. Your confidentiality will be protected to the extent provided by law. There will be no direct benefit to you from participating in the evaluation, nor will your or your family's services be impacted in any way by your responses to this survey. The information you provide will help the Administration on Aging improve its services for both older Americans and individuals with disabilities.

Attachment H: LETTER OF SUPPORT FROM THE ADMINISTRATION ON AGING FOR ORGANIZATIONS PARTICIPATING IN THE PROCESS EVALUATION

Dear [RESPONDENT NAME],

Dear [RESPONDENT NAME],

The Administration on Aging (AoA) had contracted IMPAQ International LLC and their partner, Abt Associates Inc., to evaluate the Aging and Disability Resource Center (ADRC) Program and how the ADRC approach compares to how non-ADRC organizations function. We are writing to urge you to participate in an online survey that is designed to help us better understand the operational processes of your agency.

This online survey is designed to: (1) gain an understanding of LTSS programs from State and local perspectives, (2) inform the analysis of an outcomes evaluation by exploring potential factors that may be controlled in the analyses, and (3) collect information that will guide recommendations for continuous quality improvement in the LTSS program. This study consider the effectiveness of the ADRC program as it relates to both ADRC staff and ADRC consumers, how other organizations provide LTSS to similar clients, and will influence the direction of the ADRC Program in the future. We ask that you participate in this survey and provide us with honest feedback about how LTSS are provided to clients.

We expect this survey to take approximately one hour to complete; however, it could take longer if it is necessary to collect data from other sources.

If you have any questions about your participation in this evaluation, please email Susan.Jenkins@aoa.hhs.gov.

Thank you for your participation,

[Insert signature here]

ATTACHMENT I: PROCESS EVALUATION SURVEY INVITATION FOR SITE DIRECTORS/MANAGERS OR OTHER STAFF

You have been selected to participate in an online survey sponsored by the Administration on Aging.

The survey is designed to collect information about your program including program goals, daily operations, and partnerships. Your opinions and experiences are extremely important. The information that you and others provide will be aggregated and used to make improvements to current and future Administration on Aging grant programs.

Your responses will be held in confidence and will only be used in combination with those of other agency directors; you will not be personally identified when shared with Administration on Aging, staff within your organization, or any other agency except as required by law.

This online survey is designed to: (1) gain an understanding of [ADRC or AAA] programs from State and local perspectives, (2) inform the analysis of an outcomes evaluation by exploring potential factors that may be controlled in the analyses, and (3) collect information that will guide recommendations for continuous quality improvement in the [ADRC or AAA] program.

We expect this survey to take approximately one hour to complete; however, it could take longer if it is necessary to collect data from other sources. Please visit the technical assistance exchange website <u>www.adrc-tae.org</u> with your log-in to start the survey:

Once you have accessed the survey, proceed through it by clicking on the navigation buttons. You will be able to exit and return to the survey at any time between [month day, 2012] and [month day, 2012]. The program will automatically bring you back to the last page on which you were working. Use the "Back" navigation button to review and/or edit earlier responses.

Susan, Jenkins, PhD Social Science Analyst Center for Disability and Aging Policy Administration for Community Living US Department of Health and Human Services 1 Massachusetts Avenue, NW Washington, DC 20201 Telephone-202.357.3591 Fax-202.357.3549 E-mail- <u>Susan.Jenkins@AoA.HHS.Gov</u>

Attachment J: LETTER OF SUPPORT FROM THE ADMINISTRATION ON AGING TO POTENTIAL ORGANIZATIONS SELECTED FOR THE OUTCOME EVALUATION

Dear [DIRECTOR NAME],

The Administration on Aging (AoA) has contracted with IMPAQ International, LLC and Abt Associates Inc. to evaluate the Aging and Disability Resource Center (ADRC) Grant Program. The overall purpose of the evaluation is to gather a range of program and consumer information to help AoA better understand how to best support the delivery of long-term services and supports (LTSS). The study will consider the effectiveness of different approaches to the provision of long-term care services and supports from the organizational and individual perspectives. We are contacting your organization to ask you to participate in the consumer-level data collection effort. The data supplied by your organization or network and its consumers will be combined with data from other organizations or networks to determine which approaches to service provision work best for different types of consumers and under what circumstances.

[ORGANIZATION NAME] has been selected to participate in the study based on its geographic location and other community-level attributes. We are asking for assistance from the I&R / I&A specialists in your organization or network to screen and recruit consumers to participate in a survey to be administered by the research team. We expect that screening and recruiting participants will take less than five minutes and can be done during the course of routine interaction with consumers. In fact, much of the needed information is likely already collected by your staff. Training and ongoing support will be provided to I&R/ I&A specialists by the researchers. To provide you with more information, we have included a one-page fact sheet about the evaluation with this letter.

In approximately one week, you will receive a phone call from the evaluators at Abt Associates who will provide you with more information concerning the study and formally request your organization's participation.

If you have any questions about your participation in this evaluation, please email Susan Jenkins at Susan.Jenkins@AoA.HHS.GOV.

Thank you for your participation,

ADRC EVALUTION FACT SHEET

[Will be sent with Letter of Support from the Administration on Aging to potential organizations selected for the outcome evaluation]

Sponsor: This study is being sponsored by the Administration on Aging (AoA), an operating division of the US Department of Health and Human Services

Purpose: To help AoA better understand how to support the delivery of long-term services and supports (LTSS). The study will consider the effectiveness of different approaches to the provision of long-term care services and supports from the organizational and consumer perspectives.

Benefits to your organization: While there are no direct benefits to your organization, the information that you collect will provide important insight into the provision of long-term services and supports (LTSS). This will help organizations, such as yours, and Agencies, such as AoA, improve LTSS policies and practices. The ultimate benefit is for consumers.

Your role: If your organization is able to participate in this important research, your organization will be asked to:

- 1. Provide contact information for the frontline staff (I&R/I&A) with whom consumers first come into contact. Estimated time required: varies by organization
- 2. Allow the research team to contact these staff and provide them with training and technical support regarding their role in the research study. Estimated time required: 30 minutes per staff member
- 3. Over a 3-6 month period, as I&R/I&A staff are contacted by consumers they will ask them a few screening questions and gather contact information. Estimated time required: 5 minutes per consumer.
- 4. Send the screening and contact information to the research team approximately monthly. <u>Estimated time</u> required: 15 minutes per month.

Attachment K: OUTCOME EVALUATION RECRUITMENT TELEPHONE SCRIPT

Recruitment calls are made to the directors at local-ADRC, AAA, and CIL sites that have been selected to participate in the outcome evaluation. This call is made approximately one week following the expected date that the agency director receives the AoA letter of support.

Step 1: Describe main parts of study and informed consent, answer any questions

Hello/ Good morning/ Good afternoon. My name is []. I am calling from Abt Associates about a study we are conducting for the Administration on Aging (AoA). You should have received a letter from AoA alerting you to the study within the past week or two. Did you receive the letter?

3. [If no, skip to # 2] If YES, Did you have a chance to look it over [if no, skip to #2]? To remind you, the study involves a telephone survey that will be administered to some of your consumers. It is designed to help AoA better understand the experiences of older adults and persons with disabilities in obtaining community-based support and services through organizations like yours. I am calling to answer any questions that you might have about the study and to confirm your organization's involvement. But, first let me tell you a bit about the study. Participation in this study by your organization is voluntary so you may choose not to join and will not be penalized for your decision. If you agree to participate, we will ask that your key I&R/I&A specialists participate in a 40 minute webinar training program, screen consumers who contact them over a 3-6 month period for eligibility in the study, and collect and forward this information to the research team. The eligibility screener gathers information about whether the consumer contacted you for themselves or someone else (e.g., the primary consumer), the primary consumer's age, whether the primary consumer has any of a range of physical or mental disabilities, and the type of services the consumer received or was referred to. The data collection portion requests the consumer's contact information (so that the research team can contact them to conduct the interview); whether they need any accommodations for the interview, such as a Spanish speaking interviewer or if they will be using a TTY service; the main reason for their contact with your organization; and the mode of contact (e.g., telephone, walk in). Because you likely already collect much of this is information, it is expected that the eligibility screening and data collection will take less than five additional minutes. I&R/I&A specialists will also be asked to forward the data to the research team according to a schedule we jointly determine, most likely monthly.

Say, "Is your organization able to participate in the study?"

If NO, say "Can I ask why?" "Thank you for your time."

If YES, say "Great. You will be receiving follow-up email from the research team confirming your participation, and asking for contact information for the organization's I&R/I&A specialists. With your permission, we will follow-up with them directly regarding their participation and to provide information about the training."

4. If NO (did not receive the letter) or if did not have a chance to look over study materials, let me tell you about the study.

The study involves a telephone survey that will be administered to some of your consumers. It is designed to help AoA better understand the experiences of older adults and persons with disabilities in obtaining community-based support and services through organizations like yours. Your participation in this study is voluntary so you may choose not to join and will not be penalized for your decision.

If you agree to participate, we will ask that your key I&R/I&A specialists participate in a **40 minute** webinar training program, screen consumers who contact them over a 3-6 month period for eligibility in the study, and collect and forward this information to the research team. The eligibility screener gathers information about whether the consumer contacted you for themselves or someone else (e.g., the primary consumer), the primary consumer's age, whether the primary consumer has any of a range of physical or mental disabilities, and the type of services the consumer received or was referred to. The data collection portion requests the consumer's contact information (so that the research team can contact them to conduct the interview); whether they need any accommodations for the interview, such as a Spanish speaking interviewer or if they will be using a TTY service; the main reason for their contact with your organization; and the mode of contact (e.g., telephone, walk in). Because you likely already collect much of this is information, it is expected that the eligibility screening and data collection will take less than **five additional minutes**. I&R/I&A specialists will also be asked to forward the data to the research team according to a schedule we jointly determine, most likely monthly.

Say, "Is your organization able to participate in the study?"

If NO, say "Thank you for your time."

If YES, say "Great. You will be receiving follow-up email from the research team confirming your participation, and asking for contact information for the organization's I&R/I&A specialists. With your permission, we will follow-up with them directly regarding their participation and to provide information about the training."

SECTION 3: Additional Material

Attachment L: 60-DAY FEDERAL REGISTER NOTICE

Federal Register, Volume 76 Issue 199 (Friday, October 14, 2011)[Federal Register Volume 76, Number 199 (Friday, October 14, 2011)]

[Notices]

[Page 63924]

From the Federal Register Online via the Government Printing Office [www.gpo.gov]

[FR Doc No: 2011-26552]

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Administration on Aging

Agency Information Collection Activities; Proposed Collection; Comment Request; the Evaluation of the Aging and Disability Resource Center Program

AGENCY: Administration on Aging, HHS.

ACTION: Notice.

SUMMARY: The Administration on Aging (AoA) is announcing an opportunity for public comment on the proposed collection of certain information by the agency. Under the Paperwork Reduction Act of 1995 (the PRA), Federal agencies are required to publish notice in the Federal Register concerning each proposed collection of information, including each proposed extension of an existing collection of information, and to allow 60 days for public comment in response to the notice. This notice solicits comments on the information collection requirements relating to the Evaluation of the Aging and Disability Resource Center Program.

DATES: Submit written or electronic comments on the collection of information by December 13, 2011.

ADDRESSES: Submit electronic comments on the collection of information to: Susan Jenkins at Susan.Jenkins@aoa.hhs.gov. Submit written comments on the collection of information to

Administration on Aging, Washington, DC 20201, Attn. Susan Jenkins.

FOR FURTHER INFORMATION CONTACT: Susan Jenkins at 202.357.3591.

SUPPLEMENTARY INFORMATION: Under the PRA (44 U.S.C. 3501-3520), Federal agencies must obtain approval from the Office of Management and Budget (OMB) for each collection of information they conduct or sponsor. ``Collection of information'' is defined in 44 U.S.C. 3502(3) and 5 CFR 1320.3(c) and includes agency request or requirements that members of the public submit reports, keep records, or provide information to a

third party. Section 3506(c)(2)(A) of the PRA (44 U.S.C. 3506(c)(2)(A)) requires Federal agencies to provide a 60-day notice in the Federal Register concerning each proposed collection of information, including each proposed extension of an existing collection of information, before submitting the collection to OMB for approval. To comply with this requirement, AoA is publishing notice of the proposed collection of information set forth in this document. With respect to the following collection of information, AoA invites comments on: (1) Whether the proposed collection of information is necessary for the proper performance of AoA's functions, including whether the information will have practical utility; (2) the accuracy of AoA's estimate of the burden of the proposed collection of information, including the validity of the methodology and assumptions used; (3)

ways to enhance the quality, utility, and clarity of the information to be collected; and (4) ways to minimize the burden of the collection of information on respondents, including through the use of automated collection techniques when appropriate, and other forms of information technology. The Aging and Disability Resource Center (ADRC) Program is a collaborative effort of the Administration on Aging (AoA) and the Centers for Medicare & Medicaid Services (CMS). ADRCs target services to the elderly and individuals with physical disabilities, serious mental illness, and/or developmental/intellectual disabilities. The ultimate goal of the ADRCs is to serve all individuals with long-term care needs regardless of their age or disability. The statutory

authority for the ADRC grant program is contained in Titles II and IV of the Older Americans Act (OAA) (42 U.S.C. 3032), as amended by the Older Americans Act Amendments of 2006, Public Law 109-365. (Catalog of

Federal Domestic Assistance 93.048, Title IV Discretionary Projects). 42 U.S.C. 3017 specifies that the Assistant Secretary for Aging ``shall measure and evaluate the impact of all programs authorized by this

60-Day Federal Register Notice

chapter "Evaluations shall be conducted by persons not immediately involved in the administration of the program or project evaluated." This new collection of information is necessary to determine the overall effect of ADRCs on both long term support and service systems and individuals. AoA will gather information about how ADRCs provide services and whether consumers, who access ADRCs, as compared to consumers who access other systems, report that the experience is more personalized, consumer-friendly, streamlined, and efficient. Staff of the Administration on Aging's Office of Program Innovation and Demonstration will use the information to both determine the value of the ADRC model and to improve program operations. The evaluation will include both process and outcome components. The Agency Data Collection Tool requests respondents' names and contact information about consumers' level and type of disability, and demographic characteristics including race and living status. Respondents will be asked to provide their Medicare and/or Medicaid identification numbers to allow for analysis of the effect of the ADRC program on heath care utilization and nursing home diversion. The proposed data collection tools may be found on the AoA Web site: [INSERT WEB ADDRESS WHEN DETERMINED]. AoA estimates the burden of this collection at 1,732 hours for individuals and 1,294 hours for organizations--Total Burden for Study 3,026.

Dated: October 7, 2011. Kathy Greenlee, Assistant Secretary for Aging. [FR Doc. 2011-26552 Filed 10-13-11; 8:45 am] BILLING CODE 4154-01-P

Attachment M: IRB APPROVAL OF THE DATA COLLECTION TOOLS

Institutional Review Board Notice of Approval Principal Investigator/Project Director: Rosanna Bertrand Project Title: ADRC Evaluation Sponsor Agency: Administration on Aging Abt IRB #: 0565 Protocol Approval Date: September 23, 2011 Review Type: Expedited Type of Approval: Full Implementation

Please note the following requirements:

Problems or adverse reactions: If any problems in treatment of human subjects or unexpected adverse reactions occur as a result of this study, you must notify the IRB Chairperson or IRB Administrator immediately.

Consent forms: In the event the approved study includes procedures for written informed consent, you only may use consent forms that bear the Abt Associates Inc. IRB approval stamp.

Changes in protocol, study design, or study materials: If there are changes in procedures, the study design, or study materials (e.g., survey instruments, consent forms), you must submit these materials for IRB review and approval before they are implemented.

Renewal: You are required to apply for renewal of approval at least annually for as long as the study is active. Your next review date should be on or before September 22, 2012

Teresa Doksum IRB Administrator

Date: October 23, 2011

Cc: