The Institute for Health, Health Care Policy, and Aging Research

Evaluation of NJ EASE for Caregivers: A National Family Caregiver Support Program Initiative

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EXECUTIVE SUMMARY

In 2001, the State of New Jersey was awarded an Administration on Aging grant as part of the National Family Caregiver Support Program (NFCSP). New Jersey's project, led by the Department of Health and Senior Services (DHSS) and entitled "NJ EASE for Caregivers," involved integrating a focus on caregiving into the existing long-term care system. The primary goal of the NJ EASE for Caregivers project was to develop a better support system for caregivers by expanding the scope of the existing NJ EASE system, a single-point-of-entry, information, referral, and case management system for senior services. The project included activities aimed to better identify caregivers and their unique needs, increase awareness among senior service staff of diverse caregiving situations, and better link caregivers to available services. Five NJ counties were involved in piloting different grant components. Rutgers Center for State Health Policy (CSHP) conducted an evaluation of all NJ EASE for Caregivers grant components using surveys of staff, committee members, and caregivers; focus groups; and the review of all grant documentation.

Findings

Organizational Structure

- The NJ EASE for Caregivers project was governed by a very diverse, dedicated, and effective group of individuals serving on its Advisory Committee and Subcommittees. This organizational structure fostered the inclusion of different perspectives on the realities of caregiving and serving caregivers. The inclusion of caregivers in the committees, along with senior service administrators and providers, created a dynamic learning environment for all members.
- Subcommittee members felt that all relevant perspectives (state, county, provider, and caregiver) were adequately addressed during the grant activity

decision making process. The majority also felt that the membership adequately represented the state's racial and ethnic groups and that the subcommittees were successful in integrating cultural competency issues into their work.

- Committee members were very positive about their workgroup experiences and accomplishments.

Training

- One component of the grant was the development of a three day "Caregiving Across Cultures" training, designed to enhance service skills for helping caregivers, particularly culturally and linguistically diverse caregivers. Area Agency on Aging (AAA) staff who attended the three day training gave it a high rating overall at the conclusion of the course. At the time of a later CSHP staff survey, the scores for the overall quality of the course had dropped slightly. Other responses indicated that some staff did not find the information and materials highly relevant back on the job, and many did not feel they had learned important new information. Also, the average on a question about the usefulness of the training for serving culturally diverse caregivers was at the midpoint.
- AAA staff attendees and administrators expressed concerns to DHSS and CSHP researchers about the length of the training and the burden it placed on their organizations. In response, DHSS has integrated important and effective elements of the training into existing mandatory staff training.

Caregiver Risk Screen, Assessment, and Care Planning Tools

- Three survey tools, meant to improve identification and assessment of caregivers' needs, were implemented as part of the grant. The evaluation of the three tools by staff who had used them, was mixed. Some staff felt that each tool was easy to use, provided additional information about the caregiving situation, and improved the service quality for caregivers. A significant number of staff, however, had experienced difficulty with the tools and did not find notable value in their use.
- Respondents were most unsure or reluctant to recommend continued use of the assessment tool, followed by the planning tool, and then the risk screen. In

particular, areas of concern for the assessment tool included its length, the expectation of services that it creates that may not be fulfilled, and its overlap with information already collected with other tools.

- On the other hand, consumers who had been screened or assessed with the tools reported very positive experiences, and almost all of those who received an assessment felt that it had been worthwhile.

CaregiverNJ Website

- During grant period, DHSS successfully developed a comprehensive website, CaregiverNJ (www.caregivernj.nj.gov), containing information on caregiving and services to support caregivers and care recipients. Elderly participants in a focus group for evaluating the CaregiverNJ website, found the content to be very complete and relevant for caregivers as well as non-caregiving seniors. This group had some difficulty navigating the site as many were novice internet users. The more experienced internet users found CaregiverNJ easy to navigate and information easy to find.
- All focus group participants, regardless of their level of internet and computer literacy, helped identify aspects of the site that could be improved or expanded. Particular suggestions for improving the site that emerged from the focus group included having more options for searching the site, more prominent navigation instructions for novice users, changing the home page lay-out, and increasing the links between places within the site.

Policy Coordination

- The DHSS successfully implemented a policy to improve coordination between New Jersey's Statewide Respite Care Program (SRCP) sponsors and the NJ EASE system as operated by the county AAAs. This "NJ EASE-SRCP Caregiver Services Coordination" policy required each county to develop a protocol for coordinating information, referrals, and feedback on caregiver services between the local AAA and the SRCP. Each county completed and implemented a protocol during the grant period.
- The AAA administrators in Bergen, Gloucester, Middlesex, Monmouth, and Warren counties felt that developing and implementing the protocols was not

difficult but these counties had significant coordination between the programs prior to the new policy.

Impact on Caregivers

- Respondents to our survey of caregivers were overwhelmingly white and female but varied more in terms of the type of caregiving situations they were experiencing. Caregivers who had called or visited a pilot AAA and been screened, responded positively to the experience. On average, they responded that staff were helpful and understanding, that the questions asked were relevant, and that they were satisfied overall with the service they received.
- The average satisfaction scores were even higher for caregivers who had a Care Manager come to the home and complete an assessment using the tool implemented as part of the grant project. In an open ended question, caregivers thought that a full assessment was worthwhile for them because it led to additional services and/or that Care Managers were understanding.
- Caregivers from racial and ethnic minority groups felt that staff were capable of helping people from their cultural background.

Recommendations

- Continue efforts to involve local AAA administrators, Care Managers, and intake staff more thoroughly in the development and implementation of new tools they will be required to use. Ask effected staff what type, format, and length of caregiver training would be most helpful and practical for them.
- Examine reasons for the low number of racial/ethnic minorities calling or visiting AAA offices during the grant pilot. Several of our survey questions also indicate that AAA staff found grant training and tools only moderately helpful for serving a diverse caregiver clientele. Exploring why this is the case as well as asking staff what would better help them connect with caregivers from various cultural groups, can inform future initiatives to reach all caregivers.
- Maintain involvement of caregivers as advisors for long-term care policy and program development. The NJ EASE for Caregivers Advisory Committee structure is a model for making a place for the voices of caregivers in policy decisions. Further interaction between AAA staff and non-client caregivers also holds the potential for broadening understanding among both parties.

- Continue to integrate a focus on caregivers into existing NJ EASE processes for expansion to the rest of New Jersey's Area Agencies on Aging. This evaluation indicates that incorporating important grant components into existing trainings, tools, and policies, holds potential for success.

Evaluation of NJ EASE for Caregivers: A National Family Caregiver Support Program Initiative

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Introduction

In 2001, the State of New Jersey was awarded an Administration on Aging grant as part of the National Family Caregiver Support Program (NFCSP).[1,2] With a growing understanding that unpaid family caregivers provide the majority of care for older adults and that many seniors care for related children, the goal of the NFCSP is to improve service networks to support caregivers of the elderly and grandparents raising children. New Jersey's project, led by the Department of Health and Senior Services (DHSS) and entitled "NJ EASE for Caregivers," involved integrating a focus on caregiving into the existing long-term care system.

The primary goal of the NJ EASE for Caregivers project was to develop a better support system for caregivers by expanding the scope of the existing NJ EASE (New Jersey Easy Access, Single Entry) system, a single-point-of-entry, information, referral, and case management system for senior services. Consumers enter the NJ EASE system by calling a toll-free number and are directed to the appropriate assistance within a coordinated structure of state and county organizations. Callers are routed to Area Agencies on Aging (AAAs) within their county and generally greeted by an Information and Assistance (I&A) employee who records their questions, provides information, and refers their case to others as necessary. Individuals facing complex problems may be referred to a Care Manager who can further assess their needs and plan, coordinate, and evaluate services to help.

Within the NJ EASE system, this grant project included activities designed to better identify caregivers and their unique needs, increase awareness among senior service staff of diverse caregiving situations, and better link caregivers to available services. Specifically, there were five activity areas supported by this grant: 1) The formation of an advisory committee and subcommittees to participate in decision making about grant activities and assist in grant component implementation. The committees included representation from state and county level offices, physicians, senior citizen and caregiver support and advocacy organizations, and caregivers from various New Jersey communities. 2) The development and implementation of a staff caregiver training curriculum to increase staff's awareness of caregiving issues and their ability to understand and assist caregivers from diverse backgrounds. 3) The development and piloting of a caregiver interview risk screening tool,

assessment tool, and care planning tool. 4) The development and launching of a website specifically designed to help caregivers locate information on caregiving, identify available support services, and link them to other relevant websites. 5) The assessment of state policies with the goal of identifying ways to increase coordination of state and federally funded services for caregivers.

In the initial grant plan, three NJ county AAAs were to pilot particular grant components. Bergen, Middlesex, and Monmouth county AAAs agreed to be involved in the grant and act as demonstration counties. Each of these counties had established innovative caregiver programs using Title III-E funding and DHSS viewed their involvement in NJ EASE for Caregivers as a means to enhance their existing focus on caregiver supports and services. However, due to unforeseen developments that will be explained later in this report, Middlesex and Monmouth counties decided not to pilot the screening and assessment tools and furthermore, Monmouth staff did not participate in the caregiver training curriculum. Subsequently, the Gloucester AAA agreed to use both the screening and assessment tools and the Warren AAA agreed to use the assessment tool for a three month period to further test them. However, neither of these new demonstration counties participated in the caregiver training. Ultimately, all NJ EASE for Caregivers components were piloted, but not uniformly, across three counties as originally planned. Instead, Bergen and Middlesex participated in training, Bergen and Gloucester tested both the screening and assessment tools, and Warren tested the assessment tool alone.

Other grant components, for example—policy coordination efforts and the caregiver website development—were meant to, and did, involve input and effort from all 21 New Jersey counties from the start.

Rutgers Center for State Health Policy (CSHP) was asked by the NJ DHSS to conduct an evaluation of all NJ EASE for Caregivers grant components; this report summarizes the research findings. Our evaluation addressed whether program goals were met in each activity area; administrative, staff, and consumer satisfaction with grant products; and perceptions on the program's impact on the delivery of services to caregivers. Because the grant project itself was multifaceted, our evaluation involved several different methods for gathering information to assess the grant efforts overall. This report presents the evaluation findings by each grant activity in the order found in the introduction, as well as a discussion of the impact on caregivers.

Evaluation Methods

CSHP used five primary sources of data to evaluate the NJ EASE for Caregivers project: 1) focus groups, 2) surveys, 3) qualitative interviews, 4) web site testing, 5) and review of documents and materials.

1) A focus group was conducted with a group of Information and Assistance as well as Care Management staff from Bergen County in order to identify topic areas for inclusion in a survey of pilot county AAA staff. We conducted another telephone focus group with caregivers who had contacted the pilot AAAs during the grant period, to similarly identify important themes and topics for a survey of caregivers.
2) Three separate surveys were conducted for this evaluation (see Appendix A for the survey instruments).
    a. A survey was mailed to membership of three subcommittees of the Advisory Committee: the Training, Tool, and Website Committees. DHSS provided us with the names and addresses of all members of these subcommittees to be surveyed. The response rate for this survey was 66%.
    b. AAA staff in the counties participating in grant activities were asked to complete a mail survey. The Executive Directors of the county AAAs gave us contact information for their Information and Assistance and Care Management staff who had been working to implement the grant components. We received 40 responses to this survey, resulting in a response rate of 63%. Tables 1 and 2 show that characteristics of the staff who participated in the survey.
    c. A phone survey was conducted with a sample of caregivers who had contact with one of the three pilot AAAs during the demonstration period. Caregivers may have used the toll-free NJ EASE number, called the office directly, visited the office, or been identified from existing cases as needing an assessment by staff. Bergen, Gloucester, and Warren County AAAs agreed to collect the names and phone numbers of caregivers with whom they had contact during the three month period they were testing the screening and/or the assessment tools. Caregivers were first asked if they would be willing to have CSHP staff call them, and if they agreed, their names were forwarded to us. Out of a sample of 119 caregivers, we

were able to survey 86, for a response rate of 72%. Of those individuals we made contact with, only six declined to participate.

3) The evaluation project director conducted in-depth open-ended interviews with the county level administrators of the grant activities, including Middlesex and Monmouth, where the tools were not put into practice. The interview content included questions to identify administrator perspectives on the usefulness of grant activities for better serving caregivers, the current status of county-state relationships for addressing caregiver needs, and barriers to effectively improving services for caregivers. In addition, Middlesex and Monmouth were asked about the circumstances leading to their withdrawal from the pilot. Detailed notes from each interview were recorded and analyzed to identify relevant themes.
4) We held a focus group with seniors (including caregivers and non-caregivers) to test the CaregiverNJ website's content and ease of use. A group of nine seniors was recruited and asked to navigate the website. Participants then completed a brief survey and joined in a group discussion about their experience searching for information on the website.
5) Throughout the evaluation, the project director reviewed relevant program documents as they became available. The types of documents examined were proposals, progress reports, AAA and state caregiver initiative materials, policies, training curriculum, and any other materials related to the grant. In addition, the director recorded detailed notes at all meetings with the project team at DHSS and the Advisory Committee. This documentation allowed CSHP to monitor the program's progress and track the development of associated products.

Table 1: Staff Survey Respondent Characteristics

		Number	Percent
Gender (n=40)	Male	5	12.5
	Female	35	87.5
Highest level of educational attainment (n=40)	Below HS	0	0.0
	HS Degree	2	5.0
	Some College	4	10.0
	College Degree	14	35.0
	Graduate Degree	20	50.0
Race/Ethnicity (n=39)	Black/African American	1	2.6
	Hispanic/Latino	3	7.7
	White/Caucasian	31	79.5
	Asian/Pacific Islander/Other	4	10.2
Position Type (n=39)	Information and Assistance	14	36
	Care Management	25	64

One limitation of this evaluation is that information was gathered at only one point in time. The lack of pre-test of conditions prior to grant interventions limited our ability to assess outcomes that can be attributed to grant activities. Also, due to changes in the grant plan and the non-standard way components were implemented, meaningful comparisons across the demonstration county AAAs were difficult to perform. Where possible, we examined differences by county on evaluation measures but without the broader comparison of AAA activities and county conditions, the interpretation of these findings was restricted.

Table 2: Staff Respondent Work Experience and Work Load

Work Experience and Load	Mean
Average number of years working in a social service field (n=38)	9.8
Average number of years in current job position (n=39)	4.1
Average Number of Contacts (per week) – I&A* (n=12)	41.9
Average Case Load – Care Managers (n=22)	39.0

*Refers to Information and Assistance staff who answer and direct NJ EASE callers.

Findings

Organizational Structure

The NJ EASE for Caregivers program was managed by personnel in the Division of Aging and Community Service (DACS) within the NJ Department of Health and Senior Services. A Program Management Officer and a Project Coordinator held primary responsibility for grant activity initiation and progress, with support from several other staff within the Division. This project team was very successful in organizing and maintaining an Advisory Committee dedicated to reviewing and providing input into all program components. The various subcommittees of the Advisory Committee were workgroups that conducted research, made critical decisions, and developed specific products. Subcommittee members were recruited from the larger committee and each was chaired by an individual with strong interest and expertise in the content area. For example, the Training subcommittee was co-chaired by an experienced geriatric educator who would be involved in running the course developed from the committee's work. Each subcommittee met approximately 12 times over the course of a year with the goal of achieving a particular set of tasks.

In organizing the Advisory Committee, the state program team made a strong effort to have representation from the many groups connected with caregivers and providing for their needs. Membership included administrators, Care Managers, and information and assistance staff from county AAAs; service provider organization staff; physicians; advocacy group representatives; and additional state level staff. Most uniquely, several caregivers from diverse communities in New Jersey were members of the Advisory Committee. These

individuals provided other members with insight into the realities of caregiving and what actions and services would be most beneficial for others like them in the community.

In order to assess the work performed within this organizational structure, CSHP developed and administered a survey to members of the Training, Assessment Tool, and Website subcommittees.

Subcommittee Survey Results

A survey was sent to all members of the three initial subcommittees of the Advisory Committee asking for their assessment of the group's activities and achievements. We received 24 responses to the survey; 12 from training committee members, 7 from assessment tool committee, and 5 from website committee members (66% total response rate). Overall, subcommittee members were very positive about their workgroup experiences. Members unanimously said that they were able to work productively with other committee members and of the twenty who answered the question, six said their committee was *successful* in meeting its goals, thirteen that the committee was *very successful* in meeting its goals, and the remainder (one response) thought that it was *somewhat successful* (on a five-point scale).

The survey included a set of questions about the adequacy of stakeholder representation on the committee. Respondents felt that the committees had very good representation from various stakeholders overall: eighty-two percent (of 22) thought overall representation was *representative* or *very representative* of important stakeholders, on a five-point scale. Regarding specific representation, eighty-three percent of members responded that the membership was *diverse* or *very diverse* in terms of racial and ethnic origin and only four members felt the membership was *somewhat* or *not very diverse* in this way. All members who answered the question felt that during the course of committee activities, adequate attention was given to the needs of caregivers and also to the perspectives of the county offices on aging. Also, twenty-two (of 23) members said that adequate attention was paid to the perspectives of service providers and state officials.

As one of the goals of this grant initiative was to better reach and serve caregivers from diverse racial and ethnic backgrounds, we asked subcommittee members how successful their committee was in addressing the diversity among caregivers. In response to a five-point scale question, sixteen said the committee was *very successful* and seven that it was *successful* in integrating cultural competence concerns into its work. Table 3 shows the results of the subcommittee survey.

Due to the small variability in responses and the small number of members in each subcommittee, differences in responses by subcommittee type could not be determined. It appears that members' experiences and views were comparable across the committee groups.

In sum, the members of the NJ EASE for Caregivers subcommittee expressed that their groups were inclusive and attentive to the important stakeholders for the issue they addressed and productive and successful in meeting their goals. The majority also felt that their input into the group's work was actively sought by the subcommittee chair (91%) and that their individual input had made an impact on the work products of the subcommittee (96%), making their service on the committee a positive experience. Finally, the majority (83%) felt that the organizational structure of an overarching Advisory Committee with smaller subcommittee workgroups, is an effective means of developing state program strategies and products.

Table 3: Subcommittee Survey Results*

Questions	Number	Percent
How successful was the subcommittee in meeting its goals? (n=20)		
Very successful	13	65.0
Successful	6	30.0
Somewhat successful	1	5.0
How representative of important stakeholders do you think the subcommittee membership was? (n=22)		
Very representative	9	40.9
Representative	9	40.9
Somewhat representative	4	18.2
How racially and ethnically diverse was the subcommittee membership? (n=23)		
Very diverse	6	26.1
Diverse	13	56.5
Somewhat diverse	3	13.0
Not very diverse	1	4.3
Was there adequate attention to the needs of caregivers in the subcommittee's work? (n=23)		
Yes	23	100
Was there adequate attention to the perspectives of the county agencies in the subcommittee's work? (n=24)		
Yes	24	100
Was there adequate attention to the perspectives of service providers in the subcommittee's work? (n=23)		
Yes	22	95.7
Somewhat	1	4.3
How successful was the subcommittee in integrating cultural competence concerns into its work? (n=23)		
Very successful	16	69.6
Successful	7	30.4

* For most report tables, n's for each question will vary because of question non-response.

Other Advisory Committee Activities

Although not part of the original grant plan, several other activities developed out of discussions at Advisory Committee meetings. To address certain issues members felt were of importance, two additional subcommittees were formed: a Caregiver Resource Guide subcommittee and a Diversity Outreach subcommittee. The objective of developing a Caregiver Resource Guide was to create a "guide containing information in one resource about services and programs that support caregivers in their role." The subcommittee ultimately developed a "Pocket Guide to Caregiver Resources in New Jersey," a brochure

containing key phone numbers for obtaining information on important caregiver support services such as transportation, legal services, and support groups. DHSS is planning to distribute the pocket guide to local social service agencies, senior centers, doctors offices, and to other locations where caregivers visit.

The formation of the Diversity Outreach subcommittee was stirred by Advisory Committee members' awareness that ethnic and racial minorities are often disconnected from available social services. This subcommittee's goal therefore, was to "develop and implement strategies for reaching out to culturally diverse caregivers and community leaders to make them aware of services for caregivers and help them access these services." The committee ultimately created two products, a contact list of local media organizations that serve specific ethnic and racial groups and a guide for AAA staff to help them prepare for conducting direct outreach in diverse communities. The Ethnic Media list provides AAA staff with contact information for many foreign language newspapers and ethnic television stations to facilitate the distribution of service information to the communities they serve. The "Culturally Sensitive Approaches" guide includes tips for outreach staff for understanding a particular group better, communicating clearly, and deciding when a translator is needed.

The formation of these additional committees was not originally planned but emerged from ideas stimulated by the grant Advisory Committee and the enthusiasm of its members. As these subcommittees did not begin their work until later in the grant period, CSHP researchers did not survey the members but were kept posted on their progress and reviewed their workgroup products. These committees formed, planned their work, and developed finished products in a very short period of time as a result of the efforts of dedicated members.

Caregiver Training

The Caregiver Training subcommittee's goal was to develop a NJ EASE staff training curriculum to enhance service skills for helping caregivers, particularly culturally and linguistically diverse caregivers. The subcommittee consisted of 20 members who made decisions about the content, organization, and format of the training. In order to gauge staff needs, the committee first conducted a Training Needs Assessment of intake and care management personnel in the three original demonstration counties. Guided by the needs assessment findings, the group reviewed existing training modules on caregiving and serving caregivers, current literature on relevant topics, and existing administrative policies and

services for caregivers. The group was co-chaired by the Associate Director of the New Jersey Geriatric Education Center (NJGEC), who also would be conducting the training, along with the Supervisor of Training and Research for the Division of Aging and Community Services.

The result of the subcommittee's work was the initiation of a three day training entitled "Understanding Caregiving Across Cultures" organized by the NJGEC in collaboration with DHSS. Topics covered in the training included: a demographic summary of caregivers in the United States, defining caregiving, the reality of caregiving and its stressors, the impact culture has on perspectives of caregiving, death and dying issues, resources for helping caregivers, and strategies for interacting with diverse caregivers. The training format was a combination of presentations and workgroup activities. Presentations were made by experienced providers of senior services and healthcare from diverse racial and ethnic backgrounds. Originally, Information and Assistance and Care Management staff from three pilot county AAAs were invited to participate, however only two counties, Bergen and Middlesex, ultimately completed the course. There was a limit of approximately 20 staff from each county who could participate and AAA administrators were responsible for coordinating staff attendance. The Bergen County Division of Senior Services sent 20 individuals through the course and the Middlesex County Office on Aging sent 15.

Prior to any surveying by CSHP, as part of the training, the NJGEC administered 1) a pre- and post-knowledge test covering caregiving within different cultural groups and resources available for this population 2) as well as a course evaluation survey. Overall, the participants' knowledge increased by the end of the course, with an average percentage point gain in test scores of 15.8 overall, 17.1 for Bergen, and 14.5 for Middlesex . In terms of course evaluation, reactions were generally positive (Table 4). Responses to seven evaluation questions ranged from a low average of 3.7 to a high of 4.7 on a five point Likert scale. For five out of these seven questions, Middlesex County participants rated the course slightly lower than Bergen county participants.

Table 4. Caregiving Across Cultures Training Evaluation by County

Questions	Bergen County Mean	Middlesex County Mean
How well organized was the entire program?	4.7	4.3
To what extent did the program meet the course objectives?	4.2	4.0
How relevant was this presentation in helping you serve the needs of a culturally diverse caregiving population?	3.8	4.1
How valuable were the discussions and breakouts?	3.8	3.7
How helpful were the materials?	4.2	4.0
To what extent will the program help you identify other resources in your system with whom you can network?	4.2	3.7
What is your OVERALL EVALUATION of the program?	4.0	4.1

Scale: 1=unorganized, not relevant at all, etc., 5=very well organized, very relevant, etc.

In our survey of staff, we also asked evaluative questions about the "Understanding Caregiving Across Cultures" training, particularly whether staff continued to find the information and materials provided relevant on the job. Sixteen of the survey respondents had attended the training and were able to answer related questions. On a scale of five, the mean rating of the quality of the course overall was 3.5, about a half point lower than on the equivalent question in course evaluation survey. Only six out of sixteen respondents said that the training exposed them to new information they did not already know. In particular, these respondents said they learned more about the diversity among caregivers and specific cultural traditions. Three respondents found the information and materials from the caregiving training very useful on the job, eight found them somewhat useful, and five not very useful. Finally, on a five point scale, the average rating of how useful the training has been in helping the AAAs serve the needs of a culturally diverse caregiving population was 3.1. See Table 5 for the averages on the scale questions.

Table 5. Staff Survey Training Questions (n=16)

Questions	Mean	SD*
On a scale of 1 to 5, please rate the overall quality of the caregiving training you received? (scale: 1=poor, 5=excellent)	3.5	.97
On a scale of 1 to 5, please rate the usefulness of the caregiving training for helping you serve the needs of a culturally diverse caregiving population? (scale: 1=not at all useful, 5=extremely useful)	3.1	.96

*In all tables SD refers to Standard Deviation

With such a small number of staff completing the training questions it is difficult to make a definitive statement about the impact of the caregiving training. Our results show that some staff learned new information and found course materials useful, however many did not. Interviews with the AAA administrators also suggest that the participants had already been exposed to some of the material in other mandatory training, making it redundant. From these interviews we also know that one significant concern about the training was its length. Significant burden was placed on the county offices to send key staff to this training for three full days.

County AAA administrators expressed these concerns to the DHSS project team and CSHP also presented them with preliminary survey findings. To address issues with the training, the department has already taken steps to integrate elements of the caregiving training into existing NJ EASE Information and Assistance training as well as into NJ EASE training for Care Managers. The length of these trainings will not change but they will cover information on understanding and serving caregivers more thoroughly. The information and assistance staff training will now include a half-day session on the caregiver, and cover definitions of caregiving, diversity among caregivers, caregiver demographics, and cultural variations among the population. The NJ EASE Core Care Management training, which already featured some caregiving topics, will now include additional emphasis on cultural diversity among, education of, communication with, and response to caregivers. Importantly, individuals who are currently involved in caregiving will make presentations as part of the training. DHSS also has plans to video tape caregivers telling their stories and play the videos in training sessions when caregivers are not available to present in person. In essence, the most important elements of the "Understanding Caregiving Across Cultures" training have been incorporated into existing course curriculum creating a more comprehensive but at the same time more efficient transference of information.

Caregiver Tool Development, Implementation, and Use

A central objective of the NJ EASE for Caregivers project was to develop and initiate the use of survey tools to better identify caregivers and their individual needs as well as facilitate their connection to senior services. The Tool Subcommittee's goal was to identify existing tools for use or modification. After extensive review of currently available tools and discussion about creating new ones, the subcommittee recommended the use of three separate tools: the Caregiver Risk Screen, the C.A.R.E. Tool *(*Caregivers' Aspirations, Realities, and Expectations assessment*)*, and the Caregiver Care Planning Tool. Both the screening and the care planning tool were created by the subcommittee while the assessment tool chosen had been authored by researchers based in Canada where the tool is used by the government.[3] (See Appendix B for the Risk Screen and Care Planning Tool)[4]

The purpose of the Caregiver Risk Screen is to focus attention on the needs of a caregiver when he or she reaches out for help for a care recipient. For this pilot, intake staff screened individuals when they made contact with the NJ EASE system. In addition to basic demographic information, the tool asks nine yes/no questions concerning the level of care provided and burden experienced by caregivers. The answers are scored and follow-up or a referral is planned based on the score. For those individuals with high risk scores, follow-up may include referral to a Care Manager and scheduling of a thorough needs assessment.

The C.A.R.E. tool is designed to focus specifically on the unique conditions under which caregivers work, identify areas of life that are most difficult, and find support services most appropriate to help. The tool is very comprehensive and covers ten domains of life: caregiver profile, caring work, relationship with formal agencies, housing, juggling other responsibilities, financial costs of caregiving, family dynamics, physical and emotional health, service needs, and crisis and future planning."[5] The authors recognize that Care Managers may not be able to complete the C.A.R.E. tool evaluation in one session and may need to establish trust with a caregiver before conducting it. The authors also recommend that caregivers be interviewed without the care recipient present to foster comfort, honesty, and a focus on their own needs and feelings rather than on the care recipient.

The Caregiver Care Planning Tool is designed to help Care Managers account for services received by a family, if any, and organize a plan for additional services, if needed. The tool lists the various types of information and services available to care recipients and caregivers and spaces for planning additional services and follow-up.

Implementation

As explained earlier, the AAAs in Bergen, Middlesex, and Monmouth counties volunteered to pilot NJ EASE for Caregivers components. Each verbally agreed to the grant conditions as well as signed a written agreement with DHSS which stated their agencies would participate and test all grant components. When the counties were asked to participate in training on how to use the tools, however, it became apparent that some confusion existed that using the tools was part of the pilot agreement. Middlesex and Monmouth counties, in particular, stated that they were unaware they had committed to implementing new tools upon becoming a NJ EASE for Caregivers demonstration county. Each New Jersey AAA had received Title III-E funding from the Administration on Aging as part of the National Family Caregiver Support Program, but separate from the NJ EASE for Caregivers competitive grant funding. Middlesex and Monmouth counties had successfully used their Title III-E funding to develop innovative programs to support caregivers and recipients and were under the impression that the NJ EASE for Caregivers program would primarily supplement and help further extend their existing programs, not require implementing new grant specific activities. Also, AAA staff from these counties were invited to participate in the training subcommittee but none attended due to scheduling conflicts which may have impeded the flow of information about the tools and the plan for their implementation.

After realizing that a miscommunication had occurred, all parties worked hard to develop a plan for implementing the tools in Middlesex and Monmouth. The grant project leaders met with the AAA administrators to hear their concerns about launching the tools and discuss solutions. However, both Middlesex and Monmouth AAA administrators ultimately decided that executing the tools would be too burdensome for staff and their current NJ EASE system. These AAAs therefore withdrew as demonstration counties for these aspects of the NJ EASE for Caregivers project. Monmouth County had not participated in the "Caregiving Across Cultures" training at this point, and their scheduled training session was cancelled due to the withdrawal. Representatives from Middlesex and Monmouth counties continued to participate in the Advisory Committee and further develop their own caregiver service initiatives at the county level.

The DHSS project team acted quickly to find two additional county AAAs to pilot some or all of the tools. Gloucester County had previously expressed interest in using a caregiver assessment tool and agreed to pilot the Risk Screen and C.A.R.E. tool for a three month period when invited by the DHSS. Warren County was also approached and agreed to

use the C.A.R.E. tool. As cases are not fielded by intake staff first in Warren County, the Risk Screen was not applicable to their environment.

Because of its comprehensive nature, select staff from the Bergen, Gloucester, and Warren AAAs received training on the purpose and use of the C.A.R.E. tool. This training was given by Nancy Guberman from the University of Quebec at Montreal, one of the tool's authors. After the training, the counties were asked to develop a tool implementation protocol, outlining a plan for training additional staff to use the tool, for integrating the tool into the NJ EASE system, and for tracking and using the results of the assessment. For the other tools, DHSS project team members trained AAA administrators in their use and they in turn trained the relevant personnel.

Use of Tools

The CSHP survey of staff contained individual sections on each of the three NJ EASE for Caregivers tools. Equal numbers of staff answered the questions about the Risk Screen and the C.A.R.E. tool, with 22 claiming they had seen or used each tool. Sixteen staff had seen or used the Care Planning Tool.

Across the three tools, the majority of staff felt they had received an adequate amount of training for using the Risk Screen and C.A.R.E. tool (70% each) but only 43% felt they had received enough training in the Care Planning Tool. Staff found the Risk Screen the easiest to use while the C.A.R.E. the most difficult to use. In terms of length, 9 individuals said the Risk Screen was an adequate length and 11 that it was too long. For the C.A.R.E. tool, there was unanimous agreement that it was too long. On a five point scale (1=not at all sensitive, 5=very sensitive) the mean score for the tools' cultural sensitivity was 3.4 for the C.A.R.E. and 3.11 for the Risk Screen.[6] Table 6a shows staff respondents' evaluation of the tools.

Table 6a: Staff Evaluation of Tools

	Risk Screen		C.A.R.E. Tool		Care Planning Tool	
	Mean	**SD**	**Mean**	**SD**	**Mean**	**SD**
Ease of Use	3.38	1.28	2.55	0.51	3.13	1.19
Cultural Sensitivity	3.11	0.81	3.40	0.68	NA	NA

For the Risk Screen and the C.A.R.E. tool, we asked whether staff felt each 1) provided them or their agencies with additional information they did not receive prior to using the tool, 2) impacted on the way they served caregivers, and 3) whether they would recommend continued use of the tools. Table 6b shows that about half of respondents said

that the Risk Screen and the C.A.R.E. tool each provide additional information while the remaining respondents felt the tools did not provide any information beyond what was received by using existing tools or procedures (n=7) or they did not know (n=2). In open-ended probes about the type of information received through the Risk Screen, one staff member said that knowing more detail about the psychological state of caregivers was very helpful, another that new caregiver needs were discovered and therefore additional services provided, and another that the tool helps better gauge the severity of burden in the caregiving situation. For the C.A.R.E. tool, staff mentioned that the assessment focused the Care Manager on the needs of the caregiver specifically, that it provides much more detail on the psychological and emotional condition of caregiver, and the interview helps build rapport with caregivers.

Table 6b: Additional Information Provided by Tools

Question: Does the tool provide you/your agency with additional information about caregivers that you did not receive prior to using the tool?					
	Risk Screen		C.A.R.E. Tool		
	Yes	No	Yes	No	Don't Know
Number	9	10	10	7	2
Percent	47.7	52.6	52.6	36.8	10.5

In terms of impact, respondents felt the tools had been minimally effective in improving services for caregivers. Table 6c shows the results on the perceived impact of the tools. For the Risk Screen, about half of the respondents answered that caregivers are served *the same as before* the use of the tool and the other half that caregivers are served *somewhat better*, while no one answered that caregivers are served *significantly better* with use of the tool. For the C.A.R.E. tool, about three-quarters of staff answering the question said caregivers are served *the same as before*, three that they are served *somewhat better*, and one respondent answered they were served *significantly* better. Finally, eleven out of twelve respondents answered that the Care Planning Tool resulted in no improvement in how caregivers are served within their agency. Also, for all the tools, the majority of respondents either would not recommend continued use of the tools or were not sure about recommending the tools.

Table 6c: Perceived Impact of Tools

Question: With the use of the tool…	Risk Screen	C.A.R.E. Tool	Care Planning Tool
	Number	Number	Number
Caregivers are served significantly better	--	1	--
Caregivers are served somewhat better	8	3	1
Caregivers are served the same as before	9	11	11

Staff were most uncertain about recommending their agency continue using the C.A.R.E. tool; only two respondents recommended its use within their agency, 52% answered they would not recommend the tool, and 38% were unsure (Table 6d). Those staff that did not recommend the C.A.R.E. tool were asked the reason. The most commonly cited reason was that Care Managers felt they could serve caregivers just as well without the tool, followed by it being difficult to use, and that the tool raised the expectations for services among clients too much. Other reasons given in open-ended questions included that the tool is too long and time consuming, replicates other tools in use, and leads to the same type and level of services as before because programs have not been expanded at the same time.

Table 6d: Staff Recommendation of Tools

Question: Would you recommend that your organization continue to use the tool?									
	Risk Screen			C.A.R.E. Tool			Care Planning Tool		
	Yes	No	Not Sure	Yes	No	Not Sure	Yes	No	Not Sure
Number	8	8	4	2	11	8	2	5	7
Percent	40.0	40.0	20.0	9.5	52.4	38.1	14.3	35.7	50.0

Because the Care Planning Tool is significantly different from, and serves the purpose of organizing and acting upon, the information gathered with the other tools, the survey contained one additional question pertinent to its intended use. Respondents were asked to rank how useful the tool was for managing services for caregivers. On a five point scale (1=not at all useful, 5=extremely useful), the mean ranking was a moderate 2.47.

For all three tools, a significant number of intake workers and Care Managers did not find an added value in their use. These AAA workers felt that the tools were redundant with existing ones, difficult to use, too time intensive, or unlikely to result in a higher level of service to clients. However, those who liked and recommended the tools felt that the additional information provided and the time spent with caregivers was helpful for better

relating to the clients, more thoroughly understanding the caregiving situation, or providing additional services.

Finally, the staff survey included two questions about the perceived impact of *all* NJ EASE for Caregivers grant activities for improving services to caregivers and for serving culturally diverse caregiver populations (see Questions 46 and 47 in protocol in Appendix A). Many staff were exposed to the project only through the tools so would most likely answer these questions based on their assessment of the tools ease of use and utility. The averages across all staff for these questions were around the mid-point at 2.6 and 2.9 respectively (scale 1=no impact, 5=great impact). We examined whether staff characteristics affected responses to these questions. For example, we compared the question averages by staff position type, number of years working in a social service field, and average caseload. Among these analyses, one mean difference was statistically significant. For Care Managers, those with higher caseloads (over 30 cases) answered that NJ EASE for Caregivers grant activities had less impact than Care Managers with fewer cases. The mean difference between the high and low caseload groups was 1.12 and significant at the .05 level. This finding could indicate that a strenuous workload is preventing some Care Managers from learning and implementing new techniques and finding their value. Alternatively, perhaps Care Managers with high caseloads are very experienced and feel they are serving caregivers well without the use of new outreach and assessment methods.

When asked what they believed *would* have the greatest impact on relieving stress in the lives of caregivers, staff overwhelmingly responded (73%) that expanding existing services (rather than creating new ones) would be most effective. Far fewer said that a reduction in caseloads (2 respondents), better coordination between agencies that provided services (3 respondents), or better outreach to caregivers (2 respondents) would have a great impact in helping the population. It seems that AAA staff feel that existing programs make a real difference in caregivers lives and allowing more individuals into them would have a strong positive effect on families.

CaregiverNJ Website Development

The development of a website expressly for those caring for elderly or disabled adults was another important activity of the NJ EASE for Caregivers program. The goal of the website development was to provide families caring for adults with a comprehensive guide to information and state resources available to them. The Website subcommittee started the development process by creating the plan for the content and basic design of the site.

Members used the CaregiverPA website developed by Penn State University and the SPRY Foundation as a model and a developer of this site provided consultation to the NJ EASE for Caregivers team as they shaped the NJ site.[7] After a full workplan was produced by the subcommittee, a workgroup from the Division of Aging and Community Services and DHSS Office of Information Technology Services (OITS) implemented the web development and launching.

The final design of the CaregiverNJ website (www.caregivernj.nj.gov) included three primary content areas – Basic Information, Resources and Services, and Search - and the goal of the navigation plan was for users to be able to reach all pieces of information within three mouse clicks. The Basic Information subject leads browsers to general information on the nature of caregiving, educational resources, self-help tools, and a list of NJ state agencies involved in providing assistance to seniors and their caregivers. The Resources and Services subject includes an overview of the many senior services and supports for caregivers available in the state. This section also includes links to other websites and toll free telephone numbers potentially useful to this population. Finally, the Search tab allows users to query the site for service information within a county, as most statewide services are administered through the local AAAs and each county has a unique set of resources and assistance available because of local initiatives.

The completed CaregiverNJ website was piloted within DACS in October 2003 and final changes made based on the test. The website was publicly launched in November 2003. CSHP evaluated the CaregiverNJ website through two means. First, we included questions about the site on both the AAA staff survey and on the survey of caregivers. Secondly, we did a more in-depth testing of the website through a focus group session where participants explored the site and identified its strengths and weaknesses.

Survey Results

Eleven of the AAA staff surveyed had used the CaregiverNJ website and responded to questions about its content and usefulness. Staff felt the site was easy to use and that it would be helpful to caregivers in the community; five respondents had already referred caregivers to the website. Staff also indicated it would be quite helpful to them as a resource on the job (see Table 7 for means and standard deviations). Among the caregivers surveyed, 13 had heard about the website but only 3 had actually used it. Caregivers mentioned learning about the site through a variety of sources, including a Care Manager or home health aide who visited their home, through a friend or relative, by internet browsing, and through a brochure that mentioned it. The three caregivers who had used the site responded that it was

very easy to use, that they were able to find the information they were looking for, that the site was of high quality, and that they would use the site again.

Table 7: Staff Evaluation of CaregiverNJ Website (n=11)

Questions	Mean	SD
On a scale of 1 to 5, please rate the CaregiverNJ website in terms of its ease of use. (scale: 1=very difficult to use, 5=very easy to use)	4.1	.83
On a scale of 1 to 5, please rate the CaregiverNJ website of how useful it will be as a resource for helping you with your job. (scale: 1=not at all useful, 5=extremely useful)	3.8	.75
On a scale of 1 to 5, please rate the CaregiverNJ website in terms of how helpful you think it will be for caregivers in your community. (scale: 1=not at all helpful, 5=very helpful)	4.1	.83

Focus Group

In order to evaluate the CaregiverNJ website in a more comprehensive and valid way, CSHP recruited a group of seniors to participate in a website testing focus group. With the help of the DHSS project team, we were able to use a computer lab at a local NJ senior center to hold the meeting. Seniors were recruited through the distribution of flyers at the senior center and information provided in the class registration brochure produced by the center. Eleven seniors enrolled in the focus group, while nine actually participated. The group consisted of six women and three men and five of these participants were caregivers. The age of participants ranged from 65-82 with an average age of 76. All participants were white/Caucasian and fairly educated, having received at least some college education and some graduate degrees. The caregiver participants provided care for different types of relatives including wives, cousins, mothers, and sons and spent varying amounts of time in the caring role, ranging from a couple of hours a week to seven days a week. Three of the caregivers had care recipients living with them while two did not.

The seniors in the focus group were given a website testing protocol developed by CSHP which included five caregiving scenarios and were asked to find information relevant to each situation. For example, one scenario described a female caregiver who was looking for self-help tools to help manage the care of her husband with Alzheimer's. Others asked participants to find information on county specific meal delivery services and available in-home support services. Each scenario was followed by a scale for ranking the difficulty of

finding the information. The protocol ended with a set of closed ended measures of specific website components and participant demographic information. Focus group members were also given some time to explore the site for themselves to look for information interesting or relevant to them. After members had completed the protocol we held a group discussion guided by a set of open-ended questions (see Appendix A for the testing protocol and discussion questions).

None of the participants had known about the site before the meeting but DHSS has been marketing it since that time, potentially informing more caregivers and seniors about this resource. Overall the group had varying prior experience with internet use and some participants experienced great difficulty finding the information related to the scenarios. Several of the seniors needed significant assistance during the session to navigate the website successfully and many were not able to complete all the protocol searches in the time allotted. However, three participants were more experienced computer and internet users and had much less difficulty with the tasks we gave them. Table 8a shows the mean difficulty measures for four of the scenarios (given time constraints, there were too few responses to scenario 5 to calculate) and Table 8b summarizes responses to additional questions about the design and organization of the site. Most of the means hover around the mid-point, reflecting a split in the individual responses between those who had difficulty (and chose the lower range of the scale) and those who were able to navigate more easily (and chose the upper range of the scale).

Table 8a: Ease of Finding Information on CaregiverNJ

Question	Scenario 1 Mean	Scenario 2 Mean	Scenario 3 Mean	Scenario 4 Mean
On a scale of 1 to 5, how easy was it to find information for this situation?	3.3	3.5	2.5	4.0

Scale: 1=very difficult, 5=very easy

Table 8b: Overall Evaluation of CaregiverNJ

Questions	Mean
How understandable are the menus on the home page? (scale: 1=not at all understandable, 5=very understandable)	3.2
How easy to read are the pages of this website? (scale: 1=very difficult to read, 5=very easy to read)	4.0
How well organized is the website (for example, is it easy to move around or do you get lost easily)? (scale: 1=not a all organized, 5=very organized)	3.4
How much effort did it take for you to find the things you were looking for? (scale: 1=great amount of effort, 5=small amount of effort)	3.0

In the group discussion, participants expressed excitement about the content of the CaregiverNJ website and felt it had potential to help caregivers and others find essential social service information they need. They thought having all service information centrally located would ease the search for information. Several planned on informing others about the site at their local senior centers and other community organizations. A number of focus group members explained, however, that only a small population of seniors actually use the internet and therefore the impact of such a site may be small. Participants also made specific recommendations for the improvement of the organization and navigation of the site. For example, the only search window on the home page was a New Jersey government search engine and there was no window exclusively for CaregiverNJ. This caused many users to get lost as they were directed outside the caregiver site when they tried to use the window. The group recommended that a CaregiverNJ search window be developed and that the distinction between an internal and external search be made very clear to the user.

Throughout the focus group session our website technical consultant recorded all the navigation and usability issues participants encountered while on the site. She developed a technical report summarizing the issues and recommended solutions. This report was shared with the NJ EASE for Caregivers project and web design team and several improvements to the site are planned based on the findings. For example, some of the graphics on the home page created confusion among users about how to enter different sections of the site. DHSS is planning a redesign of the home page to address this problem.

Some of the difficulties encountered by our focus group participants were due largely to inexperience with the internet rather than to "flaws" in the site itself. However, involving novice internet users helped identify fundamental design issues that may affect many older individuals using the internet. Since many caregivers are seniors and not internet savvy,

addressing these limitations in the design of websites meant to assist them is critical. Overall, our focus group participants were very pleased with the content of the CaregiverNJ site and thought it would prove helpful to caregivers.

Coordination

An overarching goal of the NJ EASE for Caregivers project was to examine the delivery structure for caregiver services funded through state and federal sources and develop policies to coordinate the two. The initial task undertaken towards this objective was to develop policies and protocols to coordinate caregiver services between New Jersey's Statewide Respite Care Program (SRCP) and those administered by Area Agencies on Aging and funded through the federal Older Americans Act. A policy subcommittee of professionals from SRCPs and the local AAAs was formed to analyze current caregiver service delivery systems funded by these two sources and create a plan for coordination.

In addressing statewide caregiver services, the nature of the policy subcommittee's work was significantly broader than that of the other subcommittees and intended to be ongoing throughout the grant period. The membership was also drawn from a wider group of professionals beyond those participating in the NJ EASE for Caregivers Advisory Committee. Therefore, CSHP did not survey the subcommittee members but instead received updates from DHSS about the group's progress, reviewed the resulting policies, and discussed policy implementation and impact with AAA administrators from the four counties involved in this project.

The first objective of the policy subcommittee was successfully met with the development of a policy requiring each NJ county SRCP sponsor and AAA to work together to develop a protocol for coordinating caregiver services between them. SRCP, funded by several state funding streams, is a program that provides relief to caregivers of disabled adults or the frail elderly through in-home or facility based services. DHSS contracts with sponsor agencies, some are AAAs but most are non-governmental organizations, to administer the program. Clients may be dually eligible for SRCP benefits and for programs administered by the AAAs so coordination between the agencies is important for providing full support to caregivers and care recipients. The policy created under this grant, called "NJ EASE-SRCP Caregiver Services Coordination," required the organizations to develop ways for sharing information with each other to facilitate the flow of accurate information to caregivers and describe a plan for how the agencies would work together to refer and

provide services to caregivers. DHSS provided the agencies with detailed procedures to guide the policy implementation as well as individual technical assistance if needed.

All New Jersey Area Agencies and their affiliated SRCP provider agencies completed and implemented coordination protocols in 2003. The protocols include steps for training AAA and SRCP staff, sharing eligibility criteria, sharing resource directories and consumer brochures, referring cases between agencies, opening and closing cases, and scheduling mutual meetings, among other activities.

We found through our interviews with Executive Directors that the four Area Agencies on Aging involved in this grant had significant coordination between the NJ EASE system and SRCP prior to the coordination policy being issued. In fact, existing coordination protocols from Warren and Bergen were attached as model samples with the initial policy memorandum. Implementation of this new policy was therefore not notably difficult for these counties. However, one Executive Director we interviewed mentioned that in practice, coordination continues to be a challenge and requires frequent monitoring. One specific problem this AAA encountered was that referrals sent to the SRCP coordinator often did not receive follow up.

Without speaking with AAA administrators from additional counties, we are not aware if the development and implementation of coordination protocols proved challenging in other locations. For counties with little prior coordination between NJ EASE and the Statewide Respite program, complying with the new policy was presumably more difficult but also may have had a significant impact on streamlining caregiver services. Nonetheless, assessing the statewide implementation and impact of the protocols was beyond the scope of this evaluation.

DHSS had also planned to expand the work of the policy subcommittee to address methods for coordinating all of the state-administered caregiver services. The subcommittee began this work by collecting information on all caregiver programs and planning a survey of all 21 counties to determine how federal and state funded programs were currently synchronized throughout the state. However, in September 2003, DHSS received an Administration on Aging/Centers for Medicare and Medicaid Services "Aging and Disability Resource Center" grant. Under this grant, the entire long-term care system in New Jersey will be reorganized. DHSS decided that continuing the policy subcommittee work was impractical and potentially redundant considering the system may soon look very different and that policy analysis will take place as part of the grant. The NJ EASE for Caregivers

program team will share the lessons learned about coordination from this project with the resource center grant project directors.

Impact on Caregivers

Our caregiver survey gave us the ability to examine the satisfaction of caregivers who had interacted with AAA staff during the piloting of NJ EASE for Caregivers grant activities. Eighty-six caregivers from either Bergen or Gloucester counties completed the phone survey and Table 9 presents the demographic characteristics of the participants.[8] The sample was homogeneous by race and ethnicity and was overwhelmingly white. 72% of the sample had less than a college degree and 53% made an income of $40,000 or less a year.

Table 10 shows the average score for several satisfaction questions. These questions refer to 1) caregivers' experience with their initial call or visit to a NJ EASE office where they would have been asked the Risk Screen tool questions and to 2) when relevant, to the C.A.R.E. tool assessment process. The averages are high for the questions about the first contact, indicating that caregivers as a whole had a positive experience with AAA staff during this initial interaction.

Table 9: Caregiver Respondent Characteristics

		Number	Percent
Gender (n=86)	Male	16	18.6
	Female	70	81.4
Age (n=86)	Under 40	6	7.0
	40 to 64	54	62.8
	65 to 74	45	17.4
	75 to 84	11	12.8
	85 or older	0	0.0
Marital Status (n=86)	Married	61	70.9
	Divorced	9	10.5
	Widowed	7	8.1
	Single	9	10.5
Highest Level of Educational Attainment (n=86)	Below HS	5	5.8
	HS Degree	28	32.6
	Some College	29	33.7
	College Degree	17	19.7
	Graduate Degree	7	8.1
Race/Ethnicity (n=86)	Black/African American	4	4.7
	Hispanic/Latino	2	2.3
	White/Caucasian	75	87.2
	Asian/Pacific Islander/Other	5	5.8
Household Income (n=78)	$0 to $20,000	17	21.8
	$20,001 to $40,000	24	30.8
	$40,001 to $60,000	10	12.8
	$60,001 to $80,000	11	14.1
	Over $80,000	16	20.5

Table 10: Caregiver Satisfaction

Questions	Mean	SD
All Respondents		
On a scale of 1 to 5, where 1 is not helpful and 5 is very helpful, how helpful was the person you spoke to? (n=84)	4.23	1.14
On a scale of 1 to 5, where 1 is not relevant and 5 is very relevant, how relevant to the reason you called or visited were the questions you were asked? (n=83)	4.34	0.97
On a scale of 1 to 5, where 1 is not capable and 5 is very capable, how capable of helping people from your religious or cultural background did the person seem? (n=59)	3.95	1.40
On a scale of 1 to 5, where 1 is not understanding and 5 is very understanding, how understanding of your needs as a caregiver was the person? (n=84)	4.43	1.00
On a scale of 1 to 5, where 1 is not satisfied and 5 is very satisfied, how satisfied were you with the service you received during this first call/visit? (n=84)	4.25	1.26
Respondents Who Received an Assessment		
On a scale of 1 to 5, where 1 is not understanding and 5 is very understanding, how understanding of your situation was the person who came to your home? (n=30)	4.90	0.40
On a scale of 1 to 5, where 1 is not at all well and 5 is very well, how well were your needs identified by this assessment process? (n=30)	4.67	0.55

The average for the cultural competency question is slightly lower than the other satisfaction questions. To examine this further, we compared the means for whites and racial/ethnic minorities in the sample on this question. Only eight non-white respondents gave a response to this question, however, this group's average satisfaction with staff's understanding of their cultural background was high (4.88). On the other hand, the average for this question among the 51 whites who answered it, was 3.8. In addition, not included in these averages are a large number of white caregivers (24) who responded that they did not know how understanding staff were about their cultural background. Perhaps the lower average on the cultural understanding question among whites who answered it, is a reflection of not having enough experience with staff to form a positive opinion on this issue. Also, being of the dominant racial group within our society, white caregivers may not have seen the

relevance of the question for them. The wording of the question also includes the issue of religious sensitivity but we did not ask respondents their religious affiliation. It is possible that some whites thought staff were not understanding of their religious background but unfortunately we had no way of testing this. Although based on a small group, the higher satisfaction among non-whites seems to indicate staff were culturally sensitive and responsive when interacting with racial and ethnic minorities during this pilot.

Thirty caregivers in the sample claimed that a Care Manager came to their home and did an assessment of their situation (using the C.A.R.E. tool) and answered questions about this experience. The average scores here are even higher than for the initial contact, showing very high satisfaction with the level of understanding by visiting Care Managers and with the outcome of the needs assessment. In addition, only one caregiver said that some of the assessment questions made him/her uncomfortable and all but two of the caregivers stated that the assessment was worthwhile for them. In an open-ended question about why they felt the assessment was worthwhile, caregiver responses fell into two major categories: first that the assessment led to additional services that helped them and secondly that the Care Managers were understanding and listened to their problems. For example one caregiver said:

> She [Care Manager] helped a lot. Things are a lot easier now. She set us up with programs that can help with funding for the house, helped fill out paperwork for my mother to get insurance, and set up therapies and got us into other programs.

Another caregiver stated:

> She [Care Manager] was very understanding and I was very comfortable with her.

The majority of caregivers who were assessed had a service plan developed for them (83%) and were involved in its development (79%). For those who received help in implementing their plan of services, only one caregiver said he/she was not satisfied with that help. Caregivers' positive experience with assessment with the C.A.R.E. tool is important in light of the fact that significant numbers of Care Managers did not see value in its use. Despite its length and level of detail, caregivers were overwhelmingly positive about their assessment with the C.A.R.E. tool and did not express that it was burdensome or unproductive.

The following table shows details of respondents' caregiving situations. A little more than half of the sample provided care on a full time basis and did so five to seven days a week. The majority of caregivers had someone else that helps care for the recipient but almost a quarter were caring for a child in addition. At the time of our survey, 54% of our sample were working, 15% claimed to have quit a job because of their caregiving responsibilities, and 43% said they regularly had to take time off from work in order to provide care.

In order to test if specific demographic and caregiving characteristics affected caregivers' evaluation of their experience with the pilot AAAs, we compared the means for our helpfulness, understanding, and overall satisfaction questions (see Table 10) by respondents gender, full-time/part-time caregiving status, work status, and county of residence. Most likely due to the small amount of overall variance in satisfaction on these measures, only one difference was statistically significant. The significant difference was by county for the helpfulness question. Specifically, staff from one county were ranked less helpful than the other and the mean difference was .53 (significant at the .05 level).

Finally, although not directly related to grant activities but important to assess the current needs of the New Jersey caregivers in the sample, we asked caregivers what type of assistance would help them most. Respite care, help with providing personal care and health related tasks for care recipient, and transportation assistance were the most commonly mentioned needs. Other desirable services mentioned were financial assistance and someone to provide companionship to the care recipient.

Table 11: Respondents' Caregiving Situation

Questions	Number		Percent	
Do you provide help on a full-time or part-time basis? (n=78)				
Full-time	43		55.1	
Part-time	35		44.9	
During a typical week, what do you think is the average amount of time you spend helping this person? (n=76)				
A couple of hours	11		14.5	
1 to 2 days	13		17.1	
3 to 4 days	9		11.8	
5 to 7 days	43		56.6	
	Number		**Percent**	
	Yes	**No**	**Yes**	**No**
Is there anyone else who provides care for this person? (n=84)	65	19	77.4	22.6
Do you also provide care for a minor child? (n=86)	19	67	22.1	77.9
Not including any pay you might get for informal care giving, do you currently have a job for pay? (n=85)	46	39	54.1	45.9
Have you ever had to quit a job in order to take care of the person you currently care for? (n=81)	12	69	14.8	85.2
Do/did you regularly take time off from work in order to provide care? (n=81)*	35	46	43.2	56.8

* This question includes all respondents who have ever worked for pay.

Conclusion and Recommendations

This evaluation found NJ EASE for Caregivers to be a very productive and valuable grant project which revealed potential models for developing caregiver programs as well as challenges to increasing awareness of and improving delivery of services to caregivers. The project team successfully implemented many activities towards achieving the grant objectives, with various lessons learned from each. Each objective is covered separately below.

Organizational Structure

The NJ EASE for Caregivers project was governed by a very diverse, dedicated, and effective group of individuals serving on its Advisory Committee and Subcommittees. This organizational structure fostered the inclusion of different perspectives on the realities of caregiving and serving caregivers. The inclusion of caregivers in the committees, along with senior service administrators and providers, created a dynamic learning environment for all members. Subcommittee members felt that all relevant perspectives (state, county, provider, and caregiver) were adequately addressed during the grant activity decision making process. The majority also felt that the membership adequately represented the state's racial and ethnic groups and that the subcommittees were successful in integrating cultural competency issues into their work. Finally, committee members were very positive about their workgroup experiences and accomplishments.

Training

Staff who attended the three day "Caregiving Across Cultures" training gave it a high rating overall at the conclusion of the course. The measure on how relevant the course was for helping staff serve a diverse caregiving population was scored slightly lower than other course elements. At the time of the CSHP staff survey, the scores for the overall quality of the course had dropped slightly. As indicated by other responses, this decline may be related to staff not finding the information and materials very relevant back on the job. Also, the average on a question about the usefulness of the training for serving cultural diverse caregivers was at the midpoint. Overall, few staff felt that the training exposed them to new material they did not already know.

AAA staff attendees and administrators expressed concerns to DHSS and CSHP researchers about the length of the training and the burden it placed on their organizations. In response, DHSS worked with NJGEC and reviewed the course evaluations to identify the most important and effective elements of the training and has integrated these into existing mandatory I&A and Care Management training.

Caregiver Risk Screen, Assessment, and Care Planning Tools

The AAA staff evaluation of the three implemented caregiver tools was mixed. Some staff felt that each tool was easy to use, provided additional information about the caregiving situation, and improved the service quality for caregivers. A significant number of staff, however, had experienced difficulty with the tools and did not find notable value in their use.

Respondents were most unsure or reluctant to recommend continued use of the C.A.R.E. tool, followed by the Care Planning Tool, and then the Risk Screen. In particular, areas of concern for the C.A.R.E. tool included its length, the expectation of services that it creates that may not be fulfilled, and its overlap with information already collected with other tools. Many Care Managers using the tool felt they could serve caregivers as well without using the tool. On the other hand, consumers who had been screened or assessed with the tools reported very positive experiences and almost all of those who received an assessment felt that it had been worthwhile.

CaregiverNJ Website

During the grant period, DHSS successfully developed a comprehensive website containing information on caregiving and services to support caregivers and care recipients. Elderly participants in a focus group for evaluating the CaregiverNJ website, found the content to be very complete and relevant for caregivers as well as non-caregiving seniors. This group had some difficulty navigating the site, as many were novice internet users. The more experienced internet users found CaregiverNJ easy to navigate and information easy to find.

All participants, regardless of their level of internet and computer literacy, helped identify aspects of the site that could be improved or expanded. Particular suggestions for improving the site that emerged from the focus group included having more options for searching the site, providing more prominent navigation instructions for novice users, changing the home page lay-out, and increasing the links between places within the site. A separate technical report summarizing all usability and navigation issues and proposing recommendations was prepared by a web consultant for CSHP and shared with the project team. DHSS is planning changes to the website based on the focus group findings and technical recommendations.

Policy Coordination

The Department of Health and Senior Services successfully implemented a policy to improve coordination between New Jersey's Statewide Respite Program sponsors and the NJ EASE system as operated by the county Area Agencies on Aging. This "NJ EASE-SRCP Caregiver Services Coordination" policy required each county to develop a protocol for coordinating information, referrals, and feedback on caregiver services between the local AAA and the SRCP. Each county completed and implemented a protocol during the grant

period. The AAA administrators in Bergen, Gloucester, Middlesex, Monmouth, and Warren counties felt that developing and implementing the protocols was not difficult, however, these counties had significant coordination between the programs prior to the new policy.

Due to the award of the "Aging and Disability Resource Center Grant" in 2003, which will ultimately result in large policy and procedural changes in New Jersey's long-term care system, the grant project team did not further pursue an examination of all of state-administered caregiver services for the purpose of identifying methods for coordinating them.

Impact on Caregivers

Respondents to our survey of caregivers were overwhelmingly white and female but varied more in terms of the type of caregiving situation they were experiencing. Caregivers who had called or visited a pilot AAA and been asked the Risk Screen questions responded positively to the experience. On average, they responded that AAA staff were helpful and understanding, that the questions asked were relevant, and that they were satisfied overall with the service they received. The average score was even higher for caregivers who had a Care Manager come to the home and complete an assessment using the C.A.R.E. tool. Also, caregivers from racial and ethnic minority groups felt that staff were capable of helping people from their cultural background.

In response to an open-ended question, caregivers thought that a full assessment was worthwhile for them because it led to additional services and/or that Care Managers were understanding. Responding to another open-ended questions, large numbers of caregivers said that respite care, help with personal care and health related needs, and transportation assistance are the services that would most help them in their caring situation. Some caregivers mentioned the need for financial assistance and companionship for the care recipient as things that would be very helpful to them.

Discussion

The findings of this evaluation point to potential challenges for synchronizing state caregiver program development, implementation, and client needs. First, although the NJ EASE for Caregivers subcommittees involved in program development felt their committees were very representative of stakeholders and successful in meeting program goals, the AAA staff participating in the resulting activities were less positive about the potential of grant activities. Perhaps due in part to limited representation from AAA staff, committee members

did not fully anticipate the difficulty of implementing program elements. The extent of the time constraints intake and Care Managers face, staff reluctance to take on new activities, and the staff's sense of task redundancy were underestimated. In light of our finding that staff see existing programs as effective, it is also possible staff felt grant activities were misdirected. Also, even when staff need and desire more knowledge and training, obtaining them is challenging in the face of tight work schedules.

Secondly, although most caregivers we surveyed welcomed the time spent with Care Managers, many Care Managers themselves expressed reservations about the length of the tool used to assess caregivers. From a staff perspective, spending long periods of time with one client is difficult due to high case loads and seemingly duplicative when similar information is gathered in other ways. This contradiction between what a client may desire or need and what staff are able to offer with limited time and resources, is a persistent dilemma that can be anticipated and addressed in a program design.

Finally, although DHSS program managers thought they had clearly communicated to the demonstration counties through oral and written means, the expected level of involvement in the pilot was underestimated by the AAAs. These misinterpretations could be indicative of larger senior service delivery structure issues, analysis of which is beyond the scope of this evaluation. For example, local Area Agencies on Aging operate very independently in many ways and maintaining clear communication with state level agencies might require mechanisms for continuous feedback between organizations.

Recommendations

- Continue efforts to involve local AAA administrators, Care Managers, and intake staff more thoroughly in the development and implementation of new tools they will be required to use. Likewise, ask effected staff again in the future what type, format, and length of caregiver training would be most helpful and practical for them. Once new program elements are drafted, solicit further feedback from relevant staff. Involving front-line staff in all steps of program development will provide perspective on the potential challenges of implementing particular tools or training modules as well as validate staff knowledge and work experience.
- Examine reasons for the low number of racial/ethnic minorities calling or visiting AAA offices during the grant pilot. The pilot of caregiver tools took place over a three month period only, however, we had expected a larger

number of minority caregivers to contact their AAA in that time period. It is possible that racial and ethic minorities were more highly represented in the group of caregivers we were not able to reach to be surveyed. Other grant activities not evaluated by this research, like the Ethnic Media contacts list and the guide to making culturally sensitive presentations, may be effective in increasing awareness about senior and caregiver services available and overcoming cultural barriers to seeking help. More direct contact with caregivers of distinct racial/ethnic backgrounds may be required to foster trust and acceptance of social services. Also, several of our survey questions indicate that AAA staff found grant training and tools only moderately helpful for serving a diverse caregiver clientele. Exploring why this is the case as well as asking staff what would better help them connect with caregivers from various cultural groups can inform future initiatives to reach all caregivers.

- Maintain involvement of caregivers as advisors for long-term care policy and program development. The NJ EASE for Caregivers Advisory Committee structure is a model for making a place for the voices of caregivers in policy decisions. Further interaction between AAA staff and non-client caregivers also holds the potential for broadening understanding among both parties. As a result of this project, DHSS has begun to take this step in having caregivers present their stories during mandatory care management and information and assistance staff training.
- Continue to integrate a focus on caregivers into existing NJ EASE processes for expansion to the rest of New Jersey's Area Agencies on Aging. This evaluation indicates that incorporating important grant components into existing trainings, tools, and policies, rather than creating separate "caregiver" components, holds potential for success and may alleviate staff concerns about overlapping work. This strategy has already been implemented for staff training and it may be worth exploring a similar approach for the caregiver screening and assessment tools.

Endnotes

[1] See U.S. Department of Health and Human Services, Administration on Aging. September 2003. *The Older American Act National Family Caregiver Support Program: Compassion in Action, Executive Summary.* Available at http://www.aoa.gov/prof/aoaprog/caregiver/overview/NFCSP_Exec_Summary_FULL_03.pdf.

[2] NFCSP Grant # 90-CG-2540.

[3] N. Guberman, P. Fancey, J. Keefe, D. Nahmiash, and L. Barylak. *C.A.R.E. Tool: An Assessment of Caregivers' Aspirations, Realities, and Expectations.* Available at: http://www.nsvu.ca/ family%26gerontology/ project/Instruments.htm.

[4] The appendix contains the most recent versions of the tools with slightly different names labeled *Caregiver Telephone Screening Tool* and *Care Intervention Plan*.

[5] Guberman et al.

[6] The survey did not contain questions about the length or cultural sensitivity of the Care Planning Tool.

[7] The site address is http://caregiverpa.psu.edu.

[8] Warren County had only completed four assessments using the C.A.R.E. tool at the time of the survey and all of the caregivers declined to have us call them.

Subcommittee name _____

Appendix A-I: NJ EASE FOR CAREGIVERS SUBCOMMITTEE SURVEY

SECTION I: MEETING ARRANGEMENTS

1. How many times did your subcommittee meet? _____

2. How many of these meetings did you attend? _____

3. How convenient for you were the dates and times of the subcommittee meetings? **(Please check the appropriate response)**

_____ Very convenient
_____ Convenient
_____ Somewhat convenient
_____ Not very convenient
_____ Not convenient at all

→ Please explain:

4. Did meeting organizers try to accommodate members' schedules whenever possible in setting up meetings?

_____ Yes
_____ Somewhat
_____ No

→ Please explain:

5. How convenient for you were the locations of the subcommittee meetings?

_____ Very convenient
_____ Convenient
_____ Somewhat convenient
_____ Not very convenient
_____ Not convenient at all

→ Please explain:

6. Did meeting organizers try to make meeting locations as convenient as possible for the members?

_____ Yes

_____ Somewhat

_____ No

→

Please explain:

SECTION II: MEMBERSHIP

7. How representative of the important stakeholder groups (county agencies, state officials, consumers, providers) do you think the subcommittee membership was?

_____ Very representative

_____ Representative

_____ Somewhat representative

_____ Not very representative

_____ Not representative at all

→

What types of stakeholders do you think were missing from the subcommittee?

8. How racially and ethnically diverse was the subcommittee membership?

_____ Very diverse

_____ Diverse

_____ Somewhat diverse

_____ Not very diverse

_____ Not diverse at all

→

Which racial or ethnic groups do you think were missing from the subcommittee?

9. Do you feel the subcommittee membership was adequately diverse in occupation, skills and knowledge, background, race, and ethnicity, to meet the goals of the NJ EASE for Caregivers program?

_____ Yes

_____ Somewhat

_____ No

→ Which groups needed more representation and why?

SECTION III: PROCESS

10. Was there adequate attention to the needs of caregivers in the subcommittee's work?

_____ Yes

_____ Somewhat

_____ No

→ Please explain:

11. Was there adequate attention to the perspectives of service providers in the subcommittee's work?

_____ Yes

_____ Somewhat

_____ No

→ Please explain:

12. Was there adequate attention to the perspectives of the county agencies in the subcommittee's work?

_____ Yes

_____ Somewhat

_____ No

→ Please explain:

13. Was there adequate attention to the perspectives of state officials in the subcommittee's work?

_____ Yes

_____ Somewhat

_____ No

Please explain:

14. How actively was your individual input into the subcommittee's work sought by the chair(s) of the subcommittee?

_____ Very actively

_____ Actively

_____ Somewhat actively

_____ Not very actively

_____ Not actively at all

Please explain:

15. What were the mechanisms used to solicit and include your input? _____

_____

_____

16. Do you think your individual input had an impact on the work products of the subcommittee?

_____ Yes

_____ Somewhat

_____ No

Please explain:

17. Were you able to work productively with other members of the subcommittee?

_____ Yes

_____ Somewhat

_____ No

→ Please explain any problems you encountered in working with other members:

18. Did the subcommittee have an adequate amount of time to complete its tasks?

_____Yes

_____No →

Please explain:

SECTION IV: OVERVIEW

19. How successful was the subcommittee in meeting its goals?

_____ Very successful

_____ Successful

_____ Somewhat successful

_____ Not very successful

_____ Not successful at all

→ Please explain any problems encountered by the group in meeting its goals:

20. How successful was the subcommittee in integrating cultural competence concerns into its work?

_____ Very successful
_____ Successful
_____ Somewhat successful
_____ Not very successful
_____ Not successful at all

→ Please explain:

21. Do you think the Advisory committee and subcommittee structure is an effective way to develop state program strategies and products?

_____ Yes
_____ Somewhat
_____ No

→ Please explain and give suggestions for alternative methods if you like:

22. In the space below, please provide any additional comments about your experiences in the subcommittee. _____

_____

_____

_____

Optional Question

Please check the type of membership you held on the subcommittee.

_____ Chair

_____ Regular member

Thank you very much for your participation in this survey.

Appendix A.II: STAFF SURVEY - NJ EASE FOR CAREGIVERS

INSTRUCTIONS

You have received this survey because your local Area Agency on Aging identified you as a NJ EASE staff member who has been involved with the NJ EASE for Caregivers demonstration program. This survey includes questions on five elements of the program: 1) Caregiver Risk Screen tool; 2) C.A.R.E. assessment tool; 3) Caregiver Care Planning Tool; 4) "Understanding Caregiving Across Cultures" training; 5) and CaregiverNJ Website.

Different NJ EASE staff have been involved in different aspects of the program; for example, some have used the tools, while others have attended training. Please answer all questions applicable to your involvement in program elements. If you have not been involved in any NJ EASE for Caregivers activities and have received this survey in error, please return it in the envelope provided.

The information that you provide in this survey is CONFIDENTIAL, meaning that we will not identify responses as coming from specific individuals in our report and only group results will be discussed. Survey results will be used in a report to the NJ Department of Health and Senior Services to inform them of the strengths and weakness of the various demonstration program elements.

Participating in this survey is voluntary. We hope that you will choose to participate. Your feedback is important for us to accurately evaluate NJ EASE for Caregivers. The survey should take about 10-15 minutes to complete.

Please return your completed survey using the enclosed business reply envelope.

GENERAL INFORMATION

1. In what New Jersey county do you work? _____

2. Please check the type of position you hold and specify your work load.

☐ Information and Assistance → Average number of contacts per week_____
☐ Care Management → Average case load_____
☐ Other, specify: _____

3. For how long have you worked in a social service field? _____ # of years _____ # of months

4. For how long have you held your current job position? _____ # of years _____ # of months

5. In your work, how frequently do you interact with caregivers of seniors or disabled adults (either by phone or in person)?

☐ Every day
☐ Several times a week
☐ Several times a month
☐ Less often than that
☐ Never

6. What is the highest level of education you have completed?

☐ Less than high school
☐ High school degree
☐ Some college, trade school, or Associate's degree
☐ College degree
☐ Graduate or Professional degree

7. What is your gender?

☐ Male ☐ Female

8. What is your racial/ethnic origin?

☐ Black/African American
☐ White/Caucasian
☐ Hispanic/Latino
☐ Asian or Pacific Islander
☐ Other, specify:_____

CAREGIVER RISK SCREEN TOOL

9. Have you seen and/or used the Caregiver Risk Screen tool?

☐ Yes, have seen only ☐ Yes, have used ☐ No (Skip to Question # 19)

10. What is your opinion about the length of the Caregiver Risk Screen?

☐ Too short
☐ Appropriate length
☐ Too long

11. Please rate the Caregiver Risk Screen in terms of its ease of use. (Circle one)

1	2	3	4	5
very difficult to use				very easy to use

12. How much training/instruction were you given on how to use the Risk Screen?

☐ Not enough
☐ Adequate amount
☐ Too much

13. In using the Risk Screen, did you encounter any significant problems not covered in training/instruction?

☐ Yes → **13a. Please explain the problems you encountered.** _____
_____
_____
_____

☐ No
☐ Not applicable, haven't used it

14. Please rate the Risk Screen on how sensitive it is to cultural differences among caregivers. (Circle one)

1	2	3	4	5
not at all sensitive				extremely sensitive

15. Does the Risk Screen provide you/your agency with additional information about caregivers that you did not receive prior to using the tool?

☐ Yes → **15a. Please explain what additional information is provided by the tool.** _____
_____
_____
_____

☐ No

16. In your opinion, how important is doing a separate screening of caregivers in order to understand and serve caregivers well?

☐ very important
☐ somewhat important
☐ not very important
☐ not at all important

17. What impact has the use of the Risk Screen had on the way you/your agency serves caregivers?

☐ Caregivers are served significantly better with use of the tool
☐ Caregivers are served somewhat better with use of the tool
☐ Caregivers are served the same as before use of the tool
☐ Caregivers are served somewhat worse than before use of the tool
☐ Caregivers are served significantly worse than before use of the tool

18. Would you recommend that your organization continue to use the Risk Screen after the demonstration "testing" period is over?

☐ Yes
☐ No
☐ Not sure

→ **18a. Why do you feel this way?** _____
_____
_____
_____

C.A.R.E. TOOL

19. Have you seen and/or used the C.A.R.E. (Caregivers' Aspirations, Realities, and Expectations) assessment tool?

☐ Yes, have seen only ☐ Yes, have used ☐ No (Skip to Question # 29)

20. What is your opinion about the length of the C.A.R.E. tool?

☐ Too short
☐ Appropriate length
☐ Too long

21. Please rate the C.A.R.E. tool in terms of its ease of use. (Circle one)

1	2	3	4	5
very difficult to use				very easy to use

22. How much training/instruction were you given on how to use the C.A.R.E. assessment tool?

☐ Not enough
☐ Adequate amount
☐ Too much

23. In using the C.A.R.E tool, did you encounter any significant problems not covered in training/instruction?

☐ Yes → **23a. Please explain the problems you encountered.**
_____
_____
_____

☐ No
☐ Not applicable, haven't used it

24. Please rate the C.A.R.E. tool on how sensitive it is to cultural differences among caregivers. (Circle one)

1	2	3	4	5
not at all sensitive				extremely sensitive

25. Does the C.A.R.E. tool provide you/your agency with additional information about caregivers that you did not receive prior to using the tool?

☐ Yes → **25a. Please explain what additional information is provided by the tool.** _____
_____
_____
_____

☐ No

26. In your opinion, how important is doing a separate <u>assessment</u> of caregivers in order to understand and serve caregivers well?

☐ very important
☐ somewhat important
☐ not very important
☐ not at all important

27. What impact has the use of the C.A.R.E. tool had on the way you/your agency serves caregivers?

☐ Caregivers are served significantly better with use of the tool
☐ Caregivers are served somewhat better with use of the tool
☐ Caregivers are served the same as before use of the tool
☐ Caregivers are served somewhat worse than before use of the tool
☐ Caregivers are served significantly worse than before use of the tool

28. Would you recommend that your organization continue to use the C.A.R.E. tool after the demonstration "testing" period is over?

☐ No → **28a. Please rank the following items from 1 to 6, with 1 being the most important and 6 being the least, in terms of how important they were in your decision NOT to recommend the tool.**

_____ Would like to use the C.A.R.E. tool but I don't have the time.
_____ The C.A.R.E. tool is too difficult to use.
_____ The information I get from the C.A.R.E. tool is not relevant for my job.
_____ Using the C.A.R.E. tool raises the expectations for services among clients too much.
_____ Caregivers are reluctant to be assessed or answer C.A.R.E. tool questions.
_____ I can address the needs of caregivers just as well without using the C.A.R.E. tool.

☐ Yes

☐ Not sure

CAREGIVER CARE PLANNING TOOL

29. Have you seen and/or used the Caregivers Care Planning Tool?

☐ Yes, have seen only ☐ Yes, have used ☐ No (Skip to Question # 35)

30. Please rate the Care Planning Tool in terms of its ease of use. (Circle one)

1	2	3	4	5
very difficult to use				very easy to use

31. How much training/instruction were you given on how to use the Care Planning Tool?

☐ Not enough
☐ Adequate amount
☐ Too much

32. Please rate how useful the Care Planning Tool is for managing services for caregivers. (Circle one)

1	2	3	4	5
not at all useful				extremely useful

33. What impact has use of the Care Planning Tool had on they way you/your agency serves caregivers?

☐ Caregivers are served significantly better with use of the tool
☐ Caregivers are served somewhat better with use of the tool
☐ Caregivers are served the same as before use of the tool
☐ Caregivers are served somewhat worse than before use of the tool
☐ Caregivers are served significantly worse than before use of the tool

34. Would you recommend that your organization continue to use the Care Planning Tool after the demonstration "testing" period is over?

☐ Yes
☐ No
☐ Not sure

34a. Why do you feel this way? _____
_____
_____
_____
_____

"UNDERSTANDING CAREGIVING ACROSS CULTURES" TRAINING

35. Did you attend the 3 day "Understanding Caregiving Across Cultures" training given by the New Jersey Geriatric Education Center (NJGEC)?

☐ Yes, all three days
☐ Yes, but not all three days

☐ No, did not attend (Skip to Question # 40)

36. Please rate the overall quality of the caregiving training you received. (Circle one)

1	2	3	4	5
Poor				Excellent

37. Did the caregiving training expose you to information you didn't already know about caregiving and the lives of caregivers?

☐ Yes

☐ No

37a. Please explain what new information you were exposed to.
_____
_____
_____
_____

38. Overall, how useful has the information/materials from the caregiving training been on the job?

☐ Very useful
☐ Somewhat useful
☐ Not very useful
☐ Not at all useful

39. Please rate the overall usefulness of the caregiving training for helping you/your organization serve the needs of a culturally diverse caregiving population. (Circle one)

1	2	3	4	5
not at all useful				extremely useful

CAREGIVERNJ WEBSITE

40. Have you seen and/or used the CaregiverNJ website (www.CaregiverNJ.nj.gov)?

☐ Yes ☐ No (Skip to Question # 45)

41. Please rate the CaregiverNJ website in terms of its ease of use. (Circle one)

1	2	3	4	5
very difficult to use				very easy to use

42. Please rate the CaregiverNJ website in terms of how useful it will be as a resource for helping you with your job. (Circle one)

1	2	3	4	5
not at all useful				extremely useful

43. Have you referred caregivers to the website?

☐ Yes ☐ No

44. Please rate the CaregiverNJ website in terms of how helpful you think it will be for caregivers in your community. (Circle one)

1	2	3	4	5
not at all helpful				very helpful

IMPLEMENTATION AND IMPACT OF NJ EASE FOR CAREGIVERS

45. During the implementation of NJ EASE for Caregivers demonstration program, how open were your supervisors to listening to your questions or concerns about the program?

☐ Very open
☐ Somewhat open
☐ Not very open
☐ Not at all open

46. Please rate the NJ EASE for Caregivers demonstration program (which includes use of the new tools and the caregiver training) on how much impact you believe it has had on improving the delivery of services to caregivers in your county. (Circle one)

1	2	3	4	5
No impact				Great impact

47. Please rate the NJ EASE for Caregivers demonstration program on how effective it has been in reaching and serving culturally diverse populations of caregivers. (Circle one)

1	2	3	4	5
not effective at all				extremely effective

48. Which ONE of the following do you think would have the <u>greatest</u> impact on relieving stress and burden in the lives of caregivers in the community you serve. Please choose only ONE answer.

☐ Expansion of existing services (e.g., JACC and CAP)
☐ Better risk screening and assessment of caregivers
☐ Reduction in caseloads for care managers so more time can be spent on each client
☐ Better coordination between the agencies that provide services to caregivers
☐ Better outreach to caregivers in the community
☐ Other (specify): _____

THANK YOU FOR YOUR PARTICIPATION!

PLEASE RETURN YOUR COMPLETED SURVEY BY USING THE BUSINESS REPLY ENVELOPE THAT HAS BEEN PROVIDED.

Appendix A.III: NJ EASE for CAREGIVERS – CONSUMER/CAREGIVER PHONE SURVEY

Evaluation of the NJ EASE for Caregivers Pilot Project
Consumer Survey Introduction and Oral Consent

Final Version

Greeting: Hello. My name is _____. I am calling for Rutgers University on behalf of the New Jersey Department of Health and Senior Services. We are conducting a survey of caregivers who have used either [insert Organization Name from sample] or NJ EASE, the state's system to assist older adults and their caregivers.

[INTERVIEWER NOTE: The respondent may not recognize the organization name or NJ EASE but they will understand that they called to speak about assisting older adults and their caregivers.

I1. Would it be possible for me to speak with_____?

1. Yes (continue survey)
2. No, not available right now (schedule callback appt.)
3. No, does not live here (S/O wrong number)

Every time you speak to a new person, state greeting.

Once you have the selected respondent: Your local senior service agency gave us your name and number as someone who recently asked for information or services and that you agreed to have Rutgers call you. This survey will give you a chance to tell us about your experiences with NJEASE and your local senior service agency . The results will be shared with the NJ DHSS and help find ways to improve services for senior citizens and their caregivers.

Confidentiality and voluntary nature: Participating in the survey is completely VOLUNTARY; you do not have to participate if you do not want to. This survey is not connected in any way to services you receive or will receive.

The fact that you participated in this survey, and your answers to our questions will be kept CONFIDENTIAL. No one from outside our research group will know that you participated in this survey. This survey should take about 20 MINUTES. If this is a convenient time, I'd like to conduct the interview now.

I2. Would that be alright?

1. Yes (continue with Q.1)
2. No (S/O I2)
3. Don't Know/Does not remember (Go to Q.S1)

Q.S1 Our records indicate that on at least one occasion, on (insert date of contact from sample) you were in contact with a senior service agency. This would have been in reference to a senior citizen for whom you provide care. Do you recall this?

1. Yes (continue with Q.1)
2. No (S/O Q.S1)
3. (Vol) Don't Know (S/O Q.S1)
4. (Vol) Refused (S/O Q.S1)

SURVEY QUESTIONS

1. When you decided to ask for help from either NJ EASE or [insert Organization Name from sample]or another senior service agency, did you call…

1. the toll-free NJ EASE number (877-222-3737),
2. or call or visit the County Office on Aging,
3. or call or visit another senior service agency? (Specify:_____)
4. (Vol) Don't Know
5. (Vol) Refused

2. Why did you call/visit? For instance, was there a particular event that prompted you to call?

_____
_____
_____

3. What type of help were you looking for? Were you looking for…

1. Information (such as on local providers or services),
2. or Referral,
3. or Services,
4. or some other type of help? (Specify:_____)
5. (Vol) Don't Know
6. (Vol) Refused

4. On a scale of 1 to 5, where 1 is not helpful and 5 is very helpful, how helpful was the person you spoke to?

[Interviewer Note: We are asking about the person who spoke with them about their situation.]

1	2	3	4	5
not helpful				very helpful

6 (Vol) Don't Know 7 (Vol) Refused

5. On a scale of 1 to 5, where 1 is not relevant and 5 is very relevant, how relevant to the reason you called or visited were the questions you were asked?

1	2	3	4	5
not relevant				very relevant

6 (Vol) Don't Know 7 (Vol) Refused

6. On a scale of 1 to 5, where 1 is not capable and 5 is very capable, how capable of helping people from your religious or cultural background did the person seem?

1	2	3	4	5
not capable				very capable

6 (Vol) Don't Know 7 (Vol) Refused

7. Did you require any special considerations because of your race, ethnicity, religion, or native language? For example, did you need an interpreter or materials translated?

1.Yes
2. No (Go to Q8)
3. (Vol) Don't Know (Go to Q8)
4. (Vol) Refused (Go to Q8)

7a. (If yes) Was the staff person able to provide you with what you needed?

1. Yes
2. No
3. (Vol) Don't Know
4. (Vol) Refused

8. On a scale of 1 to 5, where 1 is not understanding and 5 is very understanding, how understanding of your needs as a caregiver was the person?

1	2	3	4	5
not understanding				very understanding

6 (Vol) Don't Know 7 (Vol) Refused

9. On a scale of 1 to 5, where 1 is not satisfied and 5 is very satisfied, how satisfied were you with the service you received during this first call/visit?

1	2	3	4	5
not satisfied				very satisfied

6 (Vol) Don't Know 7 (Vol) Refused

10. Would you recommend NJ EASE/ the County Office on Aging/[insert Organization Name from sample] or another agency to other caregivers?

1. Yes (Go to Q11)
2. No
3. (Vol) Don't Know (Go to Q11)
4. (Vol) Refused (Go to Q11)

10a. Why not?_____

11. Did a person from the agency come to your home?

1. Yes
2. No (Go to Q20)
3. (Vol) Don't Know (Go to Q20)
4. (Vol) Refused (Go to Q20)

11a. (If yes) What occurred at that visit? Did someone…

1. come with information about services only,
2. or did someone come and do a full assessment of your situation as a caregiver,
3. or did they did they do something else? (Specify: _____)
4. (Vol) Don't Know
5. (Vol) Refused

(For those who answer that someone came and did a full assessment, ask them Q12-Q19. All others go to Q20)

FOR THOSE WHO HAD FULL ASSESSMENT

12. What is your opinion about the amount of time staff spent with you during the assessment? Was it…

1. too short,
2. an adequate amount,
3. or too long?
4. (Vol) Don't Know
5. (Vol) Refused

13. Did any questions you were asked make you uncomfortable?

1. Yes
2. No (Go to Q14)
3. (Vol) Don't Know (Go to Q14)
4. (Vol) Refused (Go to Q14)

13a. (If yes) Why did you feel this way_____
_____

14. On a scale of 1 to 5, where 1 is not understanding and 5 is very understanding, how understanding of your situation was the person who came to your home?

1	2	3	4	5
not understanding				very understanding

6 (Vol) Don't Know 7 (Vol) Refused

15. On a scale of 1 to 5, where 1 is not at all well and 5 is very well, how well were your needs identified by this assessment process?

1	2	3	4	5
not at all well				very well

6 (Vol) Don't Know 7 (Vol) Refused

17. Do you feel that having the assessment done was worthwhile for you?

1.Yes
2. No
3. (Vol) Don't Know (Go to Q18)
4. (Vol) Refused (Go to Q18)

17 a. (For either response) Why do you feel this way?_____
_____

18. What is your opinion about the amount of follow-up you received from your Care Manager after the assessment? Do you think there was…

1. not enough follow-up,
2. an adequate amount of follow-up,
3. or too much follow-up?
4. (Vol) Don't Know
5. (Vol) Refused

19. After the assessment, was a plan of services developed for you?

1. Yes (Go to Q19a)
2. No
3. (Vol) Don't Know
4. (Vol) Refused

19.1 Is a plan currently being developed or do you anticipate one will be developed in the near future?

1. Yes (Go to Q20)
2. No (Go to Q20)
3. (Vol) Don't Know (Go to Q20)
4. (Vol) Refused (Go to Q20)

19a. (If yes for Q19) How involved were you in developing the service plan? Were you…

1. very involved,
2. involved,
3. a little involved,
4. or not at all involved?
5. (Vol) Don't Know
6. (Vol) Refused

19b. After your service plan was developed, were you able to act on it yourself, or did you receive help from your Care Manager?

1. acted on own (Go to Q20)
2. received help
3. (Vol) Don't Know (Go to Q20)
4. (Vol) Refused (Go to Q20)

19b.1. (If received help) How satisfied were you with that help? Were you…

1. very satisfied,
2. satisfied,
3. somewhat satisfied,
4. or not at all satisfied?
5. (Vol) Don't Know
6. (Vol) Refused

There is a new website developed by the NJ Department of Health and Senior Services to help caregivers get information about caregiving and senior services available in New Jersey. The site is www.CaregiverNJ.nj.gov

20. Have you heard about this website?

1. Yes
2. No (Go to Q21)
3. (Vol) Don't Know (Go to Q21)
4. (Vol) Refused (Go to Q21)

20a. (If yes) Where did you learn about the website?_____
_____

21. Do you use the internet?

1. Yes
2. No (Go to Q22)
3. (Vol) Don't Know (Go to Q22)
4. (Vol) Refused (Go to Q22)

If Q.20 is "NO", skip to Q.22…all others continue.

21a. (If yes) Have you used the CaregiverNJ website?

1. Yes
2. No (Go to Q22)
3. (Vol) Don't Know (Go to Q22)
4. (Vol) Refused (Go to Q22)

21a(1). (If yes to #21a) On a scale of 1 to 5, where 1 is very difficult and 5 is very easy, how easy was the site to use?

1	2	3	4	5
very difficult				very easy

6 (Vol) Don't Know 7 (Vol) Refused

21a(2). Were you able to find the information you were looking for?

1. Yes
2. No
3. (Vol) Don't Know
4. (Vol) Refused

21a(3). On a scale of 1 to 5, where 1 is low quality and 5 is high quality, please rate the overall quality of the CaregiverNJ website?

1	2	3	4	5
low quality				high quality

6 (Vol) Don't Know 7 (Vol) Refused

21a(4). Would you use this website again?

1. Yes
2. No
3. (Vol) Don't Know
4. (Vol) Refused

To understand who is using the NJEASE/ County Office on Aging program, we would like to know a little about you and the person you provide care for.

22.

(Ask questions left to right in each row)	
22a. What is your gender? 1. Female 2. Male	22b. What is the gender of the person you provide care for? 1.Female 2. Male
22c. What is your age? _____	22d. What age is the person you care for? _____
22e. Where do you currently live? For example, do you live…(read list) 1. in an Adult community 2. in an Assisted living facility 3. in a Nursing home 4..in a Private home or apartment 5. in a Retirement community 6. in a Senior housing complex/community 7. or somewhere else? (Specify _____) 8. (Vol) Refused	22f. Where does the person you care for live? Does he/she live…(read list) 1. with you 2. in an Adult community 3. in an Assisted living facility 4. in a Nursing home 5. in a Private home or apartment 6. in Retirement community 7. in Senior housing complex/community 8. or somewhere else? (Specify_____) 9. (Vol) Refused
22g. What language is most often spoken at your home? Is it… 1. English, 2. Spanish. 3. or another language? (Specify:_____)	22h. What language is most often spoken at the home of the person you care for? Is it… (If Q.22f is "1", Do not ask…skip to Q.22i) 1. English 2. Spanish 3. or another language? (Specify:_____)
22i. What is your current marital status? Are you… 1. Married or living with partner, 2. Divorced or no longer with partner, 3. Widowed or partner is deceased, 4. Single (Never married or lived with partner)? 5. (Vol) Refused	22j. What is the marital status of the person you care for? Is he/she… 1. Married or living with partner, 2. Divorced or no longer with partner, 3. Widowed or partner is deceased, 4. Single (Never married or lived with partner)? 5. (Vol) Refused
22k. What is the highest level of education you have reached? Is it… 1. Below HS, 2. HS Degree, 3. Some College, Trade School, or Associate's Degree, 4. College Degree, 5. or Graduate Degree? 6. (Vol) Refused	22l. What is the highest level of education of the person you care for? Is it… 1. Below HS, 2. HS Degree, 3. Some College, Trade School, or Associate's Degree, 4. College Degree,

	5. or Graduate Degree? 6. (Vol) Refused
22m. What Race/ethnicity best describes you? Is it… 1. Asian or Pacific Islander, 2. Black/African American, 3. Hispanic/Latino, 4. White/Caucasian, 5. or another category? (Specify_____)	22n. What race/ethnicity best describes the person you care for? Is it… 1. Asian or Pacific Islander, 2. Black/African American, 3. Hispanic/Latino, 4. White/Caucasian, 5. or another category? (Specify_____)
22o. What category best describes your household income? Is it… 1. 0 to $20, 000, 2. $20,001 to $40,000, 3. $40,001 to $60,000, 4. $60,001 to $80,000, 5. or over $80,000. 6. (Vol) Refused	22p. What category best describes the household income of the person you care for? Is it… (If Q.22f is "1", Do not ask…skip to Q.23) 1. 0 to $20, 000, 2. $20,001 to $40,000, 3. $40,001 to $60,000, 4. $60,001 to $80,000, 5. or over $80,000. 6. (Vol) Refused

23. How is the person you care for related to you? Is he/she…

1. your spouse /companion / partner,
2. your mother / father,
3. your son / daughter,
4. your grandparent,
5. your sibling,
6. your other relative (please specify_____)
7. or your non-related friend?
8. (Vol) Don't Know
9. (Vol) Refused

Q24 omitted for this version

25. How long have you cared for this person? _____

(If Q22f is "1", skip to Q27…all others continue with Q26)

26. Do you provide help on a full-time or part-time basis?

1. Full-time
2. Part-time
3. (Vol) Refused

27. During a typical week, what do you think is the average amount of time you spend helping this person? Is it…

1. a couple of hours,
2. 1 to 2 days,
3. 3 to 4 days,
4. or 5 to 7 days?
5. (Vol) Don't Know
6. (Vol) Refused

28. Is there anyone else who provides care for this person?

1. Yes
2. No (Go to Q29)
3. (Vol) Don't Know (Go to Q29)
4. (Vol) Refused (Go to Q29)

28a. If yes, are they…

1. other family members,
2. friends,
3. or paid professional help?
4. (Vol) Don't Know
5. (Vol) Refused
6. (Vol) Other Person - Specify

29. Do you also provide care for a minor child?

1. Yes
2. No
3. (Vol) Don't Know
4. (Vol) Refused

30. Not including any pay you might get for informal care giving, do you currently have a job for pay?

1. Yes (Go to Q.31)
2. No
3. (Vol) Don't Know
4. (Vol) Refused

Q.30a Did you ever have a job for pay?

1. Yes
2. No (Go to Q.34)
3. (Vol) Don't Know (Go to Q.34)
4. (Vol) Refused (Go to Q.34)

31. Have you ever had to quit a job in order to take care of the person you currently care for?

1. Yes
2. No
3. (Vol) Don't Know
4. (Vol) Refused

[Q.32/33 - The order was switched on purpose]

33. Do/Did you have to regularly take time off from work in order to provide care?

1. Yes
2. No
3. (Vol) Don't Know
4. (Vol) Refused

32. Have you had to cut back/Did you have to cut back on your hours at work in order to provide care for this person?

1. Yes
2. No
3. (Vol) Don't Know
4. (Vol) Refused

34. If you could have any type of support, regardless of cost, what type of assistance or service would help you the most? _____
_____
_____

35. Do you have any recommendations to your local senior service agency/office on aging or the state government for helping caregivers better? _____
_____
_____

THANK YOU VERY MUCH FOR PARTICIPATING!

Appendix A.IV: CAREGIVERNJ WEBSITE FOCUS GROUP

The following are hypothetical situations in which caregivers of older adults or adults with disabilities might find themselves. Imagine you are confronting each situation and trying to find information for yourself. Please read each scenario and follow the instructions provided.

1. SITUATION: You are a 65 year old woman caring at home for your 70 year old husband with Alzheimer's disease. Now that your husband's disease is more advanced, you are beginning to feel overwhelmed by the amount of care he needs. You are physically and emotionally tired. Before reaching out to a social service agency, however, you would like to see if there are any self-help resources available to assist you with managing your husband's care and the stress you feel.
INSTRUCTIONS: **Please try to find self-help tools that may be useful to you on the CaregiverNJ website.**

1A. On a scale of 1 to 5, how easy was it to find information for this situation.

1	2	3	4	5
very difficult				very easy

1B. Use the space below to record what information you found, how you found it, and any problems you encountered.

_____

_____

_____

2. SITUATION: Your 78 year old mother lives alone in a small home. She is physically able to care for herself but often has trouble paying her electric and gas bills on her low Social Security income.
INSTRUCTIONS: **Please try to find general information on what services might be available to help your mother pay utility bills.**

2A. On a scale of 1 to 5, how easy was it to find information for this situation.

1	2	3	4	5
very difficult				very easy

2B. Use the space below to record what information you found, how you found it, and any problems you encountered.

_____

_____

_____

3. SITUATION: You live in Ocean County, NJ. You are a working mother of 2 young children and you also care for a diabetic father who lives with you. With your other responsibilities it is very difficult for you to drive your father to his many doctor's appointments and other activities in which he is involved.
INSTRUCTIONS: **Please try to find what transportation services might be available in Ocean County to help you.**

3A. On a scale of 1 to 5, how easy was it to find information for this situation.

1	2	3	4	5
very difficult				very easy

3B. Use the space below to record what information you found, how you found it, and any problems you encountered.

_____

_____

_____

4. SITUATION: Your wife has recently fractured her hip and must now use a wheelchair. You are having a difficult time assisting your wife with dressing, bathing, and other daily tasks. You live in Warren County, NJ and would like to know if any in-home support is available to you.
INSTRUCTIONS: **Please search for services in Warren County that might help you.**

4A. On a scale of 1 to 5, how easy was it to find information for this situation.

1 2 3 4 5
very difficult very easy

4B. Use the space below to record what information you found, how you found it, and any problems you encountered.

_____

_____

_____

5. SITUATION: You live in Arizona and your 83 year old mother lives by herself in Mercer County, NJ. Recently you have been concerned that your mother is not eating properly. You would like to know if healthy meals could be delivered to your mother's apartment.
INSTRUCTIONS: **Please try to find what meal services are available in Mercer County.**

5A. On a scale of 1 to 5, how easy was it to find information for this situation.

1 2 3 4 5
very difficult very easy

5B. Use the space below to record what information you found, how you found it, and any problems you encountered.

_____

_____

_____

6. INSTRUCTIONS: Please use the remaining time to explore the CaregiverNJ website for yourself, perhaps looking for information interesting or relevant to you.

Based on all of your searching of this website, please answer the following set of questions.

A. On a scale of 1 to 5, how understandable are the menus on the home page?

1	2	3	4	5
not at all understandable				very understandable

B. On a scale of 1 to 5, how easy to read are the pages of this website?

1	2	3	4	5
very difficult to read				very easy to read

C. On a scale of 1 to 5, how well organized is the website (for example, it is easy to move about or do you get lost easily)?

1	2	3	4	5
not at all organized				very organized

D. On a scale of 1 to 5, on average, how much effort did it take for you to find the things you were looking for on the website?

1	2	3	4	5
great amount of effort				small amount of effort

Information about you: So that we know who participated in this focus group, please complete these questions about yourself.

E. What is your age?_____

F. What is your gender? Please check your answer.

_____Male _____Female

G. What is your racial/ethnic origin? Please check your answer.

_____Black/African American _____ Asian or Pacific Islander

_____White/Caucasian _____Other,specify:_____

_____Hispanic/Latino

H. What is the highest level of education you have completed? Please check your answer.

_____Less than high school _____College degree

_____High school degree _____Graduate or Professional degree

_____Some college, trade school, or Associate's degree

I. Who do you provide care for (for example your mother, father, aunt, brother, etc.)?

_____

J. During a typical week, what do you think is the average amount of time you spend helping the person you care for? Please check your answer.

_____ a couple of hours a week

_____1 to 2 days a week

_____3 to 4 days a week

_____5 to 7 days a week

K. Does the person you care for live with you?

_____Yes _____No

L. Do you require a text reader in order to view websites?

_____Yes _____No

M. Do you have any vision problems that make it difficult for you to view websites easily?

_____Yes _____No

If yes, please explain:_____

_____

_____

_____

Please use the space below to record any additional comments you have about the CaregiverNJ website.

_____

_____

_____

_____

_____

_____

THANK YOU SO MUCH FOR YOUR PARTICIPATION!!!

Appendix A.V: CaregiverNJ Website Focus Group Discussion Questions

Select 2 or 3 scenarios to discuss and ask the following for each:

1. Were you able to locate the information the instructions asked you to find?

2. How easy/difficult was it to find the information? Probe: What problems did you encounter? What specific aspects of the site made it easy/difficult to find the information for this situation?

General Questions about Website

1. What is your opinion about the look of the website? Probe: Do you think it is easy/hard to see? Does it look appealing to you?

2. What is your opinion about the content of the site? Probe: Does it contain information that is useful to caregivers? Do you think it is missing anything important? What else would you like to see it contain?

3. What is your opinion about how the website is organized? Probe: Is it clear how to move about or do you get lost easily?

4. How helpful to caregivers do you think this website will be? Probe: Now that you know it exists, will you use it as a resource for finding information you need? For what purposes do you think it will be most helpful for you?

5. Do you have any other specific recommendations to the NJ Department of Health and Senior Services on how to improve the website to help caregivers more?

General Questions about Internet Use

1. What has your experience been in using the internet in general? Probe: What types of sites do you visit the most?

2. What do you like about the internet the most? What do you dislike about the internet?

3. Are their particular challenges you have faced in using the internet?

Appendix B.I: CAREGIVER (CG) TELEPHONE SCREENING TOOL

The **Caregiver Screening Tool** is designed to determine the ***needs of the caregiver***. A **Caregiver Telephone Screening** should be conducted to determine ***the caregiver's need for further assistance***. Please attach a copy of the completed New Jersey Ease Intake Form.

INTRODUCTION: I notice that you are calling for help for your (CARE RECEIVER [CR]). We are going to work on getting the services that you requested for him/her. So far, we have been talking about (CR). May I ask how you are doing? (**Wait for a response**) Do you have a few minutes to answer a few questions?

CG Name:	CG Phone #: H W	
CR Name:	CR Age: years	CR Sex: M F
Relationship of CG to CR: ❑ Wife ❑ Husband ❑ Daughter ❑ Son ❑ Daughter-in-law ❑ Son-in-law ❑ Other: _____		

1.	Are you the person who spends the most amount of time helping (CR) or making decisions for him/her?	❑ YES (2)	❑ NO (0)
2.	Does your (CR) usually live with you?	❑ YES (1)	❑ NO (0)
3.	Are you the only one taking care of (CR)?	❑ YES (2)	❑ NO (0)
4.	Are you caring for anyone else at this time?	❑ YES (2)	❑ NO (0)
5.	Do you work outside the home?	❑ YES (1)	❑ NO (0)
6.	Are you uncomfortable leaving your (CR) alone in the home?	❑ YES (3)	❑ NO (0)
7.	Are you worried or concerned about finances?	❑ YES (2)	❑ NO (0)
8.	Are you worried or concerned about your own health?	❑ YES (3)	❑ NO (0)
9.	On a scale of 0 to 5, with 0 being no stress and 5 being the highest level of stress, please rate your overall level of stress.		
	TOTAL SCORE		
May I ask your age?		AGE _____	

If *Total score = 13 or higher* OR *Score for #9 alone = 4 – 5,* refer for further assistance.

Based on the information you shared with me, we may be able to offer some additional services to assist you and your (CR). May I have someone else call you to tell you about them?

OR

If* Total Score = 12 or less*, provide caregiver with information on identified needs.

I would like to send you additional information that might be of interest to you, if not now, in the future. If you prefer, I can have someone call you at another time with additional information?

Referred further assistance ❑ YES ❑ NO ❑ Refused - Explain Below ❑ Sent Self Assessment ❑ Sent Caregiver Packet

Referred to_____, _____ Date Referred_____
name title

Action Taken:_____

_____

Comments:_____
_____
_____

I&A Screener:_____ Date of Screen:_____

10/29/03

Appendix B.II: CAREGIVER INTERVENTION PLAN

CG NAME: **Phone #**	**CR NAME:**	**DATE:**
PRESENTING PROBLEM:		

List Programs Caregiver Enrolled

✓all that apply	Information/Services	Provider/Contact	Contact to be made by:	Availability	Comments
Has/Needs	**SERVICES/PROGRAMS**				
❑ ❑	Information Services		❑ NJ Ease ❑ CR ❑ CG ❑ Other:		
❑ ❑	Training for specialized tasks you assume		❑ NJ Ease ❑ CR ❑ CG ❑ Other:		
❑ ❑	Transportation Services		❑ NJ Ease ❑ CR ❑ CG ❑ Other:		
❑ ❑	Support Groups		❑ NJ Ease ❑ CR ❑ CG ❑ Other:		
❑ ❑	Volunteer Assistance		❑ NJ Ease ❑ CR ❑ CG ❑ Other:		
❑ ❑	Housing Information		❑ NJ Ease ❑ CR ❑ CG ❑ Other:		
❑ ❑	Financial Assistance		❑ NJ Ease ❑ CR ❑ CG ❑ Other:		
❑ ❑	Mental Health Resources		❑ NJ Ease ❑ CR ❑ CG ❑ Other:		
❑ ❑	Health Insurance Counseling		❑ NJ Ease ❑ CR ❑ CG ❑ Other:		

CG NAME:	CR NAME:	DATE:

✓all that apply	Information/Services	Provider/Contact	Contact to be made by:	Availability	Comments
Has/Needs	**SERVICES/PROGRAMS**				
❑ ❑	Elder Law/Power of Attorney/ Living Wills		❑ NJ Ease ❑ CR ❑ CG ❑ Other:		
❑ ❑	Home Modifications/Assistive Technology		❑ NJ Ease ❑ CR ❑ CG ❑ Other:		
❑ ❑	Home Delivered Meals		❑ NJ Ease ❑ CR ❑ CG ❑ Other:		
❑ ❑	Program Eligibility – Financial/Clinical		❑ NJ Ease ❑ CR ❑ CG ❑ Other		
❑ ❑	Adult Day Care		❑ NJ Ease ❑ CG ❑ Other:		
❑ ❑	Statewide Respite Program		❑ NJ Ease ❑ CR ❑ CG ❑ Other		
❑ ❑	Prescription Assistance		❑ NJ Ease ❑ CR ❑ CG ❑ Other		
❑ ❑			❑ NJ Ease ❑ CR ❑ CG ❑ Other		
❑ ❑			❑ NJ Ease ❑ CR ❑ CG ❑ Other		

CG NAME:	CR NAME:	DATE:

✓all that apply	Information/Services	Provider/Contact	Contact to be made by:	Availability	Comments
Has/Needs	**SERVICES/PROGRAMS**				
❑ ❑			❑ NJ Ease ❑ CR ❑ CG ❑ Other		
❑ ❑			❑ NJ Ease ❑ CR ❑ CG ❑ Other		
❑ ❑			❑ NJ Ease ❑ CR ❑ CG ❑ Other		
❑ ❑			❑ NJ Ease ❑ CR ❑ CG ❑ Other		
❑ ❑			❑ NJ Ease ❑ CR ❑ CG ❑ Other		

Notes	Dates	Time Spent	Units

Signatures:

Caregiver_____ Date: _____

Care manager_____ Date: _____

Other: _____ Date: _____