

Systems Development for Family Caregiver Support Services

AoA Caregiver List Serv Summary

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INTRODUCTION

The second Administration on Aging (AoA) caregiver list serv session, “*Systems Development for Family Caregiver Support Services*,” was held from April 30-May 11, 2001. This session provided the aging network with an opportunity to exchange state and local information around system development activities associated with the National Family Caregiver Support Program (NFCSP). Based on feedback from the pilot list serv session, the timeframe for participant dialogue was extended from five to ten working days. The first five days were devoted to comments on the background paper and state/local systems development experience in the context of the paper, and the remaining five days were devoted to general participant information sharing on the various approaches states and AAAs are pursuing in the area of systems development. The research resource for this session was Lynn Friss Feinberg, M.S.W., Director of Research and Information Programs for the Family Caregiver Alliance.

BACKGROUND RESEARCH

Participants received a background paper entitled, “*Systems Development For Family Caregiver Support Services*,” authored by Lynn Friss Feinberg. The paper emphasizes the social and economic value of family and informal caregivers in our long-term care system and calls for a systematic approach in responding to the diverse range of caregivers’ emotional, physical, and financial needs. Few states have developed comprehensive strategies for supporting and strengthening caregiving families and the systems that have been developed, show significant variability with respect to eligibility requirements, range of services, scope of care, and sources of funding. In order to ensure that programs develop to meet the needs of a diverse range of caregivers, it is suggested to build “flexibility into the local level to enable innovation, and accountability into the state level to ensure the availability of a range of services to caregivers across the state.” In this development process, it is recommended to keep in mind the goals of promoting seamless support services, using resources efficiently, and achieving positive outcomes for caregivers.

Feinberg offers the following principles to guide systems development around the needs of family caregivers:

- Recognize the **family role** in the provision of long-term care services. Family and informal caregivers are legitimate consumers of long-term care services and should be recognized as such. Although the care recipient is traditionally seen as the consumer, the caregiver is also a client in need of support.
- Services should be easy to **access**. Caregivers need support regardless of their age, economic circumstances, geographic location, and point in their caregiving career. Examples of approaches some states have take to address access issues include: in Georgia, a mobile day care program provides services to caregivers in rural areas and in California, multi-service caregiver centers have been established throughout the state.
- “Systems should **coordinate** services for caregivers and build on existing infrastructures.” Known benefits of service coordination are decreased fragmentation and duplication. Coordination also has the added benefit of reducing start-up costs, a critical consideration given limited resources and the large demand for caregiver support.

- Support services should be **comprehensive in scope** and should offer the caregiver **choices**. Because caregivers have many needs that change throughout their caregiving career, it is critical that services be tailored to meet the needs of the individual caregiver at the appropriate point in time. It is suggested that states develop statewide standards for eligibility and scope of services, while allowing for local flexibility in service delivery.
- Programs should strive to meet the needs of an increasingly **diverse** population of caregivers. The author suggests that issues of cultural diversity could be addressed through staffing bilingual individuals and providing information in key languages of the community. Diversity also relates to the situation of the caregiver (e.g., working caregivers). One way the system in California has addressed the diverse needs of working and adult child caregivers is by offering extended/weekend hours at the Caregiver Resource Centers. The author points to the Internet as another means of meeting the information and support needs of adult child caregivers.
- Ensure **caregiver participation** in service planning, delivery, and care decisions. Participation empowers family caregivers by giving them a voice and enables them to learn about various service options, thereby increasing their understanding and comfort level with the service system.
- Systems must **respect** the needs of the caregiver while preserving the dignity of the care recipient. Programs that recognize both the caregiver and the care recipient as consumers of long-term care services will be better equipped to meet the spectrum of needs.
- A system of **accountability** must be in place to ensure quality of care. The author proposes that this be best achieved through a uniform assessment of caregiver needs and a data collection system that supports outcome measures. In addition, it is argued that long-run costs could be reduced through the development of an information system that includes: in-home psychosocial assessment of caregiver needs; reassessment at regular intervals; community resources for the caregiver and care recipient; information on the numbers of caregivers served, types of services provided, and costs of services delivered; and outcomes achieved. Investment in information systems is a key step to building a foundation for new services and policy initiatives.

*The full paper as it appeared in this list serv session can be accessed by clicking on “Listserv and Technical Advisory Group Summaries” on AoA’s “Implementing the National Family Caregiver Support Program” website at:

<http://www.aoa.dhhs.gov/carenetwork/default.htm>

AGING NETWORK RESPONSES

Participants who have had experience with developing caregiver support programs illustrated the importance of starting out by building a solid foundation for a system that can be enhanced in the future. This will allow for the broadest array of services to meet the wide range of caregiver needs. Several participants representing areas that are beginning to develop caregiver programs shared their plans and posed important questions around feasible approaches to systems development. Participant dialogue related to several of Feinberg’s system development principles:

Access

State representatives agreed that providing access to support services for a range of caregivers is key to achieving the ultimate goal of delaying institutionalization while limiting unnecessary burden on caregivers. Though Pennsylvania's Family Caregiver Support Program is characterized by great flexibility, state representatives admit that certain rules that were built into the program are restrictive. For example, caregivers must be related by blood, marriage or adoption and they must live with the care recipient in order to gain access to services. Recognizing that some caregivers are not related to the care recipient and many live in separate residences, Pennsylvania is seizing the opportunity provided by their NFCSP funding to broaden their eligibility criteria and increase access for these individuals.

Several participants agreed that extended hours and days of operation would allow working caregivers the opportunity to access services (e.g., care managers could accommodate caregivers schedules). A representative from Georgia expressed the state's interest in expanding their mobile day care program to increase access to services for caregivers in rural areas. Other participants noted the dynamic aspect of the caregiver career as an additional reason not to limit access to services. Because a caregiver's needs change as time passes, rather than merely providing a large amount of information at the first point of contact, information should be offered at various points throughout the caregiving career.

Coordination

Aging network representatives felt that service coordination and building on existing infrastructures is key to developing effective caregiver support programs. A representative from Wisconsin discussed the state requirement that each county office on aging meet with other providers of services to caregivers in order to enhance coordination. Furthermore, the state requires that the program have close coordination with the statewide Alzheimer's Family Caregiver Support Program. Wisconsin's approach is to treat the NFCSP as a new Title III program and require plan amendments to address how the aging units will carry out the requirements under III-E.

A representative from Kentucky noted the importance of developing a strong foundation on which to build upon when more resources are available. Kentucky is building a model that establishes a coordinator in each region. By building a statewide service network, they are working to create a single entry system for all caregivers and provide for a coordinated system of services targeting specific needs. Potential benefits of this approach that were offered included providing staff to: assist in the development of additional resources through grants, educate and train existing community agencies to strengthen their ability to provide caregiver services, ensure services are targeted to those most in need, ensure regional coverage, coordinate on a statewide basis, and become involved with national service partners.

A collaborative effort in Iowa is currently underway between the AAAs, the Iowa Association of AAAs, and the State Unit on Aging. Through this effort, the ESP software has been purchased to develop a standard I&A network with data being collected statewide at the Association office. They are establishing a single toll-free number to create a single point of entry as well as a marketing and education plan to establish consistency across the network.

Within the statewide structure, each AAA is then developing support services responsive to the area needs of caregivers.

In piloting Pennsylvania's caregiver program, the assessment and care management systems were not integrated with the rest of the aging services delivery system. However, after the program went statewide, these systems merged thereby allowing greater portability throughout the system as needs change. Coordination between the caregiver program and the Medicaid Waiver program has been particularly important in facilitating transitions as a family's need for assistance extends beyond what the caregiver program was designed to provide.

Georgia is currently working to fully implement a statewide single point of entry through the 12 AAAs. Like Pennsylvania, they adopted a standardized intake and screening instrument that the AAAs use to screen applicants for both the non-Medicaid funded aging program and the Medicaid Waiver program. The existing data system has been built around the care receiver as the consumer but it has the capacity to capture and track caregiver data as well. Georgia is in the process of defining what additional data related to caregivers are meaningful to collect.

Comprehensive Services Offering Choice

Several aging network participants stated their concerns regarding states funneling NFCSP money directly to existing services such as adult day care and respite. Although these programs are essential and do ease the burden of caregivers, it was expressed that caregivers have other needs including support, information, and education. Furthermore, caregivers need to learn how to access the systems and benefits, and they need to know that their work is valued. Since respite and day care cannot address all of these needs, several participants expressed concern with limiting scarce dollars to these services rather than looking to create a system that will meet a variety of caregiver needs and provide caregivers with a choice of services.

Based on experience with the Pennsylvania caregiver program, the state representative suggested that states develop a list of services that they will *not* cover rather than a list of services that they will cover. This approach would allow for program flexibility as well as consumer empowerment in accessing assistance that was not previously considered by the state or area agency on aging. Currently, the PFCSP does not have a long list of service restrictions (although it will not pay for pharmaceuticals because there is already a separate state pharmaceutical benefits program), and as long as it is stated in the care plan why the service/product will preserve or enhance the caregiving relationship, it is accepted.

Representatives from Utah and North Carolina suggested that a system of caregiver support programs should include advocacy as a vital component. Advocacy could involve promoting caregiver issues and awareness to the larger community such as business leaders, corporate human resource departments, policymakers, etc. It was expressed that advocacy can have a significant impact on the entire caregiving community at a regional, state and national level. As stated by the Utah representative, "a system that promotes to the larger community the long-term societal benefits of supporting caregivers will ultimately sustain itself through times of change and unforeseen challenges."

In North Carolina, the 17 AAAs will each hire a Regional Caregiver Specialist who, among other responsibilities, will be responsible for building community and program relations and function in an advocacy role as a primary spokesperson in the region on the family caregiver support program and the needs of family caregivers. The Specialists will also be involved in community and program coordination and resource development, working with and through a wide array of individuals and groups to develop and expand resources to address the needs of caregivers.

Caregiver Participation

A representative in Georgia provided rich information around a series of focus groups that were conducted throughout the state in anticipation of the authorization of the NFCSP. In doing so, they solicited formal/informal and traditional/non-traditional caregivers. The emerging themes from the sessions were: 1) a lack of information about and coordination of available resources, 2) needs exceeding available resources, 3) providers who are not adequately trained or informed, and 4) insufficient oversight of the existing service delivery system. Georgia is using the findings to develop strategic plans for education and training and to further develop services. The findings were shared with the AAA partners so that they can further access needs for services at the regional level.

Stakeholder input was also addressed by a Minnesota representative who remarked that the use of local caregiver experts conducting research in connection with eliciting feedback from caregivers has been used to create a vision for the Minnesota system. Their input was critical to informing the state of caregiver needs and potential approaches to take (e.g., allow direct payment to caregivers; establish outcomes for the system, community, and caregiver; and bridge funding sources).

Diversity

The issue of serving a range of caregivers prompted several comments and questions from the list serv participants. Several representatives are interested in knowing what other state's experiences are with planning and designing services for long-distance caregivers, including the possibility of varying services and eligibility in the location of the caregiver and the care recipient. Participants suggested that care planners be knowledgeable about resources and contacts not only in their own states, but also nationwide in order to address the needs of these long-distance caregivers.

A number of representatives expressed interest in using the allotted 10 percent of funding to develop programs that support grandparents raising grandchildren; however, several representatives wondered what types of services would support these caregivers. In response, a representative from Iowa expressed her region's plan to contract with an African American neighborhood center to offer weekly support sessions. A speaker will be brought in to inform grandparents of support programs while simultaneous activities will be provided for the grandchildren.

In addition, representatives from Rhode Island, Florida, and Wisconsin contributed their states' experiences in the development of grandparent support programs. In these states, partnerships were established which led to the creation of a broad range of services including support

groups, the development of a resource directory, and training conferences for grandparents. Data on the prevalence of kinship care arrangements were collected, and in Florida, a legislative initiative was introduced which now gives grandparents raising grandchildren the same legal status and access to financial support as natural and foster parents. Because legal guardianship issues are such an important topic, it was suggested that other states might want to consider working with a local bar association to inform lawyers of the needs of these grandparents. Another possibility discussed is the formation of a family caregiver assistance clinic set up at a local law school.

Accountability

The Louisiana SUA representative shared her state's client intake form which will be used to evaluate caregiver needs and prioritize clients. Information collected on the form includes: the type of caregiver, economic need, disability level of the care recipient, number of hours of care provided, and risk of care recipient nursing home placement. One of the roles of the newly created "Regional Caregiver Specialists" in North Carolina is to focus on community and program documentation, evaluation, and oversight.

The Pennsylvania caregiver program relies on a standardized assessment, customized care planning and ongoing care management; all of these components are documented in the case record. It was suggested that one way of achieving accountability is by "demonstrating consistency with the general mission of the program and requiring individualized documentation of how that is achieved in any particular case." In addition, increased reliance on information systems will help promote program longevity and growth by accounting for the public expenditures and by creating a case for increased funding in the future.

The Ohio representative shared an interesting lesson from the Performance Outcomes Measurement Project (POMP) in that many states were not able to get an accurate sample of caregiver names and phone numbers in the process of trying to collect outcome information from caregivers. It was suggested that the aging network recognize the caregiver as a client in the system by: developing a caregiver assessment tool (build into the case management process and MIS); tracking caregiver data using information systems; and designing services that are specifically for the caregiver.