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Community Caregiving Partnerships in Aging: Promoting Alliances to Support Care Providers

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SUMMARY. Although greater numbers of families are providing support to older adults, a lack of comprehensive programming in resource allocation continues to exist at the social policy level. This chapter explores how community caregiving partnerships may contribute to a solution.

KEYWORDS. Community partnerships, older adults, caregiving

Contemporary social trends have created additional demands for families and community organizations that work to provide support to older generations. One change is the demographic shifts that are occurring within the older population. The 2000 Census reports that 35 million people in the U.S. are over 65 years of age, which is an increase of 3.8 million from 1990 (U.S. Bureau of the Census, 2003). In addition to the greater number of older adults generally, the most dramatic increase is in the number within the over 85 year old population. At this point in the life course, it is probable that an older adult will be experiencing some health-related or functional impairment. As the number in the oldest cohort increases, families and society will have additional responsibility to provide assistance and care for these older adults.

A second trend is the changing profile of those family members who provide support to older adults. In a recent national study (AARP & National Alliance for Caregiving, 2005), the number, description, and impact of care upon the caregivers were highlighted. Some of the key findings from this national study were:

- There are 44.4 million caregivers (over age 18) who provide unpaid care to another adult.
- A profile of the “typical” care provider is a 46 year old female with some college education, is in the labor force, and spends more than twenty hours per week caring for her aged mother.
- Over half (59%) of caregivers work full- or part-time, and 62% report that they have had to make adjustments in their work schedule to accommodate care tasks.
- Excluding spousal care providers, about half of the caregivers report that they spend an average of \$200 per month on costs related to care provision.
- Caregivers cope with demands of care in various ways. The most common was by praying (71%), which was used most frequently by African-American (84%) and Hispanic caregivers (79%). Other typical coping mechanisms that were reported included talking with friends or relatives (71%), reading (44%), and exercising (41%).
- Formal sources of support vary by location. Those who are caring for someone in an urban area are more likely to report using formal services (58%) than those caring for someone in suburban (42%) or rural settings (44%).

Taken together, there is a clear picture that caregiving is a task assumed by significant numbers of adults, especially women. As a result of caregiving tasks, other life experiences of the care provider may be affected such as the quality of the relationship with the care recipient or the relationships with other family members. For adult children, role dynamics may become confusing for both the parent and adult child, such as when a son or daughter has to feed or bathe an older parent. Caregiving partners or spouses may lose a source of companionship as the care recipients’ levels of functioning decreases with a possible outcome of feeling isolated and lonely within their

caregiving role (Li, 2004). While the role of care giver is becoming more statistically normative, care providers may feel very alone with these multiple and diverse tasks.

A particular challenge of caregivers is the balance of family and workplace responsibilities. As the NAC/AARP study indicates, most caregivers work and many are expending hundreds of dollars per month on related expenses. For these families, it is important that the care provider remains in the labor force. Yet from an organizational perspective, studies have documented the costs associated with caregiving within the workplace such as absences, decreased morale, and decreased productivity (Barnett, Marshall & Singer, 1992; Singer, Yegidis, Robinson, Barbee & Funk 2001; Robinson, Barbee, Martin, Singer & Yegidis, 2003). As greater numbers of women have jobs and careers, the stress of family versus labor force roles seems especially acute for females (Field and Bramwell, 1998; Frederiksen & Scharlach, 1999; Pavalko & Artis, 1997).

Although greater numbers of families are providing support to older adults, a lack of comprehensive programming and resource allocation continues to exist at the social policy level. This third trend—the lack of a comprehensive system of long term and community-based support—leaves some families without access to appropriate supportive services (Morgan, Semchuk, Stewart & D’Arcy, 2002; Palley, 2003; Wiener, Tilly, & Alecxih, 2002). Without availability of formal sources of support, some families may face dire economic, social and physical hardships as a result of assuming care for an older adult.

At face value, changes in current federal policy, such as funding of faith-based initiatives, appear to broaden the circle of service providers within social welfare. In fact, during President Bush’s first week in office, he laid the groundwork for the White House Office of Faith-Based and Community Services (Fact Sheet, 2003). With this new policy focus, various organizations are becoming more integrated into service delivery operations. Coupled with this trend, however, government agencies are receiving less public support for traditional service roles (Dluhy, 1990). In addition to decreased funding for established programs, the lack of coordination between the various sources of support can create a more chaotic environment for the care provider. Within the context of shrinking fiscal resources, families who require support in care provision are unable to access services to help them with caring for an older family member.

Within this environment, community partnerships can assume a critical role in coordinating disparate services and issues across multiple networks and social agencies. In addition, partnerships can provide an opportunity to collaborate on needed community programs and promote a political agenda (Armbruster, Gale, Brady & Thompson, 1999). This chapter describes issues related to construction of caregiving partnerships, and presents models to identify ways to successfully plan and implement partnerships to address family care provision.

COMMUNITY PARTNERSHIPS

Types of Partnerships

The literature on partnerships has developed over the past forty years as changes within social services have occurred. In fact, there are various types of community relationships that represent formalized partnerships among agencies (Bailey & Koney, 2000; Reilly, 2001). A *cooperation* is a relatively informal process that exists without a defined structure or a systematic planning effort. An example is a group of neighborhood families that bring groceries to older adults who live alone.

While there may be some discussion or information exchange between the families, this system is informal and is based upon the characteristics, motivation, and overall “goodwill” of those who are involved.

A second type of alliance is a *coordination* between different groups. This type of alliance is more formalized and involves a modest amount of planning and information exchange. Most often, these types of alliances are constructed around a single issue. For example, a task force was created to deal with elder abuse prevention and prosecution in Oregon (DeMonnin & Schneider, 2005). This multidisciplinary task force was successful in bringing about legislation to better enforce and prosecute perpetrators of abuse, as well as to raise awareness of elder abuse in the community and increase protective options for older adults within the state.

The most formalized type of partnership is a *collaboration*. This type of structure brings together diverse groups in order to achieve a new structure for a shared mutual purpose. Examples of collaborations are coalitions, consortia, or alliances. These types of partnerships seek to create a unified agenda, promote a particular position, or work to increase competence within the community. During the 1960s, community collaborations began to form as a way to create a power base for social services through political advocacy initiatives (Armbruster et al., 1999). Currently, collaborations may serve various functions, including the opportunity for networking, sharing of information and resources, and realigning community activities to achieve maximum benefit (Wolff, 1993).

Successful Partnerships

While building relationships among individuals and organizations has the potential to ameliorate some of the stresses experienced by caregivers, building effective partnerships is complex. Just as the Functional Age Model specifies, interdependence exists between systems such as a care recipient and care provider, a family and the community, and a community and the larger socio-political environment. The application of this tenet to the community level provides a framework for determining the factors that are associated with those partnerships that are successful, as well as challenges in implementing effective partnerships.

Mizrahi and Rosenthal (2001) have constructed a conceptual framework based upon a study of social change coalitions, which is a common type of partnership in social services. Through interviews with coalition leaders, four major factors were related to successful functioning of coalitions. *Conditions* include the level of resources of the coalition, community climate to support the coalition, and feasibility of the coalition to exert some influence within the environment. Successful coalitions seemed to select the “right issue and timing” that fit with the priorities of the external environment.

A second dimension, *commitment*, is the tension between the degree of power and influence exerted by the coalition and the dominant ideology that is represented. Coalitions that were evaluated as being successful were able to strike a balance between action and ideals. The third dimension in the conceptual framework was *contribution*. Successful coalitions are able to share resources and assets among members, thereby contributing in meaningful ways to one another. The final factor, *competence*, primarily addresses the leadership role. Successful, or competent, leaders demonstrated skillful management of internal dynamics (e.g., decision-making, sharing responsibility) along with a goal orientation to promote sustained positive movement of the

coalition.

Other research has focused on how talents, skills, and knowledge combine to promote “partnership synergy” within community collaborations (Weiss, Anderson & Lasker, 2002). *Synergy* was conceptualized as the process wherein members’ abilities combine to enhance thinking and actions of the group and therefore enhance the partnership productivity within the community. The results indicated that two factors were primarily responsible for creating synergy. *Leadership effectiveness* was the most influential factor and involved the leader’s ability to facilitate productive interactions among the members, promote open dialogue, and bring together partnership members from diverse backgrounds and experiences. The second dimension was *partnership efficacy* which included the degree of resources available to the group, as well as the level of expertise that the various members contributed.

Alternate frameworks to address success of partnerships have also been constructed. Reilly (2001) offers several factors through a synthesis of existing research on collaborations. In his analysis, five essential components are: (1) an articulated and *meaningful purpose* to the collaborative, (2) *membership* across multiple constituencies, (3) roles, rules and communication that provides *structure* for the partnership, (4) a *process* for the partnership that allows investment of the members and leaders towards successful outcomes, and (5) *resources* such as funding and staff. As identified, these factors span the leadership, composition, and methodology of the partnership in working toward goals and outcomes.

Challenges in Forming Partnerships

The process of bringing together disparate entities to share a process, goals and outcomes is not always successful. Unfortunately, many partnerships are unable to function effectively or sustain involvement over time. Regardless of the degree of formality of the partnership, an internal structure is necessary to ensure that all members are moving in the same direction. In an attempt to identify threats to effective functioning, an analysis of decision making within community coalitions was constructed using recorded minutes of group meetings (Speer & Zippay, 2005). This study determined that many principles of good leadership and organizational functioning were applied unevenly in the least effective partnerships. Examples of particular problems included a lack of specific tasks and a lack of delegation of authority to move the agenda forward. One particular finding was a lack of assignment of particular tasks to individuals or subgroups. In partnerships where there is no accountability or responsibility, it is not surprising that outcomes are compromised.

Leaders must also be aware of how accurately a partnership’s agenda corresponds to priorities within the community. This issue is one of validity and representation, as partnerships may be effective for a segment of the population or a dimension of a particular problem without addressing the issue more comprehensively. In an analysis of how needs of family caregivers were defined, for example, the process of needs assessment techniques undertaken by Area Agencies on Aging (AAA) were examined (Kietzman, Scharlach, & Dal Santo, 2004). The findings indicated that the AAAs were successful in determining needs of certain profiles of caregivers, including White/non-Hispanic, grandparent care providers, people caring for individuals with cognitive impairments, and low income caregivers. AAAs were less successful identifying harder to reach populations, such as needs of gay/lesbian caregivers, those individuals who did not speak English, and people living in rural communities.

In research on partnerships in child welfare services, a conceptual model of environmental stressors was constructed (Mulroy, 2003). The model included the following components: uncertain funding streams such as changing priorities in ways funding sources made decisions about allocating their resources, existence of conflicting policies which creates tension and competition between potential members of the partnership, and changing demographics within the community that can create different community needs. These factors can have an impact on the ability of the partnership to establish a structure that is responsive to caregiver needs within the community.

COMMUNITY PARTNERSHIPS IN CAREGIVING

Various types of partnerships have been implemented and evaluated within aging services. Three models of community partnerships will be highlighted as examples of ways that various community systems can work together to enhance and improve the quality of care provision. Each of these three examples provides a different type of focus: a statewide initiative to provide a comprehensive network for caregiving, an effort to bridge aging and disability networks, and a lasting advocacy coalition. While this certainly is not an exhaustive list, it provides some examples of efforts to promote care provision at the community level.

CARE-NETS

The CARE-NET project is a statewide effort to establish caregiving coalitions across the State of Georgia. Initiated by the Rosalynn Carter Institute (RCI) for Caregiving at Georgia Southwestern State University and funded by a grant from the Administration on Aging. This initiative formed partnerships within twelve regions of the state. Each CARE-NET is a collaborative network of representatives from a variety of constituencies, including family care providers, aging agencies, educational institutions, businesses, and other interested groups (Dodd, Talley & Elder, 2004). The initiative was also an effort to raise awareness of caregiving issues and needs, within the context of diverse communities around the state. The purpose of these groups was to develop a comprehensive statewide system that would further caregiving capacity within all communities of the state.

Each CARE-NET represents an autonomous coalition that is connected to the others by an infrastructure initially supported by the RCI. As a beginning step in developing the coalition, each CARE-NET elected formal leaders, established by-laws, and held membership meetings. In addition, each coalition crafted a purpose and focus that fit with the needs of the particular region of the state. For example, several coalitions in rural areas included non-traditional members such as funeral home directors. Another coalition formed solely around faith-based service providers. While the individual coalitions maintained statewide connections, there was great variability in the structure and membership overall depending on the needs within the particular region.

In a formative evaluation of the coalition development that was under-taken midway through the grant, findings indicated that the majority of the CARE-NET participants perceived that their coalition was effective in reaching their goals (Kropf, 2003). In addition, the membership of the CARE-NETs was diverse and included aging service providers, family members of older adults, local business, faith-based and religious organizations, and health care providers. The overall reason that the members participated in the statewide coalition initiative was an avowed commitment to improving the experience of caregivers, by being connected to others with an

interest in care.

Several different initiatives have been undertaken by the various CARE-NETs to enhance the resources within local communities. Several coalitions have sponsored seminars on caregiving within their areas, such as *Caring for You, Caring for Me* (Haigler, Mims & Nottingham, 1998), which is a leadership preparation curriculum to promote self care skills for care providers. Other programs have included public service announcements to raise awareness of care-related issues, and sponsoring health fairs for caregivers. In the faith-based coalition, the focus was on using untapped resources within the religious organizations and raising awareness of religious leaders to issues of aging within their congregations.

An additional part of the grant was to construct a community-level assessment tool to determine whether and not to help with helping caregivers and their families. Termed the Community Caregiving Capacity Index (CCC-I), the focus of the instrument is on community-wide resources and services. Through rigorous development and field testing (Holland & Kim, 2004), the CCC-I is a multifactorial assessment protocol that includes the dimensions of available and useful health care resources, social services, in home and community services, and caregiver supports. The purpose is to provide a tool that can be used to determine the “competence” of a community to support individuals in care provision roles. As the CCC-I is more widely used, it has the potential of providing a sound assessment tool at the community level.

Aging and Developmental Disabilities

Another statewide initiative was undertaken in Georgia to bridge aging and developmental disabilities networks. Due to increased life expectancies and community-based forms of service provision, more parents and other family members are in caregiving roles for family members with disabilities into late life (Doka & Lavin, 2003; Heller, Miller & Hsieh, 1999; Malone & Kropf, 1996). This situation, the simultaneous aging process of both the parent and caregiver, is a fairly recent line of inquiry within research and practice. Although the needs of the family may straddle multiple service sectors, linkages often do not exist between aging and disability networks, the lack of which creates service gaps and unmet needs (Kropf, 1997).

In an effort to bridge these service networks, a statewide coalition initiative was undertaken between aging and developmental disability service providers. Through a series of nine coalition meetings in different parts of the state, service providers from both networks were brought together to learn more about ways to work together to bridge services. In day-long sessions, a series of panels, activities, and presentations were aimed at promoting interaction between the aging and DD providers. As a concluding segment, time to establish local planning coalitions was included so that the groups could interact beyond the course of the formal session.

At the conclusion of the initiative, an evaluation was undertaken to determine if these statewide planning meetings increased coordination across service systems (Smith, Thyer, Clements, & Kropf, 1997). Some successes were found such as increased awareness of services that are delivered by the aging and DD service sectors and enhanced professional relationships that crossed service sector boundaries. However, long-lasting structural changes to service delivery were not sustained. The goal to develop more permanent coalitions within the various regions of the state was not achieved. Participants reported that a planning infrastructure, such as a coordinating entity, was needed, and, sadly, momentum to sustain relationships was thwarted

without this additional type of support.

Advocacy

In addition to partnerships that focus on services within the community, some initiatives focus on creating relationships for advocacy purposes. One of these alliances is the Southwestern Pennsylvania Partnership for Aging (SWPPA) (Kelly, 2004). This interorganizational entity was formed in 1990 and started with 24 members. Currently, there are 398 members that include family caregivers, non-profit and for-profit aging providers, long term care and healthcare providers, businesses, governmental entities and universities committed to improving the social, emotional, physical and psychological well being of older adults.

A goal of SWPPA is to bring together diverse segments of the community to improve the context for care within this region, which has a high density for older adults. In addition to providing a forum for networking, the coalition holds an annual regional conference on some aspect of care. Due to its size and longevity, the coalition has become a recognizable force within the community, serving as a catalyst to promote positive change in programs, policies, and care systems that can improve the quality of life for older adults.

The Functional-Age Model Applied to Community Partnerships

As developed by Greene (1986; 2000), the Functional Age Model (FAM) provides a framework for assessment and intervention with older adults and their families. Although this model has been primarily used with smaller social systems, such as the individual and family, this model has potential to help practitioners understand larger systems such as community-level dynamics. Using the content on community partnerships contained within this chapter, particular ways of blending the FAM into more macro-practice principles is suggested.

As the literature on community partnerships indicates, there are two major dimensions for assessment. One area is the experience of care providers and older adults within a particular community; that is, what are the major priorities that are facing the families in this area? A second is an assessment of the effectiveness of the partnerships that are established, and ways to determine if these alliances are able to promote competent communities to support caregiving.

As the Functional Age Model states, assessment must contextualize the individual in the perspective of his or her social system. On a more macro-practice level, an analysis of the community includes the strengths, resources, and challenges that exist in supporting care providers in their roles. Using that framework, partnerships can be established around the gaps that exist within community-based and long-term care support systems. In addition, there also may be a need to raise awareness of the needs of families within the context of other organizations and roles. For example, the NAC/AARP report indicates that religious practices are important to many care providers, especially those who are African American. The Black Church, which has historically promoted social justice, is an important partner in providing emotional and spiritual support to caregiving families.

Partnerships can also promote political strength by crafting a unified political agenda. Due to the increase in the numbers of adults who hold caregiving roles, the business community needs to consider how care for older adults impacts workers. For example, childcare facilities have become

a common fixture in community and corporate life. In fact, some industries have childcare on site so parents have a convenient and accountable option while they are at work. Sadly, counterpart supports are lacking for older adults. Partnerships can form around both political and economic agendas to increase support and access to resources for caregivers such as respite, in-home services, and adult day care options.

At the level of community practice, social workers can make an important impact in creating relationships among systems that can support older adults and their caregivers. Case managers work to link families with resources within the environment, and this type of practice is critical within the fragmented service systems that exist. However, there is need to move beyond this practice model to transform service systems. Initiatives such as the partnerships highlighted within this chapter provide examples of innovative ways to change how services are provided to care providers. The leadership within a community partnership must be effective at using the internal resources to transform the service structure by forging new alliances, opening up new pathways into services (such as the aging and DD initiative), and raising the consciousness of the community about the experience of care provision. While case management will continue to be an important social work method, there is a dire need to devote energy to transform the service networks themselves.

In summary, the impacts of a changing demographic will be felt at all levels of social systems. At an individual level, a greater number of people will live longer lives than ever before. For families, this change will signal a need to provide support and assistance to older family members within their advanced years. Age-related changes also impact communities and organizations, as care providers hold other social roles and require assistance and support from employers, formal service providers, and voluntary organizations such as religious and civic organizations.

The Functional Age Model has been used as a framework for assessment and practice with older adults and their families. Within this chapter, the Model has been used to distinguish community partnerships that can potentially bridge gaps within the aging service system. Several factors that are related to successful partnerships were highlighted, as well as partnership models in aging. As our society ages, communities and formal resources will be crucial to support families who will be involved in providing even greater degrees of support to their older family members.

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