

2004

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Recommended Citation

Wilder, A., & Ansello, E. (2004). Meeting the Challenges and Opportunities of Aging with Lifelong Disabilities: The Area Planning and Services Committee. *Age in Action*, 19(4), 1-5.

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Meeting the Challenges and Opportunities of Aging with Lifelong Disabilities: The Area Planning and Services Committee

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Educational Objectives

1. To generate awareness of needs and capacities of aging adults with lifelong disabilities and their effect upon human services
2. To understand the challenges and opportunities facing aging adults with lifelong disabilities in accessing appropriate community supports and services.
3. To illustrate the benefits of intersystem collaboration among human services providers through the vehicle of an Area Planning and Services Committee.

Background

We are well aware of the "graying of America." We are also aware of the remarkable heterogeneity of the older adult population and the challenges inherent in attempting to set policy, develop programs, and administer services for such diversity. If we take a closer look at the demographics of our aging citizenry, we will see an unprecedented subgroup emerging, elders living with lifelong disabilities.

Most of us take for granted an established rhythm to the life course: we work most of our adult lives, retire, and then enjoy our golden years. But for individuals with lifelong developmental disabilities such as mental retardation, cerebral palsy, and autism, preparing for old age is a relatively new phenomenon. For example, in just the past 20 years the median life expectancy for a person with Down syndrome has nearly doubled, increasing from 25 years in 1983 to 49 years in 1997 (Yang et al., 2002). Further, it is estimated that the overall population of older adults with lifelong disabilities will double within the next 30 years (Heller, Janicki, Hammel, & Factor, 2002). Some 60% or more of today's older adults with developmental disabilities live at home with family members. Another sizeable percentage lives in group homes or other settings in the community. Only a small minority lives in any type of institutional facility. While those at mid-life or younger present a different picture, having benefited from "mainstreaming" legislation as children, older adults in their forties and beyond tended to grow up and older relatively invisibly within the community. Today, about 25% of these older adults live with a caregiver who is over the age of 60. It is a startling reality that aging parents who are in their 60s, 70s, and 80s are still providing daily care for their adult children who are in their 40s, 50s and 60s. In addressing aging with

lifelong disabilities, therefore, human services providers must plan for "two-generation geriatric families." (Janicki & Ansello, 2000)

The increasing longevity of people with lifelong disabilities creates interesting dilemmas. As a society, we can take great satisfaction in the social and medical advances that have led to longer and more vital lives for individuals with disabilities. Yet these advances have created a subgroup that tends to fall through the cracks in terms of policy development, health care and human services delivery. For example, older adults with lifelong disabilities challenge developmental services systems that are oriented to early intervention. Moreover, we should be gravely concerned about one of the primary mechanisms that fostered their growing older, namely, their parental caregivers. How do we meet the individual's continuing, and likely increasing, need for services and supports as their primary caregivers "age out" of their ability to provide daily care. Who will provide the supports and services to help individuals who wish to stay in their homes? How can we reinforce existing family caregiving? Where should services be provided? Will funding will be available for training and services? Who will advocate on behalf of those who need help?

Case Study: The APSC as Innovation

As noted, individuals who grow older with lifelong, developmental disabilities are in danger of falling through the cracks of our fragmented human services systems. Up to now, there has been little history of effective communication or collaboration between and among the various service systems that comprise the disabilities and aging networks, forcing providers into a reactive rather than a proactive mindset. At least one national study of all of the state level aging and state level developmental disabilities units has found that aging with lifelong disabilities is neither a funding nor a service priority for either system (Coogler, Ansello, Wood, & Cotter, 1997) Changing this mindset is essential if we are to meet the needs and strengthen the capacities of aging citizens with lifelong disabilities and their families. Responding to these realities, a group of service providers, planners, health care professionals, and others created the Area Planning and Services Committee for Aging with Developmental Disabilities (APSC) in the greater Richmond area in summer 2003 as a multi-agency collaboration to plan and provide age-sensitive programs and supports for the citizens in our communities.

Forming an APSC is a critical component of a strategy called the Integrated Model of Service for Older Persons with Developmental Disabilities (see Janicki & Ansello, 2000). The Model was developed and field-tested over time during the federally supported Partners I, II, & III research and demonstration projects in Virginia and Maryland, a sustained effort to improve intersystem cooperation and the capacities of service providers, older adults with lifelong disabilities, and their family caregivers. The Model maintains that meaningful response to the needs and capacities of aging adults with lifelong disabilities requires intersystem cooperation, and that this, in turn, is made likely through the three key strategies of collaboration, outreach, and capacity building. Collaboration should occur at state and local levels. The APSC is the local effort.

The APSC from the Greater Richmond Metropolitan Area is a vibrant mixture of members who are leaders in the fields of disability, aging, health services, parks and recreation services, communities of

faith, higher education, and more, plus family caregivers and others. They share a commitment to the well being of aging adults with lifelong disabilities and their family caregivers. Collaborating agencies designate in writing those who represent them in the APSC. Members represent the disabilities, health care, aging, parks and recreation, faith community, and other human service agencies in the City of Richmond, Chesterfield, Hanover, and Henrico counties. They meet monthly, becoming better acquainted with each other's organizational philosophies, priorities, and funding streams. Each meeting contains an overview of a member agency, discussions of needs and opportunities, and creative initiatives for staff training needs, the education of the general public, and more.

The focus of the APSC is to promote thoughtful understanding of issues, collaboration among systems and providers, outreach to older adults with lifelong disabilities and family caregivers, and help in building the capacities of formal and informal care providers through education, training and information. The following composite case represents real initiatives undertaken by the APSC.

Betty is 54 years old and has cerebral palsy. She has lived at home all of her life. She and her 72-year old mother share a modest home on the outskirts of Richmond. Betty has been working faithfully at the same sheltered workshop program for the past 15 years assembling medical products. She has been a reliable employee with a strong work ethic and a desire to do a good job. Lately, Betty has begun to miss work due to "not feeling well." Her employer has noted that her productivity has declined and that she is having difficulty completing a full day of work. Betty would like to cut back from full time work, but cannot stay alone at home as her mother still works in order to make ends meet. Betty and her mother will need to find alternative plans if Betty cannot, or does not want to, continue her demanding work schedule.

APSC Response

Betty represents the dilemma of success. She has grown older in a support system that is relatively unprepared for aging-related issues. She wants to retire and needs a retirement plan. There are services that would be appropriate but, as an aging person with a lifelong disability, Betty faces a predicament imposed by the historical structure of our service systems. While aging network programs may be better suited to meet her needs, at age 54 she does not meet the legal age of eligibility for Older Americans Act-funded programs, i.e., 60 years of age. APSC members discussed her situation and worked to resolve the dilemma inherent in serving a new population whose needs span two or more service networks. The APSC identified disparate eligibility criteria in various health, transportation, and social programs operated by the aging network and disabilities systems. Out of this dialogue came, among other things, the implementation of a new approach to using a valuable existing resource, the Friendship Café, as a first step for Betty.

The Friendship Café is a nutrition program sponsored by Senior Connections, the Capital Area Agency on Aging. Funded by the federal Older Americans Act and administered through the Virginia Department on Aging, the Friendship Café is open to anyone age 60 or older who meets eligibility guidelines. In addition to providing a nutritious noon meal, the program offers social and health promotion activities. The program would be perfect for Betty if she were older. As Betty is only 54 years old, she does not meet

eligibility guidelines. Rather than denying Betty access on age alone, APSC members responded with thoughtful resource sharing to secure meal funding for Betty through other channels that allow her to take advantage of the social and health promotion aspects of the Café and still partake in the meal program.

Betty's mother has begun to experience health problems that make it very difficult for her to help Betty with her care needs. She has a debilitating arthritis and cardiovascular problems. She wants to continue the lifelong pattern of living with her daughter, but it is likely that Betty's mom will soon be unable to care for her, which may mean that Betty would need to move into a group home or other facility to receive the assistance she needs. Moving is likely to be very traumatic for Betty as she will face losses on multiple levels when she leaves her mother's house, the only home she has ever known.

APSC Response

Given mother's and daughter's preferences to maintain their shared home, the APSC's first step was to initiate actions that would strengthen or maintain the mother's health. Visiting nurses assessed her overall health status, while a short-term home chore service helped with the more pressing current needs. The APSC identified the need for Betty's mother to explore and to initiate plans for the continuing care of her daughter after her own incapacity to do so; this so-called "permanency planning" is complex, involving legal, financial, and familial actions. The APSC also acknowledged the eventual reality that Betty will need help understanding why she must move and coping with the loss associated with leaving her mother's home. The APSC has undertaken an initiative in loss and bereavement issues for aging persons with lifelong disabilities, with plans to offer training and outreach. Local experts were brought in to consult with the APSC's Loss and Bereavement Subcommittee. It examined research on loss and grief, finding little related to adults with lifelong disabilities. Consulting counselors advised training for direct service staffs on loss and grief associated with the many transitions these adults experience with advancing age: loss of home, parents, friends, program staff who change jobs, etc. The APSC is formulating training programs for area service providers to enhance their ability to understand loss and bereavement behaviors, to assist elders with coping with such loss, and to screen for the need for expert help in dealing with problems associated with loss and bereavement. The intention is to have trained service providers in place by the time Betty moves from home.

Conclusion

As shown by their responses to the needs and concerns of aging adults with lifelong disabilities, the greater Richmond APSC has become a proactive vehicle to address problems and opportunities. Each APSC member carries the commitment of his or her respective agency, having been designated to participate in the collaborative processes of identifying community needs, sharing resources, resolving problems, and creating innovations that serve our elders with lifelong disabilities and their family caregivers. By working together, APSC members have created a virtual organization, one without a building or specific funding stream but one that is greater than its separate parts. As APSC member Debbie Burcham of Henrico County Mental Health/Mental Retardation remarks, "By partnering

disability services with aging services, both types of providers benefit. Providers who are very skilled in supporting persons with disabilities can share their skills with those who provide services to the aging and vice versa."

Study Questions

1. Identify the challenges and service gaps aging consumers face in accessing community supports and services.
2. What are the three key strategies of intersystem cooperation and how has the Richmond Area APSC carried out this charge?
3. Describe how the APSC can assist human services providers, consumers, and family caregivers to maximize service utilization.
4. Identify how intersystem collaboration in the form of an APSC can directly benefit someone like Betty and her mom.

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