

White House Conference on Aging

Post-Event Summary Report

Georgia Designated Event 1 of 5

Name of Event: Aging for All: Addressing the Needs of Aging Caregivers & Aging Persons with Developmental Disabilities

Date of Event: Nov. 18, 2004

Location of Event: Loudermilk Center for the Regional Community
Atlanta, GA

Persons Attending: 130

Sponsoring Organizations: Georgia Division of Aging Services (WHCOA Session Sponsor)

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WHCoA Agenda Item C: "Our Community" – One-Stop Shops
Addressing the Needs of Aging Caregivers and Aging Persons with Developmental Disabilities

■ Priority Issue # 1:

Description: Increasing Inter-Agency Collaboration - Aging and Developmental Disabilities

Barriers:

Georgia's multi-county networks serving older individuals and persons with developmental disabilities are divided along different jurisdictional lines. This impedes efficient service delivery and complicates the eligibility process.

Collaboration is difficult without the involvement of federal dollars. Fragmented state and community systems result in treatment strategies that are compartmentalized by age, diagnosis, and other client characteristics that hamper efforts to develop holistic intervention approaches. Problem factors also include:

- 1) differing boards and administrative processes for aging and developmental disabilities,
- 2) uncoordinated data systems, and
- 3) the financial challenges of siloed funding streams and agency competition for grants.

Increasing Inter-Agency Collaboration, cont.

Proposed Solutions:

KEY SOLUTION: Expand Georgia's Aging and Disability Resource Center initiative to make the centers operational statewide.

KEY SOLUTION: Increase access to integrated aging and developmental disability services by implementing a formal, system-wide campaign to support Georgia's Unlock the Waiting Lists initiative (www.unlockthewaitinglists.com).

Re-draw the state's service delivery regions for aging and developmental disabilities to align jurisdictional areas and facilitate systems-wide coordination.

Further reduce process fragmentation by

- 1) adapting policies and funding strategies to integrate service delivery systems,
- 2) developing a common assessment tool and database for aging and disability clients, and
- 3) promoting cross-training, cross-marketing, and shared caregiving solutions.

Enhance funding flexibility by

- 1) increasing available HCBS funds to reflect living patterns and reverse institutional bias,
- 2) creating joint super waivers to replace collections of uncoordinated waivers for individual programs and populations.

Frame messages in terms that legislators value and understand: saving money, promoting family values, and reaping the economic impact of individuals who are given tools to be contributing citizens. Further educate legislators about interrelated issues through visits to clients' homes.

▣ Priority Issue # 2:

Description: Increasing Access to Information - Aging and Developmental Disabilities

Barriers:

Professionals have not produced sufficient tools to help consumers increase their awareness of available support and maximize the benefits derived from services. Needed tools include face-to-face training for individuals with low literacy levels and printed materials to reach a more general audience of active and potential consumers.

Proposed Solutions:

Develop a family planning guide in participation with older caregivers and their children with developmental disabilities, using field-tested language, trainers for low-literacy populations, and a statewide awareness campaign for the guide's release to the public.

▣ Priority Issue # 3:

Description: Addressing Complex Healthcare Needs - Aging and Developmental Disabilities

Barriers:

Due to marked increases in life expectancy, primary care physicians lack the necessary education to care for aging, developmentally disabled adults -- many of whom cope with an increasingly broad range of age-related medical complications and drug-interaction risks.

Addressing Complex Healthcare Needs

Barriers, cont.

The medical model of service delivery favored for developmental disabilities inadequately addresses social factors that affect compliance, such as limited transportation options, ineligibility for Medicaid-funded transportation, and inadequate family funds for medication.

Typically, authorities who make decisions about provider policies have no experience as providers themselves. Resulting funding- and service-related inadequacies include

- 1) limitations on service hours available to clients for help with activities of daily living,
- 2) insufficient numbers of physicians who accept Medicaid,
- 3) unaffordable dental services for target populations, and
- 4) inadequate funding of homes for medically fragile, developmentally disabled children.

Proposed Solutions:

Increase the efficiency of service delivery and funding systems by

- 1) developing one-stop shops for services,
- 2) improving the Medicaid reimbursement structure and timeliness of payments, and
- 3) increasing transportation options and access.

Innovate to improve service equity between rural and non-rural areas by

- 1) providing incentives for professionals to work in rural areas;
- 2) establishing a think tank for specialty physicians to develop developmental disabilities guidelines for use by primary care physicians; and
- 3) developing a model for nurse practitioners to provide in-home coordination services, advocacy services during doctors' appointments, and prescription writing services (contingent on the state's granting nurse practitioners legal authority to do so).

▣ Priority Issue # 4:

Description: Strengthening Support for Caregivers - Aging and Developmental Disabilities

Barriers:

Families under-plan due to denial and fear of the unknown, leaving them unprepared for

- 1) aging caregivers' changes in health status and functional capacity,
- 2) declines in support for the mid-life stages of developmentally disabled adults, and
- 3) low or no caregiver income as a result of early withdrawal from the workforce.

Processes are not sufficiently user-friendly, because they require excessive information at the assessment phase and fail to reach potential consumers at logical entry points such as hospitals.

Advocates for older adults and people with developmental disabilities are speaking with two different voices about systems that are fragmented, limited in scope, and lacking a single point of entry. Discussions also lack adequate rural input.

Proposed Solutions (See p. 4)

Strengthening Support for Caregivers

Proposed Solutions:

Create a single point of entry for both populations, and expand Gateway (Georgia's coordinated intake and screening system for aging services) to include developmental disabilities.

Build on existing successful systems by

- 1) closing eligibility gaps in the National Family Caregiver Support program to address the needs of aging parents of adult children with developmental disabilities,
- 2) expanding partnerships between the Division of Aging Services (DAS) and Mental Health / Developmental Disabilities / Addictive Diseases (MHDDAD), and
- 3) implementing more consumer-directed care initiatives.

■ Priority Issue # 5:

Description: Enhancing Education and Training - Aging and Developmental Disabilities

Barriers:

Aging and developmental disabilities networks use conflicting language and lack a shared understanding of essential methods and terminology.

Proposed Solutions:

Hire a disability specialist to partner with Division of Aging Services staff on leadership of Georgia's Aging and Developmental Disability Resource Center project

Organize more joint workshops for aging and developmental disability professionals.

Develop a well-prepared workforce by

- 1) training professionals as aging and developmental disabilities intake specialists, and
- 2) educating college students through integrated coursework in gerontology and developmental disabilities.

■ Priority Issue # 6:

Description: Maximizing Financial Resources - Aging and Developmental Disabilities

Barriers:

The state has a decreasing pool of funds to support a growing population plus a state economy that negatively drives the process of developing and managing supportive services.

Georgia needs solid data on developmental disabilities, similar to that which is available in the aging network and in other states' developmental disabilities systems.

Authority is overly concentrated under the Centers for Medicare and Medicaid, which controls providers, rates, procedures, and consumer spending levels.

Maximizing Financial Resources , cont.

Proposed Solutions:

Help consumers manage resources more efficiently by

- 1) providing family caregivers with financial compensation and health benefits,
- 2) developing micro-boards to offer enhanced guidance to families,
- 3) using Life Accounts to enable individuals to receive income without jeopardizing benefits, and allowing for conversion of college savings plans to life accounts

Develop new resources – financial, volunteer-based, and in-kind – through the solicitation of privately donated services and the engagement of faith communities in service delivery.

Use existing resources wisely.

- 1) Cut costs and reduce duplicated home visits (i.e., a home visit for the aging caregiver who needs help and a home visit for the developmentally disabled care recipient) by cross-training professionals as field-based generalists guided by a state pool of experts available to provide technical assistance for aging and disability issues.
- 2) Scrutinize state health and human services budgets for signs of cost inefficiency.

Put a dollar figure on needed system improvements to assist the Governor's office and the state legislature in conducting financial forecasting. Stay attuned to potential state revenue increases and remind the Governor at such intervals of innovative ways in which the state can strengthen aging and developmental disabilities services.

■ Priority Issue # 7:

Description: Improving End-of-Life Care - Aging and Developmental Disabilities

Barriers:

Professional- and family-education efforts fail to address variations in end-of-life attitudes among caregivers in different age cohorts.

Challenges result from lack of sensitivity about end-of-life issues and the public's unwillingness to discuss needed family preparations.

Proposed Solutions:

Adopt family-centered approaches to end-of-life care by

- 1) assigning round-the-clock patient advocates,
- 2) providing life-planning training so that families can fruitfully discuss and make decisions about end-of-life issues in advance, and
- 3) cross-training professionals and families to create synergistic partnerships.

Form an action-oriented circle of support around the patient and his or her family, and train all members of the circle – including hospice and nursing home staff, relatives, and others – in how to sensitively address end-of-life issues as they pertain to aging and developmental disabilities.