



Final Report
Executive Summary
March 2005

Aging for All Final Report Executive Summary

A crisis is looming is for thousands of Georgia families and for the Georgia Legislature. While programs and services within all branches of Georgia government are being reduced and/or cut entirely, there is a quiet, steady, and ever increasing growth of aging Georgians with developmental disabilities and their aging caregivers. The graying of Georgia is here and affecting multiple vulnerable populations. Life expectancy is on the rise for all Georgians. Data alarmingly shows that life expectancy for persons with developmental disabilities has increased from 19 years in the 1930s to 66 years in 1993. While this population ages, their caregivers age as well. A common scenario often details the care of a 66 year old by his/her 86 year old parent. As a result, many Georgia parents are literally afraid to die, afraid of the circumstances of care for a vulnerable adult child and afraid that the state will not step up with that care, if needed.

During the 2004 session of the Georgia Legislature, the State Senate authorized, through SR 822, a study committee on the issue of aging and developmental disabilities. The committee's charge was to gather and analyze information on the increasing population of persons with developmental disabilities who are aging (presently estimated to number 97,785) and their aging caregivers and family members (estimates unknown). The committee's partners in this effort were the Georgia Aging and Developmental Disabilities Coalition through its ***Aging for All*** initiative, the Governor's Council on Developmental Disabilities and the Georgia Council on Aging.

Specific data, including the numbers of Georgians affected by increased longevity in the target populations, their needs, general issues, problems and conditions of these families, was to be gathered through three statewide forums. The forums were not held as a result of budgetary concerns; however, Committee partners organized a symposium. The ***Aging for All Symposium*** was held in Atlanta on November 18, 2004 and attended by one hundred fifty (150) professionals in aging and developmental disabilities, family members and other interested parties. Several legislators attended the day's activities as well. The Symposium was an initial foray into increasing long term care collaboration between the Division of Mental Health/Developmental Disabilities/Addictive Diseases and the Division of Aging Services. Senator Sam Zamarippa charged attendees to work together with care to bring about the most positive, creative and fiscally responsible outcomes for persons with developmental disabilities and their families.

An U.S. Administration on Aging (AoA) representative presented information on programmatic best practices from 15 states who have received funding for Aging and Developmental Disabilities Resource Centers. (The Division of Aging Services recently received funding to create and operate two pilot resource centers.) Dr. John Crews of the Centers for Disease Control and

Prevention, an expert on the issue of developmental disabilities and an epidemiologist, presented national (and some state) data as he informed the group that meaningful Georgia data is sparse, and largely nonexistent. The Coalition Planning Subcommittee confirmed this finding when preparing for the Symposium. Dr. Crews reported the following:

- 14,000+ Georgians age 45+ have developmental disabilities
- Sixty-six percent (66%) of all persons age 60+ with Down Syndrome have been diagnosed with dementia or Alzheimer's Disease, while 25% of persons age 40+ without Down Syndrome have the same diagnosis. This one transition is likely to create a huge impact on state resources, including funding for home care and care facilities, in the near future.
- Approximately, 17,118 Georgians with developmental disabilities live in households with caregivers age 60+.
- Twenty-six percent (26%) of all caregivers of persons with developmental disabilities are age 60+ with an additional thirty-five percent (35%) in households of middle-aged caregivers for whom transition issues are near term considerations.
- The Division of Mental Health, Developmental Disabilities and Addictive Diseases serves only 15.8% of all persons with developmental disabilities. By far, most are cared for by families, only. As a result of this relatively small service population, the Division and others agree that there are hundreds and perhaps thousands of Georgians with developmental disabilities who are *hidden* or not known to any service system or provider. The urgency is that, as these individuals age and their caregivers are institutionalized or die, these *hidden* Georgians will increasingly rely on the State for support services and/or special residential care.
- The Department of Community Health reported that, in FY 2004, 9,803 (or 10% of the total) Georgians diagnosed with developmental disabilities were enrolled in the Medicaid program. Of this number, 4,200 (or 4.3% of the total population of Georgians with developmental disabilities) were enrolled in the Mental Retardation Waiver Program.

Since Georgia data is so woefully lacking, financial planning for the impact on state resources is inadequate and has no real basis in fact. Forecasting based on these few demographics would be at least faulty and, most likely, give an entirely false picture of future needs. Some states such as Pennsylvania have begun to gather and quantify data to help legislators and others in fiscally responsible planning.

During the symposium, ten topics, chosen by the Coalition Planning Subcommittee as the most urgent, having the greatest impact, and requiring immediate response were discussed by all attendees. The topics are:

- Prioritizing Financial Resources,
- Access to Information,
- Caregiver Supports,
- Planning across the Life Span,
- Aging in Place,
- Health Care Issues,
- End of Life Care,
- Education and Training of Professionals and Paraprofessionals,
- Systems Responsiveness, and
- Collaboration across Agencies.

Based on the information gathered during the Symposium and research performed by the Coalition during the study process, the Aging and Developmental Disabilities Coalition propose the following two legislative priorities:

- **Expansion of the Aging and Developmental Disabilities Resource Centers to enhance statewide coalition building and a collaborative entry to services, and**
- **Reduction of all home and community based waiting lists to support services for all aging Georgians.**