

**Presentation of David Braddock, Ph.D.
On Aging and Developmental Disabilities
Senate Select Committee on Aging**

Thank you Mr. Chairman for the opportunity to present at this Committee sponsored inquiry on the issues pertaining to aging and the growing number of persons with developmental disabilities awaiting services in the states. For the record, I am David Braddock, Professor and Head of the Department of Disability and Human Development at the University of Illinois at Chicago. For the past 10 years I have also served as the director of our Department's research and public services Institute concerned with developmental disabilities, and known as the Institute on Disability and Human Development. This Institute serves as the "university affiliated program in developmental disabilities" for the State of Illinois. It is authorized under the Federal Developmental Disabilities Act, as amended, which is administered by the Administration on Developmental Disabilities in the U.S. Department of Health and Human Services.

Our Institute is also fortunate to have the nation's only Federally-designated Rehabilitation Research and Training Center on Aging with Mental Retardation. I serve as the co-principal investigator of this Center (Dr. Tamar Heller is the Principal Investigator) which is funded by the U.S. Department of Education's National Institute on Disability and Rehabilitation Research. I have been active in the field of developmental disabilities for 30 years and I am a former President of the American Association on Mental Retardation.

My presentation today will provide empirical information for the Committee to assist your deliberations on the increasing service and support needs of individuals with developmental disabilities who live in families with aging parents or other caregivers.

The aging of our society, coupled with the increasing longevity of persons with developmental disabilities, will be the primary focus of my remarks today. These two key forces are working in a powerful synergy that is stretching state service delivery systems well beyond their capacity to meet current and projected demands for residential, vocational, and family support services for individuals with developmental disabilities. Large and growing waiting lists are very common in the states today.

My presentation is structured to address the following seven questions:

- What is the general demographic structure of the long-term care service system for persons with developmental disabilities in the United States today, and how is it changing?
- What is the scope of the role played by family caregivers in the long-term care system?
- How large a demographic subset is the group of family caregivers aged 60 years and older?
- Can we estimate the size of the aging family caregiver cohort in each of the 50 states and can we determine how dynamic its growth pattern may be in future years as the baby boom generation ages?
- To what extent has longevity improved for persons with developmental disabilities over the past half century?
- How large are waiting lists in the states and can we expect them to continue to grow? and, in conclusion,

- What recommendations can be offered to address the limitations noted in service system capacity in the states?

STRUCTURE OF RESIDENTIAL CARE IN THE UNITED STATES

Formal, supervised out-of-home residential services were being provided to 394,284 persons in the states in 1996, according to a national study completed this past year at the University of Illinois at Chicago (Braddock, Hemp, Parish, & Westrich, 1998). Fifty-one percent of the individuals (about 200,000 persons) lived in 1-6 person settings such as small group homes, supervised apartments, foster care, and supported living placements. The vast majority of these settings are operated by private, non-profit service providers. An additional 55,227 persons resided in facilities for 7-15 persons; 100,729 individuals were living in large public or private institutions for 16 or more persons, and 38,438 persons lived in nursing homes.

The structure of the residential care system has changed markedly over the past 20 years as state-operated residential institutions reduced their census by two-thirds from 150,000 to under 60,000 persons. Concurrently, the number of persons residing in 1-6 person settings expanded ten-fold from about 20,000 individuals in 1977 to the present figure of just under 200,000 persons. Over-all system capacity, however, grew by only 36% over the 20-year period, an average growth rate of just 2% per year. Given that the U.S. general population increased by 22% during the past 20 years, the entire system of residential care grew at a very modest pace. This is remarkable in light of the fact that public funding for residential and community services expanded from \$3.5 billion in 1977 to \$22.8 billion in 1996, nearly a three-fold increase (growth rate of 167%) after adjusting for inflation.

The Medicaid program was the principal catalyst of system expansion, both in terms of persons served and resources allocated. In 1996, 71% of all public resources in the nation's MR/DD service system was associated with the federal-state Medicaid program through the Intermediate Care Facility for the Mentally Retarded (ICF/MR) authority or the Home and Community Based Services (HCBS) Waiver program. The ICF/MR program has been instrumental in the financing of large public and private institutions; the HCBS Waiver program supports a wide array of community services and supports for people with developmental disabilities.

AGING CAREGIVERS

The aging of our society directly influences demand for developmental disabilities services in the states. This occurs because the majority of people with developmental disabilities in the United States currently reside with family caregivers. As these caregivers age beyond their caregiving capacity, formal, supervised living arrangements outside the home must be established to support dependent relatives.

The aging of our society is a product of several forces, primary among them the size of the baby boom generation (persons born during 1946-64), declining fertility rates, and increased longevity. Baby boomers will begin to reach age 65 in about 11 years-in 2010. The number of persons in our society aged 65+ years is projected by the U.S. Bureau of the Census to be 35 million persons in the year 2000; the number will double by the year 2030 to 70 million due to the aging of the baby boom cohort (U.S. Bureau of the Census, 1996). Currently, 12.8% of the U.S. general population is aged 65+ years. Census Bureau demographers anticipate that this percentage will grow steadily for the next three decades, finally leveling off at 22% of the U.S. population in 2030 (Figure 2). Problems loom even larger in countries such as Japan and Germany, where the aging cohort is projected to approximate one-third of their general populations by the year 2040.

Understanding the impact of aging on the increased demand for developmental disabilities services in the states requires an appreciation on the prevalence of developmental disabilities in our society. Fujiura (in press) recommends using a prevalence rate of 1.2% based on the Survey of Income and Program Participation (SIPP) (U.S. Bureau of the Census, 1992), which collected survey data from 9 1,000 U.S. households. The 1.2% rate includes persons with mental retardation, cerebral palsy, autism, and epilepsy. Fujiura's (in press) analysis clearly illustrated that, in 1991, a majority of persons with developmental disabilities in the U.S. resided with family caregivers, as opposed to living on their own or within the formal out-of-home supervised residential care system in the states.

I updated Fujiura's 1991 data based on the more current Braddock et al. (1998) study of the formal out-of-home residential system, and on U.S. population growth through 1996. The results are presented in Figure 3, which indicates that 60% of the 3.17 million persons with developmental disabilities in the U.S. population 'in 1996 were receiving residential care from family caregivers. This "informal" system of residential care served five times the numbers served by the formal residential care system described in Braddock et al. (1998).

Fujiura's 1991 data, based on the SIPP, indicated that 25% of family caregivers were aged 60+ years across the U.S., and an additional 35% were "in the households of middle-aged caretakers for whom transition issues are near-term considerations." In Figure 4, I reconfigured Figure 3 to draw specific attention to the size of the aging family caregiver cohort (479,421 persons in 1996).

How large are the aging caregiver cohorts in each of the states? Rough estimates can be generated by taking into account differences across the states in the average age of the states' general populations. There is a 10% variation in the percentage of older individuals in the "oldest" state (Florida) versus the youngest state (Utah) (U.S. Department of Commerce, 1997). The state-by-state estimates of individuals with developmental disabilities living with older (60+ years) caregivers appear in Table 1.

INCREASED LONGEVITY

A second factor impinging on the growing demand for MR/DD services has to do with increases in the life-span of individuals with developmental disabilities. The mean age at death for persons with mental retardation was 66.2 years in 1993-up from 18.5 years in the 1930s and 59.1 years in the 1970s. The mean age at death for the general population is 70.4 years. Janicki (1996), a noted authority, has observed that, with continued improvement in their health status, individuals with mental retardation particularly those without severe impairment-can be expected to have a life span equal to that of the general population. Longevity has increased dramatically for persons with significant developmental problems such as Down Syndrome. Average age at death in the 1920s was 9 years for this group. According to Janicki, it rose to 30.5 years in the 1960s and to 55.8 years in 1993.

As persons with developmental disabilities live longer, they require long-term care for longer periods of time. This directly impacts on the finite capacities of service delivery systems in the states. The increased life expectancy of persons with mental retardation between 1970 and the present accounts for a significant percentage, perhaps as much as 20% or more, of the long term care resources now being consumed by such persons in the formal out-of-home long term care service system. The likelihood of older persons with developmental disabilities living into their own retirement and outliving their family caregivers has increased substantially in recent years. This has in turn stimulated a growing need for more services and supports. The need to provide these services is frequently unanticipated by Federal, state, and local agencies, often resulting in a crisis situation for families in the most extreme cases of need. It is unfortunately not an exaggeration to note that many family caregivers must die before the disabled relative they are caring for receives appropriate residential and community services from the state system.

WAITING LISTS FOR SERVICES

According to data collected from the states in 1996, an estimated national total of 83,101 persons with developmental disabilities are on formal state waiting lists for residential services (Prouty & Lakin, 1998) (Table 2). This figure is nearly equivalent to the total service system expansion during the previous 20 years (104,000 persons). Demographic trends suggest that waiting lists will continue to grow in the states unless a concerted effort is mounted to address them. The survey conducted by the Arc/United States (Davis, 1997) confirms the magnitude of the national waiting list issue.

Some states keep detailed waiting lists on service needs for persons with developmental disabilities. Some do not keep "official" lists although state officials informally acknowledge that significant demand for needed services exists. Prouty & Lakin's 1997 survey of waiting lists in the states noted a 38% increase in persons requesting residential services (Prouty & Lakin, 1998) compared to a survey done five years earlier in 1992 by Hayden & DePaepe (1994). Ten states did not furnish waiting list data in the 1996 survey and five states indicated that the waiting list was zero. One of the states indicating zero persons was Illinois, which is remarkable since the state has long lagged behind many other states in the development of family-scale residential alternatives. We need more accurate data from states such as Illinois.

The close connections between aging caregivers and growing waiting lists in the states can be illustrated in the vivid example of Maryland. Maryland's Developmental Disabilities Administration provided residential waiting list data to the *Baltimore Sun* (March 23, 1997). The *Sun* reported 4,682 persons waiting for services. Thirty-nine percent of these individuals were living with caregivers aged 60+ years. Twenty-four percent of the 4,682 persons waiting had caregivers aged 70+ years, and 14% were aged 80+ years. It is not likely that Maryland represents an aberration among the states. Because of the state's large population, its percentage of aging caregivers (39%) may well closely approximate the national pattern. There is no doubt that aging family caregivers are extremely oversubscribed on state waiting lists and that the Maryland data are indicative of a serious national problem.

State Initiatives

Several states have begun initiatives to address waiting lists. New Jersey, for example, appropriated \$30 million in FY 1999 to reduce its waiting list for community residential services. Between 1986-96, the New Jersey waiting list increased from 767 to 4,600. The "urgent" category in 1996 consisted of 2,286 persons. The New Jersey Department of Human Services, Division of Developmental Disabilities, projects a 10-year need for a waiting list reduction initiative comprised of \$30 million per year through the Year 2008. New Hampshire has enacted a special appropriation to address the waiting list and is requiring an annual status report to the Governor regarding progress in addressing the waiting list. Connecticut, Texas, Massachusetts, and Oregon have also commenced waiting list initiatives. Lakin (1998) has noted that waiting list initiatives in the states generally involved allocating resources in the following ways:

- The closure/consolidation of institutions;
- The conversion of ICFs/MR to HCBS programs;
- Capping reimbursement for existing programs;
- Augmenting state funding with Medicaid funding;
- Expanding family support and subsidies to prevent or delay the need for placement; and,
- Promoting flexibility in residential and day programs for persons leaving high cost programs.

POLICY CONSIDERATIONS AND RECOMMENDATIONS

Aging of the nation's baby boomers', marked improvement in the life-span of persons with developmental disabilities, and our country's traditional reliance on families to provide most developmental disabilities long-term care will have profound impacts in the years ahead. We can anticipate increased pressures on family caregivers, especially in states with a large percentage of older citizens, and also in those many states that have yet to develop an extensive array of community services and supports. Thousands of individuals with developmental disabilities await supported living, supported employment, and a broad range of family supports. Yet, only three percent of the total funding base of \$22.8 billion in the developmental disabilities field is currently targeted toward family support services, and a similar miniscule percentage (4%) is allocated for supported living, personal assistance, and supported employment services. The remaining 93% of the field's funding base finances residential and vocational facilities including large public and private institutions and group homes.

Greater flexibility in resource allocation through use of the HCBS Waiver and other Medicaid Waivers should be encouraged. In-home support programs frequently prevent more costly placements in institutions, nursing homes, and other residential settings. States and community providers need greater flexibility to access HCBS Waiver funds for those on waiting lists. States should also be provided with additional fiscal incentives to reallocate Medicaid ICF/MR funding to community and family support objectives that address waiting list and aging caregiver issues. Personal assistance legislation (MICASA, the Medicaid Community Attendant Services Act, H.R. 2020) should be supported. Improved coordination between Older Americans Act services and the MR/DD services system should be stressed.

The states should also be encouraged to adopt waiting list reduction initiatives and to conduct independent special studies of the numbers of persons awaiting various developmental services in the states. The state developmental disabilities planning councils and university affiliated programs should assist in carrying out the studies. A special initiative for family support appropriations is currently pending in the Developmental Disabilities Act appropriation bill before Congress. This special appropriation should be supported. A portion of these DD Act funds might be targeted for developing models in the states for serving aging caregivers and for carrying out carefully designed waiting list studies to inform the state planning process required under the Developmental Disabilities Act.

Thank you, Mr. Chairman, for the opportunity to speak to the Committee today.