



Data Trends and Policy Program: The Demographic Status of Americans with Intellectual and Developmental Disabilities and Related Disabilities

GLENN FUJIURA AND KIYOSHI YAMAKI

An analysis of the demography of family care for adults with intellectual and developmental disabilities (I/DD) (Fujiura, 1998) summarized the juxtaposition of three major national trends: 1) the dramatic increase in public sector spending for long-term care for persons with I/DD, 2) low to moderate growth in residential system capacity, and 3) a large, home-based population. The analysis suggested critical questions about the character of demographics among Americans with I/DD. These are not new observations; the burgeoning attention to residential transitions from the homes of aging caretakers reflects a broad recognition of the aging of the American population and the concomitant aging of family caretakers (Freedman et al., 1997; Heller & Factor, 1991). The study of national data identified over one-quarter of those living in family settings (excluding living with a spouse and in one's own residence) were in households headed by a family member 60 years of age or older. Another 35% are adults in the households of middle-aged caretakers for whom transition issues are near term considerations. The size of the cohort suggest significant and as yet unrealized demands on the states' service systems. Identification of the scope and character of the potential demand from impending transitions-from-home is a research task of considerable importance in light of contemporary fiscal constraints on long-term care expansion and extant waiting lists (Hayden, 1994).

We are in a period of great uncertainty and significant experimentation. One central implication of these undercurrents is the need to monitor changes in state and federal policy and evaluate their impact on the lives of older Americans with I/DD. This is the

context of the proposed program and the implicit issue addressed in the NIDRR priority on analyses of national data sets — to inform policy by measuring, tracking, and reporting on the extent to which society is progressing in addressing the health care, education, and employment needs of persons with I/DD. During the years of great reform in our nation’s I/DD policy, researchers and policy makers decried the absence of quality data on the size or characteristics of the population (Bruininks, 1979; Conley, 1973; Rowitz, 1984). Decades after the early policy-making efforts of the President’s Panel on Mental Retardation (1962), access to “hard” data — that is, information on demography and service outcomes — continues to be an issue. The most basic of questions on the size and characteristics of the population are the most frequently asked of researchers by legislators, policy-makers, and consumer advocates. In fact, impetus for the landmark 1994 National Health Interview Survey (NHIS) Disability Supplement was in large part due to the interest of federal agencies in gaining access to greater policy relevant information on I/DD.

Study Purpose and Objectives

Demography of Americans with I/DD and their families

1. What is the magnitude of family-based care and support of older Americans with I/DD (1994 NHIS-DS, 1993 SIPP)?
2. What are core demographics (age, SES, ethnicity and race) of caretakers of older Americans (1993 SIPP)?
3. Have age cohort distributions changed (1983-1995 NHIS)?

Economic status of Americans with I/DD

4. Have there been changes in the relative income levels and access to means-tested benefits during the 1984-93 period (1983 and 1993 SIPP)?

Ethnic and racial variations in I/DD status

5. How do demographic and economic status variables interact with racial and ethnic constituencies?

Employment and educational status of Americans with I/DD

6. What is the employment status and earned income of Americans with I/DD (1993 SIPP)?
7. What is the profile of welfare access and other means-tested benefits (1993 SIPP)?
8. What is the profile of access and use of educational and vocational rehabilitation services (NHIS-DS phase II)?

Access to health care for Americans with Intellectual Disabilities (ID)

9. What is the health profile of Americans with ID, in particular, the prevalence of secondary conditions (1994 NHIS-DS)?
10. Have there been changes in the pattern of chronic conditions between 1983 and 1995 (1983 through 1995 NHIS core files)?
11. To what extent and in what form do Americans with ID access ambulatory care, emergency care, and hospital care systems in America (NAMCS, NHDS, NHAMCS, and MEPS)?

Sample Population and Methodology

The central goal of the Data Trends and Policy Program is an extensive and systematic program of secondary analysis focused on the 1994-1995 National Health Interview Survey - Disability Supplement (NHIS-DS), 13-years of the NHIS core and family surveys, and the 1983-93 Surveys of Income and Program Participation (SIPP). This is a significant program of research. The combined 1994 and 1995 NHIS-DS is the most comprehensive survey of non-institutionalized persons with ID and other disabilities ever conducted in the US, and is the first national survey to include people with disabilities of all ages. The NHIS-DS Phase II data includes information



about approximately 40,000 people with disabilities. The SIPP is the second major nationally representative probability-based survey explicitly incorporating Americans with ID and other disabilities. The emphasis of the SIPP is on the demographics and economic status of households and individuals. Although surveys have been conducted by the Bureau of the Census annually since 1983, the SIPP has been little used in ID research (in large part due to the complexity of the file system). The SIPP is notable for its extensive employment and income data that until recently has not been evaluated in the field of ID (Yamaki, 1998).

Four other health care data systems are of potential value in explicating access to health care: the National Ambulatory Medical Care Survey (NAMCS, Centers for Disease Control), the National Hospital Ambulatory Medical Care Survey (NHAMCS, Centers for Disease Control), the National Hospital Discharge Survey (NHDS, Centers for Disease Control), and the Medical Expenditure Panel Survey (MEPS, Agency for Health Care Policy). While none of these data sets were designed for disability-specific analyses, they are rich in data on accessing various components of the American health care system. Diagnostic information is available in varying quality across these data sets. We anticipate heavy reliance on ICD-9 codes for subject selection.

The National Ambulatory Care data set provides basic event data on the provision and use of ambulatory medical care, including office visits to specialists. The survey began in 1974, and has been fielded annually since 1989. Trained interviewers gather data on a one-week period. In parallel fashion, the National Hospital Ambulatory Medical Care Survey produces statistics on U.S. hospital emergency departments and outpatient clinics; the survey has been conducted since 1992. The National Hospital Discharge Survey, conducted annually since 1965, rounds out the portrait of high risk events through the characterization of inpatient utilization. Finally, the Medical Care Expenditure Survey (formerly referred to

as the National Medical Expenditure Survey) is a representative survey of health care use, expenditures, sources of payment and insurance for the U.S. population.

Data Analysis

The capacity to evaluate each of the questions depended on the stability of sample estimates; standard errors of estimate can be excessively large if the defined subgroups are too small - a common problem in secondary analyses of ID (Fujiura & Yamaki, 1997). Exploratory analyses of these data sets indicate very limited sample sizes for low-prevalence groups such as ID. The aggregation of files across years was employed to increase sample size and thus estimate stability. Variance estimation was based on specialized error estimation algorithms designed for national data sets using complex sample designs (e.g., SUDAAN).

Findings

The series of studies conducted under the Data Trends and Policy Program resulted in the following key findings.

Employment and economic status of Americans with I/DD and related developmental disabilities. The Yamaki & Fujiura (2002) study found approximately 40% of the identified MRDD population was 45 years or older (19.6% aged 45-54; 18.8% aged 55-65). Unemployment rates, low earnings, and dependence on income benefit programs tended to be more pronounced among the oldest cohort. Major findings included: (1) the general impoverishment of the MRDD population generally, and (2) major variations in economic well-being between sub-groups within the DD population – in particular, between those with and without ID.

Construct validity of mental retardation and developmental disabilities. Demographic features of the population of Americans with mild intellectual

disabilities were estimated in an analysis of the National Health Interview Survey. The cohort was compared to the general U.S. population, persons with specific learning disabilities, and persons with a diagnosis of mental retardation. Group profiles on basic indices of adaptive functioning, and social and economic status suggest a large cohort of Americans at the margins of current conceptualizations of mental retardation (MR) who share many support needs and social and economic vulnerabilities with those labeled “MR.” Implications are discussed in terms of the “forgotten generation” report of the President’s Committee on Mental Retardation and evolving conceptions of MR. Arguments are presented that policies relevant to persons with MR would be relevant to those under a broadened conception of intellectual disability.

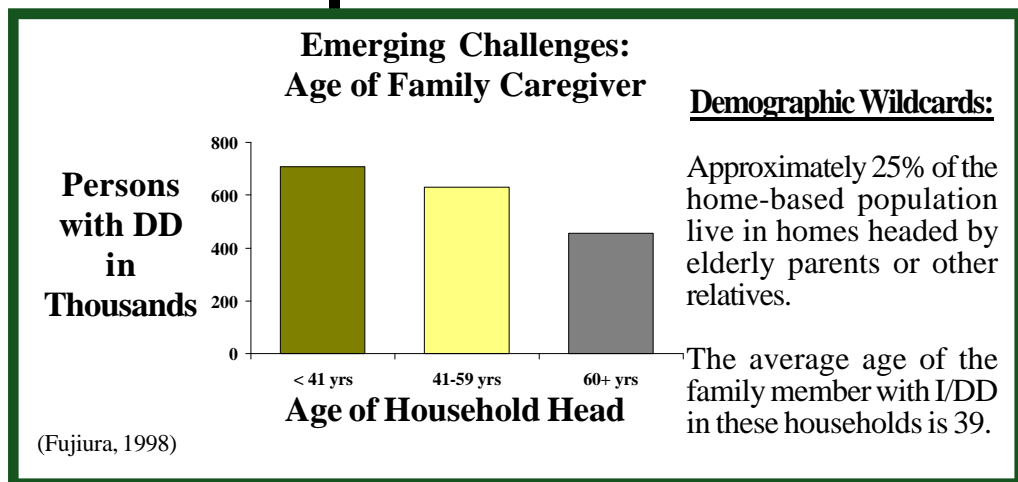
Demography of Americans with ID and their families. The aging of parents, siblings, and other relatives providing support within the family household has potentially profound implications for the future character of disability services, supports, and policy. To what extent are adults with intellectual and related developmental disabilities supported, either partially or fully, in family households by elderly family members? The demographic features of family-based care were summarized in a secondary analysis of the 1999 and 2000 National Health Interview Surveys. Results were consistent with growing concerns regarding the aging of family households. Over 40% of families supporting a child or other relative in the home were headed by persons aged 60 years or older. Study results were discussed in terms of the importance of the family as the target of policy concerns.

Health profiles of Americans with intellectual disabilities. Using the Body Mass Index (BMI) as a measure, the percentage of adults with ID in the obese category appears higher than that for the general

population and appears to be increasing over the 16-year period (Yamaki, in press). There was no similar detectable trend for adults with ID who were in the overweight category. Compared to their counterparts in the general population, a smaller proportion of women and young adults with ID maintained their weights in the healthy weight range.

Yamaki (in press) noted the following trends related to obesity among adults with ID:

- The overall percentage of healthy weight adults with ID decreased from 48% between the time period of 1985-1988 to 34% between the time period of 1997-2000.
- The prevalence of obesity among women with increased from 22% between 1985-1988 time period to 44% during the 1997-2000 time period. During the same time period, women in the general population increased from 12% to 21%.
- The prevalence of obesity among adults with ID ages 18 to 39 increased from 19% between 1985-1988 time period to 34% during the 1997-2000 time period. During the same time period, adults ages 18 to 39 in the general population increased from 9% to 17%.





Implications for Research and Practice

One of the core RRTC purposes identified in the original NIDRR announcement was to “analyze and disseminate information from national data sets and public health surveillance data on adults with ID to identify health care utilization, education, and employment patterns.” The Data Trends and Policy Program, established within the RRTC, is a series of discrete studies designed to measure, track, and report on major national population trends among persons with ID and their families. The intent of each analysis is to evaluate larger demographic trends and their implications especially for aging with ID. To date we have completed two reports intended for scientific peer-review publication – one has been published and one is currently under review. It is our expectation that all five studies will be published.

But the disability world is changing and now more than ever it is critical that the issues of disablement in America extend beyond the traditional disability and rehabilitation audiences. The new paradigm of disability requires a more universal approach. Such approaches will not develop in isolation of general domestic policy. To this end, outcomes and potential impact of the project work are indicated by recent mass media interviews given by Dr. Fujiura. These include the following newspaper articles, radio interview, and popular press magazine article:

National Public Radio. (July 9, 2002). *Housing First: People with Disabilities*. URL: www.npr.org/news/specials/housingfirst/whoneeds/physdisabled.html. *Housing First* explores the difficulty faced by Americans with special needs to find good housing, which would enhance their efforts to join, and flourish in, the mainstream of society.

Washington Post. (July 5, 2002). *U.S. Counts One in 12 Children As Disabled* by D’Vera Cohn, Washington Post Staff Writer. p. B01. URL: www.bridges4kids.org/articles/7-02/WashPost7-5-

02.html. This article describes the 2000 U.S. Census data for disabled children.

Several other articles appeared in the following newspapers and a popular press magazine: *Chicago Tribune* (July, 2001) - article on the demography of medically fragile children; *USA Today* (March, 2001), an article on the health and economic status of persons with ID; and *Rosie* (May, 2001) an article on the demography of ID.

Publications and Products

Yamaki, K. (in press). Body weight status among adults with intellectual disability in the community. *Mental Retardation*.

Fujiura, G.T. (2004). *The Demography of Aging Caretakers: Implications of the Graying of Family Households*. Manuscript in preparation. Chicago: University of Illinois at Chicago.

Fujiura, G.T. (2003). The Continuum of Intellectual Disability: Demographic Evidence for the “Forgotten Generation”. *Mental Retardation*, 41, 420-429.

Yamaki, K. & Fujiura, G.T. (2002) Employment and income status of adults with developmental disabilities living in the community. *Mental Retardation*, 40, 132-141.

Fujiura, G.T. (2001). *The Forgotten Generation. The Alert*, Spring 2001.
