

Chart Definitions, Technical Notes, Data Sources for Six-Page State Profiles

CHART PAGE 1: Public IDD Spending by Revenue Source and Fiscal Effort

1st Chart--Total Public Intellectual and Developmental Disabilities (IDD) Spending for Services: FY 1977-2015: The top chart presents total inflation-adjusted IDD spending by fiscal year during 1977-2015, and the Medicaid proportion of total spending. Medicaid consists of Home and Community Based Services (HCBS) Waiver spending, Medicaid spending for Intermediate Care Facilities for Persons with Intellectual Disabilities (ICFID); and Related Medicaid such as personal care, targeted case management, rehabilitative and clinic services, and administration.

2nd Chart--Public (IDD) Spending by Revenue Source: FY 2015: The middle pie chart summarizes the proportion of spending in the State for all IDD long-term services and supports in three categories: Federal, state, and local government spending. A column broken out from the pie chart summarizes the proportion of Federal spending for a) the HCBS Waiver; b) ICFID; c) related Medicaid; d) Social Services Block Grant (Title XX) funding; e) various other federal funds; and f) Supplemental Security Income (SSI) and Adult Disabled Child (ADC) Social Security benefits received by HCBS Waiver participants.

3rd Chart--Fiscal Effort for IDD Services: FY 1977-2015: Fiscal effort is IDD spending adjusted for state wealth, presented as IDD spending per \$1,000 of state-wide, aggregate personal income. Fiscal effort during FY 1977-2015 is shown for a) total IDD long-term service and support; b) community and family services; and c) public and private institutional services (16 + persons per facility).

CHART PAGE 2 OF STATE PROFILE: IDD MEDICAID SPENDING

1st Chart--Federal IDD Spending by Revenue Source: The top chart consists of inflation-adjusted federal Medicaid spending during 1977 through 2015 for: a) the HCBS Waiver for public and private ICFID settings, and for related Medicaid (i.e., personal care, targeted case management, rehabilitative and clinic services, and administration).

2nd Chart--Federal -State Medicaid as a Percentage of Total IDD Spending in FY 2015: The middle pie chart summarizes total IDD spending in 2015 (\$65.35 billion, U.S.) and the portion of Medicaid federal-state spending (\$49.35 billion, U.S.). The chart also indicates the proportion of total IDD spending for: a) the Medicaid HCBS Waiver; b) Medicaid ICFID settings; c) related Medicaid (e.g., administration, clinic/rehabilitative services, targeted case management, and personal assistance); d) state funds; and e) other federal funds.

3rd and 4th Charts--HCBS Waiver Participants and Waiver Cost Per Participant: The bottom line left chart presents the number of HCBS Waiver participants, by year for each year during 1982 to 2015 that the State's Waiver has been in effect. The bottom right chart, also for the years the State's Waiver has been in effect, the federal-state Waiver spending per participant.

CHART PAGE 3: Participants with Intellectual and Developmental Disabilities

1st Chart--Persons by Setting in Fiscal Year 2015: The top chart presents total persons supported by state IDD agencies in three categories if out-of-home settings: a) Settings for 16 or more persons (nursing facilities, state-operated institutions, and privately operated institutions); b) Settings for 7-15 persons (ICFID facilities and non-ICFID facilities); and settings for six or fewer persons.

A column broken out from the pie chart summarizes three sub-categories of settings within the category of six or fewer persons: a) ICFID for six or fewer persons, b) supported living (*defined below for Chart Page 4*), and c) other settings for six or fewer persons including group homes, host homes, foster care and supervised apartments.

Table--Residents with IDD by Size of Setting: 2000-2015: The table displays total residents in out-of-home settings supported by state IDD agencies and the number of persons served in settings for six or fewer persons (public and private ICFID, supported living and other residential setting for six or few persons); settings for 7-15 persons (public and private ICFID and other settings); and settings for 16 or more persons (nursing facilities, state institutions, private ICFID and other settings for 16 or more persons).

2nd Chart--Persons in Public and Private 16+ Institutions: FY 1996-2015: The bottom chart displays for each year the number of residents with IDD in public 16+ state-operated institution, in private 16+ institutions (including ICFs/ID and other settings); and in nursing facilities.

CHART PAGE 4 OF STATE PROFILE: INDIVIDUAL AND FAMILY SUPPORT

DEFINITION: Individual and family support consists of supported living, family support, and supported employment. Supported living is defined as individuals with IDD choosing where and with whom they live, in housing that is not owned by the support provider (i.e., owned by the individual, family, cooperative); and for whom individual support planning recognizes her or his desire for more independence over time.

1st Chart--Individual and Family Support Spending 1994-2015: The top chart displays inflation-adjusted spending for supported living, family support, and supported employment during 1994-2015.

2nd Chart--Individual and Family Support Participants: FY 1994-2015: The middle chart displays the number of participants in supported living, family support and supported employment during 1994-2015.

3rd Chart--Supported Living, Family Support, and Supported Employment Spending: FY 1994-2015: The bottom pie chart summarizes total inflation-adjusted spending during 1994-2015 and the proportion that HCBS Waiver funding constitutes of the total Individual and Family Support spending each year.

CHART PAGE 5 OF STATE PROFILE: INDIVIDUAL AND FAMILY SUPPORT AND TOTAL DAY WORK AND EMPLOYMENT

1st Chart-Supported Living, Family Support and Supported Employment as a Percentage of Total Spending: FY 2015: The pie chart displays total IDD spending in 2015 (\$65.35 billion, U.S.), and the proportion of total spending for individual and family support spending, private and public institutions, 7-15 person settings, 6 person or fewer ICFID settings, and 6 person or fewer HCBS Waiver, foster or host homes, and related community service settings.

2nd Chart--Day/Work and Supported Employment Participants: FY 1988-2015: The bottom column chart has two sections each year with the proportion of total day/work participants in day work/sheltered employment and the proportion in supported employment. Included with supported employment in 2015 were 15,640 follow-along work support participants in 23 states (AZ, CO, CT, DE, DC, HI, KS, LA, ME, MI, MO, NE, NH, NJ, NM, NC, OH, OR, PA, SC, SD, UT, and WA).

PAGE 6 OF STATE PROFILE: IDD CAREGIVERS AND THE PROPORTION RECEIVING IDD STATE AGENCY SUPPORT

1st Chart -- Estimated Number of Individuals with IDD by Living Arrangement: FY 2015: The top chart presents the total estimated number of persons with IDD in the state, and the proportion: a) living with family caregivers; b) living alone or with a roommate; and c) in supervised residential settings.

Sources: For prevalence of intellectual and developmental disabilities @ 1.85% of general population (Larson et al, 2001); for the proportion of persons with IDD living with family caregivers (Fujiura, 1998, 2012); and for the population base of prevalence and caregiver estimates (U.S. Census Bureau, 2016).

2nd Chart -- Estimated Number of Individuals with IDD Living with Family Caregivers by Age Group : FY 2015: The middle chart presents the number of IDD caregiving families (*from 1st chart*), and the proportion of caregiving families who are a) 40 years of age or younger; b) aged 41-59 years; and c) aged 60 or more years.

Source: (Fujiura, 1998, 2012).

3rd Chart -- Estimated Number IDD Caregiving Families and Families Supported by IDD Agencies: FY 1988-2013: The bottom column chart presents the estimated number of IDD caregiving families in the state each year, and the proportion of caregiving families who are receiving state IDD agency support.

References Cited:

- Fujiura, G.T. (2012, June). *Structure of Intellectual and Developmental Disabilities Households in the United States: Demographics of the Family in 2010*. Presented at AAIDD 136th Annual Meeting, Charlotte, NC.
- Fujiura, G.T. (1998). Demography of family households. *American Journal on Mental Retardation*, 103, 225-235.
- Larson, S.A., Lakin, K.C., Anderson, L., Kwak, N., Lee, J., & Anderson, D. (2001). Prevalence of mental retardation and developmental disabilities: Estimates from the 1994/1995 National Health Interview Survey Disability Supplements (NHIS-D). *American Journal on Mental Retardation*, 106(3), 231-252.
- United States Census Bureau. (2016). U.S. interim projections by age, sex, race, and Hispanic origin. Retrieved from www.census.gov/ipc/www/unsinterimproj.