



## **Recommendations to Improve Data Collection to Monitor, Track, and Evaluate State Approaches to Family Support Services**

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### **Introduction**

Family members provide the majority of support to people with disabilities across the life course. Families often contribute a considerable amount of their own resources to provide this care. Today, family caregivers are facing extraordinary demands that impact them financially, physically and emotionally.

The number of informal, unpaid family caregivers varies based on methodological factors, however, the most widely used estimates come from the National Alliance for Caregiving Survey, *Caregiving in the US*. In 2015, it was estimated that there were 43.5 million unpaid caregivers in the United States who on average, spend 24.4 hours per week providing care to a loved one. The majority of these individuals receive no paid help (68%), have difficulties balancing caregiving and work responsibilities (61%) and are highly stressed (38%)<sup>i</sup>.

Family support is essential to strengthening the ability of family caregivers to maintain community living and promote positive outcomes for individuals with disabilities. Flexible, individual and family-directed supports strengthen family caregivers' wellbeing, enhance self-determination and outcomes for individuals with disabilities, and decrease undesirable, costly institutional placements. Family support services include instrumental supports (formal services such as respite, financial assistance, assistive technology); information and training supports (information about disability or supports to build caregiver skills); and emotional supports (support groups, counseling).

In order to better meet the needs of families, we must improve methods to monitor, track and evaluate current approaches to family support across states. Currently, there is very limited nationally representative data available about family caregivers and family support services, let alone datasets that allow for state tracking and comparisons. Improvements will allow us to identify promising practices and assess how states are doing in supporting families.

## **Environmental Scan**

In an effort to assess current data collection efforts for supporting families, the University of Illinois at Chicago's Family Support Research and Training Center (FSTRC) conducted an environmental scan to identify existing datasets that provide relevant information about family caregiving. Advisory committee members and FSRTC center members aided this process by providing recommendations and suggestions. Ultimately, 14 relevant datasets were analyzed, summarized and compiled. The researchers did not intend on creating an exhaustive list, but instead a useful inventory of available data that provides a snapshot of the current state of family caregiving supports within and across the United States.

Findings from the environmental scan fell into three categories: 1) Datasets that provide nationally representative data; 2) Datasets that provide state-level comparison data; and 3) Scorecards which use indicators from various data sources to track state progress and make comparisons.

### National Datasets

1. American Time Use Survey
2. Behavioral Risk Factor Surveillance System
3. Caregiving in U.S.
4. Gallup Healthways
5. National Health & Aging Trends Study
6. National Survey of Children with Special Health Care Needs
7. Survey of Income and Program Participation

### State-Level Datasets

8. National Core Indicators
9. National Inventory Survey on Participant Direction
10. State of the States 12
11. Supporting Individuals and Families Information Systems Project
12. UCSF's Survey of State HCBS

### Scorecards

13. AARP Scorecard on Long-Term Services and Supports
14. UCP The Case for Inclusion

Summaries of the 14 datasets are contained in the Appendix, including: population, purpose, method, frequency, respondents, data collectors, funding, strengths, limitations and other relevant information.

## **Expert Panel Meeting**

On Nov 18th, 2015 the FSRTC convened a panel of aging and disability experts from across the country in Washington, DC. A list of meeting participants is contained at the end of this report.

After examining the inventory of existing data sources, the panel sought to determine the best methods for creating a state family support data collection system across aging and disabilities. Two questions were posed to the panel to solicit recommendations:

- 1) What indicators are needed in order to monitor, track, and evaluate state approaches to family support services and family caregiver outcomes?
- 2) How can existing national and state level datasets be improved to enhance data on family caregivers and family support services?

## **Recommendations**

### **Ideal Indicators to Monitor, Track, Evaluate Family Support Services**

In response to the first question concerning ideal indicators, responses fell into three categories: 1) Demographics of Family Caregiving Situation; 2) Impact on Families; and 3) Indicators to Assess Family Support at the State Level.

#### *Demographics of Caregiving Situation*

In order to better understand the nature of family caregiving and outcomes of family support services, the context of the caregiving situation is important. The panel noted that increasingly complex nature of family caregiving. There are often multiple caregivers involved; and it is not uncommon for family caregivers to be caring for more than one individual with disabilities. The panel suggested a number of important areas to consider when collecting data on the caregiving situation:

- Identification of all caregivers –including the primary caregiver and other caregivers involved
- Identification of care recipient(s), level/type of disabilities, relationship
- Level and duration of caregiving
- Types of caregiving tasks
- Cultural perspective of caregiver
- Informal support networks

#### *Impact on Families*

The panel also suggested a number of important areas to consider when assessing the impact of caregiving on families and evaluating potential outcomes of family support services. Some areas included:

- Caregiver burden and stress
- Caregiver satisfaction

- Caregiver health and wellbeing
- Financial impact/costs of caregiving –including impacts on caregiver employment

### *Indicators to Assess Family Support at State Level*

The crux of the first question was to develop a list of ideal indicators that if data were available could improve monitoring state efforts to support families. Conceptually, this is similar to the AARP and UCP scorecard efforts which use various data sources in order to assess state efforts over time and allow for comparisons across states.

The AARP Scorecard on Long-Term Services and Supports currently includes a “*Support for Family Caregivers*” domain that assesses three areas: 1) Legal and system supports for family caregivers; 2) Number of health maintenance tasks able to be delegated to LTSS workers; and 3) Family caregiver health and well-being (caregivers without much worry or stress, with enough time, well rested). Similarly, the UCP scorecard, which focuses specifically on individuals with intellectual and developmental disabilities, includes a “*Keeping Families Together*” domain. This domain draws upon data from the State of the States in Developmental Disabilities and the National Core Indicators project for three indicators: 1) State expenditures on family support services; 2) Percentages of families receiving family support services; and 3) States participating in NCI family surveys.

Unfortunately, current scorecard efforts are severely limited based on availability of data. The panel was charged to think about what indicators would ideally be useful to have to improve scorecard efforts across aging and disability populations. The panel suggested the following areas:

- State expenditures for family support services
- Percentage of family caregivers receiving family support services
- Data on respite services
- Waiting list for family support services
- Access to family support services during crises/transitions
- Disparities in service provision by race/ethnicity and socioeconomic status
- Availability of evidence based family caregiver support programs
- Availability of family support services through employers
- State requirements for caregiver assessments
- State policies on paid caregiving and prevalence
- Individual and family experience with service system
- Involvement of families in care coordination & decision making process

### **Recommendations for Improvements to State and National Datasets**

The second question sought to solicit specific recommendations for improvements in existing state and national data collection efforts. Many recommendations were based on the 14 datasets identified through the environmental scan. However, the panel also identified opportunities to

add questions to other national datasets that currently do not include any caregiver related questions. The panel made the following recommendations:

- *Development/Agreement on a core set of family caregiver questions that could be added to national surveys.*

Over the past decade the disability community has engaged in efforts to add a core set of six disability questions to many national surveys, including the American Community Survey (ACS) and Current Population Survey (CPS). This has led to greater consistency and ability to explore disability issues across issues covered by datasets. A similar effort should be undertaken to identify a core set of caregiver questions that could be added to surveys. The core set could include demographic caregiver questions to identify basic information such as caregiver status, characteristics of care recipient, level and duration of caregiving, and types of caregiving tasks performed. Some suggested that tested measures from the Behavioral Risk Factor Surveillance System (BRFSS) could serve as a starting point. Others suggested that NIDLRR invest in development of this core set of questions.

- *Add demographic caregiver question(s) to the core BRFSS survey*

BRFSS is the nation's premier system of health-related telephone surveys that collect state data about U.S. residents regarding their health-related risk behaviors, chronic health conditions, and use of preventive services. In 2009, the BRFSS included a question to identify caregiver status in the core BRFSS which is completed by every state.<sup>1</sup> This allowed researchers to explore the health and wellbeing of caregivers and make comparisons across states. Data was used in the first version of the AARP Scorecard. However, this question was not included in subsequent years. The panel recommended that CDC at a minimum add this question back to the core survey. CDC should also consider additional questions to provide context of the caregiving situation, such as amount of caregiving.

- *Incentivize states to complete BRFSS voluntary caregiving module at least every five years*

A voluntary BRFSS Caregiving module has been available to states to use. However, historically very few states have included it. Due to advocacy and financial assistance from the Alzheimer's Association approximately half of states completed this module in the past year. The federal government should consider providing incentives to states to conduct this module at a minimum of every five years.

- *Add caregiver questions to National Health Interview Survey*

The National Health Interview Survey (NHIS) currently does not include specific caregiving-related questions. The NHIS is a nationally representative survey providing data on the health of the civilian, non-institutionalized population of the United States.<sup>ii</sup>

<sup>1</sup> BRFSS Caregiver Question: [Prologue: People may provide regular care or assistance to a friend or family member who has a health problem, long-term illness, or disability.] During the past month, did you provide any such care or assistance to a friend or family member?

The NHIS has been administered since 1957, and is conducted by the National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention (CDC). The survey contains information on multiple aspects of health status, including activity limitations, injuries, health insurance, and access to and utilization of health care. The survey also provides information on household composition, socio-economic status, and family income and assets. However, one drawback is the design of the NHIS sample does not allow for state-level estimates. The NHIS is currently undergoing a redesign for 2018 and is open for public comment.

- *Add caregiving supplement to American Community Survey*  
The American Community Survey (ACS) currently does not include caregiving-related questions. The ACS is a continuous data collection effort by the U.S. Census Bureau that is used to produce annual estimates at the national, state, and local level on the characteristics of the United States population.<sup>iii</sup>
- *Add caregiving questions to General Social Survey to explore attitudes related to caregiving*  
The General Social Survey (GSS) gathers data on contemporary American society in order to monitor and explain trends and constants in attitudes, behaviors, and attributes.<sup>iv</sup> It is conducted by NORC at the University of Chicago, with the support of the National Science Foundation. The GSS contains a standard core of demographic, behavioral, and attitudinal questions, plus topics of special interest. The GSS could be used to potentially explore societal attitudes about caregiving or caregiving policies.
- *Add caregiving questions to Medicare Current Beneficiary Survey*  
The Medicare Current Beneficiary Survey (MCBS) is a continuous, multipurpose survey of a nationally representative sample of the Medicare population, conducted by the CMS. The central goals of MCBS are to determine expenditures and sources of payment for all services used by Medicare beneficiaries, including co-payments, deductibles, and non-covered services; to ascertain all types of health insurance coverage and relate coverage to sources of payment; and to trace processes over time, such as changes in health status and spending down to Medicaid eligibility and the impacts of program changes, satisfaction with care, and usual source of care.<sup>v</sup>
- *CMS should invest in development of a survey of family caregiver experience of care that could be used in assessing quality of care*  
The federal government has invested in the development of experience of care surveys, such as Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys. Currently, CMS in partnership with Agency for Healthcare Research and Quality (AHRQ) has invested in the development of a Home and Community-Based Services (HCBS) Experience survey. Additional investments are needed to develop surveys that assess the family caregiver experience of care, particularly related to HCBS.

- *Improve state reporting and consistency in data collection on family support services in Medicaid*  
Currently, it is very difficult to obtain consistent Medicaid data from states on respite and other family support services. CMS should improve data collection efforts within Medicaid to allow for comparisons in delivery of family support services across states.
- *Conduct national survey of caregivers of individuals under 65 similar to NHATS*  
The National Study of Caregiving (NSOC) samples from The National Health and Aging Trends Study (NHATS), which is a nationally representative sample of Medicare beneficiaries ages 65 and older. NHATS is funded by the National Institute on Aging and the NSOC is supported by the Assistant Secretary for Planning and Evaluation (ASPE). The NSOC/NHATS is an excellent source for nationally representative information about the role and experiences of informal caregivers for the older population.<sup>vi</sup> Additional federal investments are needed to explore caregivers of individuals under 65.
- *Add priority and missing questions related to caregiving National Core Indicators for people with IDD and conduct with families not receiving services*  
The National Core Indicators (NCI) has been in use since 1997. The NCI Adult Consumer Survey is currently used by approximately 43 states. However, few states participate in the family surveys. Moreover, questions primarily focus on family member receiving services and supports versus health, wellbeing of caregiver and needs for family caregiver supports and services. Additional caregiver-related questions could be added to the NCI family surveys. In addition, the survey is currently only used with individuals with I/DD and their families receiving services and supports. The NCI, or other surveys, could be used to better explore the needs of families not receiving services and supports. The Family and Individual Needs for Disability Supports (FINDs) survey is another data collection efforts that could assist with understanding the needs of families of individuals with I/DD not receiving services and supports.
- *Develop a family caregiver survey for the National Core Indicators-Aging and Disability survey*  
The National Core Indicators-Aging and Disability (NCI-AD) survey currently consists of an in-person Consumer Survey tool with approximately 50 “indicators” of outcomes of LTSS for older adults and adults with physical and other disabilities, excluding adults with ID/DD. The NCI-AD project is currently in its’ first year of regular implementation (2015-2016 data collection year). Fourteen states are participating in Consumer Survey data collection in 2015-2016. As the NCI-AD continues to develop, investments should be made in piloting development of a family caregiver survey.
- *Build on existing caregiver surveys such as Caregiving in the US, by oversampling to learn more about populations of interest*  
Caregiving in the US provides a national portrait of family caregivers that is widely used by policymakers and advocates. It has been conducted approximately every five years since 1997, contingent upon funding. It also provides a platform for oversampling in order to explore needs and experiences of certain populations of caregivers in more

detail, which has been done in previous years. Additional investments should be made in Caregiving in the US to ensure its continuation every five years and to oversample.

- *Add additional questions through State of the States to analyze data and promising practices in supports waivers.*

Supports waivers are Medicaid HCBS waivers that have increasingly been used within state I/DD service systems to provide family support. These waivers typically provide a limited amount of flexible services and supports to individuals living at home with family caregivers. The State of the States project could add some additional questions to better identify and analyze these waivers.

## Meeting Participants

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## Endnotes

<sup>i</sup> National Alliance for Caregiving (2015) Caregiving in the U.S., 2015. Washington, DC: National Alliance for Caregiving. <http://www.caregiving.org/caregiving2015/>

<sup>ii</sup> Harris, B.H., Hendershot, G., & Stapleton, D.C. (October 2005). A Guide to Disability Statistics from the National Health Interview Survey. Employment and Disability Institute, Cornell University  
<http://digitalcommons.ilr.cornell.edu/cgi/viewcontent.cgi?article=1184&context=edicollect>

<sup>iii</sup> Erickson, W. (June 2012) A Guide to Disability Statistics from the American Community Survey (2008 Forward). Employment and Disability Institute, Cornell University  
<http://digitalcommons.ilr.cornell.edu/cgi/viewcontent.cgi?article=1290&context=edicollect>

<sup>iv</sup> General Social Survey <http://gss.norc.org/About-The-GSS>

<sup>v</sup> Current Medicare Beneficiary Survey <https://www.cms.gov/Research-Statistics-Data-and-Systems/Research/MCBS/index.html?redirect=/mcbs>

<sup>vi</sup> Spillman, B.C., Wolff, J., Freedman, V.A., & Kasper, J.D. (April 2014) Informal caregivers for Older Americans: An Analysis of the 2011 National Study of Caregiving. Office of Disability, Aging and Long-Term Care Policy Office of the Assistant Secretary for Planning and Evaluation U.S. Department of Health and Human Services.  
<https://aspe.hhs.gov/report/informal-caregiving-older-americans-analysis-2011-national-health-and-aging-trends-study>

# Appendix: Dataset Summaries



## Family Support Dataset Summaries

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**Project Team: Joe Caldwell, Katie Arnold, Evelyn Ingargiola, and Randa Abdelrahim**

### INTRODUCTION

The University of Illinois at Chicago's Family Support Research & Training Center (FSRTC) is a collaboration of researchers and organizations that are focused on synthesizing and generating knowledge about the needs and experiences of families who provide support to children and adults with disabilities across the life course. The FSRTC is funded by The United States Department of Health and Human Services, Administration for Community Living (ACL) and the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR).

ACL and NIDILRR requested that we convene experts to identify and assess current methods for monitoring, tracking, and evaluating states' approaches to supporting families.

In preparation for this meeting, we conducted an environmental scan to identify existing datasets that provide relevant information about family caregivers and family caregiver supports. Findings fell into three categories: 1) Datasets that provide nationally representative data; 2) Datasets that provide state-level comparison data; and 3) Scorecards which use indicators from various data sources to track state progress and make comparisons.

This brief provides summaries of the datasets. As you review, please consider the following questions:

- 1) Ideally, what indicators are needed in order to monitor, track, and evaluate state approaches to family support services and family caregiver outcomes?
- 2) How can existing national and state level datasets be improved to enhance data on family caregivers and family support services?

These two questions will form the basis of our discussion at the November meeting. The goal of the meeting is to develop recommendations in these areas to improve data collection.

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## NATIONAL DATASETS

### American Time Use Survey (ATUS)

**Population:** Persons age 15 or over

**Purpose:** Time-use surveys measure the amount of time people spend doing various activities, such as work, childcare, housework, watching television, volunteering, and socializing

**Method:** The data are collected through telephone interviews. Census Bureau interviewers use Computer Assisted Telephone Interviewing, a system that automatically advances interviewers to the next question based on a respondent's answers to previous questions.

**Frequency:** Annually (2015 Report: <http://www.bls.gov/news.release/elcare.nr0.htm>)

**Respondents:** nearly 25,000 individuals were interviewed for the ATUS

**Data Collectors:** conducted by the U.S. Census Bureau for the Bureau of Labor Statistics (BLS)

**Funding:** Federal (The Bureau of Labor Statistics)

**Strengths:** Annual, sample size and representation of the population

**Limitations:** Focus on Elderly so it might not be related to disability, introduced in 2011, so fairly new, not long term data.

**Relevant Info:** The survey asks questions about the time you may have recently spent assisting or caring for an adult who needed help because of a condition related to aging. It includes the frequency of help provided; Time daily, Time monthly, and Time yearly. It also collects information about the number of people received care and their relationship with the caregiver. It allows researchers to look at caregiver employment.

## **Behavioral Risk Factor Surveillance System (BRFSS)**

**Population:** Adults household aged 18 and older

**Purpose:** The CDC's BRFSS is used to collect prevalence data among adult U.S. residents regarding their risk behaviors and preventive health practices that can affect their health status. The BRFSS questionnaire was developed in collaboration between CDC and public health departments in each of the states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands.

**Method:** The survey is conducted using Random Digit Dialing (RDD) techniques on both landlines and cell phones. In-house interviewers are also conducted in State Health Departments.

**Frequency:** In 2009, CDC included a single question in the core BRFSS survey identifying caregiver status.

[Prologue: People may provide regular care or assistance to a friend or family member who has a health problem, long-term illness, or disability.] During the past month, did you provide any such care or assistance to a friend or family member?

In 2009 and 2010 a voluntary caregiver module was offered to states. However, uptake was low (2 states in 2009; 3 states in 2010). CDC is repeating the voluntary module and approximately 24 states are expected to participate in 2015.

**Respondents:** 491,773 interviews were conducted in 2013

**Data Collectors:** State health departments, telephone call centers or universities.

**Funding:** Primarily federal funding for core survey; state contribution for voluntary modules.

**Strengths:** National survey; core question identifying caregiver status allowed for state comparisons

**Limitations:** Historically low participation of states.

**Relevant Info:** The BRFSS included a core question to identify caregiver status. The voluntary caregiver module includes information about the age and sex of the care recipient; relationship of the care recipient to the caregiver; care recipient's major diagnosis (e.g., heart disease, cancer, stroke, or diabetes); care recipient's functional limitations (e.g., moving around or self-care) as defined by the International Classification of Functioning, Disability, and Health; duration of caregiving; hours per week of caregiving; difficulties for the caregiver that were created by caregiving (e.g., stress, lack of time, and health problems); and travel time to reach the care recipient.

## Caregiving in the U.S.

**Population:** unpaid Caregivers of adults or children with special needs

**Purpose:** The purpose of this study is to present a portrait of unpaid family caregivers.

**Method:** Primarily quantitative online interviews (telephone interviews in previous years)

**Frequency:** 1997, 2004, 2009, 2015.

**Respondents:** In 2015, online interviews with 1,248 caregivers ages 18 and older who provide care to an adult age 18 or older.

**Data Collectors:** National Alliance on Caregiving (Greenwald & Associates)

**Funding:** Funded by AARP and a mix of corporate, foundation, and non-profit funding.

**Strengths:** Nationally representative sample provides data frequently used by policymakers and advocacy groups.

**Limitations:** Conducted approximately every 5 years (contingent on funding). The 2009 study included caregivers of children. In 2015, population was identified for prevalence only.

**Relevant Info:** The core areas include the following:

- The prevalence of caregivers in the United States
- Demographic characteristics of caregivers and care recipients
- The caregiver's situation in terms of the nature of caregiving activities, the intensity and duration of care, the health conditions and living situation of the person to whom care is provided, and other unpaid and paid help provided
- How caregiving affects caregiver stress, strain, and health
- Information needs related to caregiving
- Public policy and caregiver support

In 2015, unique areas of exploration included::

- Medical/nursing tasks
- Hospitalization of care recipients
- Supports provided to and impacts on working caregivers
- Older caregivers ages 65-plus

## Gallup Healthways

**Population:** adults aged 18 and older

**Purpose:** The Gallup-Healthways Well-Being Index provides an in-depth, nearly real-time view of Americans' well-being.

**Method:** Gallup interviews U.S. adults aged 18 and older living in all 50 states and the District of Columbia using a dual-frame design, which includes both landline and cellphone numbers. Gallup samples landline and cellphone numbers using random-digit-dial methods. Gallup purchases samples for this study from Survey Sampling International (SSI). Gallup chooses landline respondents at random within each household based on which member had the most recent birthday. Each sample of national adults includes a minimum quota of 50% cellphone respondents and 50% landline respondents, with additional minimum quotas by time zone within region. Gallup conducts interviews in Spanish for respondents who are primarily Spanish speaking. Since it began in 2008, the Gallup-Healthways Well-Being Index survey has been conducted every day, excluding major holidays and other events, for 350 days per year

**Frequency:** Results related to caregivers were published from a special survey identifying caregivers.

**Respondents:** The findings are based on 140,853 interviews with American adults employed full time conducted Jan. 2-Nov. 24, 2010, as part of the Gallup-Healthways Well-Being Index

**Data Collectors:** Gallup and Healthways

**Funding:** N/A

**Strengths:** National study, included respondents who are primarily Spanish speaking.

**Limitations:** Focuses only on eldercare.

**Relevant Info:** The Gallup-Healthways Well-Being Index score comprises six sub-indexes, which measure how Americans rate their lives, emotional health, work environment, physical health, healthy behaviors, and access to basic necessities. AARP Scorecard uses a composite score of four indicators analyzed by MIT AgeLab for caregivers.

## **National Health and Aging Trends Study (NHATS)**

**Population:** Helpers identified by NHATS participants during the Round 1 Sample Person (SP) interview

**Purpose:** The National Study of Caregiving (NSOC) is a national study of people who help their older family members and friends with their daily activities. The NSOC looked at the important role of family members and friends in providing help and care for the growing aging population. The study information is used to understand the many important ways that people help their older relatives and friends with their daily activities and how this experience affects those who help.

**Method:** Conducting telephone interviews with individuals who have a family member or friend participating in The National Health and Aging Trends Study (NHATS).

**Frequency:** Took place only once in 2011

**Respondents:** Approximately 2,000 individuals participated in the survey.

**Data Collectors:** The Johns Hopkins Bloomberg School of Public Health and Westat -an employee owned corporation providing research services to agencies of the U.S government-conducted the study.

**Funding:** Federal (U.S. Department of Health and Human Services, Assistant Secretary for Planning and Evaluation; National Institute on Aging (NIA) at the National Institutes of Health)

**Strengths:** Caregivers were allocated by the person who is receiving support. Weighted responses to reduce bias of differential nonresponse, no single “primary caregiver” interviewed, instead up to 5 eligible caregivers/helpers interviewed

**Limitations:** examined only caregivers who provide support for elderly

**Relevant Info:** The interviews consisted of 9 sections; Care Activities, duration of Care, aspects of Caregiving, support, environment, participation, health and Wellbeing, household composition and demographics, employment and caregiving, health insurance and income

## National Survey of Children with Special Health Care Needs

**Population:** children with special health care needs; 18yrs or younger

**Purpose:** to assess the prevalence and impact of special health care needs among children eighteen years or younger in the United States, and to evaluate change over time. The NS-CSHCN data provides an estimated number of children with special health care needs in each state population, and the estimated percent of households with children having one or more CSHCN under 18 years old.

**Method:** cross-sectional telephone (cell and landline) survey of households with one or more children under 18yrs of age. Independent random samples from all 50 states and DC..

**Frequency:** 2000-2001, 2005-2006, 2009-2010

**Respondents:** parents or guardians. 40,242 detailed CSHCN interviews in 2009/2010; at least 750 interviews in each state. A total of 196,159 household screening interviews were completed from July 2009 through March 2011, resulting in 40,242 completed special-needs interviews, including 2,991 from cell-phone interviews. The weighted overall response rate was 43.7% for the landline sample, 15.2% for the cell-phone sample, and 25.5% overall.

**Data Collectors:** Data collection was conducted under contract with NORC at the University of Chicago. The National Center for Health Statistics of the Centers for Disease Control and Prevention oversees the sampling and telephone interviews for the survey

**Funding:** Federal (Maternal and Child Health Bureau, U.S. Department of Health and Human Services). Additional for specific questions: CDC's National Center for Birth Defects and Developmental Disabilities and the Lucile Packard Foundation for Children's Health

**Strengths:** Survey administered in six languages. Households reached using cell phone and landline numbers. Detailed methodology booklet and clear fact sheet. Interviewer training, screening, advance letters, weighted responses, analyzing of missing data are all strengths of this dataset.

**Limitations:** Not annual and high nonresponse.

**Relevant Info:** Survey topics ranged from child's health and functional status and demographics to adequacy of health care coverage. Of the many topics covered in this survey, 'access to healthcare', 'care coordination', 'family centeredness', 'transition to adulthood' and 'impact of child's health on the family' included questions regarding family support.

## Survey of Income and Program Participation (SIPP)

**Population:** adult household members ages 15+

**Purpose:** to provide information about the income and program participation of individuals and households in the United States, and to provide information about the principal determinants of income and program participation. Other topics covered in the SIPP include family dynamics, education, disability status, retirement, assets, health insurance, child-care, food security and informal caregiving. A major use of the SIPP has been to evaluate the use of and eligibility for government programs and to analyze the impacts of modifications to those programs.

**Method:** telephone interview or in-person visit; national longitudinal panel survey. Each panel features a nationally representative sample interviewed over a multi-year period lasting approximately four years. The SIPP includes “core” and “topical” questionnaires, including questions that are asked at every interview, and those that are asked periodically.

**Frequency:** The SIPP has been conducted every three years, but starting in 2014 it will be an annual survey. Informal Caregiving was a topical module in the May-Aug 2011 wave of the 2008 panel. Topical modules are not included in the SIPP on a routine basis.

**Respondents:** The 2014 SIPP will have data on 52,000 households; a nationally representative sample. Sample sizes have ranged from approximately 14,000 to 52,000 interviewed households

**Data Collectors:** US Census Bureau

**Funding:** US Census Bureau

**Strengths:** detailed methodology, oversampling, weighted data analysis and procedures for following families who move.

**Limitations:** Sample attrition due to longitudinal design. Informal caregiving was only a topical module, in 2008.

**Relevant Info:** The previous informal caregiving topical module of the SIPP included topics such as the number of hours spent on informal caregiving in past month, the relationship of caregiver to care recipient, the kind of assistance that was needed, hours of professional (paid) home health care, etc.

## STATE BY STATE DATASETS

### NCI: National Core Indicators

**Population:** Individuals with Intellectual and Developmental Disabilities. In 2014, pilot testing began on a new NCI-AD for individuals with physical disabilities and older adults.

**Purpose:** to create a standard set of performance and outcome measures that can be used to track performance of public service systems over time, to compare results across states, and to establish national benchmarks.

**Method:** voluntary surveys distributed randomly to representative samples of each state population. The adult survey is completed by individuals receiving services and supports. Three surveys relate to family support (

- Adult Family Survey (adults living in family home)
- Family Guardian Survey (adults living outside family home)
- Child Family Survey(children living at home)

**Frequency:** annually, since 1997 form individuals with I/DD.

**Respondents:** NCI Adult Consumer Survey is currently used by 43 states Fourteen states participate in the Adult Family Survey, seven states participated in the Child Family Survey, and twelve states participated in the Family Guardian Survey.

**Data Collectors:** NASDDDS, NASUAD, and HSRI.

**Funding:** primarily state funded. From 2011-2016, the Administration on Intellectual and Developmental Disabilities (AIDD) contributed funding to support the expansion of the program to an additional five states per year.

**Strengths:** Ability to compare across states

**Limitations:** Few states participate in the family survey for individuals with I/DD; currently, there is no family survey for the NCI-AD. Questions primarily focus on family member receiving services and supports versus health, wellbeing of caregiver and needs for family caregiver supports and services.

**Relevant Info:** Data on more than 15 family indicators are collected from three of the four surveys. These surveys are the Adult Family Survey, Family Guardian Survey, and the Child Family Survey. The data on the 15 family indicators was divided into seven subdomains: Choice and Control, Family Outcomes, Satisfaction, Family Involvement, Community Connections, Access and support Delivery, and Information and Planning.

## **National Inventory Survey on Participant Direction**

**Population:** Individuals and families participating in self-directed programs

**Purpose:** To determine the number of publicly funded participant-directed programs nationwide and create descriptions of program characteristics to define a continuum of "participant directedness." This inventory identifies best practices, challenges and implications for future development and implementation of participant directed services.

**Method:** Data was collected from five sources: (1) Surveys of state administrators of PD-LTSS programs, (2) the Medicaid waiver database, (3) program websites including online manuals, pamphlets and factsheets, (4) a program's financial management services (FMS) provider, and (5) data/information requests to state agencies

**Frequency:** Conducted once. Data were collected from June 2013 to April 2014

**Respondents:** The 2013 National Inventory includes data from 277 programs from all 50 states and the District of Columbia.

**Data Collectors:** The National Resource Center for Participant-Directed Services (NRCPPDS)

**Funding:** AARP, Atlantic Philanthropies, and Robert Wood Johnson Foundation

**Strengths:** Results of this survey are used within the Participant Direction Domain for the State Long-Term Services and Supports (LTSS) Scorecard

**Limitations:** Not all 277 programs that participated answered each question. Some of the facts and figures, depending on the question posed, are based on only 252, 96, or 23 programs, for example. However, the number of programs that each statistic is based upon is clearly stated in the facts and figures document.

### **Relevant Info:**

The 2013 NRCPPDS NI captures emerging trends, including new program development, growth in enrollment, and the use of managed care as a service delivery system, all of which are expected to continue to play an important role in the reshaping of the current landscape of participant direction. Participant direction is available in every state and the District of Columbia. The majority of states have between 1,000 – 5,000 participants enrolled in PD-LTSS programs. While the data indicate moderate growth in participant direction nationwide compared to 2010, less than six-percent of Medicaid eligible individuals nationwide are enrolled in participant direction programs. Ability to look at programs that allow family members to be paid.

## State of the States (SOS)

**Population:** Individuals with Intellectual and Developmental Disabilities

**Purpose:** to investigate the determinants of public spending for intellectual and developmental disabilities services across the United States. Longitudinal record of state revenue, spending, and programmatic trends reveals the impact of federal and state fiscal policy over time. State trends in community living, public and private residential institutions, family support, supported employment, supported living, Medicaid Waivers, demographics, and related areas are all covered in the State of the States survey.

**Method:** Survey of state I/DD service agencies

**Frequency:** Biennial; since 1977.

**Respondents:** 174 intellectual and developmental disabilities, Medicaid, and health and human services staff in all 50 states and Washington, DC.

**Data Collectors:** Coleman Institute at the University of Colorado; IDHD at the University of Illinois at Chicago

**Funding:** Project of National Significance by Administration on Intellectual and Developmental Disabilities and US Department of Health and Human Services

**Strengths:** Extensive collaboration with each state's I/DD agency personnel in order to guide development of specialized fiscal classification system that is sensitive to each state's budgeting terminology. States are provided with previous year's data for reference.

**Limitations:** variability in state definition and services funded under 'family support', variable state budgeting systems, and varied reliability of spending figures reported in official state budgets.

**Relevant Info:** The State of the States defines 'family support' to include: Respite Services, Financial Support, In-Home Support, Education and Training Assistive and Medical Technology, Health and Related Professional Services, Family Training/Counseling, Transportation, Case Management/Service Coordination, Recreation/Leisure, Other Family Support and Cash-Subsidy Family Support. Total spending to support families, supported living/personal assistance spending, and supported employment spending determined the total individual family support.

## **Supporting Individuals and Families Information Systems Project (FISP)**

**Population:** Individuals with Intellectual and Developmental Disabilities (IDD)

**Purpose:** Establishes and refines a comprehensive program of annual data collection from states on family support, and conducts longitudinal data analysis, policy studies, and dissemination activities to better understand and promote effective supports for families and individuals with intellectual and/or developmental disabilities (IDD) who direct their own support

**Method:** surveys of directors of state IDD agencies and large state residential facilities

**Frequency:** Annual, since 2011.

**Respondents:** more than 300 state and individual facility respondents in all 50 states

**Data Collectors:** University of Minnesota (Research and Training Center on Community Living, at the Institute on Community Integration), National Association of State Directors of Developmental Disabilities Services, Human Services Research Institute, Council for Quality and Leadership.

**Funding:** This project is funded through cooperative agreements from the Administration on Community Living, U.S. Department of Health and Human Services and supplemental support from the National Institute on Disability and Independent Living Rehabilitation Research, U.S. Department of Education

**Strengths:** 2013 data included US territories. Designated project staff work with new state respondents to properly fill out survey. Operational definition guide, FAQ's, webinars and previous years' responses are available to respondents.

**Limitations:** Lack of unified definition of family support across states, some incompatibility with FISP survey definitions. Variation in states' funding and policy data maintained. High turnover rate of state IDD directors, who receive the survey and provide the data. Missing data: the FISP compensates for missing data by substituting the state's data from the previous year when applicable.

### **Relevant Info:**

Family Profiles 1) compares the age and living arrangements of people with intellectual or developmental disabilities (IDD) receiving Medicaid Home and Community Based (HCBS) Waiver Funded long-term supports and services (LTSS). 2) Compares the number of people with IDD who lived in individualized versus congregate settings (2000, 2005,2010,2012). 3) Compares the number of people ages 22 years or older with the number of people who were 21 years or younger who lived in ICF/IID on June 30, 2012. 4) Compares the number of people with IDD who received HCBS Waiver funded LTSS to the number who lived in an ICF/IDD

## UCSF's Surveys of State HCBS Programs

**Population:** All states that participate in at least one of the three most commonly used Medicaid HCBS Programs: 1. the state plan home health program, 2. the optional state plan personal care services (PCS) program and 3. the 1915(c) HCBS waiver program.

**Purpose:** to track participants and expenditures in the Medicaid HCBS state plan home health program and the optional state plan personal care program, as well as to track and understand state policy regarding the state plan home health program, the optional state plan personal care program and the 1915(c) waiver program.

**Method:** Written survey emailed and faxed to state persons in charge of programs

**Frequency:** Annual

**Respondents:** 1. The state plan home health program has 51 states, 2. The optional state plan personal care program has 34 states, and 3. The 1915(c) waiver program has 48 states. Note that states have multiple responses due to multiple programs

**Data Collectors:** Terence Ng of the University of California San Francisco

**Funding:** Community Living Policy Center and Kaiser Family Foundation

**Strengths:** Only nationwide tracking survey since 2002 for all 3 programs. Comprehensive and responsive to changing policies and regulations

**Limitations:** Certain state only nuances may not be captured, some programs handled by contractors so states may not have accurate and up to date information

**Relevant Info:** The University of California San Francisco sends out three separate surveys to respective/participating states, divided by Medicaid program. 1. the state plan home health program, 2. the optional state plan personal care services (PCS) program and 3. the 1915(c) HCBS waiver program.

## SCORECARDS

### AARP State Scorecard

Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Disabilities, and Family Caregivers

**Population:** the elderly, adults with disabilities, and their family caregivers.

**Purpose:** measures and ranks state-level performance of LTSS systems across five dimensions: (1) affordability and access, (2) choice of setting and provider, (3) quality of life and quality of care, (4) support for family caregivers, and (5) effective transitions.

**Method:** Data for the AARP State Scorecard is compiled from thirty-one preexisting surveys and datasets. Data from the “support for family caregivers” dimension came from data sources including but not limited to: Expecting Better for All Working Families: A Special Section of the Second Edition of Expecting Better, Gallup Healthways Well-Being Index, and the AARP Public Policy Institute survey on nurse delegation in home settings. The Scorecard ranks the states from highest to lowest performance on each indicator. Then, the rankings across all indicators within each of the five dimensions are averaged to determine each state’s dimension ranks, and then the dimension ranks are averaged to arrive at an overall ranking.

**Frequency:** 2011 & 2014

**Respondents:** N/A

**Data Collectors:** AARP

**Funding:** the AARP Foundation, the SCAN Foundation and the Commonwealth Fund

**Strengths:** All states are ranked. Definitions for indicators included.

**Limitations:** The Scorecard does not include Intellectual Disabilities or Chronic Mental Illness or children with disabilities in its sample. Only adults with physical disabilities and the elderly are included. However, most family caregiving indicators cross populations.

**Relevant Info:** Dimension 4, Support for family caregivers, consists of three indicators:

- a) Legal and system supports for family caregivers available in states and localities
- b) The extent to which registered nurses are able to delegate health maintenance tasks to non-family members (LTSS workers)
- c) Caregiver Wellbeing.

## UCP The Case For Inclusion

**Population:** Individuals with intellectual and developmental disabilities and their families

**Purpose:** The Case for Inclusion is an annual ranking state Medicaid programs performance in serving individuals with intellectual and developmental disabilities and their families, produced by the United Cerebral Palsy (UCP).

**Method:** UCP uses mainly data from the National Core Indicators (NCI), a survey that uses in-person interviews and extensive questioning to better reflect the true health, safety and quality of life of individuals, with 39 States participating and 19 States publicly reporting their survey results in 2014. UCP score States in five sections; promoting independence, tracking health safety and quality of life, keeping families together, promoting productivity, reaching those in need. In total, NCI-related data measures make up 18 points of the 100-point Case for Inclusion scale.

**Frequency:** Annual since 2006

**Respondents:** 50 states and the District of Columbia

**Source/s:** Research and Training Center on Community Living, Administration on Children and Families, Centers for Medicare and Medicaid Services, Coleman Institute, Institute for Community Inclusion, Kaiser Family Foundation, Mathematica, National Association of State Directors of Developmental Disabilities Services, National Core Indicators (Human Services Resource Institute, and the US Census Bureau.

**Data Collector/s:** United Cerebral Palsy, an international advocate, educating and providing support services for children and adults with a spectrum of disabilities through an affiliate network

**Funding:** Sponsored by the UCP

**Limitations:** Only focused on individual with I/DD. Limited indicators related to family caregiving.

**Relevant Info:** Used three indicators for a “Keeping Family Together” domain. These include number of families receiving family support services per 100K, spending per family, and whether or not the state uses the NCI family survey.