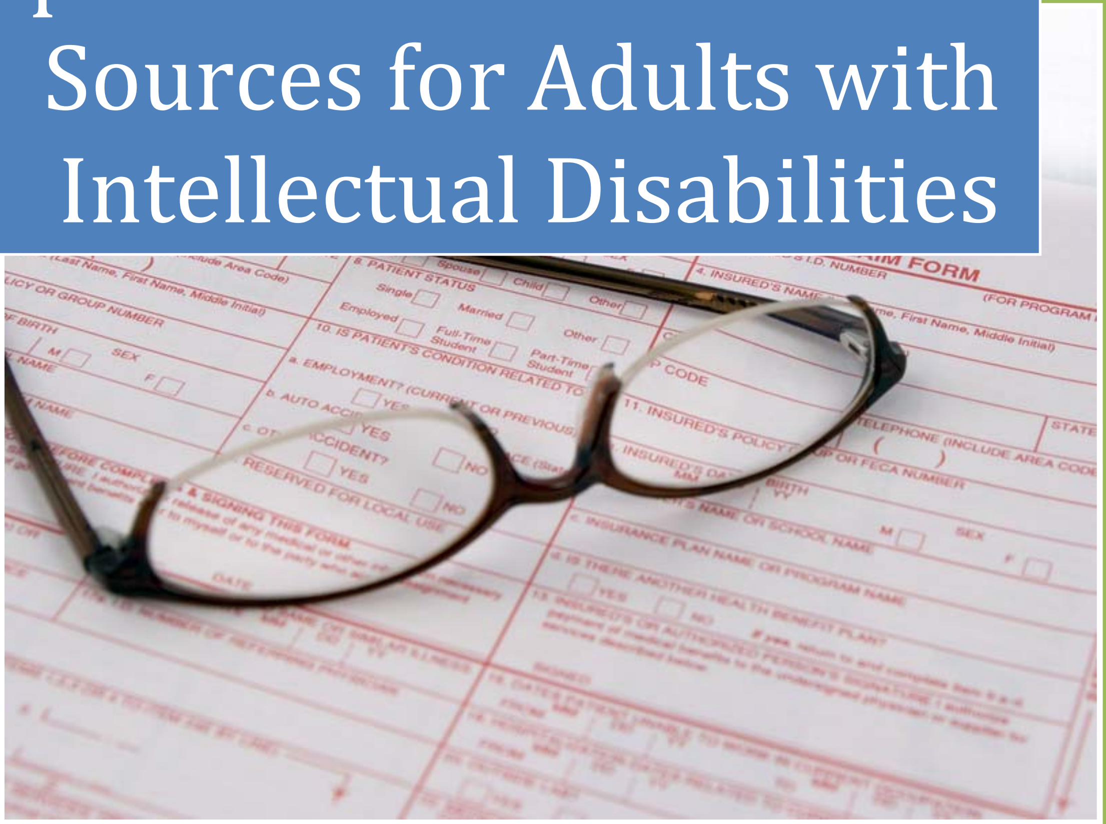
2011

Compendium of Health Data Sources for Adults with Intellectual Disabilities



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Additional project materials can be accessed by contacting the Principal Investigator at Alexandra.Bonardi@umassmed.edu.

Table of Contents

Introduction

This compendium is the summary of a review of national, state, or regional surveillance efforts and major data sources that currently capture health information pertaining to adults with intellectual disability in the United States. The review and development of this compendium was completed by members of the CDDER/HSRI project team awarded the 2010 Research Topic of Interest (RTOI): Health Surveillance of Adults with Intellectual Disability, awarded by the Association of University Centers on Disabilities (AUCD) and funded through a cooperative agreement with the Centers for Disease Control and Prevention (CDC) National Center on Birth Defects and Developmental Disabilities (NCBDDD).

Methodology

Identification of data sources

The CDDER-HSRI team began with a literature and web-based review to identify databases that either collect population health information on adults with intellectual disability directly or could be adapted for this purpose.
Studies were collected through a literature review with the National Library of Medicine and other sources, using key words of 'intellectual disabilities', 'mental retardation', 'developmental disabilities' combined with key words for targeted measures such as 'health', 'quality of life', 'access', 'health promotion', 'health care access', 'health care utilization', 'surveillance', 'population health'.

In addition, a general web search was performed using these key words, and a targeted search was conducted on the major U.S. studies and projects in other countries on health in people with ID.

Major databases included in review

1) Social Sciences Variable Database http://www.icpsr.umich.edu/icpsrweb/ICPSR/ssvd/index.jsp

   Search for "Intellectual Disability" produced 171 valid responses (from a total of 4963) with the following response categories for specific conditions: Autism (3), Cerebral Palsy (7), Down Syndrome (3), Hydrocephalus (1), Mental Retardation (9), Mental Disability (1), Pervasive Developmental Disorder (1), Retardation (1), ADD (11), ADHD (7), Learning Disability (7), Mental Problems (1), Speech Problems (1), Epilepsy (13), Seizure Disorder (1), Brain Damage (2), Brain Injury (4), Head Injury (1), Bipolar Disorder (22), Schizophrenia (10), Major Depression (1), Alcoholism (2), Anorexia (1), Bulimia (1), Eating Disorder (1), Anxiety Disorder (2), Borderline Personality Disorder (1), Drug Abuse (2), Obsessive compulsive Disorder (2), Post Traumatic Stress Disorders (1), Depression (1), Nervous Condition (2), Depression (20), Other Unfamiliar Condition (15), Other Familiar Condition (13), Don't Know (2).

   Search for "learning disability" resulted in 16 surveys and studies. **Search for "retarded"** resulted in a 116 surveys and studies (not listed).

2) Agency for Healthcare Research and Quality (AHRQ) Master Measures List.

Presented as a MS Excel workbook, this includes descriptive information on a variety of measures for consideration in recommending the core set for Adult Medicaid as determined by the Agency for Healthcare Research and Quality (AHRQ) and the Centers for Medicare and Medicaid Services (CMS). Data collected for measures include: NCQA given ID number, NQF ID, Measure Owner, Measure Name, Description, Numerator, Denominator, Specific Condition, Condition Type, Measure Type, IOM Framework Category, Unit of Measurement, Age and Gender information, Service Sector, **Data Source**, In-Use information, Meaningful Use, and Use by State. **Some data was not available for all measures.*

Study Review Inclusion Criteria

The project team identified 101 potential health surveillance data sources from preliminary literature review. The sources went through an initial screening process to assess their potential to inform ongoing health surveillance for adults with intellectual disabilities. Sources that met a set of 4 initial criteria were fully reviewed, while sources that did not meet these criteria and therefore showed less potential to inform health surveillance for this population were given an abbreviated review. Appendix A includes those sources that were identified but not included in this compendium.

The following algorithm was used for this process:

Criteria for inclusion of data source:

1. The dataset includes a population on a national, state, regional, or large metro area.
2. The dataset can be sorted to identify people with a disability. The study can either identify people with I/DD uniquely, or include them as part of an identified subgroup (i.e., people with disabilities).
3. The data set collects health related information or has an identifier that allows it to be matched to a database that includes health information. Data sets that have the potential for matching were included.
4. It collects information on adults (major national children's databases may be included in methods review).

→If the study met all of the criteria, then a full review was performed.

→If the study did not meet one or more of these criteria, only a partial review was completed including the following information:

- Narrative Description of Study
- Study Location
- I/DD Group Uniquely Identifiable?
- Is I/DD included in larger disability subgroup?
- Known linkages
- Potential linkages

Review Methodology

Data sources meeting the criteria above were reviewed using published and web-based source material to catalog the sampling methods, definitions used, known and suspected biases in sampling and data collection methods.

For each data source, the project team gathered, at a minimum, the following information:

1) Data Source
2) Narrative Description of Study
3) Study Location
4) I/DD Group Identification
5) Population Definitions: Inclusion Criteria
6) Populations Definitions: Exclusion Criteria
7) Dates of Data Collection
8) Health-Related Measures
9) Sampling Methodology
10) Response Rate
11) Sample Size
12) Data Collection Method
13) Data Collection Methodology Details
14) Data Collection Tools
15) Periodicity of Updates
16) Known Linkages
17) Potential Linkages
18) Data Access Costs (where available)

Critical Review

After information about the data sources was gathered in the review process, the potential of the data source to inform health surveillance of adults with I/DD was discussed by the CDDER/HSRI project group. Thirty eight (38) studies/ surveys/ data sets that showed a high potential were flagged to undergo a critical review process by data specialists in the CDDER/HSRI project team. The questions considered during this process are detailed in Appendix II. Information considered during the critical review process is included throughout the narrative for each data source.

Sorting for Presentation in this Compendium

Based on the multi-step process outlined above, the data sources are sorted into those that appear to have the highest potential to inform and serve as a foundation for **future** US Health Surveillance of Adults with Intellectual or Developmental Disability, those with moderate potential, and those with low potential. It should be noted that each data set presented has its own limitations. Data sets that result from a one-time survey or do not have the potential to be repeated are not considered useful for future surveillance although they are included in the review because there may be useful methodological elements of the survey. Future work by researchers and policy makers will certainly be necessary to develop robust information to describe the health of this population.

Data Sources Listing

Sources with High Potential to Inform U.S. Health Surveillance for Adults with I/DD:

Sources with Moderate Potential to Inform U.S. Health Surveillance for Adults with I/DD:

Sources with Low Potential to Inform U.S. Health Surveillance for Adults with I/DD:

Studies in other countries:

Health Data Sources with the Highest Potential to Inform Health Surveillance for Adults with I/DD

Data Source Name	Primary Data Collection?	Updated Regularly?	Adults Only?	Includes Adults w/ I/DD?	Can identify adults w/ I/DD?	Informs Health Domains?	Potential to inform health surveillance in I/DD pop.	pg. no.
American Community Survey	Y	Y	N	Y	N	Y, but limited	Yes, with question modification to identify I/DD group	13
Behavioral Risk Factor Surveillance System	Y	Y	Y	Y	N	Y	Yes, with question modification to identify I/DD group	15
California Health Interview Survey (CHIS)	Y	Y	N	Y, but may be limited	N	Y	Limited	18
Current Population Survey	Y	Y	N	Y	N	N, only other disabilities	Likely with linkages	21
Decennial Census	Y	Y - decade	N	Y	N	Limited	Yes, with question modification to identify I/DD group	24
Health and Retirement Study	N	Y	Y	Possibly	N	Y	Yes, with question modification to identify I/DD group or through linkages(non-institutionalized populations age 50+)	27
Healthcare Cost and Utilization Project	Y	Y	N	Y	Unclear – through linkage or ICD codes?	Y	Yes, with question modification to identify I/DD group or through linkages	29

Data Source Name	Primary Data Collection?	Updated Regularly?	Adults Only?	Includes Adults w/ I/DD?	Can identify adults w/ I/DD?	Informs Health Domains?	Potential to inform health surveillance in I/DD pop.	pg. no.
Longitudinal Health & Intellectual Disability Study (LHIDS)	Y	Y (only for 2009 – 2014)	Y	Y	Y	Y	Yes, for a subgroup	31
Medicaid Statistical Information System (MSIS)	N	Y	N	Y	Y	Y – health care utilization	Yes, for a subgroup (State Medicaid program participants)	34
Medicare Claims	N	Y	N	Y	Unclear – through linkage or ICD codes?	Y	Yes with linkages, for a subgroup (Medicare recipients)	36
Medicare Current Beneficiary Survey (MCBS)	Y	Y	Y	Y	Y	Y	Yes with linkages, for a subgroup (Medicare recipients)	38
Medicare Health Outcomes Survey (HOS)	Y	Y	Y	Y, possibly	N	Y	Yes with linkages, for a subgroup(Medicare Managed Care Recipients)	41
Minimum Data Set (MDS) Repository	Y	Y	Y	Y	Y	Y	Yes, for a subgroup (Nursing Home Residents)	43
National Comorbidity Survey Replication (NCS-R)	Y	N	Y	Y	N	Y	Yes, with question modification to identify I/DD group	46
National Core Indicators Project - Consumer Survey	Y	Y	Y	Y	Y	Y	Yes, for a subgroup (State agency I/DD program participants in participating states)	49
National Death Index (NDI)	N	Y	N	Y	Through linkage	Y	Likely with linkages	51

Data Source Name	Primary Data Collection?	Updated Regularly?	Adults Only?	Includes Adults w/ I/DD?	Can identify adults w/ I/DD?	Informs Health Domains?	Potential to inform health surveillance in I/DD pop.	pg. no.
National Health Interview Survey (NHIS)	Y	Y	N	Y	Y	Y	Yes	53
National Survey of Homeless Assistance Providers and Clients	Y	N	N	Y	N – part of disability group	Y	Yes, with question modification to identify I/DD group or through linkages (Homeless population)	56
Special Olympics Data Set	Y	Y	N	Y	Y	Y	Yes, for a subgroup (Special Olympics participants/ a convenience sample)	58
State Vocational Rehabilitation Service Agency Closure Data (RSA-911)	N	Y	Y	Y	Y	N – only Medical insurance	Yes, for a subgroup (Prev. Vocational Rehab clients)	60
Surveillance, Epidemiology and End Results (SEER)	N	Y	N	Y	Through linkage	Y	Yes, likely with linkages	62

Information Sheets for Data Sources with High Potential to Inform Health Surveillance for Adults with I/DD

American Community Survey

At-a-Glance
U.S.
Primary Data
Adults & Children
Annual

Narrative Description: Funded by the U.S. Census Bureau for the purpose of giving communities the current information needed to plan investments and services. Information from the survey generates data that helps determine the distribution of more than $400 billion in federal and state funds each year. Conducted annually.

I/DD Group Identification

Included in broader 'Disability' subgroup: Yes

I/DD Group Uniquely Identifiable? No

Questions (data fields) identifying 'I/DD' or 'Disability': Do you have serious difficulty hearing?
Do you have difficulty seeing even when wearing glasses?
Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?
Do you have serious difficulty walking or climbing stairs?
Do you have difficulty dressing or bathing?
Because of a physical, mental, or emotional condition do you have difficulty doing errands alone such as visiting a doctor's office or shopping?

Notes on ID Identification: Survey asks two questions about mental disabilities and four questions about physical or sensory disabilities. Not possible to disaggregate data by I/DD, nor is it possible to reliably separate I/DD from other disabilities.

Study Methodology

Inclusion Criteria: Any person with an address, including group housing facilities (randomly selected)

Exclusion Criteria: None

Sampling Methodology: Two separate samples: 1) housing unit (HU) addresses and persons in group quarters (GQ) facilities (began including as of 2006, incl. jails, college dorms, nursing homes). Sampling frame is derived from Census Bureau's Master Address File (MAF). Independent HU address samples selected for each of 3,143 counties in U.S. (incl. DC). GQ samples selected independently within each state. GQ sample rates of individuals were low between 2006-2007, and were increased in 16 states with small GQ populations starting in 2008. Residence rule: Residents living at the sample address at the time of the interview and who have lived or plan to live at the housing unit for more than 2 months are in the scope of the survey.

Suspected biases in sampling methodology: Homeless people excluded, Addresses not counted in Census Bureau's Master Address File

Likelihood of including people with I/DD: Likely included. No subgroups of people with I/DD should be underrepresented except homeless population.

Response Rate: 98%. Response rate is consistently very good

Sample Size: 3 million

Organizational level to which sample is powered: State

Data Collection

Dates of Collection: 1-year, 3-year, and 5-year data. Jan 1 - Dec. 31st of each year

Method: Primary data collection

Data Collection Tools: Survey

Aspects of the data collection methodology that may limit information collected from people with I/DD: People with I/DD may be less likely to respond to paper forms.

Is a proxy used for people with I/DD? Proxy possible however, will not know because of paper/mail survey format.

Measures of reliability or validity for the data collection tool(s): Not clear, but seems that multiple quality studies were performed.

Periodicity of Updates: Annually

Health-Related Measures

Domains of Health-Related Measures: ADL/IADL limitations. Insurance / disability benefit receipt or program participant

Suspected biases in measurement of indicators? Unknown

Perceived weaknesses in health measures: Unknown

Applicability of health measures to people with I/DD: Measures have limited importance for health surveillance of people with I/DD

Known Linkages: None

Potential Linkages: Census data

Contains functional measures or levels of disability? No

Data Access Costs: Unknown

Citation or Website: http://www.census.gov/acs/www/

Critical Review Comments

- Data source collects information with limited use for health surveillance, and currently does not identify people with I/DD. This data source could be adapted to improve its ability to inform health surveillance of adults with I/DD by adding a specific question about I/DD
- The following methodology has potential application for health surveillance of adults with I/DD: Housing-unit based surveying, particularly the methodology for sampling persons in group quarters (including jails, college dorms, nursing homes).

Behavioral Risk Factor Surveillance System

At-a-Glance
U.S.
Primary Data
Adults
Monthly by States

Narrative Description: Sponsored by the Centers for Disease Control and Prevention (CDC), the Behavioral Risk Factor Surveillance System (BRFSS) collects uniform, state-specific data on preventive health practices and risk behaviors. Currently, data are collected monthly in all 50 states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, and Guam. An annual population-based survey of households conducted separately by each state and targeted to the civilian non-institutional adult population (ages 18 or over) residing in households with telephones.

I/DD Group Identification

Included in broader 'Disability' subgroup: Yes

I/DD Group Uniquely Identifiable? Not in the core questions. Possibly in state-added questions

If yes, is it possible to separate DD from ID? Not in Core questions, possibly in state-added questions

Questions (data fields) identifying 'I/DD' or 'Disability': Two Core Questions (disability screeners): 1) Are you limited at all in any activities because of physical, mental, or emotional problems? 2) Do you currently have any health problem that requires you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone?

Notes on ID Identification: The 2010 survey includes an optional module 18 on Cognitive Impairment; questions are related to memory loss, confusion, and Alzheimer's. (p. 61-65 of manual). Not possible to disaggregate data by I/DD, nor is it possible to reliably separate I/DD from other disabilities

Study Methodology

Inclusion Criteria: Adults 18 years or older, who have a telephone

Exclusion Criteria: Living in an institutional setting. (No proxy responses allowed)

Sampling Methodology: Population is non-institutionalized adults with a telephone. Home telephone numbers are obtained through random-digit dialing. Adults 18 years or older are asked to take part in the survey. Only one adult is interviewed per household. Participants are not compensated. a sample record is one telephone number in the list of all telephone numbers selected for dialing. To meet the BRFSS standard for the participating states' sample designs, sample records must be justifiable as a probability sample of all households with telephones in the state. Extensive info on sampling and data (weighting, etc.) is available from the Overview: BRFSS 2009 (http://www.cdc.gov/brfss/technical_infodata/surveydata/2009.htm)

Suspected biases in sampling methodology: For all people surveyed - those without landline phones or unable to use the phone excluded; institutionalized adults excluded; for people with I/DD - less likely to answer the phone, thus underrepresented

Likelihood of including people with I/DD: Likely included. Those with mild I/DD are probably over-represented due to computer assisted telephone interview (CATI) sampling method.

Response Rate: Unknown

Sample Size: Each state has at least 4,000 interviews (National Center for Chronic Disease Prevention and Health Promotion 2006).

Organizational level to which sample is powered: State, MMSAa

Data Collection

Dates of Collection: State health departments conduct monthly telephone surveillance. Data forwarded to CDC and aggregated annually.

Method: Primary data collection

Data Collection Methodology Details: BRFSS consists of 3 types of questions:

Core component. A standard set of questions asked by all states.

Optional CDC modules. Sets of questions on specific topics (e.g., cardiovascular disease, arthritis, women's health) that states elect to use on their questionnaires. In 2009, 29 optional modules were supported by CDC. The module questions are generally submitted by CDC programs and have been selected for inclusion in the editing and evaluation process by CDC. For more information, see http://apps.nccd.cdc.gov/BRFSSModules/ModByState.asp?Yr=2009 .

State-added questions. Questions developed or acquired by participating states and added to their questionnaires. State-added questions are not edited or evaluated by CDC.

Data Collection Tools: Telephone survey conducted with a standardized questionnaire.

Aspects of the data collection methodology that may limit information collected from people with I/DD: People with I/DD may be less likely to respond

Is a proxy used for people with I/DD? No proxy.

Measures of reliability or validity for the data collection tool(s) Unknown.

Periodicity of Updates: Annually by the CDC. States collect data monthly

Health-Related Measures

Domains of Health-Related Measures: In the Core questions: General Health Status, Body Mass (weight, height, obesity), Limitations in Work/Usual Activities , Substance Abuse/Dependence , Specific Chronic Conditions/Medical Conditions , Use of or Need for Assistive Equipment/Home Modifications

Suspected biases in measurement of indicators? Unknown

Perceived weaknesses in health measures: Unknown

Applicability of health measures to people with I/DD: Measures are highly applicable

Known Linkages: None

Contains functional measures or levels of disability? None

Data Access Costs: Unknown

Citation or Website: http://www.cdc.gov/brfss/

Notes: 1) The BRFSS collects information on a core set of health conditions, many related to disability, that might be used to produce state-level estimates of prevalence and could potentially be used to study subgroups defined by specific health conditions. The data contained in the BRFSS, however, is focused on disease prevalence and risk behaviors, and so so quite limited with respect to their ability to address broader disability issues. (Livermore, Limitations of the National Disability System). 2) State specific disability questions. Vary by year and state. CDC has a searchable database for key question words. A search of 'disability' in this database produced approximately 760 results from states ranging from 1995 – 2011. Questions may duplicate, but are more likely similar in scope. A review of all questions is needed to determine if and where duplicate entries exist. Note: Some questions ask respondents to self-identify as having ID/DD/MR https://www.ark.org/brfss_questions/default.aspx

Critical Review Comments

- This data source could be adapted to improve its ability to inform health surveillance of adults with I/DD by adding a specific question about I/DD
- Methodology limits the group with I/DD included, but collects highly-relevant information for health surveillance

California Health Interview Survey (CHIS)

At-a-Glance
U.S.
Primary Data
Adults & Children
Every two years

Narrative Description: Funded by the state of California for the purpose of gathering data on the health status of Californians. Conducted every 2 years. CHIS is the nation's largest state health survey.

I/DD Group Identification

Included in broader 'Disability' subgroup: Yes

I/DD Group Uniquely Identifiable? No

Questions (data fields) identifying 'I/DD' or 'Disability': Because of a physical, mental, or emotional condition lasting 6 months or more, do you have any of the following: Any difficulty learning, remembering, or concentrating? Any difficulty dressing, bathing, or getting around inside the home? Any difficulty going outside the home alone to shop or visit a doctor's office? Any difficulty working at a job or business? Do you have a physical or mental condition that has kept you from working for a least a year?

Notes on ID Identification: Asks five questions about mental conditions. . Not possible to disaggregate data by I/DD, nor is it possible to reliably separate I/DD from other disabilities.

Study Methodology

Inclusion Criteria: Any Californian with a landline. Beginning in 2007, people from cell phone only households were also selected.

Exclusion Criteria: institutionalized populations (no proxy response allowed)

Sampling Methodology: Random-digit-dial (RDD) sample included telephone numbers assigned to both landline and cellular service. Stratified land-line sample by geographic region. Cell RDD sample was stratified by area code. Within each household, one adult (age 18 and over) respondent was randomly selected. In those households with adolescents (ages 12-17) and/or children (under age 12), one adolescent and one child were randomly selected; the adolescent was interviewed directly, and the adult most knowledgeable about the child's health completed the child interview.

Suspected biases in sampling methodology: For all people surveyed - those without phones or unable to use the phone excluded; (starting in 2007 cell-phone only houses are sampled) institutionalized adults excluded; for people with I/DD - less likely to respond to a phone survey, thus may be underrepresented. Those with limited communication ability may be excluded due to proxy limitations.

Likelihood of including people with I/DD: Likely included. Those with mild I/DD may be included more often than those with more significant I/DD due to sampling method.

Response Rate: Response rate appears to be low, ranging 30 to 35%. The CHIS 2007 screener completion rate for the landline sample was 35.5 percent, and higher for households that were sent the advance letter. For the cell phone sample, the screener completion rate was 30.5 percent in cell-only households.

Sample Size: 2007: Adults 51,048, Children 9,913, Adolescents 3,639

Organizational level to which sample is powered: Not clear, but numbers may be big enough for county and city level. Certainly state level.

Data Collection

Dates of Collection: 2001- present

Method: Primary data collection

Data Collection Tools: Telephone survey

Aspects of the data collection methodology that may limit information collected from people with I/DD: People with I/DD may be less likely to respond due to phone interview format.

Is a proxy used for people with I/DD? No proxy

Measures of reliability or validity for the data collection tool(s) Quality studies performed, mostly to investigate non-coverage and non-response, but also to investigate effects of different survey methods

Periodicity of Updates: Every two years

Health-Related Measures

Domains of Health-Related Measures: Health Conditions (general health, asthmas, diabetes, hypertension, heart disease, flu shot, cancer hx and screening) and Health Behaviors (Physical Activity, dietary intake, sun exposure, cigarette use, alcohol use). Health Care utilization and access, and health insurance.

Suspected biases in measurement of indicators? Unknown

Perceived weaknesses in health measures: Unknown

Applicability of health measures to people with I/DD: Measures are highly applicable

Known Linkages: None

Potential Linkages: Unclear, but access to additional demographic variables is possible through request and review process.

Contains functional measures or levels of disability? None

Data Access Costs: Unknown

Citation or Website: http://www.chis.ucla.edu/

For more information: California Health Interview Survey/UCLA Center for Health Policy Research/ 10960 Wilshire Blvd, Suite 1550, LA CA. Telephone: (866) 275-2447

Critical Review Comments

- This data source could be adapted to improve its ability to inform health surveillance of adults with I/DD by adding a specific question about I/DD
- Methodology limits the group with I/DD included, but collects highly-relevant information for health surveillance

Current Population Survey

At-a-Glance
U.S.
Primary Data
Aged 15+
Annual

Narrative Description: The Current Population Survey (CPS) is a monthly sample survey of about 60,000 households that provides statistics on employment and unemployment in the United States. Conducted by the Bureau of Census for the Bureau of Labor Statistics. Beginning in June 2008, questions were added to the CPS designed to identify persons with a disability in the civilian non-institutional population age 16 and over. 2009 is the first calendar year for which annual averages are available.

I/DD Group Identification

Included in broader 'Disability' subgroup: Yes

I/DD Group Uniquely Identifiable? No

Questions (data fields) identifying 'I/DD' or 'Disability': From 2008, six questions identify persons with disabilities. In the CPS, persons are classified as having a disability if there is a response of "yes" to any of these questions: This month, we want to learn about people who have physical, mental, or emotional conditions that cause serious difficulty with their daily activities. Please answer for household members who are 15 years and older.

Is anyone deaf or does anyone have serious difficulty hearing?

Is anyone blind or does anyone have serious difficulty seeing even when wearing glasses?

Because of a physical, mental, or emotional condition, does anyone have serious difficulty concentrating, remembering, or making decisions?

Does anyone have serious difficulty walking or climbing stairs?

Does anyone have difficulty dressing or bathing?

Because of a physical, mental, or emotional condition, does anyone have difficulty doing errands alone such as visiting a doctor's office or shopping?
(http://www.bls.gov/news.release/archives/disabl_08252010.pdf)

Study Methodology

Inclusion Criteria: Age and residential status. 15 years and older. non-institutionalized population. Labor force statistics are tabulated for individuals age 16 and over.

Exclusion Criteria: None (institutionalized population not included)

Sampling Methodology: The population covered by the CPS is limited to the civilian non-institutionalized working-age population, over the age of 16 (not on active duty).

Each month, about 60,000 occupied units are eligible for interview. Some 4,500 of these households are contacted without obtaining interviews because occupants are not at home after repeated calls or are otherwise unavailable. This represents a non-interview rate ranging between 7 and 8 percent. In addition to the 60,000 occupied units, about 12,000 sample units in an average month are visited but found to be vacant or otherwise ineligible for enumeration. Part of the sample is changed each month.

The rotation plan provides for three-fourths of the sample to be common from one month to the next, and one-half to be common with the same month a year earlier. http://www.bls.gov/cps/eetech_methods.pdf.

The CPS is administered to a household for 4 months in a row, followed by 8 months where the household is not part of the survey, and then the household is again included for another 4 months. Those households in the survey for the first time, or for the first time after the 8-month break, are asked the disability questions. Replacement households and new household members are also asked the disability questions. During months where the questions are not asked, the responses collected earlier are retained to establish disability status in the same manner used for other demographic questions (about race, sex, etc.)

Suspected biases in sampling methodology: Homeless people excluded, institutionalized adults excluded, military excluded.

Likelihood of including people with I/DD: Likely included. No subgroups of people with I/DD should be underrepresented

Response Rate: Not fully known. Response rate appears to be acceptable initially. Response rate on follow-up was not available.

Sample Size: The 2009 current sample design includes about 72,000 “assigned” housing units from 824 sample areas (http://www.bls.gov/cps/eetech_methods.pdf)

Organizational level to which sample is powered: National

Data Collection

Dates of Collection: 1940 - present

Method: Primary data collection

Data Collection Methodology Details: The CPS questions for identifying individuals with disabilities are only asked of household members age 15 and older. Each question asks the respondent whether anyone in the household has the condition described, and if the respondent replies "yes," they are then asked to identify everyone in the household with the condition. Information on the disability questions and the limitations of the CPS disability data is available on the BLS Web site at http://www.bls.gov/cps/cpsdisability_faq.htm.

Data Collection Tools: Automated questionnaire and computer-assisted interviewing by phone or in person.

Aspects of the data collection methodology that may limit information collected from people with I/DD: People with I/DD may be less likely to respond

Is a proxy used for people with I/DD? Proxy possible. However, will not know if proxy used.

Measures of reliability or validity for the data collection tool(s) Unclear. Multiple quality studies were performed in development.

Periodicity of Updates: Annual

Health-Related Measures

Domains of Health-Related Measures: No health measures collected except for information on other disabilities and employment status

Suspected biases in measurement of indicators? N/A

Perceived weaknesses in health measures: N/A

Applicability of health measures to people with I/DD: N/A

Known Linkages: American Community Survey and Consumer Expenditure Survey. CPS have been linked to SSA administrative records, and in some years, to CMS Medicare records

Contains functional measures or levels of disability? None

Data Access Costs: Unknown

Citation or Website: http://www.census.gov/cps/

For more information: Current Population Survey

News release: http://www.bls.gov/news.release/archives/disabl_08252010.pdf

http://www.bls.gov/cps/demographics.htm#disability

Notes: Disability microdata from the CPS is available from the U.S. Census Bureau. Beginning with data for 2009, disability status variables are part of the basic monthly data files at http://www.bls.census.gov/cps_ftp.html. The 2008 disability data is in a separate extract file at www.bls.census.gov/cps_ftp.html#cpsbasic_extract. As with all CPS microdata, personally identifiable information has been removed. A disability supplement is planned for May, 2012. More information is available at: http://disabilitysupplement.econsys.com/

Critical Review Comments

- This data source could be adapted to improve its ability to inform health surveillance of adults with I/DD by adding a specific question about I/DD. It may be possible to identify people with I/DD through linkage with other data sources listed above
- Methodology (housing-unit based surveying) has potential, but collects information that has limited use for health surveillance

Decennial Census

At-a-Glance
U.S. and PR
Primary Data
Adults & Children
Every decade

Narrative Description: The U.S. Census is collected every 10 years. In 1990 and 2000, the U.S. census contained both a short and a long form. After 2000, the long form was replaced by the American Community Survey.

I/DD Group Identification

Included in broader 'Disability' subgroup: Yes

I/DD Group Uniquely Identifiable? No

Questions (data fields) identifying 'I/DD' or 'Disability': Long-form questionnaire Items 16 and 17 for Census 2000. Item 16 was a two-part question that asked about the existence of the following long-lasting conditions: (a) blindness, deafness, or a severe vision or hearing impairment (sensory disability) and (b) a condition that substantially limits one or more basic physical activities, such as walking, climbing stairs, reaching, lifting, or carrying (physical disability). Item 17 was a four-part question that asked if the individual had a physical, mental, or emotional condition lasting 6 months or more that made it difficult to perform certain activities. The four activity categories were: (a) learning, remembering, or concentrating (mental disability); (b) dressing, bathing, or getting around inside the home (self-care disability); (c) going outside the home alone to shop or visit a doctor's office (going outside the home disability); and (d) working at a job or business (employment disability). For data products that use the items individually, the following terms are used: sensory disability for 16a, physical disability for 16b, mental disability for 17a, self-care disability for 17b, going outside the home disability for 17c, and employment disability for 17d. For data products that used a disability status indicator, individuals were classified as having a disability if any of the following three conditions were true: (1) they were 5 years old and over and had a response of ''yes'' to a sensory, physical, mental or self-care disability; (2) they were 16 years old and over and had a response of ''yes'' to going outside the home disability; or (3) they were 16 to 64 years old and had a response of ''yes'' to employment disability.

Study Methodology

Inclusion Criteria: Each person was to be enumerated as an inhabitant of his or her ''usual residence'' in Census 2000. Usual residence is the place where the person lives and sleeps most of the time. This place is not necessarily the same as the person's legal residence or voting residence. In the vast majority of cases, however, using these different bases of classification would produce substantially the same statistics, although there might be appreciable differences for a few areas.

Each person whose usual residence was in the United States was to be included in the census, without regard to the person's legal status or citizenship.

Exclusion Criteria: Citizens of foreign countries temporarily traveling or visiting in the United States who had not established a residence.

Americans temporarily overseas were to be enumerated at their usual residence in the United States. With some exceptions, Americans with a usual residence outside the United States were not enumerated in Census 2000. U.S. military personnel and federal civilian employees stationed outside the United States and their dependents living with them, are included in the population counts for the 50 states for purposes of Congressional apportionment but are excluded from all other tabulations for states and their subdivisions (The counts of overseas U.S. military personnel, Data Collection and Processing Procedures C–1 U.S. Census Bureau, Census 2000).

Federal civilian employees, and their dependents, were obtained from administrative records maintained by the employing federal departments and agencies. Other Americans living overseas who were not affiliated with the U.S. government were not included in the census.

Sampling Methodology: All addresses were contacted in the Master Address File (MAF), including both traditional and non-traditional databases. A sampling ratio of about one long form (sample) questionnaire for every six households was used in 2000.

Suspected biases in sampling methodology: None

Likelihood of including people with I/DD: Likely included. No subgroups of people with I/DD should be underrepresented

Response Rate: 67% Final Response Rate for Census 2000 (http://www.census.gov/dmd/www/rates.html)

Sample Size: 308,745,538 in 2010

Organizational level to which sample is powered: Probably MMSAs

Data Collection

Dates of Collection: 1790 - present. Long form use stopped in 2000 and was replaced by American Community Survey

Method: Primary data collection

Data Collection Methodology Details: People under formally authorized, supervised care or custody, such as in federal or state prisons; local jails; federal detention centers; juvenile institutions; nursing or convalescent homes for the aged or dependent; or homes, schools, hospitals, or wards for the physically handicapped, mentally retarded, or mentally ill; or in drug/alcohol recovery facilities were counted at these places.

Efforts were also made to contact people who had no residence or were transient.

Short forms could be completed on paper forms or online. Long forms were completed on paper only.

Those households who received the census form in the mail could request the questionnaire in Spanish, Chinese, Tagalog, Vietnamese, or Korean. Those individuals or households who believed that they were not included on a form or did not receive a form could use the Be Counted questionnaires available in public areas. The Be Counted forms were printed in English, Spanish, Chinese, Tagalog, Vietnamese, and Korean.

Data Collection Tools: Short (7 subjects) and Long Forms (34 subjects) (per technical documentation for summary file 3 for census 2000)

Aspects of the data collection methodology that may limit information collected from people with I/DD: People with I/DD may be less likely to respond

Is a proxy used for people with I/DD? Proxy possible. However, will not know

Measures of reliability or validity for the data collection tool(s): Not clear, but seems that multiple quality studies were performed

Periodicity of Updates: Every 10 years. Long form will not be used after 2000 and was replaced by American Community Survey

Health-Related Measures

Domains of Health-Related Measures: Income, household size and characteristics, employment, kitchen facilities

Suspected biases in measurement of indicators? N/A

Perceived weaknesses in health measures: N/A

Applicability of health measures to people with I/DD: N/A

Known Linkages: None

Contains functional measures or levels of disability? None

Data Access Costs: Varies, see: http://www.census.gov/mp/www/cat/

Citation or Website:

http://factfinder.census.gov/servlet/DatasetMainPageServlet?_program=DEC&_submenuId=datasets_5&_lang=en&_ts=

Notes: 1990 census did not include the same disability questions. The case-finding methods used for people without residences and other challenging-to-count groups may be of interest.

Critical Review Comments

- This data source could be adapted to improve its ability to inform health surveillance of adults with I/DD by adding a specific question about I/DD and with additional health measures
- Methodology has potential, but collects information that has only a small amount of usefulness for health surveillance

Health and Retirement Study

At-a-Glance
U.S.
Primary Data
Aged 51+
Biennial

Narrative Description: The HRS is a large-scale longitudinal project that studies the labor force participation and health transitions that individuals undergo toward the end of their work lives and in the years that follow. Since 1998, HRS has provided information about the U.S. population over age 50 through biennial surveys with samples of that population.

I/DD Group Identification

Included in broader 'Disability' subgroup: Yes

I/DD Group Uniquely Identifiable? No

Questions (data fields) identifying 'I/DD' or 'Disability': In demographics:

LB123: In grade school or high school, did you ever have a problem in learning the usual lessons, such that you regularly attended special classes, received special training sessions, or had to attend a different school for more than six months?

LB120: Before you were 16 years old, were you ever disabled for six months or more because of a health problem? That is, were you unable to do the usual activities of classmates or other children your age?

Notes on ID Identification: The identification of I/DD is complicated in this group as there is no direct question about the existence of I/DD. There are multiple questions about existing disabilities, but no category for I/DDs. There is also a cognition test that may be able to identify some level of I/DD.

Study Methodology

Inclusion Criteria: Birth year: For practical reasons, the decision was made to add new cohorts every six years rather than at each wave of data collection. Therefore, in 1998 the target population was defined as those born in 1947 or before, and thus approximately age 51 and older. Since new cohorts were not added in 2000 or 2002, the target populations were approximately 53 and older in 2000, and 55 and older in 2002. In 2004, a supplementary sample was added to make the total sample representative of those born in 1953 or before, and thus also approximately age 51 and older.

See reference for specific re-interview criteria: http://hrsonline.isr.umich.edu/sitedocs/sampleresponse.pdf

Exclusion Criteria: None

Sampling Methodology: Sample of housing units was generated using a multi-stage, clustered area probability frame. http://hrsonline.isr.umich.edu/sitedocs/sampleresponse.pdf

Suspected biases in sampling methodology: Homeless, people in residing in institutions excluded.

Likelihood of including people with I/DD: Likely included; though older persons with I/DD are more likely to live in institutions (and thus excluded from the study by design)

Response Rate: Response rate is consistently high. HRS: 81% - 89% per wave for initial contact. Re-interview is 91% - 95% per wave

Sample Size: HRS: 9,759 - 12,654 per wave

Organizational level to which sample is powered: National, state, possibly local

Data Collection

Dates of Collection: 1991 - present (in its current form)

Method: Primary data collection

Data Collection Methodology Details: Multiple surveys

Data Collection Tools: Multiple surveys, see: http://hrsonline.isr.umich.edu/modules/meta/2008/core/codebook/h08_00.html

Aspects of the data collection methodology that may limit information collected from people with I/DD: People with I/DD may be less likely to respond

Is a proxy used for people with I/DD? Proxy may be used

Measures of reliability or validity for the data collection tool(s) Unknown

Periodicity of Updates: Biennial

Health-Related Measures

Domains of Health-Related Measures: Physical health, functional limitations, work/employment, housing, health services, assets/finances

Suspected biases in measurement of indicators? Unknown

Perceived weaknesses in health measures: Unknown

Applicability of health measures to people with I/DD: The measures are not as important for health surveillance of people with I/DD, with exception of physical health

Known Linkages: Numerous, see: http://hrsonline.isr.umich.edu/index.php?p=dflow

Contains functional measures or levels of disability? May be possible to pair cognition element of the survey with question regarding special education

Data Access Costs: Unknown

Citation or Website: http://hrsonline.isr.umich.edu/

Critical Review Comments

- This study shows potential for non-institutionalized populations over age 50. This data source would be more useful for health surveillance of adults with I/DD if questions were modified to specifically identified people with I/DD within people with disabilities and additional health measures were collected. Linkage with SSA, Medicare, or NDI may improve the ability to identify this subgroup.
- The use of housing-unit based surveying and proxy interviewing in this source may be useful in future surveillance efforts of adults with I/DD.

Healthcare Cost and Utilization Project

At-a-Glance
U.S.
Secondary Data
Adults & Children
Ongoing Collection

Narrative Description: The Healthcare Cost and Utilization Project (HCUP, pronounced "H-Cup") is a family of health care databases and related software tools and products developed through a Federal-State-Industry partnership and sponsored by the Agency for Healthcare Research and Quality (AHRQ). HCUP databases bring together the data collection efforts of State data organizations, hospital associations, private data organizations, and the Federal government to create a national information resource of patient-level health care data (HCUP Partners). HCUP includes the largest collection of longitudinal hospital care data in the United States, with all-payer, encounter-level information beginning in 1988. These databases enable research on a broad range of health policy issues, including cost and quality of health services, medical practice patterns, access to health care programs, and outcomes of treatments at the national, State, and local market levels.

HCUP's objectives are to:

* Create and enhance a powerful source of national, state, and all-payer health care data.

* Produce a broad set of software tools and products to facilitate the use of HCUP and other administrative data.

* Enrich a collaborative partnership with statewide data organizations aimed at increasing the quality and use of health care data.

* Conduct and translate research to inform decision-making and improve health care delivery.

I/DD Group Identification

Included in broader 'Disability' subgroup: Unclear

I/DD Group Uniquely Identifiable? Unclear

If yes, is it possible to separate DD from ID? Unknown

Questions (data fields) identifying 'I/DD' or 'Disability': Unclear

Notes on ID Identification: It's not clear from the data descriptions whether I/DD would be identifiable in each of the 6 data sources that go into this database. It is possible that I/DD would appear as a diagnosis code, but it is not clear if I/DD would be coded for an episodic care visit (ex. ER, ambulatory surgery, etc.). Additional work would need to be done to determine if this information was consistently available.

Study Methodology

Inclusion Criteria: Varies by data set, each contain subgroups of health services users

Exclusion Criteria: Varies by data set

Suspected biases in data collected: Only includes persons who were in a hospital, an ER, or had ambulatory surgery. The population included may have a poorer health status than the general population.

Likelihood of including people with I/DD: Likely included

Organizational level to which data is powered: National, state, local

Data Collection

Dates of Collection: Starting in 1988 - present

Method: See documentation of individual data sources: http://www.hcup-us.ahrq.gov/databases.jsp

Periodicity of Updates: Ongoing collection

Health-Related Measures

Domains of Health-Related Measures: Diagnoses and procedures

Suspected biases in measurement of indicators? Only procedures and diagnoses that were important for payment are likely reported

Perceived weaknesses in health measures: Chronic diagnoses likely underreported

Applicability of health measures to people with I/DD: May have some limited use for surveillance of health screenings and acute diagnoses requiring medical attention

Known Linkages: None

Contains functional measures or levels of disability? No

Data Access Costs: Varies depending on data request, discounts for students. Costs vary widely depending on number of years requested, and states requested in data set.

Citation or Website: http://www.ahrq.gov/data/hcup/

Critical Review Comments

- While this data source is not currently useful for general surveillance of adults with I/DD, it may be useful to examine reasons for inpatient admissions, emergency room visits and ambulatory surgery. Longitudinal analyses may also be possible.
- More work is needed to validate the identification of people with I/DD through ICD/health service codes

Longitudinal Health & Intellectual Disability Study (LHIDS)

At-a-Glance
U.S.
Primary Data
Adults
Longitudinal/annual for 5 years

Narrative Description: Survey to caregivers of adults with ID about the health behaviors of the people with ID. Survey conducted via mail annually for 5 years.

The goals of the study are:

1. Examine changes across time in five primary health behaviors and their impact on health and function in adults with ID by gender, age group, level of ID and residential setting.

2. Examine the impact of bone mineral density, strength and balance across time on health and function in adults with ID.

3. Examine the impact of health behavior changes across time on psychosocial well-being and community participation in adults with ID.

I/DD Group Identification

I/DD Group Uniquely Identifiable? Yes

If yes, is it possible to separate DD from ID? Unknown

Questions (data fields) identifying 'I/DD' or 'Disability': Inclusion criteria

Notes on ID Identification: N/A

Study Methodology

Inclusion Criteria: In order to qualify for the study, the adult the person cares for or supervises must:

1. Have an intellectual disability.

2. Be at least 18 years of age or older.

3. Live in the United States.

In addition, the person must be:

1. A caregiver or worker associated with an adult with intellectual disabilities (e.g., a family member, residential house manager, case manager, direct support staff).

2. Knowledgeable about his or her health-related behavior (for example, physical activity levels, types of food he/she eats, and current health status).

Exclusion Criteria: None

Sampling Methodology: Participants are recruited through two Special Olympics events (World Winter Games and National Summer Games), managed care organizations, and online announcement in various agencies or networks that serve people with developmental disabilities such as ARC, Easter Seals etc.

Suspected biases in sampling methodology: A convenience sample, recruiting through Special Olympics and other networks. Some of these sources may be more likely to include people with mild intellectual disabilities, or people with good advocacy supports. May also exclude people with caregivers whose are non-native English speakers or who are not literate.

Likelihood of including people with I/DD: Definitely included

Response Rate: Unknown

Sample Size: Year 1: Over 1500 (personal communication)

Organizational level to which sample is powered: National, state

Data Collection

Dates of Collection: 5 -year period beginning in 2009. Year 1 closed in December 2010

Method: Survey

Data Collection Methodology Details: Survey is mailed to caregivers. Survey takes about 45 minutes to complete. A $5 gift card is given for every survey completed.

Data collection was conducted using mixed-model approaches (paper or web version of the same questionnaire) for 4 years.

Eligibility screening questions are used for informants (e.g., family caregiver, health care provider, residential staff etc.) prior to their participation in the study.

Data Collection Tools: Mailed Survey

Aspects of the data collection methodology that may limit information collected from people with I/DD: N/A

Is a proxy used for people with I/DD? Proxy responses only

Measures of reliability or validity for the data collection tool(s) Unclear

Periodicity of Updates: Surveys will be conducted once per year for a period of five years. NIDRR funding for project is five years, but team is interested in extending beyond this time if funding is available (per presentation by PI)

Health-Related Measures

Domains of Health-Related Measures: Health status: informant-rated health, healthy days, chronic health conditions

Physical function: assistive device use, function limitation, falls in the past 12 months

Health care access: preventive health screening, health insurance

Health behaviors: physical activity, weight control, dietary habits, smoking, alcohol consumption, & oral hygiene

Social participation & Special Olympics involvement

Sociodemographics: Diagnosis related to ID, Level of ID, age, body weight & height, gender, race, current living status, employment, day program

Suspected biases in measurement of indicators? Unknown

Perceived weaknesses in health measures: Unknown

Applicability of health measures to people with I/DD: Measures highly applicable

Known Linkages: None

Contains functional measures or levels of disability? Unclear

Data Access Costs: Not known

Citation or Website: http://www.rrtcadd.org/Research/Health_Function/Cohort/LHIDS/Info.html

Critical Review Comments

- This data source has a high potential to inform health surveillance for adults with I/DD. It is somewhat limited by its recruitment methods, and could be improved by recruiting through sources like HMO's and local DDS networks to limit sampling biases. In its current form, the sampling methodology limits the generalizability of findings.

Medicaid Statistical Information System (MSIS)

At-a-Glance
U.S.
Secondary data
Adults & Children
Ongoing Collection

Narrative Description: MSIS data are used by CMS to produce Medicaid program characteristics and utilization information for those states. These data also provide CMS with a large-scale database of state-level eligibility and services for other analyses.

The purpose of MSIS is to collect, manage, analyze and disseminate information on those who are eligible for services, beneficiaries, utilization and payment for services covered by State Medicaid programs. States provide CMS with quarterly computer files containing specified data elements for: (1) persons covered by Medicaid (Eligible files); and, (2) adjudicated claims (Paid Claims files) for medical services reimbursed with Title XIX funds. These data are furnished on the Federal fiscal year quarterly schedule, which begins October 1 of each year.

I/DD Group Identification

Included in broader 'Disability' subgroup: No (due to waiver status)

I/DD Group Uniquely Identifiable? Yes

If yes, is it possible to separate DD from ID? Unclear, may be possible by diagnosis code

Questions (data fields) identifying 'I/DD' or 'Disability': Waiver status with MR/DD designation

Notes on ID Identification: Individual eligible records consist of demographic and monthly enrollment data. There is a code for dually-eligible people, as well as waiver status, the latter of which will often include "MR/DD" specification.

Study Methodology

Inclusion Criteria: Each state eligible file contains one record for each person covered by Medicaid for at least one day during the reporting quarter.

Exclusion Criteria: None

Suspected biases in data collected: Only persons covered by Medicaid are represented; i.e. only people with I/DD receiving services from the state

Likelihood of including people with I/DD: Definitely included

Organizational level to which data is powered: National, state, local

Data Collection

Dates of Collection: Complete data for Federal fiscal year 1999 - present

Method: Secondary data collection

Data Collection Methodology Details: Paid Claims Files contain information from adjudicated medical service related claims and capitation payments. Four types of claims files (inpatient, long term care, prescription drugs and non-institutionalized services) are submitted by the states. These are claims that have completed the state's payment processing cycle for which the state has determined it has a liability to reimburse the provider from Title XIX funds. Claims records contain information on the types of services provided, providers of services, service dates, costs, types of reimbursement, and epidemiological variables.

Periodicity of Updates: Quarterly

Health-Related Measures

Domains of Health-Related Measures: Only health care utilization measures collected; some health information may be deduced from types of health care and meds

Suspected biases in measurement of indicators? Only health care services that were billed and paid for collected

Perceived weaknesses in health measures: Only health care services that were billed and paid for collected

Applicability of health measures to people with I/DD: Health care utilization is important; highly applicable

Known Linkages: None

Potential Linkages: Any data set using SSN for states that use SSN as identifier

Contains functional measures or levels of disability? None

Data Access Costs: Unknown

Citation or Website: https://www.cms.gov/MSIS/

Critical Review Comments

- This data source is a good surveillance source, especially for preventive health care. However, it is limited to people who receive services, and the information on health measures is limited. It can, however, be linked to other governmental data sources on health care utilization and to state files.

Medicare Claims

At-a-Glance
U.S.
Secondary Data
Adults & Children
Ongoing Collection

Narrative Description: Medical claims and expenditure data for people enrolled in Medicare. Available from the Centers for Medicare and Medicaid Services up to about 2-years behind current data.

I/DD Group Identification

Included in broader 'Disability' subgroup: Unclear

I/DD Group Uniquely Identifiable? Unclear, may be possible by diagnosis code

If yes, is it possible to separate DD from ID? N/A

Questions (data fields) identifying 'I/DD' or 'Disability': Unclear

Notes on ID Identification: It is not clear from the data descriptions whether I/DD would be identifiable in this data. It is feasible that I/DD would appear as a diagnosis code, but it is not clear if I/DD would be coded for an episodic care visit (ex. ER, ambulatory surgery, etc.).

Study Methodology

Inclusion Criteria: People enrolled in Medicare

Exclusion Criteria: None

Suspected biases in data collected: Only persons covered by Medicare are represented; i.e. only people with I/DD who are covered under Medicare

Likelihood of including people with I/DD: Definitely included; the elderly group may be over-represented; as well as those with more severe disabilities due to dually eligible status and care needs

Organizational level to which data is powered: National, state, local

Data Collection

Dates of Collection: Dates differ across data type. Refer to the CMS Data Availability Table for more details: http://www.resdac.org/Tools/TBs/TN_015_CMS%20Data%20Availability_508%20.pdf

Method: Secondary Data

Periodicity of Updates: Unknown

Health-Related Measures

Domains of Health-Related Measures: Only health care utilization measures collected; some health information may be deduced from types of health care and meds

Suspected biases in measurement of indicators? Only health care services that were billed and paid for are collected

Perceived weaknesses in health measures: Only health care services that were billed and paid for collected

Applicability of health measures to people with I/DD: Health care utilization is important; highly applicable

Known Linkages: Can be linked to other government data sources on health care utilization; can also be linked to state files

Contains functional measures or levels of disability? None

Data Access Costs: Unknown

Citation or Website: https://www.cms.gov/home/medicare.asp and http://www.resdac.org/Medicare/data_available.asp

Critical Review Comments

- Potential source of surveillance data if people with I/DD can reliably be identified through ICD coding. Additional work is needed to determine the full extent to which this source can inform surveillance. The data is limited to people receiving Medicare services.
- The data source has potential to inform preventive health care and other service utilization. However, it is limited in that it does not provide information on health measures.

Medicare Current Beneficiary Survey (MCBS)

At-a-Glance
U.S. and Puerto Rico
Primary Data
Adults
3 data collection points in 4 years

Narrative Description: The Medicare Current Beneficiary Survey (MCBS) is a continuous, multipurpose survey of a representative national sample of the Medicare population, conducted by the Office of Strategic Planning of the Centers for Medicare & Medicaid Services (CMS) through a contract with Westat. 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; to trace processes over time, such as changes in health status and spending down to Medicaid eligibility and assess the impacts of program changes, satisfaction with care, and usual source of care.

I/DD Group Identification

I/DD Group Uniquely Identifiable? Yes

If yes, is it possible to separate DD from ID? Unclear. May be possible using ADL/IADL items

Questions (data fields) identifying 'I/DD' or 'Disability': MR diagnosis, ADLs and IADLs

Notes on ID Identification: MR diagnosis is included as a reason for Medicare eligibility; variables included on ADLs and IADLs

Study Methodology

Inclusion Criteria: Aged and disabled beneficiaries enrolled in Medicare Part A (hospital insurance), or Part B (medical insurance), or both, and residing in households or long-term care facilities in the United States and Puerto Rico

Exclusion Criteria: None

Sampling Methodology: Nationally representative sample of aged and disabled Medicare beneficiaries, stratified by age group. To ensure that annual samples yield enough persons with long-term care facility stays to produce statistically reliable data, disabled persons under age 65 and persons age 80 and over are oversampled.

Suspected biases in sampling methodology: Only persons covered by Medicare are represented; i.e. only people with I/DD who are covered under Medicare

Likelihood of including people with I/DD: Definitely included; the elderly group may be over-represented; as well as those with more severe disabilities due to dually eligible status and care needs

Response Rate: Response rate is acceptable at 12,486 (69.5%) in 2003

Sample Size: 17,967 (in 2003)

Organizational level to which sample is powered: National, possibly state

Data Collection

Dates of Collection: Began in 1991. As of Sept 2011, the data available is CY 1991 – 2009 for the Access to Care Module with the next release in Summer 2012. The data available is CY 992 – 2007 for the Cost and Use Module with the next data release scheduled for Fall 2011. (Dates according to http://www.resdac.org/Tools/TBs/TN_015_CMS%20Data%20Availability_508%20.pdf)

Method: Primary data collection

Data Collection Methodology Details: For people living in community, in-person survey, about 12% conducted with proxy. For people living in facilities, mostly proxy interviews with facility representatives.

Data Collection Tools: Baseline Questionnaire and Community Core Questionnaire (for those living in community); Facility Screener, modified Baseline and Core Questionnaires (for those living in facilities)

Aspects of the data collection methodology that may limit information collected from people with I/DD: People with I/DD may be less likely to respond

Is a proxy used for people with I/DD? Proxy may be used

Measures of reliability or validity for the data collection tool(s) Unknown

Periodicity of Updates: Each sample member interviewed three times in 4-year period

Health-Related Measures

Domains of Health-Related Measures: Utilization of health services, medical care expenditures, health insurance coverage, sources of payment for health services, health status and functioning, and beneficiary information such as income, assets, living arrangement, family assistance, and quality of life. Two types of files are available: "Access to Care" and "Cost and Use."

Suspected biases in measurement of indicators? Unknown

Perceived weaknesses in health measures: Unknown

Applicability of health measures to people with I/DD: Measures are highly applicable

Known Linkages: Does not appear to be linked or linkable to other sources.

Contains functional measures or levels of disability? Possibly ADL/IADLs can be used with MR diagnosis

Data Access Costs: No costs noted. All requests for MCBS data must be developed and reviewed with the assistance of the Research Data Assistance Center. Contact ResDAC for access information: http://www.resdac.umn.edu

Citation or Website: https://www.cms.gov/LimitedDataSets/11_MCBS.asp

For more information: http://www.cms.gov/mcbs/downloads/HHC2003appendixA.pdf

Notes: Link under FMI is citation for sampling methodology and other technical documentation.

Critical Review Comments

- This data source is useful in its current state for health surveillance of adults with I/DD who receive Medicare. A strength of this data source is that it includes measures of health status.
- The sampling methodology, which includes people in facilities, may be useful for other studies.
- The data may be able to be linked to Medicare files.

Medicare Health Outcomes Survey (HOS)

At-a-Glance
U.S.
Primary Data
Adults
Annual

Narrative Description: Conducted annually by CMS. Two cohorts surveyed each year, one new and one follow-up. Gathers health status data for people receiving Medicare managed care. Data used for quality improvement activities, plan accountability, public reporting, and improving health. All managed care plans with Medicare Advantage (MA) contracts must participate.

I/DD Group Identification

Included in broader 'Disability' subgroup: Possibly; unclear.

I/DD Group Uniquely Identifiable? No

Questions (data fields) identifying 'I/DD' or 'Disability': "Disabled" as a reason for Medicare entitlement

Study Methodology

Inclusion Criteria: Includes people with Medicare who are disabled and under age 65

Exclusion Criteria: For data collection years 1998-2009, beneficiaries with End Stage Renal Disease (ESRD). See http://www.hosonline.org/Content/ProgramOverview.aspx for information on criteria for various years.

Sampling Methodology: A random sample of Medicare beneficiaries is drawn from each participating Medicare Advantage Organization and surveyed every spring. Two years later, these same respondents are surveyed again.

Suspected biases in sampling methodology: Only persons covered by Medicare managed care are represented. May be bias in who responds to this mail survey; for example, people with limited English proficiency or literacy are less likely to respond.

Likelihood of including people with I/DD: Most likely included; the elderly and people with more severe disabilities (possibly including those who are dually-eligible)may be over-represented

Response Rate: The 2007 Cohort 10 Baseline Medicare HOS had a response rate of 64.4% http://www.hosonline.org/Content/SurveyResults.aspx

Sample Size: The Medicare Advantage Organization baseline sample size is 1200 as of 2007; The 2007 Cohort 10 Baseline Medicare HOS included a random sample of 321,005 beneficiaries from 286 MAOs.

Organizational level to which sample is powered: National

Data Collection

Dates of Collection: 1998 - present

Method: A random sample of Medicare beneficiaries is drawn from each Medicare Advantage Organization and surveyed every spring (i.e., a baseline survey is administered to a new sample of members [cohort or group] each year). Two years later, these same respondents are surveyed again (i.e., follow up measurement).

Data Collection Tools: The Medicare HOS questionnaire consists of four components: physical and mental health status questions; questions for case mix and risk adjustment purposes; questions added to collect results for select HEDIS Effectiveness of Care measures, and questions added by CMS as required by the 1997 Balanced Budget Act. Physical and mental health functioning are the primary outcome measures which are derived from the core health status component.

Aspects of the data collection methodology that may limit information collected from people with I/DD: People with I/DD may be less likely to respond

Is a proxy used for people with I/DD? Proxy may be used

Measures of reliability or validity for the data collection tool(s) Unknown

Periodicity of Updates: Annual updates include primary cohort and two year follow up cohort.

Health-Related Measures

Domains of Health-Related Measures: Health status and functioning; many very specific measures

Suspected biases in measurement of indicators? Unknown

Perceived weaknesses in health measures: Unknown

Applicability of health measures to people with I/DD: Measures are highly applicable

Known Linkages: Some linkages described, including to National Cancer Institute SEER and part D drug information. Details available at http://www.hosonline.org/Content/WhatsNew.aspx

Potential Linkages: Research Identifiable Files (RIFs) may be requested.

Contains functional measures or levels of disability? No

Data Access Costs: Unknown

Citation or Website: http://www.hosonline.org/Default.aspx

Notes: Medicare beneficiaries who are disabled and under 65 are included and would include a portion of adults with I/DD who are Medicare eligible and receiving Medicare managed care (Medicare Advantage).

Critical Review Comments

- This data source could be adapted to improve its ability to inform health surveillance of adults with I/DD by adding a specific question about I/DD.
- The health measures collected in this data source are highly applicable. However, it is not clear how many people with I/DD receive managed care, and would therefore be included in this survey.

Minimum Data Set (MDS) Repository

At-a-Glance
U.S.
Primary Data
Adults
Ongoing Collection

Narrative Description: The Minimum Data Set (MDS) is part of the U.S. federally mandated process for clinical assessment of all residents in Medicare or Medicaid certified nursing homes. This process provides a comprehensive assessment of each resident's functional capabilities and helps nursing home staff identify health problems.

Resident Assessment Protocols (RAPs) are part of this process, and provide the foundation upon which a resident's individual care plan is formulated. The Resident Assessment Instrument Minimum Data Set Version 2.0 (RAI-MDS 2.0) is a comprehensive, standardized tool used to assess residents in long-term care (LTC) settings. MDS assessment forms are completed for all residents in certified nursing homes, regardless of payment source for the individual resident. MDS assessments are required for residents on admission to the nursing facility and then periodically, within specific guidelines and time frames. In most cases, participants in the assessment process are licensed health care professionals, usually Registered Nurses, employed by the nursing home. MDS information is transmitted electronically by nursing homes to the MDS database in their respective states. MDS information from the state databases is captured into the national MDS database at Centers for Medicare and Medicaid Services (CMS).

Categories of MDS (Minimum Data Set)

1) Cognitive patterns
2) Communication and hearing patterns
3) Vision patterns
4) Physical functioning and structural problems
5) Continence
6) Psychosocial well-being
7) Mood and behavior patterns
8) Activity pursuit patterns
9) Disease diagnoses
10) Other health conditions
11) Oral/nutritional status
12) Oral/dental status
13) Skin condition
14) Medication use
15) Treatments and procedures

I/DD Group Identification

I/DD Group Uniquely Identifiable? Yes

If yes, is it possible to separate DD from ID? Yes - see notes on ID/DD identification

Questions (data fields) identifying 'I/DD' or 'Disability': Conditions related to MR/DD Status (separate codes for Down Syndrome, Autism, Epilepsy, Other Organic Condition, Other Non-Organic Condition). Section AB, item 10 on MDS 2.0. Item A1550 on MDS 3.0.

See Resident Assessment Instrument:Q9: Mental Health History: Does resident's RECORD indicate any history of mental retardation, mental illness, or developmental disability problem? (Yes/No)

Q10:Conditions Related to MR/DD status: Check all conditions that are related to MR/DD status that were manifested before age 22,and are likely to continue indefinitely)

Not applicable—no MR/DD (Skip to AB11) MR/DD with organic condition, Down's syndrome, Autism, Epilepsy, Other organic condition related to MR/DD, MR/DD with no organic condition

Notes on ID Identification: Analysis by Sheryl Larson is an example: http://rtc.umn.edu/docs/factsheetnursinghomeres2000.pdf

"IDD was Identified by admission screening saying person has Mental Retardation or Developmental Disabilities and/or ICD codes of Mental Retardation, Spina Bifida, Down Syndrome, Autism, Edward's syndrome, Klinefelters Syndrome, Patau's syndrome, Phenylketonuria, Microcephaly, Anecephalus, Sex Chromosome Anomaly, Congenital Hypothyroidism, Tuberous Sclerosis, Prader-Willi Syndrome, Cornelia de Lange, Bardet-Biedl. Individuals with cerebral palsy, epilepsy or hydrocephalus who did not have one of these other diagnoses were not included in this group."

Study Methodology

Inclusion Criteria: Resident of a certified nursing home that participates in Medicaid or Medicare. All residents are included, regardless of their individual payment source.

Exclusion Criteria: None

Sampling Methodology: All clients in certified nursing homes.

Suspected biases in sampling methodology: Only persons covered by Medicare or Medcaid who are in nursing homes are represented.

Likelihood of including people with I/DD: Most likely included; the elderly group will be over-represented as well as people who need assistance with activities of daily living or nursing assistance.

Response Rate: Assessment Counts Reports done by Quarter: 3rdQ 2010:4,398,214 assessments done nationally http://www.cms.gov/MDSPubQIandResRep/05_assesscntreport.asp#TopOfPage

Sample Size: As of Third Quarter 2010, 4.5% of active residents had MR/DD related condition. National total number of residents = 1,346,134. http://www.cms.gov/MDSPubQIandResRep/04_activeresreport.asp?isSubmitted=res3&var=AB10A&date=32

Organizational level to which sample is powered: National, state, local

Data Collection

Dates of Collection: MDS 2.0 beginning October 1998. MDS 3.0 beginning October 2010. Nursing homes have been collecting MDS since 1990; since June 1998, States have transmitted MDS to the CMS central repository.

Method: Primary data collection

Data Collection Methodology Details: Records review and individual case review by clinician.

Data Collection Tools: Resident assessment and care screening tool https://www.cms.gov/NursingHomeQualityInits/downloads/MDS20MDSAllForms.pdf

Is a proxy used for people with I/DD? N/A review done by clinician

Measures of reliability or validity for the data collection tool(s) N/A

Periodicity of Updates: Ongoing data collection. All residents in Medicare and/or Medicaid certified facilities are assessed at admission, annually, for a significant change in status assessment, significant correction of prior assessment, and a quarterly review assessment. Also, residents receiving Medicare skilled nursing facility PPS payment require more frequent assessments (5, 14, 30, 60, 90 days).

Facilities are required to electronically transmit MDS data to the States. The State agencies have the overall responsibility for collecting MDS data in accordance with CMS specifications. The State is also responsible for preparing MDS data for retrieval by a national repository established by CMS.

Health-Related Measures

Domains of Health-Related Measures: Accidents, Behavioral/Emotional Patterns, Clinical Management, Cognitive Patterns, Elimination/Incontinence, Infection Control, Nutrition/Eating, Pain Management, Physical Functioning, Psychotropic Drug Use, Quality of Life, Skin Care, Post-Acute Care, falls, accidents, health status, indicators of mental illness

Suspected biases in measurement of indicators? Unknown

Perceived weaknesses in health measures: Unclear

Applicability of health measures to people with I/DD: Applicable; though more so to the elderly population

Known Linkages: See the RESDAC publication: Linking the Nursing Home Minimum Data Set with other CMS Facility Data. The article describes matching data with other CMS facility data such as the Provider of Services File (POS), Online Survey, Certification and Reporting (OSCAR), or the Nursing Home Compare Database. http://www.resdac.org/tools/TBs/TN-007_LinkingMDStoFacilitydata_508.pdf

Contains functional measures or levels of disability? Yes

Data Access Costs: No costs noted. Available from ResDAC: http://www.resdac.org/MDS/data_available.asp#1

Citation or Website: https://www.cms.gov/MDSPubQIandResRep/

For more information: http://www.cms.gov/NursingHomeQualityInits/45_NHQIMDS30TrainingMaterials.asp#TopOfPage

Notes: MDS 3.0 (implemented beginning October 2010) was developed to improve accuracy and includes a direct interview with residents.

Please note that InterRAI holds the copyright to Version 2.0 of the RAI for long term care outside of the U.S.. Therefore, this revised Version 2.0 of the RAI/MDS manual should not be reproduced outside of the United States without permission of InterRAI. Within the U.S., Version 2.0 is in the public domain.

Critical Review Comments

- This data source is useful in its current format for health surveillance in adults with I/DD living in nursing homes, including SNF-based and the elderly. However, this subgroup represents only a small segment of adults with I/DD.
- Survey questions and categorical diagnoses used may be adapted for adult population not in nursing homes.

National Comorbidity Survey Replication (NCS-R)

Narrative Description: The NCS-R is one of three linked CPES studies (see notes column). The National Comorbidity Survey Replication (NCS-R) is a probability sample of the United States carried out a decade after the original 1992 NCS (NCS-1) was conducted. The NCS-R repeats many of the questions from the NCS-1 and also expands the questioning to include assessments based on the diagnostic criteria of the American Psychiatric Association as reported in the Diagnostic and Statistical Manual - IV (DSM-IV), 1994. The two major aims of the NCS-R were first, to investigate time trends and their correlates over the decade of the 1990s, and second, to expand the assessment in the baseline NCS-1 in order to address a number of important substantive and methodological issues that were raised by the NCS-1.

At-a-Glance
U.S.
Primary Data
Adults
Administered Twice

I/DD Group Identification

Included in broader 'Disability' subgroup: Yes

I/DD Group Uniquely Identifiable? No

Questions (data fields) identifying 'I/DD' or 'Disability': Mental or Emotional Disability, Learning Disability

Study Methodology

Inclusion Criteria: The NCS-R survey was administered to a sample of non-institutionalized English-speaking adults aged 18 or older residing in households located in the coterminous United States.

Exclusion Criteria: None

Sampling Methodology: Nationally representative probability sample

Suspected biases in sampling methodology: Homeless, institutionalized, and people who spoke no English were excluded; people with I/DD may be less likely to be able to complete the survey due to communication difficulties.

Likelihood of including people with I/DD: Likely included. No subgroups of people with I/DD should be underrepresented

Response Rate: Unknown

Sample Size: The survey was administered in two parts. Part 1 included a core diagnostic assessment of all 9,282 respondents. Part 2 included questions about risk factors, consequences, other correlates, and additional disorders. Part 2 was administered only to 5,692

Organizational level to which sample is powered: national, state

Data Collection

Dates of Collection: Collected from 2001-2003

Method: Primary data collection

Data Collection Methodology Details: For the most part, interviews were conducted using laptop computer-assisted personal interview (CAPI) methods in the homes of the respondents.

Data Collection Tools: Available through: http://www.icpsr.umich.edu/icpsrweb/ICPSR/studies/189/detail#scope-of-study

Aspects of the data collection methodology that may limit information collected from people with I/DD: People with I/DD may be less likely to respond

Is a proxy used for people with I/DD? No proxy used.

Measures of reliability or validity for the data collection tool(s) Unknown

Periodicity of Updates: Only administered twice

Health-Related Measures

Domains of Health-Related Measures: Mental, psychiatric, and behavioral problems; chronic conditions; tobacco; psych meds

Suspected biases in measurement of indicators? Unknown

Perceived weaknesses in health measures: Unknown

Applicability of health measures to people with I/DD: All measures are highly applicable; particularly psych meds

Known Linkages: Linked to two other CPES surveys: National Survey of American Life (NSAL), and the National Latino and Asian American Study (NLAAS).

Contains functional measures or levels of disability? Yes

Data Access Costs: Public use data available online; restricted use data through ICPSR. Costs not available.

Citation or Website: http://www.icpsr.umich.edu/icpsrweb/ICPSR/studies/189/detail#scope-of-study

For more information: see CPES website http://www.icpsr.umich.edu/icpsrweb/CPES/index.jsp

Notes: The Collaborative Psychiatric Epidemiology Surveys (CPES), with support from the National Institute of Mental Health (NIMH), were initiated in recognition of the need for contemporary, comprehensive epidemiological data regarding the distributions, correlates, and risk factors of mental disorders among the general population, with special emphasis on minority groups. The primary objective of the CPES was to collect data about the prevalence of mental disorders, impairments associated with these disorders, and their treatment patterns from representative samples of majority and minority adult populations in the United States. Secondary goals were to obtain information about language use and ethnic disparities, support systems, discrimination, and assimilation, in order to examine if and how closely various mental health disorders are linked to social and cultural issues. To this end, CPES joins together three nationally representative surveys: the National Survey of American Life (NSAL), and the National Latino and Asian American Study (NLAAS). These studies collectively provide the first national data with sufficient power to investigate cultural and ethnic influences on mental disorders. In this manner, CPES permits analysts to approach analysis of the combined dataset as though it were a single, nationally representative study. Each of the CPES studies has been documented in a comprehensive and flexible manner that promotes cross-survey linking of key data and scientific constructs.

Critical Review Comments

- This source has useful measures, likely includes people with ID and disaggregation should be possible. However, it was only collected twice and may not have representative samples of people with ID due to lower likelihood of response from this population.

National Core Indicators Project - Consumer Survey

At-a-Glance
U.S.
Primary Data
Adults
Annual

Narrative Description: The National Core Indicators (NCI) began in 1997 as a collaborative effort between the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI). The goal was to encourage and support NASDDDS member agencies in developing a standard set of performance measures that could be used by states to manage quality and be used across states for making comparisons and setting benchmarks. Fifteen states initially worked on the Core Indicators Project, as it was originally known, and pooled their resources to develop valid and reliable data collection protocols. Over time, NCI has become an integral piece of over half the states' quality management systems and aligns with basic requirements for assuring quality in HCBS Waivers. NCI states and project partners continue working toward the vision of utilizing NCI data to not only improve practice at the state level, but also add knowledge to the field, influence state and national policy, and inform strategic planning initiatives for NASDDDS.

I/DD Group Identification

I/DD Group Uniquely Identifiable? Yes

If yes, is it possible to separate DD from ID? Yes

Questions (data fields) identifying ‘I/DD’ or ‘Disability’: Consumer Survey BI-9 and BI-10

Study Methodology

Inclusion Criteria: Adults over 18 who are receiving at least one service other than case management.

Exclusion Criteria: None

Sampling Methodology: Minimum of 400 per state, randomly drawn from service population. Typically 20+ states per year.

Suspected biases in sampling methodology: Only people with I/DD who are receiving services in states are included; many states have different inclusions criteria (e.g. exclude people in institutions)

Likelihood of including people with I/DD: Definitely included; depending on the state people in institutional settings etc., maybe under-represented

Response Rate: Response rate is acceptable at approx. 65% consumer response; proxy can be used for Section II

Sample Size: Approx. 10,000

Organizational level to which sample is powered: National, state

Data Collection

Dates of Collection: Annually, 1998-present

Method: Primary data collection, some record review

Data Collection Tools: Adult Consumer Survey

Aspects of the data collection methodology that may limit information collected from people with I/DD: When proxy does not answer, information is solicited from respondent, who may not know/remember/ be able to respond

Is a proxy used for people with I/DD? Proxy is used for health measures section

Measures of reliability or validity for the data collection tool(s) Studies performed

Periodicity of Updates: Annual

Health-Related Measures

Domains of Health-Related Measures: Health status, preventive health and dental exams, cancer screenings, height & weight, moderate exercise, health and safety domain, tobacco use, psychotropic medications

Suspected biases in measurement of indicators? Bias may be introduced with questions that relate to self-reporting of perceived health and access, as well as through proxy response.

Perceived weaknesses in health measures: Health measures section is often filled out by proxy , who may not have all the pertinent info - lots of "don't knows" included in dataset.

Applicability of health measures to people with I/DD: Highly applicable

Known Linkages: None

Potential Linkages: Could be linked to consumer ID by individual states

Contains functional measures or levels of disability? None

Data Access Costs: Unknown

Citation or Website: http://www2.hsri.org/nci/

Critical Review Comments

- This source has application for health surveillance in its current form. However, the health measures collected are limited, the data is limited only to participating states, and data only include people receiving services through state I/DD systems.
- Methodology used in this survey include in-person interview, random sampling of participants from those receiving services may be useful in future surveillance efforts.

National Death Index (NDI)

At-a-Glance
U.S.
Secondary Data
Adults & Children
Ongoing Collection

Narrative Description: The National Death Index (NDI) is a central computerized index of death record information on file in the State vital statistics offices. Working with these State offices, NCHS established the NDI as a resource to aid epidemiologists and other health and medical investigators with mortality ascertainment activities.

•Available to investigators solely for statistical purposes in medical and health research. Not accessible to organizations or the general public for legal, administrative, or genealogy purposes.

•A national file of identifying death record information (beginning with deaths in 1979) compiled from computer files submitted by State vital statistics offices. Death records are added to the NDI file annually, approximately 12 months after the end of a particular calendar year.

I/DD Group Identification

Included in broader 'Disability' subgroup: No

I/DD Group Uniquely Identifiable? No

Study Methodology

Inclusion Criteria: Decedent died in U.S. State

Exclusion Criteria: None

Sampling Methodology: All eligible persons included

Suspected biases in sampling methodology: Only records kept and submitted by State vital statistics offices are included.

Likelihood of including people with I/DD: Definitely will include

Organizational level to which data is powered: National, state, local

Data Collection

Dates of Collection: 1979 – present. Appears to be about a 2 year lag time on availability

Method: Data collected from state vital records

Periodicity of Updates: Ongoing collection

Health-Related Measures

Domains of Health-Related Measures: Cause of death

Suspected biases in measurement of indicators? Unknown

Perceived weaknesses in health measures: None

Applicability of health measures to people with I/DD:

Known Linkages: Linked to NCHS surveys:

- National Health Interview Survey (NHIS)
- NHANES I Epidemiologic Follow-up Study (NHEFS)
- Second National Health and Nutrition Examination Survey (NHANES II)
- Third National Health and Nutrition Examination Survey (NHA

Potential Linkages: Numerous linkages possible. The National Death Index Retrieval program can be used to match the NDI files to other sources. The program requires at least 1 of seven conditions to be met for matching:

1. Social Security Number
2. Exact month and +/- 1 year of birth, first and middle initials, last name.
3. Exact month and day of birth, first and middle initials, last name
4. Exact month and day of birth, first and last name
5. Exact month and day of birth, first and middle initials, last name.
6. Exact month and year of birth, first name, father's insurance
7. If the subject is female: exact month and year of birth, first name, last name (user's record) and father's surname (NDI record).

See http://www.cdc.gov/nchs/data/ndi/NDICriteria_Front.pdf

Contains functional measures or levels of disability? none

Data Access Costs: See http://www.cdc.gov/nchs/data/ndi/Users_Fees_Worksheet.pdf

Citation or Website: http://www.cdc.gov/nchs/ndi.htm

For more information: Email ndi@cdc.gov to obtain a free NDI User's Manual and/or more information about the NDI.

Notes: NDI is a matching service that requires the researcher to submit a list of names for which death information is being requested. May have utility because of linkage to other NCHS surveys.

Critical Review Comments

- This data source may be highly useful for mortality surveillance if linked to other data sources that identify people with ID, including NCHS surveys.

National Health Interview Survey (NHIS)

At-a-Glance
U.S.
Primary Data
Adults & Children
Annual

Narrative Description: The National Health Interview Survey (NHIS) is the principal source of information on the health of the civilian non-institutionalized population of the United States and is one of the major data collection programs of the National Center for Health Statistics (NCHS) which is part of the Centers for Disease Control and Prevention (CDC). The National Health Survey Act of 1956 provided for a continuing survey and special studies to secure accurate and current statistical information on the amount, distribution, and effects of illness and disability in the United States and the services rendered for or because of such conditions. The survey referred to in the Act, now called the National Health Interview Survey, was initiated in July 1957. Since 1960, the survey has been conducted by NCHS, which was formed when the National Health Survey and the National Vital Statistics Division were combined.

NHIS data are used widely throughout the Department of Health and Human Services (DHHS) to monitor trends in illness and disability and to track progress toward achieving national health objectives. The data are also used by the public health research community for epidemiologic and policy analysis of such timely issues as characterizing those with various health problems, determining barriers to accessing and using appropriate health care, and evaluating Federal health programs.

I/DD Group Identification

I/DD Group Uniquely Identifiable? Yes

If yes, is it possible to separate DD from ID? Yes, possibly

Questions (data fields) identifying 'I/DD' or 'Disability': Mental Retardation or Other Developmental Problem

Study Methodology

Inclusion Criteria: Civilian non-institutionalized population residing in the United States at the time of the interview

Exclusion Criteria: Patients in long-term care facilities; persons on active duty with the Armed Forces (their dependents are included); persons incarcerated in the prison system; and U.S. nationals living abroad.

Sampling Methodology: The National Health Interview Survey is a cross-sectional household interview survey. Sampling and interviewing are continuous throughout each year. The sampling plan follows a multistage area probability design that permits the representative sampling of households and non-institutionalized group quarters (e.g., college dormitories). For more detail: http://www.cdc.gov/nchs/nhis/about_nhis.htm#sample_design

Suspected biases in sampling methodology: Does not include institutionalized population

Likelihood of including people with I/DD: Definitely included

Response Rate: The conditional response rate was 80.1%, and the final response rate was 65.4%.

Sample Size: In 2009, data were collected on 27,731 adults in the Sample Adult questionnaire. Citation: http://www.cdc.gov/nchs/data/series/sr_10/sr10_249.pdf

Organizational level to which sample is powered: national, state, possibly local

Data Collection

Dates of Collection: Annually since 1957, current version since 1997

Method: Primary data collection

Data Collection Methodology Details: Data are collected through a personal household interview conducted by interviewers employed and trained by the U.S. Bureau of the Census according to procedures specified by the NCHS.

For the Family Core component, all adult members of the household 17 years of age and over at home at the time of the interview are invited to participate and respond. Beginning in 1997 data, were collected for active duty military personnel provided there is one civilian in the family; however, these persons are not weighted for analytic purposes. For children and adults not at home during the interview, information can be provided by a responsible adult family member, 18 years of age and over, residing in the household. For the Sample Adult questionnaire, one civilian adult per family is randomly selected; generally this individual must self-report responses in this section. Information for the Sample Child questionnaire is obtained from a knowledgeable adult in the household, usually a parent.

The Census Bureau, under a contractual agreement, is the data collection agent for the NHIS. Nationally, the NHIS uses about 400 interviewers, trained and directed by health survey supervisors in each of the 12 Census Bureau Regional Offices. Supervisors are career Civil Service employees and interviewers are part-time employees, selected through an examination and testing process. Interviewers receive thorough training in basic interviewing procedures and concepts and procedures unique to the NHIS.

The revised NHIS questionnaire fielded since 1997 uses a computer assisted personal interviewing (CAPI) mode. The CAPI version of the NHIS questionnaire is administered using a laptop computer and interviewers enter responses into the computer during the interview. This computerized mode offers distinct advantages in timeliness of the data and improved data quality.

Data Collection Tools: The revised NHIS questionnaire, implemented since 1997, has Core questions and Supplements. The Core questions remain largely unchanged from year to year and allow for trends analysis and for poolingdata from multiple years to increase sample size for analytic purposes. The Core contains four major components: Household, Family, Sample Adult, and Sample Child.

The Household component collects limited demographic information on all individuals living in a particular house. The Family component verifies and collects additional demographic information on each member of each family in the house, including data on health status and limitations, injuries, healthcare access and utilization, health insurance, and income/assets. The Family Core component allows the NHIS to serve as a sampling frame for additional integrated surveys as needed.

One sample adult and one sample child (if any children are present) are randomly selected from each family in the NHIS and information on each is collected with the Sample Adult Core and the Sample Child Core questionnaires. Because some health issues are different for children and adults, these two questionnaires differ in some items but both collect basic information on health status, health care services, and health behaviors. http://www.cdc.gov/nchs/nhis/nhis_questionnaires.htm

Aspects of the data collection methodology that may limit information collected from people with I/DD: People with I/DD may be less likely to respond

Is a proxy used for people with I/DD? Proxy possible; however, generally questionnaires answered by proxy not used in final database

Measures of reliability or validity for the data collection tool(s) Unknown

Periodicity of Updates: Annual

Health-Related Measures

Domains of Health-Related Measures: Core Survey includes family demographics plus information on one sample adult and one sample child: health status and limitations, injuries, healthcare access and utilization, health insurance, and income and assets. Supplements include various topics such as: Cancer Screening, Complementary and Alternative Medicine, Children's Mental Health, and Healthcare Utilization.

Suspected biases in measurement of indicators? Unknown

Perceived weaknesses in health measures: Unknown

Applicability of health measures to people with I/DD: All measures are applicable

Known Linkages: National Center for Health Statistics (NCHS) Linked Resources; Mortality data; Medicare Enrollment and Claims data; Social Security Benefit History data; Medical Expenditure Panel Survey (MEPS) Linkage Files; National Immunization Provider Records Check

Contains functional measures or levels of disability? yes, possibly

Data Access Costs: Online files are free; linked data from AHRQ data center costs $300 plus $105/hour. For details see: ftp://ftp.cdc.gov/pub/Health_Statistics/NCHS/Datasets/NHIS/summary.pdf

Citation or Website: http://www.cdc.gov/nchs/nhis/about_nhis.htm

For more information: website has extensive information and related links

Notes: Very rich source of data with linkages and I/DD flag.

Critical Review Comments

- Good potential as a surveillance source since I/DD is uniquely identifiable and the source collects measures across numerous health domains. However, the sample of people with I/DD that are included in the survey may be small.

National Survey of Homeless Assistance Providers and Clients

At-a-Glance
U.S.
Primary Data
Adults & Children
Once; no updates

Narrative Description: NSHAPC was created to provide updated information on homeless assistance programs and the clients who use them to federal agencies responsible for administering homeless assistance programs and to other interested parties.

I/DD Group Identification

Included in broader 'Disability' subgroup: Yes

I/DD Group Uniquely Identifiable? No

Questions (data fields) identifying 'I/DD' or 'Disability': H1128 in Client Data - "ever enrolled in special classes because of a learning disability or other disability"

Study Methodology

Inclusion Criteria: Not clear; receiving homeless services from providers?

Exclusion Criteria: Not clear

Sampling Methodology: Within 76 sample areas, the in-scope provider-programs were sorted by type of program and size, with size defined in terms of the number of services provided in specified months' time estimated from CATI data. A systematic sample of programs was selected with probability proportional to size. Then, the Memorandum of Understanding (MOU)/Advance Preparation Visit (APV) Phase consisted of visiting the selected survey providers and completing an agreement to participate while observing the selected program in operation. The next phase of the client sampling procedure was to select a random sample of clients using the services on the randomly selected date and time. Sample selection varied by program., with a target number of 6 or 8 clients per provider. http://www.census.gov/prod/www/nshapc/datadocu/appsatod.pdf

Suspected biases in sampling methodology: Only includes homeless people actually receiving services from homeless shelters and providers

Likelihood of including people with I/DD: Likely included; those with mild I/DD likely overrepresented

Response Rate: Unknown

Sample Size: 4,207

Organizational level to which sample is powered: National

Data Collection

Dates of Collection: October-November 1996

Method: Primary data collection

Data Collection Methodology Details: Once a client was selected to be interviewed, and the survey's purpose had been explained, a census field representative completed an approximately 45 minute interview . At the conclusion of the interview, the respondent was given $10.00 by cooperating staff from the provider.

Data Collection Tools: In-person interview

Aspects of the data collection methodology that may limit information collected from people with I/DD: People with I/DD may be less likely to respond

Is a proxy used for people with I/DD? No proxy

Measures of reliability or validity for the data collection tool(s) Not clear

Periodicity of Updates: None

Health-Related Measures

Domains of Health-Related Measures: Major health conditions, last check-up for medical and dental services, place of check-up, treatment times, any prescribed medications, access to medical services http://www.census.gov/prod/www/nshapc/datadocu/cb_cli.pdf

Suspected biases in measurement of indicators? Unknown

Perceived weaknesses in health measures: Unknown

Applicability of health measures to people with I/DD: Measures are applicable

Known Linkages: None

Contains functional measures or levels of disability? None

Data Access Costs: Free to download, $50 on CD

Citation or Website: http://www.census.gov/prod/www/nshapc/NSHAPC4.html

For more information: NSHAPC Assistance/Martha Burt, The Urban Institute, 2100 M Street, NW, Washington, DC 20037; 202-261-5551; mburt@ui.urban.org

Critical Review Comments

- This data source could be very useful for homeless people with I/DD if better screening questions are asked and survey was periodic (only done in 1996).
- The methodology used to find homeless people through providers of homeless services may be useful for future surveillance efforts.

Special Olympics Data Set

At-a-Glance
International - includes U.S.
Primary Data
Adults & Children
Event-based Collection

Narrative Description: Special Olympics collects data from athletes who participate in voluntary vision, hearing, oral health, medical, and health promotion screenings. This database is promoted as the world's largest dataset describing health data for people with ID. The "Healthy Athletes" screenings are entered into the "Healthy Athletes Software" system, which compiles data by event and by region. The data is derived from a large convenience sample. Athletes self-identify as having an intellectual disability, and Special Olympics athletes likely represent a skewed population of people with intellectual disability.

I/DD Group Identification

I/DD Group Uniquely Identifiable? Yes

If yes, is it possible to separate DD from ID? Unknown

Questions (data fields) identifying 'I/DD' or 'Disability':

Notes on ID Identification: People who attend events and voluntary screenings are presumed to be in the I/DD population. No diagnostic information included.

Study Methodology

Inclusion Criteria: Special Olympics participants who consent to participate in Healthy Athletes Screening and have their screening information entered in to a database. Athletes must have an independent physical exam prior to participating in athletic events.

Exclusion Criteria: None

Sampling Methodology: Convenience sample of athletes who volunteer for health screenings.

Suspected biases in sampling methodology: Only people with I/DD who participate in Special Olympics events are included. People who decline to be screened will be excluded.

Likelihood of including people with I/DD: Includes only people with I/DD; people with more severe diagnoses or serious physical limitations likely underrepresented

Response Rate: At the 2007 World Games in Shanghai, 7,000 athletes from 155 countries participated in the Games. 4,879 athletes participated in one or more screenings, for a total of 18,536 screening sessions completed and recorded. http://www.healthoneglobal.org/olympics.html

Sample Size: See under response rate.

Organizational level to which sample is powered: International, national

Data Collection

Dates of Collection: Collected at ~ 600 Healthy Athletes Screening events in 65 countries annually.

Method: Primary data collection

Data Collection Methodology Details: Screening completed at Special Olympics events by trained Healthy Athletes volunteers (including health and allied health professionals) using structured format. Data is entered in to the web-based Special Olympics Healthy Athletes Software (HAS) system http://www.2010specialolympics.org/page13238.asp (DOMAIN NAME EXPIRED TWO MONTHS AGO AND IS PENDING RENEWAL

Data Collection Tools: All of the manuals, forms and related documents are listed for each of the screening programs at following website: http://resources.specialolympics.org/Sections/Healthy_Athletes_Resources.aspx

Aspects of the data collection methodology that may limit information collected from people with I/DD: No

Is a proxy used for people with I/DD? No proxy is used

Measures of reliability or validity for the data collection tool(s) No

Periodicity of Updates: Collected at each event

Health-Related Measures

Domains of Health-Related Measures: Preventive screening (immunizations, bone density), dental, vision, hearing, evaluation for physical therapy needs, skin/nail integrity.

Suspected biases in measurement of indicators? Unknown

Perceived weaknesses in health measures: Unknown

Applicability of health measures to people with I/DD: Measures are highly applicable

Known Linkages: Little linking possible because the screening data has not historically been linked to individuals. The primary purposes of this data collection are to enhance access to health care at the events for the athletes , and for advocacy - less emphasis on rigorous standards for data to date, although some say this is changing.

Contains functional measures or levels of disability? None

Data Access Costs: For more information: Darcie Mersereau, MPH, Manager, Research and Evaluation, Special Olympics, Inc., dmersereau@specialolympics.org

Citation or Website: N/A

Notes: This dataset is large enough that studies comparing athletes by region have been possible.

Critical Review Comments

- Good health surveillance source for a large convenience sample of people with I/DD. The information collected contains many health measures, is highly relevant, and is assessed by clinicians
- It is limited by a lack of an identifier for each athlete across events, which prevents its use longitudinally and across events due to repeat screenings of athletes.

State Vocational Rehabilitation Service Agency Closure Data (RSA-911)

At-a-Glance
U.S.
Secondary data
Adults
Annual

Narrative Description: State VR agencies are required to submit information on all closed cases for any given year to the Rehabilitation Services Administration (RSA). The RSA has information on over 600,000 'closures'.

I/DD Group Identification

I/DD Group Uniquely Identifiable? Yes

If yes, it is possible to separate DD from ID? Unclear

Questions (data fields) identifying 'I/DD' or 'Disability': Primary and secondary disability are coded (primary = substantial impediment to employment, secondary = physical or mental impairment that contributes to but is not the primary basis of impediment to employment.

Study Methodology

Inclusion Criteria: Recipients of State VR services who exit VR services in any given year.

Exclusion Criteria: People who did not receive VR services AND people who are actively receiving VR services (i.e. the case was not closed)

Sampling Methodology: All eligible recipients included in sample

Suspected biases in sampling methodology: Only persons who received VR services and exited them were be included

Likelihood of including people with I/DD: Definitely included; those with mild I/DD and younger likely overrepresented

Organizational level to which data is powered: National, state, possibly local

Data Collection

Dates of Collection: November 30th is deadline for states to submit data after the close of their fiscal year.

Method: Administrative (Existing Records)

Periodicity of Updates: Annual

Health-Related Measures

Domains of Health-Related Measures: Medical insurance coverage at application and at closure. No other health outcome information is collected reported.

Suspected biases in measurement of indicators? Unknown, but unlikely

Perceived weaknesses in health measures: Unknown, but unlikely

Applicability of health measures to people with I/DD: Not particularly important measures

Known Linkages: A study of employment outcomes has included State MR/DD data and VR (RSA) data, but this has not linked the two databases per se. Example: ICI - State Trends in Employment Services for People with Developmental Disabilities: Multiyear comparisons based on state MR/DD Agency and Vocational Rehabilitation (RSA) data [Butterworth, J., Gilmore, D., Kiernan, W, Schalock, R.]

Potential Linkages: The RSA 911 field collects SSN so it is technically possible to link to databases that also collect that information (e.g. SSA data), but no evidence was found that this has been attempted, and no evidence was found that this will be attempted in the future.

Contains functional measures or levels of disability? No

Data Access Costs: Free database, available for download.

Citation or Website: Reporting manual for the RSA Case Services Report available at : http://www2.ed.gov/policy/speced/guid/rsa/pd/2009/pd-09-01.doc This includes information on all data elements

Notes: Analyses of the RSA-911 data can be found in: Butterworth, J., Gilmore, D. & Schalock, R. L. (1998). Rates of vocational rehabilitation system closure into competitive employment. Mental Retardation, 36 (4), 336-337 An analysis of the utility of the database for looking at AT outcomes is available at: http://www.r2d2.uwm.edu/atoms/archive/technicalreports/tr-rsa911.pdf

Critical Review Comments

- This data source is of limited use for health surveillance because only individuals who receive VR services are represented and the health information it collects is limited. It may be useful in studying this subset or if efforts are made to link this to other data sources.

Surveillance, Epidemiology and End Results (SEER)

At-a-Glance
U.S.
Primary Data
Adults & Children
Ongoing Collection

Narrative Description: Information is collected on cancer incidence, prevalence and survival from specific geographic areas representing 28 percent of the U.S. population. Reports are compiled on all of these results, along with cancer mortality for the entire country. Data has been collected from 1973-2007. The data comes from: nine states (New Mexico, Hawaii, Utah, Iowa, Connecticut, Greater California, Kentucky, Louisiana, New Jersey), five metropolitan areas (Metro Atlanta plus a sample of rural Georgia, the Greater Bay Area [San Francisco-Oakland and San-Jose Monterey], Los Angeles, Seattle, Detroit), and the Alaska Native Tumor Registry. SEER itself does not contain disability information; however, people with ID can be identified through a link to Medicare (see linkage section)

I/DD Group Identification

Included in broader 'Disability' subgroup: No, may be identified through linkage

I/DD Group Uniquely Identifiable? No, may be identified through linkage

Questions (data fields) identifying 'I/DD' or 'Disability': None

Notes on ID Identification: SEER itself does not contain disability information; however, people with ID can be identified through a link to Medicare.

Study Methodology

Inclusion Criteria: Varies by registry, but generally includes all reported cancers diagnosed in area residents

Exclusion Criteria: None.

Sampling Methodology: Geographic areas are selected, but otherwise no sampling performed

Suspected biases in sampling methodology: Only persons with incidence of cancer are included; for SEER-Medicare data, only persons with incidence of cancer who are on Medicare

Likelihood of including people with I/DD: Most likely included; the elderly will be over-represented; also any diagnosis with a concurrent higher incident of cancer

Response Rate: N/A, individual responses not used

Sample Size: Over 79 million people live in the monitored geographic areas

Organizational level to which sample is powered: State level (for select states)

Data Collection

Dates of Collection: 1973 - present

Method: Collection of state/area cancer registries

Periodicity of Updates: Ongoing collection

Health-Related Measures

Domains of Health-Related Measures: Health -related variables include: cancer incidence, prevalence and survival

Suspected biases in measurement of indicators? Unknown

Perceived weaknesses in health measures: Unknown

Applicability of health measures to people with I/DD:

Known Linkages: The data can be linked to Medicare: http://healthservices.cancer.gov/seermedicare/

The SEER Medicare database is a unique resource that can be used for research related to the health care provided to persons age 65 and older with cancer. The database results from the linkage of two large population-based data sources: SEER cancer registries data and Medicare enrollment and claims files. Medicare's master enrollment file is used to identify persons in the SEER data who are Medicare beneficiaries. For people who are Medicare eligible, the SEER-Medicare data includes claims for covered health care services, including hospital, physician, outpatient, home health, and hospice bills. Currently, the SEER Medicare database includes more than 2.4 million persons with cancer. The linked SEER-Medicare data can be used for various studies that span the continuum of cancer control activities, such as:

- Treatment and outcomes
- Quality of care
- Health care systems and services
- Screening and surveillance
- Economics of cancer
- Survivorship and end-of-life issues

as well as the Medicare Health Outcomes Survey http://outcomes.cancer.gov/surveys/seer-mhos/

and the National Longitudinal Mortality Study http://surveillance.cancer.gov/disparities/nlms/

Contains functional measures or levels of disability? None

Data Access Costs: Access to data is free. Fees are associated with access to the SEER-Medicaid data set. See http://healthservices.cancer.gov/seermedicare/obtain/cost.html for details

Citation or Website: http://seer.cancer.gov/

Notes: Replaces National Cancer Database

Critical Review Comments

- This data source is useful for on-going surveillance of cancer in this population due to the Medicare link, particularly because much of this population is dually-eligible. Additional demographic variables may be available from linked Medicare data.

Information Sheets for Data Sources with Moderate Potential to Inform Health Surveillance for Adults with I/DD

Collaborative Psychiatric Epidemiology Surveys (CPES)

Narrative Description: The National Institute of Mental Health Collaborative Psychiatric Epidemiology Surveys (CPES) provides data on the distributions, correlates, and risk factors of mental disorders among the general population, with special emphasis on minority groups. This project combines three nationally representative surveys: the National Co morbidity Survey Replication (NCS-R), the National Survey of American Life (NSAL), and the National Latino and Asian American Study (NLAAS). Detail is provided here and in the individual studies. The National Survey of American Life was renamed the American Community Survey.

At-a-Glance
U.S.
Primary Data
Adults
One merger of data 2001-2003

Collaborative Psychiatric Epidemiology Surveys (CPES) began in response to a need for contemporary, comprehensive epidemiological data regarding distributions, correlates and risk factors of mental disorders among the general population, with special emphasis on minority groups. The primary objective of the CPES is to collect data about the prevalence of mental disorders, impairments associated with these disorders, and their treatment patterns from representative samples of majority and minority adult populations in the United States. Secondary goals are to obtain information about language use and ethnic disparities, support systems, discrimination and assimilation, in order to examine whether and how closely various mental health disorders are linked to social and cultural issues. (*From profile of data source at the Inter-University Consortium for Political and Social Research* www.icpsr.umich.edu)

I/DD Group Identification

I/DD Group Uniquely Identifiable? Yes

If yes, is it possible to separate DD from ID? Yes, with 'Mental Retardation' variable

Questions (data fields) identifying 'I/DD' or 'Disability': The following questions asked of informants:

- "What disability would they think you have?" (CPES VOO446)
- " You mentioned that you have been limited in your activities for the past three months because of your health. What is the health problem that causes you to have these limitations?" (CPES V00603)
- "You mentioned that a physical or emotional condition causes you to have difficulty in __" (CPES V00529). Possible choices are Physical Handicap, Learning, Physical Illness, Mental Illness, Not due to a condition, or other. If choose 'Learning Disability' the possible choices are ADD, MR, Autism, Stuttering, or other.

Study Methodology

Inclusion Criteria: Respondent must indicate that they have a 'Learning Disability' before identifying that the disability is "mental retardation". Age 18+. Resident of household located in the coterminous United States.

Exclusion Criteria: Homeless or institutionalized people and people who don't speak English were excluded from sample.

Sampling Methodology: Population : The CPES represents the English-speaking non-Hispanic White, African American, and Caribbean Black populations; the English- and Spanish-speaking Mexican, Puerto

Rican, and Cuban populations; and the English-, Tagalog-, Vietnamese-, and Chinese-speaking Chinese, Filipino, and Vietnamese populations of the United States. Individuals of "other" race/ethnic background and "other" Latino and Asian ancestry were also included, but U.S. population representation of these groups was not possible. Detail is unknown about methods to locate, recruit, and contact subjects, or info on sample design.

Response Rate: NCS-R's response rate was 70.9%. NSAL's response rate was 72.3% overall and 70.7% for African Americans, 77.7% for Caribbean Blacks, and 69.7% for Whites. NLAAS's response rate was 75.5% for the Latino surveys and 65.6% for the Asian surveys.

Sample Size: Unknown

Data Collection

Dates of Collection: The majority of all respondents were interviewed in 2001.

Method: Primary data collection

Data Collection Tools: The vast majority of all the interviews were administered by lay interviewers using computer-assisted personal (face-to-face) interviews (CAPI). All interviews started as CAPI interviews. Some interviews were administered by phone if an interviewer was not available locally who spoke the respondent's preferred language or if the respondent preferred to be interviewed over the phone. Some interviews were also very long and had to be completed in more than one session, with later sessions more likely to be conducted over the phone. The core questionnaire was based largely on the World Health Organization's (WHO) expanded version of the Composite International Diagnostic Interview (CIDI) developed for the World Mental Health (WMH) Survey Initiative, the WMH-CIDI.

Periodicity of Updates: New data is not collected but periodic 'data cleaning' updates occur (see notes).

Domains of Health-Related Measures: See individual studies

Known Linkages: None

Data Access Costs: Unknown

Citation or Website: http://www.icpsr.umich.edu/CPES/index.html

Notes: Much information about CPES and its constituent surveys is available in Special Issue 2 of the International Journal of Methods in Psychiatric Research, Volume 13, Number 4, 2004 entitled "The NIMH Collaborative Psychiatric Epidemiology Surveys Initiative

The master CPES datasets are periodically updated as various, typically small, errors are detected. Diagnostic algorithms are periodically updated as well. This updating will continue in the future as needed and public users will be informed of these updates. It is important for public users to recognize that, these changes will be impossible to reproduce results reported in earlier publications.

Family Health Study

At-a-Glance
U.S.: Wisconsin
Primary Data
Adults & Children
Annual

Narrative Description: The Wisconsin Family Health Survey is a statewide random-sample telephone survey of all household residents, including children. This survey includes topics such as health insurance coverage, health status, health problems, and use of health care services.

I/DD Group Identification

Included in broader 'Disability' subgroup: Yes

I/DD Group Uniquely Identifiable? No

Questions (data fields) identifying 'I/DD' or 'Disability': Question about adults in household: Do they have any physical or mental limitations?

Notes on ID Identification: Identifying question is asked of single-household responder

Study Methodology

Inclusion Criteria: People living in homes with a working landline telephone in Wisconsin

Exclusion Criteria: None

Sampling Methodology: The Family Health Survey uses a random sample of all Wisconsin households with landline telephones through Random Digit Dialing. Each county is sampled separately in seven strata. An eighth sample stratum consisted of telephone prefixes previously found to include at least 20 percent black respondents. This oversample, primarily within Milwaukee, was necessary to assure sufficient representation of the black or African American population in survey results.

Response Rate: The final overall response rate was 52 percent. (2009, Wisconsin Health Insurance Coverage, 2009. Annual report completed in October 2010)

Sample Size: 2,400 Wisconsin households are sampled each year. Annual data set includes about 6,000 Wisconsin household residents. (per October 25, 2007 webcast)

Data Collection

Dates of Collection: 1995 - present

Method: Primary data collection

Data Collection Methodology Details: Telephone survey, conducted throughout the year. Questions are answered by one person in the household. Each telephone number was called at least 10 times before being designated unanswered. The adult in each household who knows the most about the health of all household members is selected to answer all survey questions during the telephone interview.

Data Collection Tools: Phone interview

Periodicity of Updates: Annual

Domains of Health-Related Measures: Health Status and Activity Limitations

Health Care Utilization

Health Conditions

Health Insurance

Employment Insurance

Program Participants

Social Connectedness & Emergency Preparedness

Demographics

Income

Known Linkages: None

Data Access Costs: Unknown

Citation or Website: http://www.dhs.wisconsin.gov/stats/familyhealthsurvey.htm

Notes: Land-line only sampling, excludes younger households and more minorities that may be cell-phone only, or unavailable during survey times. Unlikely that people with ID/DD will respond.

Medical Expenditure Panel Survey (MEPS)

At-a-Glance
U.S.
Adults & Children
Primary Data
Annual

Narrative Description: The Medical Expenditure Panel Survey (MEPS) is a set of large-scale surveys focusing on families and individuals, their medical providers, and employers across the United States. MEPS is the most complete source of data on the cost and use of health care and health insurance coverage.

MEPS currently has three major components: the household component, the insurance component, and the medical provider component. The Household component data are based on questionnaires given to individual household members and their medical providers. The insurance component estimates come from a survey of employers to collect health insurance plan information. The medical provider component samples hospitals, physicians, home health care providers, and pharmacies. (In 1996 only, MEPS also included a Nursing Home Component that gathered information from a sample of nursing homes and residents. These data are only available through the AHRQ Data Center or one of the Census Bureau's Research Data Centers.)

The **household component** is explained in detail in this section.

I/DD Group Identification

Included in broader 'Disability' subgroup: Yes, for adults

I/DD Group Uniquely Identifiable? Yes, only for children

If yes, is it possible to separate DD from ID? No

Questions (data fields) identifying 'I/DD' or 'Disability':

Does anyone in a household experience confusion or memory loss that interferes with daily activities or has problems making decisions to the point that it interferes with daily activities? (COGLIM31)

Does anyone in a household require supervision for their own safety? (COGLIM53)

Notes on ID Identification: N/A

Study Methodology

Inclusion Criteria: Respondents are drawn from the previous year's National Health Interview Survey

Exclusion Criteria: Institutionalized persons (Included in 1996 only)

Sampling Methodology: The MEPS usesa complex sampling methodology to ensure a nationally representative population. The MEPS-HC collects data from a nationally representative sample of households through an overlapping panel design. A new panel of sample households are selected each year, and data for each panel is collected for two calendar years. The two years of data for each panel are collected in five rounds of interviews over a two and a half year period. This provides continuous and current estimates of health care expenditures at both the individual and household level for two panels each calendar year.

Response Rate: 63% in 2009

Sample Size: Approximately 30,000 individuals per year

Data Collection

Dates of Collection: 1996 to present

Method: Primary data collection

Data Collection Methodology Details: MEPS is a large-scale and comprehensive data collection effort that includes many types of survey questions, some only pertaining to subsets of the diverse respondents participating in the survey. Data is collected using an intricate system of skip patterns and questionnaire modules grouped into sections. Computer-assisted personal interview (CAPI) using a laptop computer.

Data Collection Tools: Survey questionnaire

Periodicity of Updates: A new panel of sample households selected each year, and data for each panel are collected for two calendar years.

Domains of Health-Related Measures: Access to health care; physical and mental health conditions identified through medical events or disability days; dental care, health conditions requiring emergency room care, health status, medical provider visits, priority conditions, prescribed medications. Details available at http://www.meps.ahrq.gov/mepsweb/survey_comp/hc_ques_sections.jsp

Known Linkages: In May 2011, MEPS data from 1996 through 2009 will be linked to person records on NHIS files. Because the NHIS is linked with Social Security Administration, Medicare, and National Death Index data, and soon will be linked to Medicaid data, the MEPS also will be linked with these sources.

Data Access Costs: The AHRQ Data Center charges a user fee of $300.00 for approved Data Center projects to cover technical assistance, simple file construction, and up to four hours of programming support. This fee will be waived for full-time graduate students working on dissertations or other degree requirements, and Federal Government agencies. The Data Center fee is also waived for using a Census Bureau's Remote Data Center (RDC); however, the applicant will be responsible for any additional fees required by the Census Bureau while working at the RDC.

Citation or Website: http://www.meps.ahrq.gov/mepsweb/

National Health and Nutrition Examination Survey (NHANES)

At-a-Glance
U.S.
Adults & Children
Primary Data
Annual

Narrative Description: The National Health and Nutrition Examination Survey (NHANES) is a program of studies designed to assess the health and nutritional status of adults and children in the United States. The survey uniquely combines interviews and physical examinations. NHANES is a major program of the National Center for Health Statistics (NCHS). NCHS is part of the Centers for Disease Control and Prevention (CDC) and has the responsibility of producing vital and health statistics for the Nation.

The NHANES program began in the early 1960s and has been conducted as a series of surveys focusing on different population groups or health topics. In 1999, the survey became a continuous program with a changing focus on a variety of health and nutrition measurements to meet emerging needs. The survey examines a nationally representative sample of about 5,000 persons each year. These persons are located in counties across the country, 15 of which are visited each year.

The NHANES interview includes demographic, socioeconomic, dietary, and health-related questions. The examination component consists of medical, dental, and physiological measurements, as well as laboratory tests administered by highly trained medical personnel.

Findings from this survey will be used to determine the prevalence of major diseases and risk factors for diseases. Information will be used to assess nutritional status and its association with health promotion and disease prevention. NHANES findings are also the basis for national standards for such measurements as height, weight, and blood pressure. Data from this survey is used in epidemiological studies and health sciences research, which help develop sound public health policy, direct and design health programs and services, and expand the health knowledge for the Nation.

I/DD Group Identification

Included in broader 'Disability' subgroup:

I/DD Group Uniquely Identifiable? No

Questions (data fields) identifying 'I/DD' or 'Disability': In the physical functioning section, question PFQ063B asks people aged 5 years or older about functional limitations in activities caused by long-term physical, mental, and emotional problems or illness. If a functional limitation is reported, the respondent is then asked what condition or health problem causes them to have difficulty or need help with the activity. "Mental retardation" is one of the response options to this question. This question was Included starting with the 2005-2006 data.

Difficulties asked about include:

- Managing money
- Walking for a quarter
- Walking up ten steps
- Stooping, crouching, kneeling
- Lifting or carrying 10 pounds
- Doing chores around the house
- Preparing meals
- Getting in and out of bed
- Walking between rooms on the same floor
- Standing up from an armless chair
- Using a fork or knife or drinking from a cup
- Dressing yourself
- Standing up for long periods
- Sitting for long periods
- Reaching up over head
- Grasping/holding small objects

- Going out to things like shopping, movies or sporting events
- Attending social events
- Doing things to relax at home or for leisure
- Pushing or pulling large objects

Notes on ID Identification: This survey asks about I/DD as a reason for a specific activity limitation. It may miss people who have I/DD but do not report certain limitations.

Study Methodology

Inclusion Criteria:

Exclusion Criteria:

Sampling Methodology: Starting in 2007, a new sampling methodology was implemented. All Hispanics were oversampled, instead of just Mexican Americans. Also, adolescents are no longer oversampled.

Primary Sampling Units are generally single counties, although small counties are sometimes combined to meet a minimum population size. In the years 1999-2001, NHANES was based on a design linked to the National Health Interview Survey (NHIS). The NHANES PSUs were a subset of the PSUs previously selected for the NHIS. An independent set of PSU's was selected for 2002-2006; the sampling frame for this design was all counties in the United States.

The additional stages of selection in the probability design for NHANES 1999-2004 remain very similar to past NHANES designs. Clusters of households are selected, each person in a selected households is screened for demographic characteristics, and one or more persons per household are selected for the sample.

Response Rate: For NHANES 2009-2010, there were 13,272 persons selected for the sample, 10,537 of those were interviewed (79.4 percent) and 10,253 (77.3 percent) were examined in the MEC.

Sample Size: about 5,000 people annually

Data Collection

Dates of Collection: early 1960s - present

Method: primary data collection

Data Collection Tools: Direct survey and examination

Health interviews are conducted in respondents' homes. Health measurements are performed in specially-designed and equipped mobile centers, which travel to locations throughout the country. The study team consists of a physician, medical and health technicians, as well as dietary and health interviewers. Many of the study staff are bilingual (English/Spanish).

Periodicity of Updates: annually

Domains of Health-Related Measures: The NHANES interview includes questions about health behaviors, substance use, physical fitness and activity, weight, reproductive health and dietary intake. The examination component consists of medical, dental, and physiological measurements, as well as laboratory tests administered by trained medical personnel.

Data Access Costs: Free. For data users and researchers, survey data are available on the internet and on easy-to-use CD-ROMs.

See access policy: http://www.cdc.gov/nchs/data/nhanes/nhanes_release_policy.pdf

Known Linkages: SSA, mortality, medicare utilization and expenditure survey

Citation or Website: http://www.cdc.gov/nchs/nhanes.htm

http://www.cdc.gov/nchs/nhanes/nhanes2009-2010/PFQ_F.htm

Notes: Survey administration involves a cognitive testing process.

Out of the approximately 9,000 surveys done each year, it looks like there are less than 10 people reporting difficulty due to mental retardation in any given year, and the data is missing for about half (and sometimes more) of the respondents for most questions in this section. 253 people aged 19 and under reported receiving special education or EI.

National Health Interview Survey on Disability (NHIS-D)

At-a-Glance
U.S.
Primary Data
Adults & Children
Once; no updates

Narrative Description: Prompted by the passage of the ADA in 1990, several collaborating federal agencies planned this survey to gather information for understanding and developing disability policy. Administered over a 2-year period (1994-1995) as part of the NHIS.

I/DD Group Identification

I/DD Group Uniquely Identifiable? Yes

If yes, is it possible to separate DD from ID? Yes

Questions (data fields) identifying 'I/DD' or 'Disability': DD conditions, ADL and IADL items, functional limitation questions. MR identified in Section II, Part B, Q1a.

Notes on ID Identification: Contains extensive information about functioning, specific conditions, and duration of individual impairments.

Study Methodology

Inclusion Criteria: U.S. households and non-institutionalized group living quarters

Exclusion Criteria: Institutional group living settings

Sampling Methodology: Four representative panels of U.S. households. Oversampled for Black persons in 1994.

Response Rate: 90%

Sample Size: 49,000 households containing 132,000 persons (1994 sample)

Data Collection

Dates of Collection: 1994-1995

Method: Primary data collection

Data Collection Tools: In-person survey tool

Periodicity of Updates: Only administered once

Domains of Health-Related Measures: Health conditions and service utilization, some current health topics

Known Linkages: Linked to Medicare enrollment and claims data

Data Access Costs: Unknown

Citation or Website: http://www.cdc.gov/nchs/nhis/nhis_disability.htm

Notes: The data from the one collection can inform the health status of people with I/DD. The methods and models of collection have potential application in future surveillance efforts.

National Home and Hospice Care Survey, 2007

At-a-Glance
U.S.
Primary Data on Agencies
N/A
Last updated in 2007

Narrative Description: The 2007 National Home and Hospice Care Survey (NHHCS) is one in a continuing series of nationally representative sample surveys of U.S. home health and hospice agencies. It is designed to provide descriptive information on home health and hospice agencies, their staffs, services, and patients. NHHCS was first conducted in 1992 and repeated in 1993, 1994, 1996, 1998, 2000, and 2007.

I/DD Group Identification

I/DD Group Uniquely Identifiable? Yes

If yes, is it possible to separate DD from ID? Unclear

Questions (data fields) identifying 'I/DD' or 'Disability': Diagnoses listed using ICD-9 codes

Study Methodology

Inclusion Criteria: All agencies that participated in the survey were either certified by Medicare and/or Medicaid or licensed by a state to provide home health and/or hospice services and currently or recently served home health and/or hospice patients.

Exclusion Criteria: Agencies that provided only homemaker services or housekeeping services, assistance with instrumental activities of daily living (IADLs), or durable medical equipment and supplies were excluded .

Sampling Methodology: Stratified, two stage probability design

Response Rate: Agency response rate of 71% unweighted and 59% weighted; Patient response rate of 95% unweighted and 96% weighted.

Sample Size: 1036 agencies and 9416 patients (2007) - see website for more details

Data Collection

Dates of Collection: first conducted in 1992 and repeated in 1993, 1994, 1996, 1998, 2000, and 2007

Method: Primary collection through interviews with agency staff and review of records

Data Collection Tools: Questionnaires

Periodicity of Updates: Last updated in 2007

Health-Related Measures

Domains of Health-Related Measures: Functioning, aids needed, services provided, medications, advance directives, insurance and payer information

Known Linkages: National Home Health Aide Survey (supplemental survey)

Potential Linkages: Possibly other NCHS surveys.

Data Access Costs: Available through NCHS Research Data Center: http://www.cdc.gov/rdc/B5AprovProj/AP540.htm

Citation or Website: http://www.cdc.gov/nchs/nhhcs.htm

For more information: http://www.cdc.gov/nchs/nhhcs/nhhcs_questionnaires.htm

Notes: Potential to exploring further for health surveillance of people with I/DD receiving home and hospice care. Appears to have good data on medications, and use of advance directives in long-term care populations (see data brief on website).

National Latino and Asian American Study

At-a-Glance
U.S.
Primary Data
Adults
Once; no updates

Narrative Description: Provides national information on similarities and differences in mental illness and service use of Latinos and Asian Americans.

I/DD Group Identification

Included in broader 'Disability' subgroup: Yes

I/DD Group Uniquely Identifiable? No

Questions (data fields) identifying 'I/DD' or 'Disability': Screening Document, section 10.4

Study Methodology

Inclusion Criteria: Respondents were required to be 18 years of age or older, living in the non-institutionalized population of the coterminous United States or Hawaii, of Latino, Hispanic, Spanish , or Asian descent.

Exclusion Criteria: None

Sampling Methodology: Unclear

Response Rate: Unclear

Sample Size: 2,554 Latino respondents and 2,095 Asian American respondents. http://www.multiculturalmentalhealth.org/nlaas.asp#docs

Data Collection

Dates of Collection: May 2002 - November 2003

Method: Primary data collection

Data Collection Methodology Details: Unclear

Data Collection Tools: Unclear, seems to be an interviewer-administered survey

Periodicity of Updates: None

Domains of Health-Related Measures: Mental Health disorders and chronic conditions, service utilization

Known Linkages: None

Data Access Costs: Free

Citation or Website: http://www.multiculturalmentalhealth.org/nlaas.asp

For more information: cpes@icpsr.umich.edu

Notes: Epidemiologic survey to estimate prevalence, but not an ongoing survey

National Longitudinal Survey of Adolescent Health

At-a-Glance
U.S.
Primary Data
Adolescents
Once; no updates

Narrative Description: Longitudinal study of a nationally representative sample of adolescents in grades 7-12 in the United States during the 1994-95 school year. The cohort has been followed into young adulthood with four in-home interviews, most recently in 2008. Combines longitudinal survey data on respondents' social, economic, psychological and physical well-being with contextual data on the family, neighborhood, community, school, friendships, peer groups, and romantic relationships.

I/DD Group Identification

I/DD Group Uniquely Identifiable? Yes

If yes, is it possible to separate DD from ID? No

Questions (data fields) identifying 'I/DD' or 'Disability': In-Home Parent Questionnaire, question C37

Notes on ID Identification: Parent indicates if student is "mentally retarded" in Wave I, also asks about disability in general. This information is only available in the In-Home part of the survey. The following details in this profile pertain only to the In-Home survey.

Study Methodology

Inclusion Criteria: Wave I: High school included 11th grade and had more than 30 students. "Feeder" school included 7th grade and sent more than 5 students to that high school. All students on the "feeder" school roster were eligible to participate.

Wave II: All adolescents in In-Home interview in Wave I.

Wave III: All those from Wave I who could be located and re-interviewed.

Wave IV: All those from Wave I who could be located and re-interviewed.

Exclusion Criteria: Wave I: High schools with no 11th grade and fewer than 30 students. "Feeder" schools that sent fewer than 5 students to the high schools. Schools that refused to participate. Students and/or parents who refused to participate.

Sampling Methodology: Wave I: 80 high schools representative of U.S. schools with respect to region of country, urban city, size, type, and ethnicity were selected. Each high school identified "feeder" schools - schools that included 7th grade and sent more than 5 students to that high school. All students on the "feeder" school roster were eligible to participate. For In-Home questionnaire, students on the roster were stratified by grade and sex, about 17 students were selected from each stratum. Parent of each adolescent was asked to complete the Parent Questionnaire.

Response Rate: Unclear for In-Home respondents. Wave IV: 80.3% of eligible sample interviewed (presumably of all those in Wave I)

Sample Size: Wave I (1995): 12,015 adolescents in In-Home questionnaire.

Data Collection

Dates of Collection: Wave I: April-December 1995.

Wave II: April-August 1996.

Wave III: August 2001- April 2002.

Wave IV: 2007-2008.

Method: Primary data collection

Data Collection Methodology Details: In-person survey

Data Collection Tools: http://www.cpc.unc.edu/projects/addhealth/codebooks

Periodicity of Updates: No updates

Domains of Health-Related Measures: Questions on health, health care utilization, other disabilities, illnesses, medications, physical and biological measurements.

Known Linkages: None

Potential Linkages: Possibly using SSN or the identifier that was used to find original sample members.

Data Access Costs: Public- use data - free. Restricted-use data - unclear

Citation or Website: http://www.cpc.unc.edu/projects/lifecourse/research_projects/add_health

For more information: Russ Hathaway, ICPSR   rhataway@umich.edu

National Longitudinal Transition Study-2

At-a-Glance
U.S.
Primary Data
Children Only
Longitudinal study with closed cohort

Narrative Description: National Longitudinal Transition Study-2 (NLTS2) is funded by the U.S. Dept. of Education and involves a large, nationally representative sample of students receiving special education who were ages 13 through 16 and in at least 7th grade on December 1, 2000. The oldest youth will be 26 at the time of final data collection. Statistical summaries generated from NLTS2 will generalize to students receiving special education nationally in this age group, to each of the 12 federal special education disability categories, and to each single-year age cohort.

I/DD Group Identification

I/DD Group Uniquely Identifiable? Yes

If yes, is it possible to separate DD from ID? No

Questions (data fields) identifying 'I/DD' or 'Disability': Unclear

Notes on ID Identification: Three different data sources identify the student's disability: Disability category assigned by LEA, Parent report of "disabilities or conditions" for which student receives special education, Disabilities (including secondary conditions) noted in student

Likelihood of including people with I/DD: Definitely included

Study Methodology

Inclusion Criteria: The NLTS2 data collection plan is designed to collect in-depth longitudinal information on the secondary school and postsecondary experiences of 13- to 16-year-olds in at least 7th grade and receiving special education services at the beginning of the 2000-2001 school year.

Exclusion Criteria:

Sampling Methodology: Stratified sample, see http://www.nlts2.org/studymeth/nlts2_sampling_plan2.pdf for details

Response Rate: Repeat response rate expected to be about 75%. Unable to find actual rate

Sample Size: 2649 expected in cohort. Based upon enrollment data broken out by disability category

http://www.nlts2.org/studymeth/nlts2_sampling_plan2.pdf

Data Collection

Dates of Collection: fall 2000 - 2010

Method: Primary data collection

Data Collection Tools: Questionnaires given to multiple sources: student, parent, teacher, school

Periodicity of Updates: None -- longitudinal study with closed cohort

Domains of Health-Related Measures: Physical health : general health status, regular exercise, risk behaviors, hospitalizations.

Activity and substance use as reported by students.

Also, questions related to some mental health domains, sexual activity/STDs, health services

Known Linkages: None

Data Access Costs: Appears to be free. http://www.nlts2.org/data_tables/datatable_training.html

Citation or Website: http://www.nlts2.org/index.html

National Vital Statistics System

At-a-Glance
U.S.
Secondary Data
Adults & Children
Ongoing collection

Narrative Description: The National Vital Statistics System is the oldest and most successful example of inter-governmental data sharing in Public Health. The shared relationships, standards, and procedures form the mechanism by which the National Center for Health Statistics (NCHS) collects and disseminates the Nation's official vital statistics. These data are provided through contracts between NCHS and vital registration systems operated in the various local jurisdictions legally responsible for the registration of vital events – births, deaths, marriages, divorces, and fetal deaths. Additional programs related to the National Vital Statistics System include:

- Linked Birth and Infant Death Data Set (birth/infant death)
- National Survey of Family Growth (reviewed separately - JB)
- Matched Multiple Birth Data Set (birth data only)
- National Death Index (NDI)(reviewed separately)
- National Maternal and Infant Health Survey (1988)
- National Mortality Followback Survey (1993)

I/DD Group Identification

Included in broader 'Disability' subgroup: Possibly

I/DD Group Uniquely Identifiable? Possibly through ICD-9 codes

If yes, is it possible to separate DD from ID? Possibly through ICD-9 codes

Questions (data fields) identifying 'I/DD' or 'Disability': Possibly diagnosis codes

Notes on ID Identification: N/A

Study Methodology: See individual data sources

Known Linkages: None.

Potential Linkages: The death information has potential for linkage to many other sources given the often public availability of identifying fields such as social security number, date of birth and name (per state laws). With increased protections, the other data sources may have application for linkage to many other sources using these fields.

Data Access Costs: Unknown

Citation or Website: http://www.cdc.gov/nchs/nvss.htm

North Carolina Behavioral Risk Factor Surveillance System (BRFSS) Survey, 2001

At-a-Glance
U.S.: North Carolina
Primary Data
Adults
One time collection

Narrative Description: Data provided by the NC State Center for Health Statistics. A random telephone survey of adults (not ID-specific) designed to collect information about health status, health behaviors, and use of health services related to the leading causes of illness and death. This is a state-added questionnaire. In 2000, a set of questions about disability were added to the survey for that year. This is a follow-up survey with wave 1 and wave 2.

I/DD Group Identification

Included in broader 'Disability' subgroup: Yes

I/DD Group Uniquely Identifiable? No

Questions (data fields) identifying 'I/DD' or 'Disability': Disability status is determined by a respondent answering YES to any of these questions: 1) "Are you limited in any way in any activities because of physical, mental, or emotional problems?" (2) "Do you now have any health problem that required you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone?" (3) "A disability can by physical, mental, emotional, or communication related. Do you consider yourself to have a disability?" (4) "Because of any impairment of health problem, do you have any trouble learning, remembering, or concentrating?" What has a doctor said is the major health problem, long-term illness, or disability that the person you care for has?

Study Methodology

Inclusion Criteria: A "No" answer on all four questions were assigned to the "No Disability" group

Exclusion Criteria: None

Sampling Methodology: Population is any NC resident with a phone. Subjects were contacted by phone.

Response Rate: Unknown

Sample Size: 1598 in the Disability group; 946 in the DD group.

Data Collection

Dates of Collection: Data collected in 2000; reported in 2001

Method: Primary data collection

Data Collection Methodology Details: Additional survey questions about disability:

- Are you limited in any way in any activities because of physical, mental, or emotional problems?
- Do you now have any health problem that requires you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone?

- A disability can be physical, mental, emotional, or communication related. Do you consider yourself to have a disability?
- When did your disability begin?
- Because of any impairment or health problem, do you have any trouble learning, remembering, or concentrating?
- What is the farthest distance you can walk by yourself, without any special equipment or help from others?
- What is your major impairment or health problem?
- For how long have your activities been limited because of your major impairment or health problem?
- Because of any impairment or health problem, do you need the help of other persons with your PERSONAL CARE needs, such as eating, bathing, dressing, or getting around the house?
- Because of any impairment or health problem, do you need the help of other persons in handling your ROUTINE NEEDS, such as everyday household chores, doing necessary business, shopping, or getting around for other purposes?
- Is there anyone else)in your household who is limited in any way in any activities because of any physical, mental, or emotional problem or who uses special equipment?
- How much does your disability, impairment, or health problem limit the amount or type of work you can do at a job, at school, or around the house?
- How much does your disability, impairment, or health problem limit you in other activities, such as sports, social and community life, or family life?

Data Collection Tools: Telephone survey

Periodicity of Updates: Questions in the follow-up survey were only asked in 2000

Domains of Health-Related Measures: Physical activity: "no exercise in the past month"; tobacco use; obesity; inadequate emotional support (no one to talk to about personal things or often feels lonely), high blood pressure, cardiovascular disease, arthritis, diabetes, chronic pain, never had a pap test, never had a mammogram, never had a dentist visit or no visit in last 5 years; never had teeth cleaning or no cleaning in past 5 years; general health status

Known Linkages: None

Data Access Costs: Unknown

Citation or Website: http://www.epi.state.nc.us/SCHS/brfss/results.html

Notes: website for general BRFSS study: http://www.cdc.gov/brfss/

Online Survey Certification and Reporting (OSCAR)

At-a-Glance
U.S.
Primary Data
Adults and Children
Every 15 months, Rolling per facility

Narrative Description: Online Survey, Certification and Reporting (OSCAR) is a data network maintained by the Centers for Medicare and Medicaid Services, (CMS) in cooperation with the state long-term care surveying agencies. OSCAR is a compilation of all data elements collected by surveyors during the inspection survey conducted at nursing facilities for certification and participation in Medicare and Medicaid.

OSCAR is the most comprehensive source of facility level information on the operations, patient census and regulatory compliance of nursing facilities. Data elements collected on CMS forms 1539, 671, 672, 673 and 2567 are included in OSCAR data.

The OSCAR database includes nursing home operational characteristics and aggregate patient characteristics for each facility. Onsite evaluations are conducted by state survey agencies. The findings of these surveys are entered into the OSCAR database. The evaluations occur at least once during a 15-month period, or when investigating a complaint being investigated. Information on nursing homes operational characteristics are reported on CMS Form 671, and patient characteristics are reported on CMS Form 672.

I/DD Group Identification

I/DD Group Uniquely Identifiable? Yes

If yes, is it possible to separate DD from ID? Yes

Questions (data fields) identifying 'I/DD' or 'Disability': F108 on CMS form 672 "Mental Retardation" http://www.cms.gov/cmsforms/downloads/CMS672.pdf

Notes on ID Identification: Mental Retardation'(F108) is one resident condition noted under 'Mental Status'.

Study Methodology

Inclusion Criteria: Nursing home residents in CMS certified nursing homes at the time of survey.

Exclusion Criteria: None

Sampling Methodology: 100% of the residents in the facility are surveyed

Data Collection

Dates of Collection: Ongoing.

Method: Primary but aggregate reporting

Data Collection Tools: CMS forms 1539, 671, 672, 673 and 2567

Periodicity of Updates: Facilities must be surveyed at least once during any 15 month period.

Domains of Health-Related Measures: ADLs (functional), diagnoses, categories of care (hospice, chemotherapy….), assistive devices.

Known Linkages: None

Data Access Costs: Unknown

Citation or Website: None. Basic information is available here: http://www.medicare.gov/NHCompare/Static/tabSI.asp?language=English&activeTab=3&subTab=0

Notes: Data are reported in aggregate by states. Most resident level info is from the Minimum Data Set. It might be possible to analyze de-identified individual level information on nursing home residents.

OSCAR may be changing its name to CASPER or QIES.

When facilities are surveyed, new survey data overwrites previous data, limiting OSCAR's usefulness as a research database. Data are kept only for 1 year, except for aggregate resident characteristics and deficiency information, which are kept for four inspection surveys. A large amount of OSCAR data is available for annual cross-sections released by HCFA on the Provider of Service Public Use File. Certain groups such as the Cowles Research Group (CRG) routinely purchase and archive the complete OSCAR database, which may make it more useful for research. (http://www.longtermcareinfo.com/about_oscar.html)

Panel Study of Income Dynamics (PSID)

At-a-Glance
U.S.
Primary Data
Adults & Children
Usually every 2 years

Narrative Description: The Panel Study of Income Dynamics (PSID), begun in 1968, is a longitudinal study of a representative sample of U.S. individuals (men, women, and children) and the family units in which they reside. It emphasizes economic and demographic behavior, but its content is broad, including sociological and psychological measures. The study is conducted at the Survey Research Center, Institute for Social Research, University of Michigan and is funded by the National Institute of Child Health and Human Development, the National Science Foundation, and the Economic Research Service of U.S. Department of Agriculture. http://psidonline.isr.umich.edu/

Additional studies within the PSID are the **Child Development Supplement (CDS waves I-II-III)**(1997,2002, 2007), funded by the National Institute of Child Health and Human Development, the National Science Foundation, and the Economic Research Service of U.S. Department of Agriculture. This study focused on the human capital development of approximately 3,600 children age 0-12 in PSID families, and included extensive measures of the children's home environment, family processes, children's time diaries in home and school, school and day care environment, and measures of their cognitive, emotional and physical functioning. The process occurs through personal interviews.

The **Transition into Adulthood Study** (2005, 2007, 2009, 2011) This study was designed to collect information from all children who had participated in the Child Development Supplement who had turned age 18 and had completed high school and had families still active in PSID. The study collects data on young adult developmental pathways and outcomes, filling a gap between the detailed information about development from early and middle childhood through adolescence (as measured in CDS-I, CDS-II, and CDS-III), and the detailed information on adulthood once these youth assume the role of economic independence and become PSID heads and wives.

Disability and Use of Time (2009), interviewed 395 couples in PSID in which at least one spouse was over age 60.

I/DD Group Identification

Included in broader 'Disability' subgroup: Yes

I/DD Group Uniquely Identifiable? Yes, for those included as children.

Questions (data fields) identifying 'I/DD' or 'Disability': For children, CDS asks primary caregiver specifically if doctor has ever told them the child has mental retardation in 1997, 2002 and 2007 surveys. (Q31A4H)

For adults, mental impairments identified using three questions from the 2011 PSID (and previous years). These questions identify whether a doctor has ever told the person that they have or had: (1) any emotional, nervous, or psychiatric problems; (2) permanent loss of memory or loss of mental ability; or (3) a learning disorder. The age at onset/diagnosis is also asked. The PSID restricts the questions used to identify disability to heads and wives of a family unit.

Notes on ID Identification: Modified Woodcock Johnson included in main study but no clear definition in data. See p. 9 of http://digitalcommons.ilr.cornell.edu/cgi/viewcontent.cgi?article=1207&context=edicollect for details of disability definition.

Study Methodology

Inclusion Criteria: The original PSID core sample is representative of the population of U. S. households in 1967. The sample has remained representative of the non-immigrant population over time by including new family members and following old family members as they leave to form new families. In 1997, to make the PSID representative of the entire U.S. population, the PSID added a sample of immigrant families who arrived after 1967.

Exclusion Criteria: Residents of institutions

Sampling Methodology: The original 1968 PSID sample consisted of two independent samples: a cross-sectional national sample and a national sample of low-income families. The cross-sectional sample was drawn by the Survey Research Center (SRC). Commonly called the SRC sample, this was an equal probability sample of households from the 48 contiguous states and was designed to yield about 3,000 completed interviews. The second sample came from the Survey of Economic Opportunity (SEO), conducted by the Bureau of the Census for the Office of Economic Opportunity. In the mid-1960's, the PSID selected about 2,000 low-income families with heads under the age of sixty from SEO respondents. The sample, known as the SEO sample, was confined to Standard Metropolitan Statistical Areas (SMSA's) in the North and non-SMSA's in the Southern region. The PSID core sample combines the SRC and SEO samples.

Sampling details by year available at http://psidonline.isr.umich.edu/Guide/documents.aspx

Response Rate: Unknown

Sample Size: PSID interviewed 8,690 families, including 24,385 individuals in 2009.

Data Collection

Dates of Collection: Began in 1968, usually every 4 years.

Method: Primary data collection

Data Collection Methodology Details: Primarily telephone survey with computer assisted interviewing. If no phone in household then in-person interview conducted.

Data Collection Tools: All questionnaires for Main Interview, CDS and TA at http://psidonline.isr.umich.edu/Guide/documents.aspx

Periodicity of Updates: Somewhat funding dependent. Usually every 4 years.

Domains of Health-Related Measures: This study focuses on work-limitation and economic measures but also asks the head of household/wife about health diagnoses, BMI, and diagnoses that have been given by a physician.

See Appendix B of The GUIDE to DISABILITY DATA in PSID for complete list of questions. http://digitalcommons.ilr.cornell.edu/cgi/viewcontent.cgi?article=1207&context=edicollect

Known Linkages: None

Data Access Costs: Unknown

Citation or Website: http://psidonline.isr.umich.edu/

For more information: A guide to disability statistics in the Panel Study of Income Dynamics http://digitalcommons.ilr.cornell.edu/cgi/viewcontent.cgi?article=1207&context=edicollect

Notes: Changes in PSID collection methods over time, and especially the lack of information on family members other than the head (and, beginning in 1981, his wife) limit the PSID data’s ability to capture overall trends in the United States adult population with disabilities. Although the CDS does identify children who have an intellectual disability, the sample size is small. As a longitudinal study, it does offer some methodological guidance for a targeted study.

Social Security Statistical Supplements *(or Annual Statistical Supplement)*

At-a-Glance
U.S.
Secondary data
Adults
Annual

Narrative Description: Annual reports on program recipients in the OASDI, SSI, Medicare, Medicaid, Unemployment Insurance, Workers Compensation, Temporary Disability Insurance, Black Lung Benefit and Veteran's Benefit.

I/DD Group Identification

Included in broader 'Disability' subgroup: Yes

I/DD Group Uniquely Identifiable? No

Questions (data fields) identifying 'I/DD' or 'Disability':

The Disabled Adult Child eligibility (for OASDI retired or disabled parent). See Table 3.c6 at http://www.ssa.gov/policy/docs/statcomps/supplement/2010/3c.html

Disabled adult child is defined as an individual who is 18 years of age or older and has a disability that began before age 22. (http://www.workworld.org/wwwebhelp/ssdac.htm) Disability is defined as "The inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months". (http://www.workworld.org/wwwebhelp/didisability.htm)

Notes on ID Identification: Adults with I/DD likely meet the above criteria for 'Disabled Adult Child' and are included.

Study Methodology

Inclusion Criteria: Recipients of social benefits programs noted under 'description'

Exclusion Criteria: None

Data Collection

Dates of Collection: Unknown

Method: Existing Records

Periodicity of Updates: Annual report

Domains of Health-Related Measures: Refer to individual studies

Known Linkages: None

Data Access Costs: Unknown

Citation or Website: http://www.ssa.gov/policy/docs/statcomps/supplement/

Survey of Income and Program Participation (SIPP)

At-a-Glance
U.S.
Primary Data
Aged 15+
Conducted 4 times

Narrative Description: The Survey of Income and Program Participation (SIPP) is a multi-panel, longitudinal survey conducted by the U.S. Census Bureau. The SIPP covers the civilian, non-institutionalized population of residents living in the United States, and collects data on source and amount of income, labor force information, program participation and eligibility data, and general demographic characteristics.

The survey design is a continuous series of national panels in which the same households are interviewed every four months for periods ranging from 2 1/2 to 4 years. Since a 1996 redesign, the Census Bureau has completed three SIPP Panels (1996, 2001, 2004) and fielded another (2008). An Automated field testing instrument was field tested in 2010 and a new, re-engineered SIPP is expected to be conducted annually beginning in 2013. The survey was also designed to provide a broader context for analysis by adding questions on a variety of topics not covered in the core section. These questions are labeled "topical modules" and assigned to particular interviewing waves of the survey. Topics covered by modules include personal history, child care, wealth, program eligibility, child support, utilization and cost of health care, disability, school enrollment, taxes, and annual income. The 2008 panel is scheduled to include topical modules on Adult and Child Functional Limitations and Disability (May 2010 - Aug 2010). Interviews are conducted by personal visit and follow-up telephone calls, with computer- assisted interviewing. All household members 15 years and older are interviewed by self-response, if possible; proxy response is permitted when individuals are unavailable for interviewing (including those under 15).

I/DD Group Identification

Included in broader 'Disability' subgroup: Yes

I/DD Group Uniquely Identifiable? Yes - in the disability topical module.

If yes, is it possible to separate DD from ID? Yes

Questions (data fields) identifying 'I/DD' or 'Disability' :

In the core interview: Do you have a physical, mental, or health condition that limits the kind of work you can do? (note, the wording of this has changed over the years)

In the disability supplement:

Does the person have: a) A learning disability such as dyslexia? b) Mental retardation? c) A developmental disability such as autism or cerebral palsy? d) Alzheimer's

http://www.infouse.com/disabilitydata/womendisability/appendices_surveys.php#sipp

Notes on ID Identification: 'Mental Retardation' is the term used.

Study Methodology

Inclusion Criteria: Civilian, non-institutionalized population of U.S. residents. All household residents 15 or older are interviewed. Individual and group quarters are included. Group quarters frame includes boarding houses, hotel rooms, and institutions 'found in the decennial census but are not counted as housing units.' (SIPP User's guide Chapter 2 SIPP Sample Design and Interview Procedures). Good surveillance source; there are shortcomings: health measures are limited, data limited to participating states only, data only include people receiving services through state I/DD systems. http://www.census.gov/population/www/cen2010/resid_rules/resid_rules.html

Exclusion Criteria: None

Sampling Methodology: According to the user's guide: Chapter :SIPP Sample Design and Interview Procedures, the sample design is complex. The Census Bureau uses a 2-stage sample design, using primary sampling units (counties linked with similar counties in same state form strata). The second stage involves sampling within primary sampling units from non-overlapping sample frames: unit area; group quarters, housing unit coverages, a coverage on census counts, a coverage improvement frame, and a new-construction frame. http://www.census.gov/sipp/usrguide.html

Response Rate: Unknown

Sample Size: The initial sample for each panel is targeted at 40,000 households. There is a noted attrition in subsequent waves. SIPP uses ratio estimation, where sample estimates are adjusted to independent estimates of the national population by age, race, sex, and Hispanic origin. This weighting partially corrects for bias due to undercoverage, but biases may still exist when people missed by the survey differ from those interviewed in ways other than the age, race, sex, and Hispanic origin. How this weighting procedure affects other variables in the survey is not precisely known. All of these considerations affect comparisons across different surveys or data sources. (Ref: http://www.census.gov/hhes/www/disability/sipp/disab02/awd02.html)

Data Collection

Dates of Collection: Since a 1996 redesign , the Census Bureau has completed three SIPP Panels (1996, 2001, 2004) and fielded another (2008).

Method: Primary data collection

Data Collection Methodology Details: Data collection in waves (8-13, depending on the panel year). Reference period for questions is the previous 4 months, unless otherwise specified. Initial visit to household with computer assisted interviewing. Follow up by phone or in-person visits.

Data Collection Tools: Specific questions available at the following link. http://www.census.gov/sipp/top_mod/2008/topmod08.html

Periodicity of Updates: 1994 - 2008 panel data currently available

Domains of Health-Related Measures: Health and Disability supplement. Gathers data for all sample members about their general health (rated poor to excellent), functional limitations (using the standard ADL battery of questions), work disability, and need for personal assistance. Respondents are asked about any hospital stays during the reference period, other periods of illness, other health facilities used, and their health insurance coverage. Information on children is collected from a designated parent or guardian. (Variations are also asked as Functional Activities, Disability Status of Children, and Disability Questions.) [84-3 for Health and Disability; 88-6, 89-3 for Functional Activities; 85-6, 86-3, 87-6, 88-3, 88-6, 89-3 for Disability Status of Children; 96-4 for Disability Questions]

Known Linkages: Linkages between core files (of SIPP) allow for cross sectional or longitudinal estimates.

Potential Linkages: From p. 333 in 'Chapter 9: Program Participants (Stapleton, Wittenburg, and Thornton) in "Counting Working Age People with Disabilities" (2009) eds: Houtenville, Stapleton, Weather, and Burkhauser.

The SIPP has been matched to Current Population Survey Data and to SSA administrative records. [Neither of these provide the ability to determine ID, and there is limited health information]

For SIPP-CPS data matches, use of SIPP – SSA data matched data requires researchers "to obtain 'Census Special Sworn Status' , have their projects approved by the Census Bureau, and the relevant agencies, and access data through the restricted-access data facilities operated by the Census Bureau. These requirements substantially limit the use of the matched data. To address this limitation, yet continue to meet confidentiality requirements, the Census bureau has created a "synthetic" SIPP file, which is available to researchers without substantial restriction. http://www.census.gov/sipp/synth_data.html The codebook (available at the link), shows that files include receipt of disability benefits by start date and total benefits received. There is no indication of the reason for eligibility for disability benefits or the any health indicators.

Data Access Costs: http://www.census.gov/sipp/

Citation or Website: data available at http://www.nber.org/data/sipp.html

For more information: Guide to Disability Statistics in the SIPP available at http://digitalcommons.ilr.cornell.edu/edicollect/1195/ Historical background and more detailed information on the SIPP can be found at http://www.sipp.census.gov/sipp . Census/ADA report: http://www.census.gov/hhes/www/disability/sipp/disab02/awd02.html

Notes: This survey identifies a population with MR/ID in topic modules, but little health information is available.

Survey of Inmates in local jails

At-a-Glance
U.S.
Primary Data
Adults
Conducted 5 times

Narrative Description: Conducted periodically, these surveys sponsored by the U.S. Census provide information on individual characteristics of jail inmates, current offenses and detention status, characteristics of victims, criminal histories, family background, gun possession and use, prior drug and alcohol use and treatment, medical and mental health history and treatment, vocational programs and other services provided while in jails, as well as other personal characteristics. Data are collected through personal interviews with a nationally representative sample of inmates in local jails. The survey utilized a two-stage sample design in which jails were selected in the first stage and inmates within local jails were selected in the second stage.

I/DD Group Identification

Included in broader 'Disability' subgroup: Yes

I/DD Group Uniquely Identifiable? Yes, possibly

If yes, is it possible to separate DD from ID? No

Questions (data fields) identifying 'I/DD' or 'Disability': One of the options for 'why were you not looking for work' is "Medical condition, ill health, or mental disability".

Notes on ID Identification: Do you have a learning disability, such as dyslexia or attention deficit disorder? Have you ever been enrolled in special education classes or SPED? Do you consider yourself to have a disability?

Study Methodology

Inclusion Criteria: The sample for the 2002 survey was selected from the universe of all jails in the U.S., which were enumerated in the 1999 Census of Jails. Inmates within the jails at the time of the survey were eligible for inclusion.

Exclusion Criteria: None

Sampling Methodology: In the 2002 Survey of Inmates in Local Jails, offenders were randomly selected from a nationally representative sample of facilities. Detailed descriptions of methodology and sample design can be found in Profile of Jail Inmates, 2002, available at http://bjs.ojp.usdoj.gov/content/pub/pdf/pji02.pdf

Response Rate: Unknown

Sample Size: 2002: nearly 7000 inmates surveyed. http://bjs.ojp.usdoj.gov/content/pub/pdf/pji02.pdf

Data Collection

Dates of Collection: 1978, 1983, 1989, 1996, and 2002

Method: Primary data collection

Data Collection Methodology Details: Face- to- face computer assisted interview.

Data Collection Tools: http://bjs.ojp.usdoj.gov/content/pub/pdf/quest_archive/siljq02.pdf
"Disability Section on Page 13"

Periodicity of Updates: No known updates planned

Domains of Health-Related Measures: Medical conditions such as diabetes, TB, heart conditions, substance abuse, mental health conditions

Known Linkages: None

Data Access Costs: Unknown

Citation or Website: Report: Medical Problems of Jail Inmates
http://bjs.ojp.usdoj.gov/content/pub/pdf/mpji.pdf

Survey of Inmates in State and Federal Correctional Facilities

At-a-Glance
U.S.
Primary Data
Adults
Last update in 2002

Narrative Description: Designed by the Department of Justice and conducted by the Census Bureau, the Survey of Inmates in State and Federal Correctional Facilities is comprised of two distinct surveys. Both surveys use the same data collection instrument, and data files resulting from combining both have the same variables and record layout. The Survey of Inmates in State Correctional Facilities (SISCF) was conducted for the Bureau of Justice Statistics (BJS) by the Bureau of the Census. The Survey of Inmates in Federal Correctional Facilities (SIFCF) was also conducted for the BJS and the Federal Bureau of Prisons (BOP) by the Bureau of the Census. These surveys provide nationally representative data on State prison inmates and sentenced Federal inmates held in Federally owned and operated facilities. Through personal interviews from June through October of the survey year, inmates in both State and Federal prisons provided information about their current offense and sentence, criminal history, family background and personal characteristics, prior drug and alcohol use and treatment programs, gun possession and use, and prison activities, programs and services. Surveys of State prison inmates were conducted in 1974, 1979, 1986, 1991 and 1997. Sentenced Federal prison inmates were first interviewed in the 1991 survey. Beginning in 1997, data collected for the State and Federal surveys were combined into one file. http://www.icpsr.umich.edu/icpsrweb/NACJD/sisfcf/#Data

I/DD Group Identification

Included in broader 'Disability' subgroup: Yes

I/DD Group Uniquely Identifiable? No

Questions (data fields) identifying 'I/DD' or 'Disability': Variables listed at http://bjs.ojp.usdoj.gov/content/pub/pdf/sisfcf04_q.pdf

There are a number of questions that may together start to suggest people in the sample that may be candidates for I/DD diagnoses. Some of these questions include:

S9Q15d. "Do you have a learning disability, such as dyslexia or attention deficit disorder?"

S9Q15g. "Have you ever been enrolled in special education classes or SPED?"

S9Q16. "Do you consider yourself to have a disability?"

Amount of schooling completed. Reason for not looking for work (S 7 Q4 b) answer 10 "in school/special program".

Question S7Q6a . Before your arrest on ___, were you living in a: In a group living situation or institution, such as a hospital, halfway house, recovery home, dormitory, etc.?

Question S7Q7g. "Were you or anyone living with you receiving public assistance or welfare, for example, Temporary Assistance for Needy Families, food stamps, Medicaid, Women, Infants and Children Program (WIC), or housing assistance, before you were admitted to prison?"

S7Q11a1. "During the month before your arrest… did you personally receive any money/income from: Social security, supplemental security income (SSI), or Social Security Disability Insurance (SSDI)?"

S7Q12b. "Was there ever a time while you were growing up that you lived in a foster home, agency or institution?"

S9Q6d. "Have you ever had a stroke or a brain injury?" (May be useful in screening out people with I/DD vs. other acquired brain injuries)

Study Methodology

Inclusion Criteria: Residents in state and federal correction facilities.

Exclusion Criteria: None

Sampling Methodology: The sample for the 2004 survey was selected from the universe of all federally-owned and -operated prisons as provided by the Federal Bureau of Prisons. The sample design was a stratified two-stage selection, in which prisons were selected in the first stage and inmates to be interviewed were selected in the second stage. In the first sampling stage, one female and two male facilities were selected with certainty based on the size of the facilities. The remaining facilities were separated into seven separate strata based on the security level of the facility and the male and female populations of each prison. Due to the large proportion of drug offenders in the Federal system, the second-stage sampling for the Federal survey involved a two-step process to ensure increased representation of nondrug offenders within the sample while still including enough drug offenders to produce reliable estimates on the drug offender population. First, an oversample of inmates was selected to ensure a large enough sample of non-drug offenders was selected; from this initial list, 1 of every 3 drug offenders was retained. The weighting procedure consisted of a base weight for each inmate, and four adjustment factors that produced the final weight for the survey.

Response Rate: Non-response in the SISCF and SIFCF resulted from failing to obtain cooperation with sample prisons (first stage non-response) or failing to obtain completed interviews with sampled inmates (second stage). In the weighting of the sample, the NIF adjusted the weights for second stage non-response. The NIF was calculated based on gender, race, age and stratum. However, biases exist in the estimates to the extent that non-interviewed inmates have different characteristics from those of interviewed inmates in the same age-gender-ethnicity-stratum group. Total non-response for each survey includes both first and second stage non-response.

Sample Size: Unknown

Data Collection

Dates of Collection: 1974, 1979, 1986, 1991, 1997, 2004. Sentenced Federal prison inmates were first interviewed in the 1991 survey.

Method: Primary data collection

Data Collection Methodology Details: Data was collected through face-to-face interviews with inmates using computer-assisted personal interviewing.

Data Collection Tools: http://bjs.ojp.usdoj.gov/content/pub/pdf/sisfcf04_q.pdf

Periodicity of Updates: Latest data available: 2002

Domains of Health-Related Measures: Alcohol, tobacco and drug use, sexual and physical assault, height and weight, medical conditions, mental health and disabilities

Known Linkages: None

Data Access Costs: Unknown

Citation or Website: Report: Medial Problems of Prisoners
http://bjs.ojp.usdoj.gov/index.cfm?ty=pbdetail&iid=1097

Notes: The Survey of Inmates in State and Federal Correctional Facilities is comprised of two distinct surveys. Both surveys used the same data collection instrument, and data files resulting from the combination of the two have the same variables and record layout. Beginning in 1997, data collected for the State and Federal surveys was combined into one file.

Information Sheets for Data Sources with Little or No Potential to Inform Health Surveillance for Adults with I/DD

America's Health Rankings

Narrative Description: America's Health Rankings combines individual measures of health determinants with the resultant health outcomes into one, comprehensive view of a state's health. Additionally, it discusses health determinants separately from health outcomes and provides related health, economic and social information to present a comprehensive profile each state's overall health.

America's Health Rankings® employs a unique methodology, developed and periodically reviewed by a panel of leading public health scholars, which balances the contributions of various factors including smoking, obesity, binge drinking, high school graduation rates, children in poverty, access to care and incidence of preventable disease, when determining a state's overall health. The report is based on data from the U.S. Departments of Health and Human Services, Commerce, Education and Labor; U.S. Environmental Protection Agency; the American Medical Association; the Dartmouth Atlas Project; the Trust for America's Health; the World Health Organization; and the Organization for Economic Co-operation and Development (OECD). Aggregate data pulled from a variety of sources.

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: No

I/DD Group Uniquely Identifiable? No

Known Linkages: None

Citation or Website: http://www.americashealthrankings.org/

American Housing Survey

Narrative Description: The survey is conducted by the Census Bureau for the Department of Housing and Urban Development (HUD).The American Housing Survey (AHS) collects data on the Nation's housing, including apartments, single-family homes, mobile homes, vacant housing units, household characteristics, income, housing and neighborhood quality, housing costs, equipment and fuels, size of housing unit, and recent movers. National data is collected in odd numbered years, and data for each of 47 selected Metropolitan Areas is currently collected about every six years. The national sample covers an average of 55,000 housing units. Each metropolitan area sample covers 4,100 or more housing units. The AHS returns to the same housing units year after year to gather data; therefore, this survey is ideal for analyzing the flow of households through housing.

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: Possibly, if the household or primary respondent has disability-related income such as disability payments, worker's compensation, veteran's disability or "other disability payment"

I/DD Group Uniquely Identifiable? No

Questions (data fields) identifying 'I/DD' or 'Disability': Receipt of disability-related income such as disability payments, worker's compensation, veteran's disability or "other disability payment"

Periodicity of Updates: Biannual surveys

Domains of Health-Related Measures: None

Known Linkages: Some links discussed here: HUD webpage & other census housing data: http://www.census.gov/hhes/www/housing/ahs/related.html

Citation or Website: http://www.census.gov/hhes/www/housing/ahs/ahs.html

Notes: In 2005 and beyond, disability-related income sources are reported separately from other income sources to make it easier to count the number of households with disabled persons. No questions about health indicators are asked.

American Time Use Survey

Narrative Description: Measures the amount of time people spend doing various activities, such as paid work, childcare, volunteering, and socializing. ATUS is sponsored by the Bureau of Labor Statistics and conducted by the U.S. Census Bureau. The ATUS sample includes about 26,000 households drawn from households that have completed the final month of interviews for the CPS. The data files include information collected from over 98,000 interviews conducted from 2003 to 2009. ATUS has been administered annually since 2003.

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: Yes

I/DD Group Uniquely Identifiable? No

Questions (data fields) identifying 'I/DD' or 'Disability': Disability status is asked as part of the Unemployed category and includes individuals who say they did not work or have a job last week because they were disabled or unable to work. A second question: Do you have a disability that prevents you from accepting any kind of work during the next six months? http://www.bls.gov/tus/tuquestionnaire.pdf (p.33, 13, and 15.)

Notes on ID Identification: Contains very limited information about work disability.

Domains of Health-Related Measures: None

Known Linkages: Data linked with the CPS. Other links and publications discussed here: http://www.bls.gov/tus/overview.htm#1

Data Access Costs: Unknown

Citation or Website: Data files: http://www.bls.gov/tus/datafiles_2009.htm

Study: http://www.bls.gov/tus/

Notes: No health indicators included

Commission to Build a Healthier America - What Drives Health

Narrative Description: From February 2008 to December 2009, the Commission studied prevention, wellness and broader factors that influence good health – researching and reviewing evidence, collecting new data and listening to experts, leaders and citizens around the country. The Commission and its research team produced a series of charts and publications capturing this data, as well as a database of experts, organizations, reports and more references during the work of the Commission. No information found on data that was collected.

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: No

I/DD Group Uniquely Identifiable? No

Known Linkages: None

Citation or Website: http://www.commissiononhealth.org/

Community Health Status Indicators

Narrative Description: The goal of Community Health Status Indicators (CHSI) is to provide an overview of key health indicators for local communities and encourage dialogue about ways to improve a community's health. CHSI 2009 reported about 205 health indicators (around 537 data measurements) for 3,141 current counties in 50 states and the District of Columbia. The data used to construct the Community Health Status Indicators (CHSI) was obtained from a variety of federal agencies including the Department of Health and Human Services, Environmental Protection Agency, Census Bureau, and Department of Labor. The data reported is publicly available.

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: No

I/DD Group Uniquely Identifiable? No

Notes on ID Identification: Vulnerable populations include 'severely work disabled' (Severe work disability is defined as the inability to work due to health problems — mental or physical.) Not possible to separate the data. Data is aggregate from a variety of different sources. http://www.communityhealth.hhs.gov/Companion_Document/CHSI-Data_Sources_Definitions_And_Notes.pdf p.23

Known Linkages: Demographic Information section was updated with Census 2008 population data; All causes of death in Summary Measure of Health section was updated with NCHS 1996-2005 Mortality data; National Leading Causes of Death, Measures of Birth and Death, Relative Health Importance sections were updated with NCHS 1996-2005 Vital Statistical data;. Infectious Diseases in Environmental Health section and Infectious Disease Cases in Preventative Services Use sections were updated with 1998-2007 data from National Center for Infectious Diseases, CDC; Health indicators in Vulnerable Population section, and Access to Care section were updated with various data sources.

Citation or Website: http://communityhealth.hhs.gov/homepage.aspx?j=1

Notes: This aggregate data is pulled from a number of other sources

Comprehensive Laboratory Services Survey (CLSS)

Narrative Description: The CLSS measures the extent to which state public health laboratories (SPHLs) fulfill 11 Core Functions of public health laboratories . The survey is distributed biennially to all state health agencies.

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: No

I/DD Group Uniquely Identifiable? No

Known Linkages: None

Citation or Website: http://www.healthindicators.gov/Resources/DataSources/CLSS_33/Profile

Consumer Expenditure Survey

Narrative Description: Program consists of two surveys, the quarterly Interview Survey and the Diary Survey. Both provide information on the buying habits of American consumers, including data on expenditures, income, and consumer unit (families and single consumers) characteristics. The U.S. Census Bureau collects survey data for the Bureau of Labor Statistics. Subsample of CPS

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: Yes

I/DD Group Uniquely Identifiable? No

Questions (data fields) identifying 'I/DD' or 'Disability': People with disabilities are only identified if they are listed as not working due to "disability" or who are "unable to work".

Notes on ID Identification: Work limitations and disability benefit receipt/program participation

Domains of Health-Related Measures: None

Known Linkages: None

Data Access Costs: Unknown

Citation or Website: http://www.bls.gov/cex/

DVA: Veterans' health, compensation, pensions, and vocational rehabilitation program data

Narrative Description: Program data is administrative data from Veterans Benefits Administration. Disability-related data is limited to disability compensation payments paid to veterans disabled by disease or injury incurred or aggravated during military service. Of interest is the 2001 National Survey of Veterans (NSV) which had over 20,000 respondents. All respondents were asked whether they had a disabling condition. Those who answered affirmatively were asked whether their disabling condition was service-related. In addition, everyone was asked whether they had a service-connected disability rating. A service-connected disability is any disability incurred in or aggravated during a period of active military service where the veteran did not receive a dishonorable discharge or the disability was not due to willful misconduct of the veteran. Data is unavailable for veterans with disabilities unrelated to service.

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: No

I/DD Group Uniquely Identifiable? No

Known Linkages: Profile of Veterans (http://www.va.gov/vetdata/docs/SpecialReports/Profile_of_Veterans_2009_FINAL.pdf): 2009 This report uses data from the 2009 American Community Survey to compare the demographic and socioeconomic characteristics of Veterans and non-Veterans. It also explores differences between male and female veterans. The American Community Survey (ACS)includes numerical comparisons of Veterans to non-veterans and socioeconomic data such as educational attainment, median income, and employment, poverty, disability, and service-connected disability rating status. Tables pertaining to Veterans are R2101, S2101 and B21001 through B21100. Individual table descriptions are found under "List All Tables.

Unemployment Rates of Veterans (http://www.va.gov/vetdata/docs/SpecialReports/Unemployment_Rates_FINAL.pdf): 2000 to 2009 This report compares trends in unemployment rates between Veterans and non-Veterans using data from 10 years of the Current Population Survey.

Citation or Website: http://www.va.gov/vetdata/

Equal Employment Opportunity Commission data

Narrative Description: The Census 2000 Special Equal Employment Opportunity (EEO) Tabulation was a special tabulation contracted and paid for by a consortium of four Federal Agencies: the Equal Employment Opportunity Commission (EEOC), the Department of Justice (DOJ), the Department of Labor (DOL), and the Office of Personnel Management (OPM). The occupation and EEO information questions have become part of the American Community Survey (ACS) 2006-2010. See the ACS review for additional information

Location: U.S.

Known Linkages: U.S. Census data

Citation or Website: http://www.eeoc.gov/

HIV/AIDS Reporting System

Narrative Description: The annual HIV/AIDS Reporting System (also known as the HIV Surveillance Report) provides an overview on the current epidemiology of HIV disease in the United States and dependent areas. CDC funds state and territorial health departments to collect surveillance data on persons diagnosed with HIV infection. Data is analyzed by CDC and then displayed by age, race, sex, transmission category, and jurisdiction (where appropriate). Prior to the 2008 reporting year, the report was referred to as the HIV/AIDS Surveillance Report. The report is published annually in late summer or early fall.

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: No

I/DD Group Uniquely Identifiable? No

Notes on ID Identification: Only semi-related question is on the source of most income or financial support in the past 12 months. SSI/SSDI is a response choice. Listed in one of the supplemental reports (http://www.cdc.gov/hiv/topics/surveillance/resources/reports/pdf/MMP_2005_Report_6.pdf)

Known Linkages: None

Citation or Website: http://www.cdc.gov/hiv/topics/surveillance/resources/reports/index.htm

Longitudinal Study of Generations (California)

Narrative Description: The Longitudinal Study of Generations research project began in 1971 as a survey of intergenerational relations among 300 three-generation California families: grandparents (then in their sixties), middle-aged parents (then in their early forties), and grandchildren (then aged 16 to 26).

The study investigates what changes and what stays the same in intergenerational relations of the family over decades , and with the aging of each generation, explores how these changes impact the well-being of individuals within the family.

Location: U.S.: CA

I/DD Group Identification

I/DD Group Uniquely Identifiable? Yes

If yes, is it possible to separate DD from ID? Yes

Questions (data fields) identifying 'I/DD' or 'Disability': NEUROLOGIC DISORDERS: category of "mental retardation" and "Speech and learning disabilities"; also under MEMORY/COGNITIVE IMPAIRMENT category of "Mental retardation"

Notes on ID Identification: Proxy responses may be given by spouses

Study Methodology

Inclusion Criteria: Families were randomly drawn from a subscriber list of 840,000 members of a California Health Maintenance Organization in Los Angeles. Families were recruited by enlisting a grandfather over the age of 60 who was part of a three-generation family that was willing to participate.

Exclusion Criteria: None

Sample Size: 300 families

Data Collection

Dates of Collection: 1971 - present

Method: Primary data collection

Data Collection Methodology Details: Computer-assisted self-interview (CASI); face-to-face interview; mail questionnaire; self-enumerated questionnaire; telephone interview

Data Collection Tools: See above

Periodicity of Updates: 1971, 1985, 1988, 1991, 1994, 1997, 2000

Domains of Health-Related Measures: Common scales used:

Affectual Solidarity Reliability, Consensual Solidarity (Socialization), Associational Solidarity, Functional Solidarity, Intergenerational Social Support, Normative Solidarity, Families, Structural Solidarity, Intergenerational Feelings of Conflict, Management of Conflict Tactics, Rosenberg Self-Esteem, Depression

(CES-D), Locus of Control, Bradburn Affect Balance, Eysenck Extraversion/Neuroticism, Anxiety (Hopkins Symptom Checklist), Activities of Daily Living (IADL/ADL), Religious Ideology, Political Conservatism, Gender Role Ideology, Individualism/Collectivism, Materialism/Humanism, Work Satisfaction, Gilford-Bengtson Marital Satisfaction

See http://www.icpsr.umich.edu/cgi-bin/file?comp=none&study=22100&ds=1&file_id=976813

Known Linkages: None

Data Access Costs: free

Citation or Website: http://www2.ed.gov/rschstat/eval/rehab/vr-final-report-3.pdf

Notes: Methodology that may be useful for health surveillance for adults with I/DD: Recruitment of participants through family members

Data not useful for surveillance

Longitudinal Survey of the Vocational Rehabilitation Services Program

Narrative Description: The purpose of the study is to assess performance of the state-federal Vocational Rehabilitation (VR) services program in helping eligible individuals with disabilities achieve positive, sustainable economic and noneconomic outcomes as a result of receiving VR services.

Initiated in fall 1992, the longitudinal study tracks VR participation and post-VR experiences for up to three years following exit from the program, from a sample of applicants to, and consumers of, VR services. The sample was selected to approximate a national population.

Location: U.S.

I/DD Group Identification

I/DD Group Uniquely Identifiable? Yes

If yes, is it possible to separate DD from ID? Yes

Questions (data fields) identifying ‘I/DD’ or ‘Disability’: Question about the type of disability. This includes a large number of different categories that allow for identification of "mental retardation" as well as numerous other developmental disabilities.

Study Methodology

Inclusion Criteria: Applicants to, and consumers of, VR services

Exclusion Criteria: None

Sampling Methodology: The study implemented a two-stage design that involved selecting a stratified random sample (with probability proportional to size) of 40 local VR offices (located in 32 state VR agencies in a total of 30 states), and, among those offices, a sample of 8,500 applicants and current and former consumers of VR services. The study implemented a cohort design, randomly selecting 25 percent of the sample from the population of persons at application to VR, 50 percent of the sample from the population of persons already accepted for and receiving services, and 25 percent of the sample from the population of persons at exit or after exiting VR services. Each study participant was followed for three years. The cohort design accommodated the typical time-in-services among VR consumers (22 months), such that the study would account for VR experiences and post-VR outcomes for up to three years after program exit. http://www2.ed.gov/rschstat/eval/rehab/vr-final-report-3.pdf

Additional details available at: http://www.ilr.cornell.edu/edi/LSVRSP/UsersGuide.pdf

Response Rate: Unknown

Sample Size: 8,500

Data Collection

Dates of Collection: The study's sample acquisition and data collection activities began in December 1994 and were completed in January 2000, with sample acquisition occurring over a two-year period. Each of the study's 8,500 participants tracked for three years.

Method: Primary data collection

Data Collection Methodology Details: Data collection included computer-aided interviews with study participants, abstraction of data from consumers' case records, and mailing surveys to VR agencies. A battery of baseline interviews were conducted with each study participant upon entry into the study

Data Collection Tools: http://www.ilr.cornell.edu/edi/lsvrsp/Application/Index.cfm?CFID=5386588&CFTOKEN=12522994&jsessionid=f0307d61bc1d8940d67c32302d422d12335a

Periodicity of Updates: None planned

Domains of Health-Related Measures: work history, functioning, vocational interests and attitudes, independence and community integration, and consumer perspectives on their VR participation

Known Linkages: None

Data Access Costs: Free

Citation or Website: http://www.ilr.cornell.edu/edi/LSVRSP/UsersGuide.pdf

http://www.ilr.cornell.edu/edi/lsvrsp/Application/index.cfm

For more information: http://www.ilr.cornell.edu/edi/lsvrsp/Application/index.cfm

Notes: Not useful for health surveillance. The information collected does little to inform health measures.

Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP)/Disabilities Survey

Narrative Description: To address the problem of developmental disabilities among children, CDC, and the Georgia Department of Human Resources initiated the Metropolitan Atlanta Developmental Disabilities Study (MADDS) in 1984. For this study, conducted in Atlanta during 1984-1990, investigators devised methods for determining the prevalence of intellectual disabilities, cerebral palsy, legal blindness, hearing loss, and epilepsy among children 10 years of age. Children who had these conditions were identified by searching record systems of sources likely to contain information relating to evaluation or treatment of children with developmental disabilities (e.g., schools, hospitals, and state programs for persons who have developmental disabilities). The majority of the children were identified through special education departments within Atlanta area public school systems. The success of this study prompted CDC to establish the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) in 1991, an ongoing system for monitoring the occurrence of selected developmental disabilities. MADDSP is located at CDC in the National Center on Birth Defects and Developmental Disabilities.

The two principal objectives of MADDSP are to a) provide regular and systematic monitoring of prevalence rates of selected developmental disabilities according to various demographic characteristics of children and their mothers AND b) provide a framework for initiating special studies of children who have the selected developmental disabilities by establishing a population-based case series of such children.

MADDSP was established to identify all children who have one or more of four developmental disabilities -- intellectual disability, cerebral palsy, hearing loss, and vision impairment -- in the five-county (i.e., Clayton, Cobb, Dekalb, Fulton, and Gwinnett) metropolitan Atlanta area. Autism spectrum disorders were added as a fifth disability beginning in the 1996 study year.

Location: U.S.: Greater Atlanta Area

I/DD Group Identification

I/DD Group Uniquely Identifiable? Yes

If yes, is it possible to separate DD from ID? Yes

Questions (data fields) identifying 'I/DD' or 'Disability': For the 2000 study year, a case child in MADDSP is defined as a child:

- who is 8 years old any time during the study year of interest;
- whose parent(s) or legal guardian(s) reside in the five-county metropolitan Atlanta area at some time during the study year of interest; and
- who has one or more of the five developmental disabilities.

Notes on ID Identification: Intellectual Disability is defined as a condition marked by an intelligence quotient (IQ) of <=70 on the most recently administered psychometric test. In the absence of an IQ score, a written statement by a psychometrist that a child's intellectual functioning falls within the range for intellectual disability is acceptable. The severity of the intellectual disability is defined according to the following International Classification of Disease, Ninth Edition, Clinical Modification (ICD-9-CM) categories: mild (an IQ of 50-70), moderate (an IQ of 35-49), severe (an IQ of 20-34), and profound (an IQ of <20).

Autism Spectrum Disorders (ASD) are defined as a constellation of behaviors indicating social, communicative, and behavioral impairment or abnormalities. The essential features of ASD are (a) impaired reciprocal social interactions, (b) delayed or unusual communication styles, and (c) restricted or repetitive behavior patterns.

A child is included as a confirmed case of ASD if he or she displays behaviors (as described by a qualified professional) consistent with the Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition (DSM-IV) diagnostic criteria for Autistic Disorder, Pervasive Developmental Disorder-Not Otherwise Specified (including Atypical Autism), or Asperger's Disorder. A qualified professional is defined as an educational, psychological or medical professional with specialized training in the observation of children with developmental disabilities (e.g., special education teacher, clinical / developmental / school psychologist, speech/language pathologist, learning specialist, social worker, developmental pediatrician, child psychiatrist, pediatric neurologist). Behavioral descriptions are reviewed by autism experts using a coding scheme based on DSM-IV criteria to determine autism case status.

Study Methodology

Inclusion Criteria: Child living in the five-county (i.e., Clayton, Cobb, Dekalb, Fulton, and Gwinnett) metropolitan Atlanta area

Exclusion Criteria: None

Sampling Methodology: No sampling performed, 100% of children eligible for surveillance are included.

Response Rate: N/A

Sample Size: In 1996, the study area had a population of 33,309 8-year-olds and 289,456 children 3-10 years of age.

Data Collection

Dates of Collection: 1991- present

Method: Existing Records

Data Collection Methodology Details: The ascertainment methodology of MADDSP relies on the consequences of Part B of Public Law 94-142 "as amended", the Individuals with Disabilities Education Act (IDEA), which mandates that the public schools provide a free and appropriate education for all disabled children between the ages of 3 and 21 years. As a result, most children eligible for MADDSP are either enrolled in special education programs at nine public school systems serving the study area or in other Georgia Department of Education programs for children who have developmental disabilities (e.g., state schools for children who are hearing or vision impaired and regional psychoeducational centers). Additional sources used to identify children include Georgia Department of Human Resources facilities for children with a developmental disability, area pediatric hospitals and the clinics associated with these facilities, comprehensive diagnostic and evaluation centers for individuals with developmental disabilities, as well as a number of private physicians and clinicians who provide diagnostic services for children with developmental disabilities.

Periodicity of Updates: Ongoing surveillance

Domains of Health-Related Measures: Hearing and Vision Loss, Cerebral Palsy

Known Linkages: Metropolitan Atlanta Congenital Defects Program Birth Defects Registry (MADDSP) also identifies a case population of school-aged children with developmental disabilities that serves as an essential component for epidemiologic studies (CADDRE) examining risk factors for developmental disabilities in the metropolitan Atlanta area.

Data Access Costs: Unknown

Citation or Website: http://www.cdc.gov/ncbddd/dd/maddsp.htm

Notes: Limited health information in this actual survey, but it may be possible to obtain information on other health domains through linkages

Monitoring the Future (MTF)

Narrative Description: An ongoing study of the behaviors, attitudes, and values of American secondary school students, college students, and young adults. Each year, a total of approximately 50,000 8th, 10th and 12th grade students are surveyed (12th graders since 1975, and 8th and 10th graders since 1991). In addition, annual follow-up questionnaires are mailed to a sample of each graduating class for a number of years after their initial participation. The Monitoring the Future Study has been funded under a series of investigator-initiated competing research grants from the National Institute on Drug Abuse, a part of the National Institutes of Health. MTF is conducted at the Survey Research Center in the Institute for Social Research at the University of Michigan.

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: No

I/DD Group Uniquely Identifiable? No

Known Linkages: None

Citation or Website: http://monitoringthefuture.org/

Multiple Cause of Death, 1999 - 2006

Narrative Description: The Multiple Cause of Death data available on WONDER (What is WONDER? Does it need to be defined first? are county-level national mortality and population data spanning 1999-2006. These data are available in two separate data sets: one data set for years 1999-2004 with 3 race groups, and another data set for years 2005-2006 with 4 race groups and 3 Hispanic origin categories. Data is based on death certificates for U.S. residents. Each death certificate contains a single underlying cause of death, up to twenty additional multiple causes, and demographic data. The number of deaths, crude death rates or age-adjusted death rates can be obtained by place of residence (total U.S., state, and county), age group, race, Hispanic ethnicity (years 2005-2006 only), gender, year of death, and cause-of-death (4-digit ICD code or group of codes).

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: No

I/DD Group Uniquely Identifiable? No

Known Linkages: Unknown

Potential Linkages: Possibly at the state level through DD Agency and Public Health Agency agreements. I believe this is done "manually" in some states (e.g., DD Agency requests death certificates and compares with mandatory critical incident reports).

Citation or Website: http://wonder.cdc.gov/mcd.html

For more information: http://wonder.cdc.gov/wonder/help/mcd.html

Notes: I/DD diagnosis may be included (identified with ICD code) if listed as one of the multiple causes of death, but this seems to be rare.

National Ambulatory Medical Care Survey, 2007

Narrative Description: The National Ambulatory Medical Care Survey (NAMCS) is a national survey designed to meet the need for objective, reliable information about the provision and use of ambulatory medical care services in the United States. Findings are based on a sample of visits to non-federal employed office-based physicians who are primarily engaged in direct patient care.

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: No

I/DD Group Uniquely Identifiable? No

Known Linkages: None.

Citation or Website: http://www.cdc.gov/nchs/ahcd.htm

Notes: Useful data fields (e.g., medications prescribed) but no disability flag. Sampling is done based on doctor's offices, not by personal characteristics.

National Beneficiary Survey (NBS)

Narrative Description: The National Beneficiary Survey is a component of the Social Security Administration's (SSA) evaluation of the Ticket to Work and Self-Sufficiency program (TTW). The survey, sponsored by SSA's Office of Retirement and Disability Policy and conducted by Mathematica Policy Research (Mathematica), collects data from a national sample of Social Security Disability Insurance (DI) and Supplemental Security Income (SSI) beneficiaries and a sample of TTW participants. The NBS collects data on knowledge of TTW, participation in TTW, program experiences of beneficiaries who use their Tickets, and perceptions about TTW and other SSA programs designed to help beneficiaries with disabilities find and keep jobs. Though some sections of the NBS target beneficiary activity directly related to TTW, most of the survey captures more general information on SSA beneficiaries, including their disabilities, interest in work, employment, barriers to work, and use of services. The survey is conducted using computer-assisted telephone interviewing (CATI). Beneficiaries who do not respond to the CATI interview or prefer or require an in-person interview, are interviewed using computer-assisted personal interviewing (CAPI). In an effort to ensure that the survey represents the full range of beneficiary perspectives, the survey is fielded using procedures that accommodate the needs of respondents with all kinds of disabilities. The first three rounds of the NBS were conducted in 2004, 2005, and 2006. The fourth round of the NBS is being conducted in 2010.

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: Yes

I/DD Group Uniquely Identifiable? No

Questions (data fields) identifying 'I/DD' or 'Disability': "Cognitive disability, which includes mental retardation, learning disorders, and intracranial injuries."

Known Linkages: Unknown.

Citation or Website: http://www.ssa.gov/disabilityresearch/publicusefiles.html

For more information: http://www.ssa.gov/disabilityresearch/nbs.html

Notes: Minimal health data (one item on health status, questions about health insurance). Small sample and not likely to include a substantial number of people with I/DD.

National Consumer Assessment of Healthcare Providers and Systems (CAHPS) Benchmarking Database

Narrative Description: The primary purpose of the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Database is to facilitate comparisons of CAHPS survey results by and among survey sponsors. This compilation of survey results from a large pool of sponsors into a single national database enables participants to compare their own results to relevant benchmarks (i.e., reference points such as national and regional averages). The CAHPS Database also offers an important source of primary data for research related to consumer assessments of quality as measured by CAHPS surveys.

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: No

I/DD Group Uniquely Identifiable? No

Known Linkages: N/A

Citation or Website: http://www.cahps.ahrq.gov/content/ncbd/ncbd_Intro.asp

Notes: Very limited information easily available. Note: CMS (through Thomson Reuters) is developing a CAHPS tool for waiver participants, so this data source may inform perceptions of quality from the people served by waivers in the future.

National Children's Study

Narrative Description: The National Children's Study will examine the effects of the environment, broadly defined to include factors such as air, water, diet, sound, family dynamics, community and cultural influences, and genetics on the growth, development, and health of children across the United States, following them from before birth until age 21. . The goal of the Study is to improve health and well-being of children and contribute to understanding the role various factors have on health and disease. Findings from the Study will be made available as research progresses, making potential benefits known as soon as possible.

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: Unknown

I/DD Group Uniquely Identifiable? Unknown

If yes, is it possible to separate DD from ID? Unknown

Questions (data fields) identifying 'I/DD' or 'Disability': Unknown

Known Linkages: None

Citation or Website: http://www.nationalchildrensstudy.gov/Pages/default.aspx

Notes: Children only. Study is under development.

National Crime Victimization Survey (NCVS)

Narrative Description: The National Crime Victimization Survey (NCVS) series was designed to achieve three primary objectives: develop detailed information about the victims and consequences of crime, estimate the number and types of crimes not reported to police, and provide uniform measures of selected types of crime. All persons in the United States 12 and older were interviewed in each household sampled. Each respondent was asked a series of screen questions to determine if he or she was victimized during the six-month period preceding the first day of the month of the interview. The data include type of crime; severity of the crime; injuries or losses; time and place of occurrence; medical expenses incurred; number, age, race, and sex of offender(s); and relationship of offender(s) to the victim (stranger, casual acquaintance, relative, etc.). Demographic information on household members included age, sex, race, education, employment, median family income, marital status, and military history. A stratified multistage cluster sample technique was employed, with the person-level files consisting of a full sample of victims and a 10 percent sample of non-victims for up to four incidents.

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: No

I/DD Group Uniquely Identifiable? No

Known Linkages: None

Citation or Website: http://www.icpsr.umich.edu/icpsrweb/ICPSR/series/95

National Hospital Ambulatory Medical Care Survey (NHAMCS)

Narrative Description: Designed to collect data on the utilization and provision of ambulatory care services in hospital emergency and outpatient departments. Findings are based on a national sample of visits to the emergency departments and outpatient departments of non-institutionalized general and short-stay hospitals.

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: No

I/DD Group Uniquely Identifiable? No

Known Linkages: None

Citation or Website: http://www.cdc.gov/nchs/ahcd.htm

Notes: Could be useful methodology if a diagnosis of ID/DD was added in list of diagnoses not related to visit.

National Hospital Discharge Survey

At-a-Glance
U.S.
Primary and Secondary Data
Adults & Children
Annual

Narrative Description: National probability survey designed to meet the need for information on characteristics of inpatients discharged from non-Federal short-stay hospitals in the United States

Location: U.S.

I/DD Group Identification

I/DD Group Uniquely Identifiable? Yes

If yes, is it possible to separate DD from ID? Possibly (see notes)

Questions (data fields) identifying 'I/DD' or 'Disability': ICD-9 codes

Notes on ID Identification: Identifiable only when ICD-9 code is filled in hospital data, which is probably rare

Study Methodology

Inclusion Criteria: Patients discharged from non-institutional short-stay hospitals located in the 50 states and District of Columbia

Exclusion Criteria: VA hospitals and military hospitals, hospitals with less than 6 inpatient beds, before 1988 - only hospitals with average LOS of less than 30 days.

Sampling Methodology: Starting in 1988, the sample was selected from a frame of short-stay hospitals listed in the 1987 SMG Hospital Market Data Base. The hospitals with the most beds and/or discharges annually were selected with certainty. The remaining sample was selected using a three-stage stratified design: 1) sample of Primary Sampling Units (PSU's) used by the National Health Interview Survey, 2) within PSU's, hospitals were stratified or arrayed by abstracting status (whether subscribing to a commercial abstracting service) and within abstracting status arrayed by type of service and bed size, 3) within these strata and arrays, a systematic sampling scheme with probability proportional to the annual number of discharges was used to select hospitals. http://www.cdc.gov/nchs/nhds/nhds_sample_design.htm

Response Rate: ranges from 79.5% of hospitals in 1988 to 94.6% in 1997 http://www.cdc.gov/nchs/data/series/sr_01/sr01_039.pdf

Sample Size: Prior to 2008 - about 500 hospitals; 270,000 patients. Starting in 2008 - about 239 hospitals. http://www.cdc.gov/nchs/nhds/about_nhds.htm

Organizational level to which sample is powered: Unknown

Data Collection

Dates of Collection: Annually since 1965

Method: Both primary and secondary

Data Collection Methodology Details: One is a manual system in which sample selection and medical transcription from the hospital records to abstract forms is performed by the hospital's staff or by staff of the U.S. Census Bureau on behalf of NCHS. The other data collection procedure is an automated system in which NCHS purchases electronic data files from commercial organizations, State data systems, hospitals, or hospital associations.

Data Collection Tools: Medical abstract form http://www.cdc.gov/nchs/data/hdasd/nhds_form_updated.pdf

Periodicity of Updates: Annual

Domains of Health-Related Measures: ICD-9 Diagnoses (up to 7) and ICD-9 Surgical and Diagnostic Procedures (up to 4)

Known Linkages: None

Data Access Costs: Free

Citation or Website: http://www.cdc.gov/nchs/nhds/about_nhds.htm

For more information: Hospital Care Team
Ambulatory and Hospital Care Statistics Branch
National Center for Health Statistics
3311 Toledo Road
Hyattsville, MD 20782
(301) 458-4321
nhds@cdc.gov

Notes: Unlikely to be useful because people with ID can only be identified through ICD code at time of discharge

National Immunization Survey (NIS)

Narrative Description: The National Immunization Survey (NIS) is sponsored by the National Center for Immunizations and Respiratory Diseases (NCIRD) and conducted jointly by NCIRD and the National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention. The NIS is a list-assisted random-digit-dialing telephone survey followed by a mailed survey to children's immunization providers that began data collection in April 1994 to monitor childhood immunization coverage. The target population for the NIS is children between 19 and 35 months living in the United States at the time of the interview. Data from the NIS is used to produce timely estimates of vaccination coverage rates for all childhood vaccinations recommended by the Advisory Committee on Immunization Practices (ACIP). Estimates are produced for the nation and non-overlapping geographic areas consisting of the 50 states, the District of Columbia, and selected large urban areas.

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: No

I/DD Group Uniquely Identifiable? No

Known Linkages: None

Citation or Website: http://www.cdc.gov/nchs/nis/about_nis.htm

Notes: Restricted to children.

National Longitudinal Survey of Older Men

Narrative Description: One of six surveys designed by the United States Department of Labor comprising the National Longitudinal Survey (NLS) Series. The survey's original purpose was to study employment patterns among men in their 40s and 50s on the verge of making decisions about the timing and extent of their withdrawal from the labor force and plans for retirement.

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: No

I/DD Group Uniquely Identifiable? No

Known Linkages: None

Potential Linkages: Possibly using SSN or the identifier that was used to find original sample members.

Citation or Website: http://www.bls.gov/nls/oldyoungmen.htm

National Longitudinal Survey of Youth

Narrative Description: National Longitudinal Survey of Youth 1979 (NLSY79) and the National Longitudinal Survey of Youth 1997 (NLSY97) are both funded by the Bureau of Labor Statistics. Each addresses key questions about the economic, social, and academic experiences of respondents and examines a myriad of issues surrounding youth entry into the work force and subsequent transitions in and out of it.

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: No

I/DD Group Uniquely Identifiable? No

Known Linkages: None

Potential Linkages: Possibly using SSN or the identifier that was used to find original sample members.

Citation or Website: http://www.norc.org/projects/national+longitudinal+survey+of+youth.htm

National Notifiable Disease Surveillance System

Narrative Description: Surveillance system by CDC; a list of notifiable diseases, updated periodically. Reporting mandated at state level

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: No

I/DD Group Uniquely Identifiable? No

Known Linkages: None

Potential Linkages: None

Citation or Website: http://www.cdc.gov/ncphi/disss/nndss/nndsshis.htm

National Nursing Home Survey

Narrative Description: A continuing series of national sample surveys of nursing homes, their residents, and staff. Although each survey emphasized different topics, all provided some common basic information about nursing homes, their residents, and staff.

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: No

I/DD Group Uniquely Identifiable? No

Known Linkages: None

Citation or Website: http://www.cdc.gov/nchs/nnhs.htm

National Profile of Local Health Departments (NPLHD)

Narrative Description: NHPLD is the most comprehensive source of information on the infrastructure and programs of local health departments in the U.S. All local health departments in the U.S. are surveyed about their organization, responsibilities, workforce, funding, and other topics. Funded by the National Association of County and City Health Officials. Data available from 1989, 1992-93, 1996-97, 2005, 2008.

Core components include activities, community assessment and planning, emergency preparedness, funding, governance, jurisdictional information, and workforce. Supplemental components address topics such as core competencies. All health departments in the U.S. meeting the definition of a local health department. Hawaii and Rhode Island are excluded because state health departments in those states operate on behalf of local public health and have no sub-state units.

The 2008 survey was fielded through an email sent to the top agency executive of every eligible LHD. The email included a link to a web-based questionnaire, preloaded with information specific to the LHD. Paper questionnaires were available for a subset of small LHDs. A core set of questions was sent to all LHDs. In addition, the survey included three modules of supplemental questions, one of which was included in the questionnaire for a random sample of LHDs. Survey responses were weighted for national estimates.

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: No

I/DD Group Uniquely Identifiable? No

Known Linkages: None

Citation or Website: http://www.healthindicators.gov/Resources/DataSources/NPLHD_103/Profile

National Survey of America's Families (NSAF)

Narrative Description: The National Survey of America's Families provides a comprehensive look at the well-being of children and non-elderly adults. Provides quantitative measures of child, adult and family well-being in America, with an emphasis on persons in low-income families

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: No

I/DD Group Uniquely Identifiable? No

Known Linkages: None

Citation or Website: http://www.urban.org/center/anf/nsaf.cfm

National Survey of Black Americans

Narrative Description: The National Survey of Black Americans (NSBA) series was developed by the Program for Research on Black Americans at the Institute for Social Research, University of Michigan. It was initiated in 1977 with funding provided by the National Institute of Mental Health, Center for the Study of Minority Group Mental Health. The series was developed to address the limitations in the existing research literature on the study of Black Americans. It seeks to provide an appropriate theoretical and empirical approach to concepts, measures, and methods in the study of Black Americans. The size and representativeness of the sample permit systematic investigation of the heterogeneity of the adult Black population. The series furnishes data on major social, economic, and psychological aspects of Black American life.

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: No

I/DD Group Uniquely Identifiable? No

Known Linkages: None

Citation or Website: http://www.icpsr.umich.edu/icpsrweb/ICPSR/series/164

National Survey of Family Growth

Narrative Description: Gathers information on family life, marriage and divorce, pregnancy, infertility, use of contraception, and men's and women's health. The survey results are used by the U.S. Department of Health and Human Services and others to plan health services and health education programs, and do statistical studies of families, fertility, and health.

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: No

I/DD Group Uniquely Identifiable? No

Known Linkages: None

Citation or Website: http://www.cdc.gov/nchs/nsfg.htm

National Survey of Midlife Development in the United States (MIDUS II), 2002 - 2009

Narrative Description: 5 projects that are a longitudinal follow-up to MIDUS study (on all MIDUS respondents).

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: No

I/DD Group Uniquely Identifiable? No

Known Linkages: None

Citation or Website: http://www.midus.wisc.edu/

National Survey of Residential Care Facilities

Narrative Description: NSRCF is designed to produce national estimates of these places and their residents. The sponsor is the Centers for Disease Control and Prevention's National Center for Health Statistics (NCHS). NSRCF will collect information about the characteristics of residential care places and the people who live there:

- Facility characteristics, such as size, ownership, staffing, certification status, and services provided
- Resident demographics, such as age, sex, race, and marital status
- Resident health, functional status, and involvement in activities
- Resident services used and charges

In-person interviews will be conducted with residential care administrators, caregivers, and staffs. To obtain resident characteristics, three to six residents (based on facility size) will be randomly selected to participate in the survey. Interviews will not be conducted with residents. This information will help policy makers, health care planners, and providers better understand, plan for, and serve the future long-term care needs of the U.S. aging population.

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: No

I/DD Group Uniquely Identifiable? No

Known Linkages: None

Citation or Website: http://www.cdc.gov/nchs/nsrcf.htm

Notes: (First national survey coming in 2010)

National Survey on Drug Use and Health

Narrative Description: The National Survey on Drug Use and Health (NSDUH) provides national and state-level data on the use of tobacco, alcohol, illicit drugs (including non-medical use of prescription drugs) and mental health in the United States. NSDUH began in 1971 and is currently conducted on an annual basis.

NSDUH is authorized by Section 505 of the Public Health Service Act, which requires annual surveys to collect data on the level and patterns of substance use.

This year approximately 70,000 individuals, age 12 and older, will be randomly selected from all over the United States and asked to participate.

The primary objectives of NSDUH are to:

- provide accurate data on the level and patterns of alcohol, tobacco and illicit substance use;
- track trends in the use of alcohol and various types of drugs;
- assess the consequences of substance use and abuse; and
- identify those groups at high risk for substance use and abuse.

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: No

I/DD Group Uniquely Identifiable? No

Known Linkages:

Aldworth J, Colpe LJ, Gfroerer JC, Novak SP, Chromy JR, Barker PR, Barnett-Walker K, Karg RS, Morton KB, Spagnola K.The National Survey on Drug Use and Health Mental Health Surveillance Study: calibration analysis. Int J Methods Psychiatry Res. 2010 Jun;19 Suppl 1:61-87.

RTI International, Research Triangle Park, NC, USA. The 2008 Mental Health Surveillance Study used data from clinical interviews administered to a sub-sample of respondents to calibrate mental health screening scale data from the National Survey on Drug Use and Health (NSDUH) for estimating the prevalence of SMI in the full NSDUH sample. http://www.ncbi.nlm.nih.gov/pubmed/20527006

Citation or Website: http://oas.samhsa.gov/nhsda.htm

Old Age, Survivors, and Disability Insurance (OASDI) Public Use Microdata File

At-a-Glance
U.S.
Secondary Data
Adults
Ongoing Collection

Narrative Description: The SSA has only one listing of an OASDI public use microdata file, for 2001 (released in 2003). This dataset includes a representative 1% sample of U.S. residents eligible to receive old age, survivors and disability benefits as of December 2001. The latest public use file available is the 2004 Public Use File (released in 2005), which includes a representative 1% sample of beneficiary records and can be linked to longitudinal earnings information.

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: Yes

I/DD Group Uniquely Identifiable? No

Questions (data fields) identifying 'I/DD' or 'Disability': As noted in 'ID notes'. Eligibility for adult children of retired or disabled workers is noted, and the disability must occur prior to age 22. People with I/DD may also be eligible for retirement or disability benefits because of own work history.

Notes on ID Identification: There may be the possibility of a presumptive identification because eligibility codes for adult children of beneficiaries include ' adult child (over 18) of a retired or disabled worker. The child must have acquired the disability prior to age 22.' This lacks specific definition of ID.

Study Methodology

Inclusion Criteria: Those eligible for old age survivors and disability insurance for the reference period.

Exclusion Criteria: Those not eligible for old age survivors and disability insurance for the reference period.

Sampling Methodology: Information about beneficiaries needed to administer the OASDI program resides on SSA's Master Beneficiary Record (MBR) file, which in December 2004 contained records for approximately 47 million individuals who were entitled to receive an OASDI benefit for that month. Data in the benefit subfile are an extract from the MBR, consisting of a 1 percent random, representative sample of approximately 470,000 records. These records are representative of OASDI beneficiaries entitled to receive an OASDI benefit payment for December 2004. Each record in the benefit and earnings subfiles has a unique identifier that allows each earnings record to be linked to its appropriate benefit record. Both subfiles are available as flat text files or SAS data sets. Since the sample for this public-use file is a representative, 1 percent random sample of persons entitled to receive an OASDI benefit payment for December 2004, all records have weight equal to 100. Variances and standard errors can be approximated with the standard formulas used for simple random sampling. http://www.ssa.gov/policy/docs/microdata/earn/index.html#design

Response Rate: Administrative data collected on all eligible recipients. 47 million individuals

Sample Size: 47 Million individuals in December 2004

Data Collection

Dates of Collection: Public use data files available for December 2001 and 2004

Method: Existing records with administrative data collected for eligibility and program administration.

Data Collection Tools: N/A

Domains of Health-Related Measures: None

Known Linkages: None

Data Access Costs: Limited public data available for free.

Citation or Website: http://www.ssa.gov/policy/docs/microdata/earn/index.html#design

Older Americans 2008: Key Indicators of Well-Being

Narrative Description: A chartbook (report) that lists 38 Population, Economic, and Health Indicators for the American Population over 65. It compiles data from national datasets. Appendix B provides good descriptions of each dataset used, along with contact information for more information, with particular participation paid to 'Race and Hispanic origin' http://www.aoa.gov/agingstatsdotnet/Main_Site/Data/2008_Documents/OA_2008.pdf

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: Yes - some measures include information about functional difficulty or disability but not useful for this population

I/DD Group Uniquely Identifiable? No

Questions (data fields) identifying 'I/DD' or 'Disability': See above

Known Linkages: None

Citation or Website:

http://www.aoa.gov/agingstatsdotnet/Main_Site/Data/2008_Documents/OA_2008.pdf

Notes: P. 67 of the report notes that there is a need for better information about functional limitations and disability..."the concept of disability encompasses many different dimensions of health and functioning and complex interactions with the environment. Furthermore, specific definitions of disability are used by some government agencies to determine eligibility for benefits. As a result, disability is often measured in different ways across surveys and censuses, and this has led to disparate estimates of the prevalence of disability."

Organization for Economic Cooperation and Development Factbook Datasets

Narrative Description: Factbook is published annually with analyses. In addition, datasets are publicly available. The indicators dataset includes more than 100 indicators on population, economic production, foreign trade and investment, energy, labor force, information and communications, public finances, innovation, the environment, foreign aid, agriculture, taxation, education, health and quality of life. Data is provided for all OECD member countries with area totals, and in some cases, for selected non-member economies.

OECD member countries: Australia, Austria, Belgium, Canada, Chile, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Israel, Italy, Japan, Korea, Luxembourg, Mexico, Netherlands, New Zealand, Norway, Poland, Portugal, Slovak Republic, Slovenia, Spain, Sweden, Switzerland, Turkey, United Kingdom, United States

Location: International

I/DD Group Identification

Included in broader 'Disability' subgroup: No

I/DD Group Uniquely Identifiable? No

Known Linkages: None.

Citation or Website: http://www.oecd.org/site/0,3407,en_21571361_34374092_1_1_1_1_1,00.html

Participant Experience Survey (MR/DD Version)

At-a-Glance
U.S. - selected states
Primary Data
Adults
Varies by State

Narrative Description: The PES provides State officials with information about program participants' experience with the services and supports they receive under the 1915(c) waiver program — the Medicaid Home and Community Based Services waivers.

Three specific target populations: 1) elderly and non-elderly adults with physical disabilities, 2) adults with MR/DD, 3) adults with brain injury

The PES provides indicators of program participants' experience in four priority areas:

- Access to Care: Are program participants' needs for personal assistance, adaptive equipment, and case manager access being met?
- Choice and Control: Do program participants have input into the types of services they receive and who provides them?
- Respect/Dignity: Are program participants treated with respect by providers?
- Community Integration/Inclusion: Do program participants participate in activities and events of their choice outside their homes when they want to?

PES was developed by the MedStat group under contract to CMS. As reported in the 2007 Measures Scan (http://www.ahrq.gov/research/ltc/hcbsreport/hcbsapiiia.htm#centers), approx. 3-5 states were using this tool as a means to collect information about participants experiences.

Location: U.S. - selected states

I/DD Group Identification

I/DD Group Uniquely Identifiable? Yes

If yes, is it possible to separate DD from ID? No - dependent on state eligibility

Questions (data fields) identifying 'I/DD' or 'Disability': Inclusion criteria

Notes on ID Identification: All respondents are receiving MR/DD HCBS waiver support.

Study Methodology

Inclusion Criteria: Eligible for and actively receiving MR/DD HCBS Waiver supports in a state that has opted to use this survey.

Exclusion Criteria: None

Sampling Methodology: Depends on state choice of sampling

Response Rate: N/A

Sample Size: Depends on state

Data Collection

Dates of Collection: Version 1 released in 2003

Method: Primary data collection

Data Collection Methodology Details: Face to face interview or proxy

Data Collection Tools: http://www.hcbs.org/files/28/1389/5_PES_MRDD.pdf

Periodicity of Updates: varies by state

Domains of Health-Related Measures: No direct health measures listed in questionnaire. http://www.hcbs.org/files/28/1389/5_PES_MRDD.pdf

Known Linkages: None

Data Access Costs: Unknown

Citation or Website: http://www.hcbs.org/moreInfo.php/doc/652

Notes: It is unknown whether this information(collected by individual states) is available to researchers.

State of the States

Narrative Description: Research project administered by the University of Colorado, funded in part by the Administration on Developmental Disabilities. Established to investigate the determinants of public spending for intellectual/developmental disabilities (I/DD) services in the United States, the project maintains a 33-year longitudinal record of revenue, spending, and programmatic trends in the 50 states, the District of Columbia, and the nation as a whole. Does not collect health information.

Location: U.S.

I/DD Group Identification

I/DD Group Uniquely Identifiable? Yes

If yes, is it possible to separate DD from ID? N/A

Data Collection Methodology Details: administered exclusively by mail.

Known Linkages: None

Data Access Costs: Not known

Citation or Website: https://www.cu.edu/ColemanInstitute/stateofthestates/index.html

State Tobacco Activities Tracking & Evaluation System

Narrative Description: The State Tobacco Activities Tracking and Evaluation (STATE) System is an electronic data warehouse containing current and historical state-level data on tobacco use prevention and control. The STATE System is designed to integrate many data sources to provide comprehensive summary data while facilitating research and consistent data interpretation. The STATE System was developed by the Centers for Disease Control and Prevention in the Office on Smoking and Health (OSH), National Center for Chronic Disease Prevention and Health Promotion.

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: No

I/DD Group Uniquely Identifiable? No

Known Linkages: None

Citation or Website: http://apps.nccd.cdc.gov/statesystem/Default/Default.aspx

Survey of Consumer Finances

Narrative Description: The Survey of Consumer Finances (SCF) is a triennial survey of the balance sheet, pension, income, and other demographic characteristics of U.S. families. The survey also gathers information on the use of financial institutions. The study is sponsored by the U.S. Federal Reserve Board in cooperation with the U.S. Department of the Treasury. Since 1992, data has been collected by the National Organization for Research at the University of Chicago (NORC). Data from the SCF are widely used, from analysis at the Federal Reserve and other branches of government to scholarly work at the major economic research centers.

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: No

I/DD Group Uniquely Identifiable? No

Known Linkages: None

Citation or Website: http://www.norc.uchicago.edu/projects/Survey+of+Consumer+Finances.htm

Survey of Occupational Injuries and Illnesses (SOII)

Narrative Description: SOII remains the largest occupational injury and illness surveillance system in the country, providing injury and illness counts and rates for a variety of employer, employee, and case characteristics based on a sample of over 230,000 establishments. Figures are calculated nationally and in 44 participating states and territories (including the District of Columbia), allowing for detailed analyses of the magnitude, patterns, and trends in occupational injuries and illnesses. The survey captures data from Occupational Safety and Health Administration (OSHA) logs of workplace injuries and illnesses maintained by employers. The estimates cover nearly all private-sector industries, as well as State and local government (as of 2008 data). Small farms with fewer than 11 employees, Federal government agencies, self-employed and household workers are outside of the scope of the SOII because they are not covered by the Occupational Safety and Health Act of 1970. More on the scope and coverage of the SOII can be found at http://www.bls.gov/opub/hom/homch9_a.htm#scope_SOII.

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: No

I/DD Group Uniquely Identifiable? No

Known Linkages: None

United States Renal Data System (USRDS)

Narrative Description: The United States Renal Data System (USRDS) is a national data system that collects, analyzes, and distributes information about end-stage renal disease (ESRD) in the United States. The USRDS is funded directly by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) in conjunction with the Centers for Medicare & Medicaid Services (CMS). USRDS staff collaborates with members of CMS, the United Network for Organ Sharing (UNOS), and the ESRD networks, sharing datasets and actively working to improve the accuracy of ESRD patient information.

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: No

I/DD Group Uniquely Identifiable? No

Known Linkages: None

Potential Linkages: None

Citation or Website: http://www.usrds.org/

U.S. National Modifiable Disease Surveillance Systems

Narrative Description: National reporting system for set of diseases

Location: U.S. and PR

I/DD Group Identification

Included in broader 'Disability' subgroup: No

I/DD Group Uniquely Identifiable? No

Known Linkages: None

Potential Linkages: None

Citation or Website: http://www.cdc.gov/ncphi/disss/nndss/nndsshis.htm

U.S. Healthy People 2010

Narrative Description: The U.S. Healthy People data presents aggregate data that is pulled from a number of other sources (listed below). Info on Healthy People 2020: http://www.healthypeople.gov/2010/hp2020/Objectives/files/Draft2009Objectives.pdf

Additional sources are being considered for HP2020 objective, but as of mid-year 2011, sources have not been be finalized for all of the measures.

National Health Interview Survey (NHIS)
National Health and Nutrition Examination Survey (NHANES)
National Vital Statistics System—Mortality (NVSS-M)
Youth Risk Behavior Surveillance System (YRBSS)
National Survey of Family Growth (NSFG)
National Hospital Discharge Survey (NHDS)
National Vital Statistics System—Natality (NVSS-N)
United States Renal Data System (USRDS)
School Health Policies and Programs Study (SHPPS)
National Survey on Drug Use and Health (NSDUH)
National Hospital Ambulatory Medical Care Survey (NHAMCS)
Behavioral Risk Factor Surveillance System (BRFSS)
Medical Expenditure Panel (MEPS)
HIV/AIDS Reporting System
National Crime Victimization Survey (NCVS)
National Notifiable Disease Surveillance System (NNDSS)
Monitoring the Future (MTF)
State Tobacco Activities Tracking & Evaluation System (STATE)
Survey of Occupational Injuries and Illnesses (SOII)
National Profile of Local Health Departments (NPLHD)
Comprehensive Laboratory Services Survey (CLSS)
National Immunization Survey (NIS)

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: Yes

I/DD Group Uniquely Identifiable? No

Questions (data fields) identifying 'I/DD' or 'Disability': Various, depending on original data source

Notes on ID Identification: Some aggregate data is presented for people with disabilities, but insufficient information is present to distinguish people with I/DD from people with other types of disabilities. Some original data sources may have additional information on type of disability

Periodicity of Updates: Annual

Known Linkages: None

Potential Linkages: None

Data Access Costs: Unknown

Citation or Website:

Notes: The ability to inform health surveillance for people with I/DD varies by data source. Those sources with relatively higher potential to inform surveillance have been individually reviewed in this compendium.

Youth Risk Behavior Surveillance System (YRBSS)

Narrative Description: The Youth Risk Behavior Surveillance System (YRBSS) monitors priority health-risk behaviors and the prevalence of obesity and asthma among youth and young adults. The YRBSS includes a national school-based survey conducted by the Centers for Disease Control and Prevention (CDC) and state, territorial, tribal, and district surveys conducted by state, territorial, and local education and health agencies and tribal governments. In these surveys, conducted biennially since 1991, representative samples of students in grades 9–12 are drawn

Location: U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: No

I/DD Group Uniquely Identifiable? No

Known Linkages: None

Potential Linkages: None

Citation or Website:

Notes: Excluded because surveys youth grades 9 to 12, and does not collect information on disability indicators

Studies in other countries:

Canadian Provincial Health Data Sets

Narrative Description: The Canadian Provincial Health Data Sets refers to data collected in administrative databases from three Canadian provinces:

1) Manitoba: Persons with ID were identified among the general population of Manitoba using data held at the Manitoba Centre for Health Policy. Data came from the following sources to comprise a population-Based Research Registry: hospital data, family services, education, home care, physician, pharmaceuticals, immunization, vital statistics, nursing home, and costs (unspecified), as well as national data surveys and census data. Rates of preventable hospitalizations were calculated and compared between persons with and without ID. Multiple regression analysis was used to adjust for age, sex, and rural/urban place of residence.

2) Ontario: Conducted by the Institute of Clinical Evaluative Sciences (ICES), an Ontario based institute, with access to HEALTH databases. ICES received a grant to link social service database to health databases. Prior research relied only on health databases to identify persons with intellectual disability. ICES looked at hospital data, emergency room data, and physicians' claims linked with databases from the Ministry of Community and Social Services. They also looked at primary care related variables such as Utilization (e.g. proportion who have visited a primary care physician, average number of visits to ER in year etc.) and Indicators (e.g. proportion who received cancer screening, diabetes care, polypharmacy).

3) Quebec: Data came from several sources, including: Repository for healthcare utilization databases, census & national surveys (No survey relevant to identify persons with IDD, but provided information on the general population & neighborhood), Students with disabilities and their school attendance and supports, Parents allocation requests for their child with disability (incl. IDD), Adults requesting allocation for person with disability or social welfare, employers requesting aid to hire persons with disability, agencies providing specialized services in IDD.

Secondary analyses of the above datasets focused on how ID is routinely coded. Results found that adapted strategies are needed to identify persons with ID in the administrative databases. However, by using already existing health data from administrative databases collected by provincial governments, it is possible in Canada to track health and health service indicators.

Location: Non-U.S.

<u>I/DD Group Identification</u>

Included in broader 'Disability' subgroup: Yes

I/DD Group Uniquely Identifiable? Possibly

If yes, is it possible to separate DD from ID? Unknown

Questions (data fields) identifying 'I/DD' or 'Disability': Unknown; access to original databases is limited

Citation or Website: R. Balogh, V. Cobigo, Y. Lunsky, H. Ouellette-Kuntz. Symposium: North American approaches to health surveillance in intellectual disabilities Using administrative datasets in Canada. Presented at the IASSID conference, Rome 2010

Canadian Index of Wellbeing (Prototype), Canadian Community Health Survey, Cycle 3.1 (2005) (CCHs), Participation and Activity Limitation Survey (2006) (PALS)

Narrative Description: The Canadian Index of Wellbeing (CIW) is a national index that measures wellbeing in Canada across a wide spectrum of domains. Health status is primarily assesed by the following Healthy Populations subdomains: personal wellbeing, life expectancy/mortality, physical health conditions, functional health and mental health.Three additional subdomains—lifestyle and behavior, health care and public health—include indicators of health determinants not directly addressed in other CIW Domains. Two indicators particularily related to disability are short-term (2 week) disability andlong-term (6 month) disability. Going forward, the CIW will provide periodic reports on the wellbeing of specific population sub-groups.

The Community Health Survey (CCHs)is a cross-sectional survey of 130,000 Canadians aged 12 years and over, representing residents of all provinces and territories.

The Participation and Activity Limitation Survey (PALS) is a national, cross-sectional survey of 39,000 Canadians (≥15 years old) utilizing a census sampling frame and including all individuals with activity limitations.

Data for the CCHs and the PALS come from other sources:

1) Canadian Community Health Survey, National Population Health Survey
http://www.statcan.gc.ca/concepts/nphs-ensp/index-eng.htm

The National Population Health Survey is a longitudinal survey on the health of Canadians. Conducted by Statistics Canada since 1994-95, the survey is designed to measure the health status of Canadians and to add to the existing body of knowledge about the determinants of health. The NPHS, which relies on respondents' self-reported health information, surveys the same group of respondents every two years for up to 20 years.

2) Canadian Community Health Survey, Mental Health and Well-being

http://www.statcan.ca/english/freepub/82-617-XIE/htm/51100116.htm

http://www.statcan.ca/english/freepub/82-617-XIE/htm/51100115.htm

Going forward, the CIW will provide periodic reports on the wellbeing of specific population sub-groups.

Location: Non-U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: Yes

I/DD Group Uniquely Identifiable? No

Questions (data fields) identifying 'I/DD' or 'Disability': Do you have autism or any other developmental disorder such as Down's syndrome, Asperger's syndrome or Rhett syndrome? (CCHs)

Has a doctor, psychologist or other health professional ever said that you/(____) had a developmental disability or disorder? These include, for example, Down syndrome, autism, Asperger syndrome, mental impairment due to a lack of oxygen at birth, etc. (PALS)

Citation or Website: http://www.ciw.ca/en/Home.aspx

England Department of Health Survey of Adults with Learning Difficulties

At-a-Glance
Non-U.S.
Primary Data
Aged 16+
Once; no updates

Narrative Description: The Department of Health commissioned BMRB Limited to conduct a major survey of people with learning difficulties in England.

Thesurvey aimed to:

- Establish from people with learning difficulties themselves what their lives are like including where they live and with whom, what they do during the day, and what their needs, wants and aspirations are
- Describe current use of services by people with learning difficulties, as well as their views on the services, to help establish the gaps between what is currently provided for people with learning difficulties and what they would like.

Location: Non-U.S.

I/DD Group Identification

I/DD Group Uniquely Identifiable? Yes

If yes, is it possible to separate DD from ID? No

Questions (data fields) identifying 'I/DD' or 'Disability': Case identification questions:

1. Does anybody aged 16 or over who lives in your household, OR that you have responsibility for, have learning difficulties? (This may also be known as a learning disability or mental handicap.)

2. Does the person you mentioned before have a general difficulty in learning things?

3. Does anyone aged over 16 in your household or that you have responsibility for have a general difficulty in learning things?

4. Did they have this difficulty when they were a child?

Study Methodology

Inclusion Criteria: Have a learning difficulty, be at least 16 years old

Included people with learning difficulties living in their own homes, people living with their parents or other relatives and people living in different types of supported accommodation. This included people living in supported living schemes, residential care and in NHS accommodation.

Exclusion Criteria: People with LD who did not want to participate

Sampling Methodology: Cases found from existing weekly survey done of private households England (N=4,000). Additional questions asked if respondent had learning difficulties, or if they lived with or supported an adult with learning difficulties (after explanation of what is meant by learning difficulties)

Also used information from Social Services Departments in three main types of supported accommodations.

1. Housing provided under the government's 'Supporting People' program. The Office of the Deputy Prime Minister (ODPM) had a list of all places in the schemes that they thought were supporting people with learning disabilities.
2. Registered Residential Care Homes. At the time of the survey the National Care Standards Commission (NCSC) listed all registered residential care homes that supported people with learning disabilities.
3. Hospitals and residential homes run by the NHS. The Department of Health had a list of all NHS Trusts that provide supported accommodation for people with learning disabilities.

Response Rate: For individuals found through BMBS survey: Agreeing to re-contact (76%)

Sample issued (sufficient contact details) (74%)

Of those sampled:

Ineligible respondents (35%)

Eligible sample (65%) (See "APPENDIX 2 – BMRB's Omnibus survey recruitment validation exercise and final questions" for rates for other sources http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4119948.pdf)

Sample Size: 2,898 people were interviewed between July 2003 and October 2004

From BMRB's survey of people in private households with learning difficulties, 1,072 adults were found and 750 were interviewed

Social Services Departments identified 675 people with learning difficulties living in private households, of these 480 were interviewed

Supporting People Schemes identified 822 people, of which 562 were interviewed

Registered Residential Care Homes: 1.312 identified and 919 interviewed

People Living in Accommodation Provided by NHS Trusts: 326 identified, 263 interviewed

Data Collection

Dates of Collection: July 2003 to October 2004

Method: Primary data collection

Data Collection Methodology Details: In-home interviews were used. Some questions included picture cues or additional explanation.

In one out of every four interviews, (24%) staff talked to the person with learning difficulties. In the rest of the interviews a support person was present. Most support people were parents, another relative or paid caregivers. In just under half of the interviews (46%), the person with learning difficulties answered most of the questions.

Data Collection Tools: Interview

Periodicity of Updates: None

Health-Related Measures

Domains of Health-Related Measures: Daily support needs, finances, work and day activities, social contact and involvement, community participation, mobility, chronic conditions, comorbid disabilities

Daily support needs:

- Get dressed in the morning
- Put on a pair of shoes
- Have a shower or a bath
- Order something to eat or drink at a cafe
- Drink a cup of tea
- Wash your clothes
- Make a sandwich
- Fill in a form (for example if you were applying for a job)
- Find out what is on TV tonight
- Pay money into your bank or post office

Data Access Costs: Unknown

Citation or Website: http://www.lancs.ac.uk/staff/emersone/FASSWeb/Emerson_05_ALDE_Main.pdf

Irish National Disability Survey 2006

Narrative Description: In 2004, the Irish Government decided that the Central Statistics Office (CSO) would conduct a National Disability Survey (NDS) after the 2006 Census of Population. The main purpose of the NDS was to establish the severity and impact of disability. The National Disability Authority (NDA) had commissioned research in 2003 to develop and pilot an appropriate research instrument to establish the prevalence and impact of disability in Ireland. This pilot study formed the basis for the Government decision to conduct a National Disability Survey. Two questions on disability were included in the Irish Census of Population for the first time in 2002. In 2006, two slightly more detailed questions on disability were included on the Census form. The NDS sample was selected based on responses to these questions. The NDS questionnaires were based on the social model of disability, which defines disability as the outcome of the interaction between a person with an impairment and the environmental and attitudinal barriers s/he may face. The questionnaires were broadly divided into two parts. Section 1 collected a range of data on nine specific disability types including: level of severity, age of onset of disability, aids used or needed to assist with daily life, cause of the disability and in some cases frequency of occurrence. The rest of the questionnaire dealt with topics related to activity and participation such as education, employment, transport and the built environment as well as collecting basic demographic information.

Location: Non-U.S.

I/DD Group Identification

Included in broader 'Disability' subgroup: Yes

I/DD Group Uniquely Identifiable? No

Questions (data fields) identifying 'I/DD' or 'Disability':

Do you have any difficulty with intellectual functions due to a condition such as acquired brain injury, Down Syndrome, brain damage at birth? (b117, b122)

Do you have any difficulty with interpersonal skills due to any condition such as autistic spectrum disorders?

Do you have any difficulty in learning everyday skills such as reading, writing, using simple tools, learning the rules of a game due to a condition such as ADHD (Attention Deficit Hyperactive Disorder) or dyslexia

Have you been diagnosed as having an intellectual disability?

Domains of Health-Related Measures: Only one question on "general health" status

Data Access Costs: Unknown

Citation or Website:

http://www.cso.ie/releasespublications/documents/other_releases/nationaldisability/National%20Disability%20Survey%202006%20First%20Results%20full%20report.pdf

Notes: The survey is a one-time study and mainly provides detailed prevalence estimates of different types of disabilities. Other data collected include work, education, transportation, residence, and social participation variables. These results are not included in the first report.

National Intellectual Disability Database (NIDD)

Narrative Description: Established in 1995, it is a database of information about people receiving intellectual disability services in Ireland, or are in need of these services. The database's objective is to ensure that accurate information is available about the needs of people with intellectual disabilities. Services are planned and coordinated on the basis of information contained in the database. Contains info on over 25,000 people. This data source does not include health information.

Location: Non-US

I/DD Group Identification

I/DD Group Uniquely Identifiable? Yes

If yes, is it possible to separate DD from ID? N/A

Known Linkages: None

Potential Linkages: Personal Identification details are contained in the database

Data Access Costs: Unknown

Citation or Website:

http://www.citizensinformation.ie/en/health/health_services_for_people_with_disabilities/intellectual_disability_database.html

National Physical and Sensory Disability Database (NPSDD)

At-a-Glance
Ireland
Primary Data
Adults & Children
Annual

Narrative Description: The National Physical and Sensory Disability Database (NPSDD) outlines the specialized health services currently used or needed by people with physical/sensory disability. The Database assists in informing the regional and national planning of these services by providing information on current service use and future service need. The NPSDD was established in 2002 and currently more than 27,000 people are registered on the Database.

Location: Ireland

I/DD Group Identification

I/DD Group Uniquely Identifiable? Yes

If yes, is it possible to separate DD from ID? No

Questions (data fields) identifying 'I/DD' or 'Disability': Administration Detail question X

Notes on ID Identification: Asks whether the person is in the NIDD

Study Methodology

Inclusion Criteria: Individuals in Ireland who have a physical/sensory or speech & language disability and who are using, or requiring a specialized health and personal social service.

Exclusion Criteria: Those 66 yrs. of age and older

Sampling Methodology: Voluntary

Response Rate: Unknown

Sample Size: Over 27,000

Data Collection

Dates of Collection: Ongoing

Method: Primary data collection

Data Collection Methodology Details: Individuals wishing to participate are interviewed, ideally by their key worker or, if not, by a data collector.

Data Collection Tools: Survey

Periodicity of Updates: Individual record reviewed and updated annually

Domains of Health-Related Measures: Access to health services For more information see: http://www.hrb.ie/fileadmin/Staging/Documents/In_House_Research_Info_Systems/DDU/Other_PDF_docs/NPSDD_form.pdf

Known Linkages: None

Potential Linkages: Personal Identification details are contained in the database

Data Access Costs: Unknown

Citation or Website:

http://www.dohc.ie/publications/national_physical_and_sensory_disability_database_information_pack.html

Pomona Project

At-a-Glance
Non-U.S.
Primary Data
Adults
Once; no updates

Narrative Description: Phase I: 2002 – 2004. The Pomona project aimed to determine which health indicators, if any, currently existed in Member States for people with ID, and propose a new set of health indicators if none existed. Project partners were asked to identify and examine existing health surveys in Europe. Pomona I used prevalent definitions of Intellectual Disabilities within the field at that time

Phase II: 2005 – 2008. This project applied a set of 18 health indicators from Pomona I to identify the health status and needs of adults with ID by gathering data from participants with ID across participating European countries.

Location: Non-U.S.

I/DD Group Identification

I/DD Group Uniquely Identifiable? Yes

If yes, is it possible to separate DD from ID? No

Questions (data fields) identifying 'I/DD' or 'Disability': Should something be written here?

Notes on ID Identification: Identified as having ID prior to start of interview

Study Methodology

Inclusion Criteria: Adults with ID

Exclusion Criteria: None

Sampling Methodology: Population was all Individuals with ID (total number in population is Not known). Respondents were identified through service providers, family organizations, support groups such as Special Olympics, and local decision makers with access to networks of people with ID. Service providers within the health area were also identified and listed by location, name, and number of service users. Most Member States utilized service providers' registers to identify samples of potential participants, either living in the family home or alone. A minority of Member States identified samples through additional sources. These included family support organizations, multidisciplinary community teams, family physician networks, and disability organizations. It was acknowledged that this was largely a sample of convenience. Partners were instructed to identify a 'health area' t large enough to ensure an array of typical living circumstances for adults with intellectual disabilities, but would also be of a manageable size for partners to conduct face-to-face interviews. The health area would be specified by population demographics (number of residents, age and gender profiles if available), by service provision for people with intellectual disabilities (organizations providing residential, educational, employment provision etc.,) and if possible, data regarding the number of people with intellectual disabilities residing in the region.

Response Rate: Response rates varied considerably across countries, ranging from less than 25% to 100% and 0% - 75%.

Sample Size: From this health area, approximately 80 adults with intellectual disabilities should complete the POMONA health survey. This sample size would result in approximately N=1,120 interviews completed across all 14 participating countries.

1269 individuals with ID across 13 Member States80 per area. Total interviewed was 1269, Pomona Final Report, p. 37: http://www.pomonaproject.org/action1_2004_frep_14_en.pdf

Data Collection

Dates of Collection: 2007 and 2008

Method: Primary data collection

Data Collection Methodology Details: The predominant method of data collection was by interview (70%) or a combination of interview and postal questionnaire (14%). Nine percent (9%) of the questionnaires were administered exclusively by post. Fourteen percent (14%) of the interviews were attended solely by the person with intellectual disabilities and 52% of interviews included the person with intellectual disabilities and a third person. About one-third (34%) of interviews were attended by a proxy instead of the person with intellectual disabilities.

Data Collection Tools: Interview and postal questionnaire

Periodicity of Updates: Administered one time

Domains of Health-Related Measures: Health Status: BMI, oral health, sensory impairments, mortality, co-morbidity; Health Determinants: physical activity, medication, lifestyle indicators; Health System indicators: annual health check, insurance coverage, access to medical equipment, health promotion activities

Known Linkages: None

Data Access Costs: Unknown

Citation or Website: http://www.pomonaproject.org/index.php

Notes: Phase II confirmed the analysis of Pomona I; no surveillance system exists for determining the health of people with ID exists across Europe. However, ad hoc systems that surveyed related data remain a possibility.

Scores on the Activities of Daily Living Scale and the Support Needs Scale (SNS) were gathered on participants during the survey. Data may aid in constructing a viable definition of ID. The mean score of participants on the ADL was 74.6. The average score on the SNS was 46.

Appendix I: Data sources excluded from review

Databases identified through literature searches that were excluded from review because they did not fit inclusion criteria for this review: Adults population, Large region or national, ability to identify population with disability or ID.

While these data sources are not included in the final compendium of data sources, the methods used may have been reviewed by the project team to inform methodological recommendations in the 'recommendations' section of the report.

- Paralysis Population Survey (University of New Mexico) 2009
- Study to Explore Early Development (SEED)
- Gateways and Pathways Project (GAPP) 1997-2000, St. Louis, Missouri
- Longitudinal Study of Generations, 1971, 1985, 1988, 1991, 1994, 1997, 2000 [California]
- Los Angeles Family and Neighborhood Study (L.A.FANS)
- Project on Human Development in Chicago Neighborhoods (PHDCN): Extended Family Health, Wave 3, 2000-2002
- Social Environment and Biomarkers of Aging Study (SEBAS) in Taiwan, 2000
- The 500 Family Study [1998-2000: United States]
- Welfare, Children, and Families: A Three-City Study
- CRELES: Costa Rican Longevity and Healthy Aging Study, 2005 (Costa Rica Estudio de Longevidad y Envejecimiento Saludable)
- Census of Public and Private Juvenile Detention, Correctional, and Shelter Facilities, 1986-1993: [United States]
- Child Care and Children with Special Needs: Challenges for Low Income Families, 2002-2005
- Chinese Household Income Project, 2002
- Comparative Study of Community Power Research, 1920-1964
- Detroit Area Study, 1959: The Vitality of Supernatural Experience and a Fiscal Research Program
- Detroit Area Study, 1985: Life Events in Everyday Experience
- Detroit Area Study, 1999: Life and Death Decision Making
- Developing and Validating a Brief Jail Mental Health Screen in Maryland and New York, 2005-2006
- Drug Abuse Treatment Outcome Study--Adolescent (DATOS-A), 1993-1995: [United States]
- Equality of Educational Opportunity (COLEMAN) Study (EEOS), 1966
- Eurobarometer 54.2: Impact of New Technologies, Employment and Social Affairs, and Disabilities, January-February 2001
- Eurobarometer 60.0: Consumer Rights, Data Protection, Education Through Sport, Product Safety, E-Commerce, Attitudes Towards People With Disabilities, and the Euro, September 2003
- Experience of Violence in the Lives of Homeless Persons: The Florida Four City Study, 2003-2004
- General Social Surveys, 1972-2008 [Cumulative File]

- Geriatric Home Care Utilization: San Francisco, 1968-1975
- Inventory of Long-Term Care Places, 1986
- Juvenile Detention and Correctional Facility Census, 1982-1985
- Latino National Political Survey, 1989-1990
- Mortality Detail and Multiple Cause of Death, 1981
- National Fertility Survey, 1965
- National Head Start/Public School Early Childhood Transition Demonstration Study, 1991-1999
- National Opinion Survey of Crime and Justice, 1995
- National Survey of Ambulatory Surgery: 1994, 1995, 1996, and 2006
- Political Action Panel Study, 1973-1981
- Recent College Graduates Survey, 1989-1990: CD-ROM Version [United States]
- Risk Assessment and Schemes for Sexual Recidivism: A 25 Year Follow-Up of Convicted Sex Offenders Referred to the Massachusetts Treatment Center, 1959-1984
- Sacramento Area Latino Study on Aging (SALSA Study), 1996-2008: Neuroclinical Exam Data
- Student-Parent Socialization Study, 1965
- Survey of Low Income Aged and Disabled, 1973-1974
- Toledo Adolescent Relationships Study (TARS): Wave 1, 2001
- United States Entrepreneurial Assessment, 2004

Databases identified during the review (added for review by project team members) but excluded from the final compendium:

- Linked Birth and Infant Death Data Set (birth/infant death) National Vital Statistics System (the datasets that are linked are referenced separately)
- National Survey of Family Growth
- Matched Multiple Birth Data Set (birth data only)
- National Maternal and Infant Health Survey (1988)
- National Mortality Followback Survey (1993)
- United States Renal Data System (USRDS)
- School Health Policies and Programs Study (SHPPS)

Data sources reviewed and removed from compendium of data sources because they do not inform ongoing surveillance in the population:

- Community Residences Health Survey
    - *Survey of 1371 adults with ID over the age of 40 living in group homes in two geographic regions of New York State. Conducted in 2002 (approx.)*
- Family Health Study
    - *Conducted by the New York State Institute for Basic Research in Developmental Disabilities*

- European Health Interview & Health Examination Surveys Database
    - *An inventory of over 200 national and multi-country health surveys implemented in EU Member States as well as EFTA countries, EU Candidate Countries and USA, Canada and Australia.*
- Florida Linked Record Database
    - *Department of Health birth certificate records were electronically linked with Department of Education school records to create a sample of 327,831 children. 7149 were classified as having MR.*
- National Survey of Residential Care Facilities
    - *Excluded from compendium because it is a one-time survey. Questionnaire does allow for identification of adults with ID living in group setting.*
    - *Survey results to be released in December 2011*
- Medicad HCBS Measure Scan: Project Methodology

Appendix II: Guide to Study Review

The following guide was used for review of each of the data sources included in the compendium. For all fields: information only needs to be recorded for adult populations.

Data Source

List information source(s) used to inform health-related measures for subjects in the study.

Narrative Description of Study

Give an overview of the study. Include the following information:

- Purpose of the study
- Funder
- Overall study design
- Frequency of data collection

Study Location: US or Non-US

Complete this information by using the geographic location of subjects used for the data source. List either: US, Non-US or Both.

I/DD Group Identification

Included in broader 'Disability' subgroup: (Y/N)

Is information collected in the study in a way that makes any people with I/DD identifiable only as part of another subgroup (i.e. people with disabilities)? If so, list "yes". Otherwise list "no".

Is ID/DD Group Uniquely Identifiable? Y/N

Is information collected in the study in a way that makes any people with I/DD identifiable either an I/DD-specific subgroup? If so, list "yes". Otherwise list "no".

Notes on I/DD Identification

Provide any information relevant to the identification of a subgroup with I/DD. This should include inclusion/exclusion criteria for the subgroup, and any limitations or noted details about the subgroup's definition.

What fields identify ID/DD or Disability Group?

Detail information or data fields used to identify subjects for inclusion in the subgroup with I/DD. It may also include fields used to exclude people without I/DD. Include any information used to distinguish the level of I/DD and age of onset.

Population Definitions: Inclusion Criteria

List any details provided on subject inclusion for the study. Include any details provided about the fields used for inclusion and the sources of this information. Include available details about:

- age,
- gender
- residential setting
- support levels
- geographic location

Population Definitions: Exclusion Criteria

List any details provided on subject exclusion criteria for the entire study. Include any details provided about the fields used for exclusion and the sources of this information. Include any available details listed above for inclusion criteria.

Dates of Data Collection

List the dates over which the health measures were made for the subjects. For studies using secondary data, list both the access date to the primary information and the original date range of the primary data collection if possible. For studies with ongoing data collection, note that data collection is on-going and provide a study close date if available.

Health-Related Measures

Provide details on the domains represented by the health-related measures, including those that define health status, access to health care services, participation, advocacy, and quality measures. Be sure to list the reference for the information.

Sampling Methodology

List the following details about the study population. If a control or comparison group is used, include details for these groups as well.

- The population from which the sample is drawn
- Methods used to locate, recruit and contact subjects
- Any matching between subjects
- The sampling design, including:
    - Involvement of different sampling arms, stages, units or clusters
    - Any over-sampling of particular groups

For longitudinal studies, list the subject retention and follow-up frequency and periods.

A moderate level of detail should be included in this field as it is an important area that may define inclusion/exclusion for people with I/DD. Include citation for source of information.

Response Rate

For studies with primary data collection, list the response rate if provided. The most recent year's data is preferred. Include the year of the information.

For longitudinal studies, also list retention rate or loss-to-follow-up for each follow-up period.

Include citation for source of information.

Sample Size

List the sample size for the entire study. If possible, also list the sample size for the subgroup containing individuals with I/DD. The most recent year's data is preferred. Include the year of the information. Include citation for source of information.

Data Collection Method (Primary collection vs. Existing Records)

For studies that collect data directly from study subjects, list "Primary collection". For studies using other existing data sources, list "Existing Records". If proxy information is used for people with I/DD, list this under "notes"

> Note: For studies that use health care records – if the study consents each person in the study list it as "primary collection"; if the study instead uses de-identified claims data or electronic health records, enter "existing records".

Data Collection Methodology Details

Provide any details of the data collection methodology that may either exclude I/DD, or help to ensure they are included.

Data Collection Tools (Primary collection only)

For studies that conduct primary data collection, list the tools used and any details provided about these tools. Specify whether the tool is investigator-designed, or whether it is an established tool (if so, provide reference). Discuss any validation conducted of the tool.

Include citation for source of information.

Periodicity of Updates

If the data is updated, list the frequency of updates. If it is not, list "N/A".

Known Linkages

Provide any information on linkages that are identified by researchers, are currently in place or have already been performed.

Potential Linkages

Use this field to list linkages not explicitly identified by researchers, but that may be feasible (and reasonable) given the data source. Include the purpose of the linkage, i.e. to include additional health domains, or further identify I/DD group, etc.

Data Access Costs

List any costs associated with accessing data from the study. If data access does not appear to be available, list “N/A”.

Citation or Website

List any information sources used to population information in this table. Include contacts for data access, if available.

For more information

List any contact information given for data access, study information, or additional resources related to the project. List as much contact information as available

Notes

List any other information that seems relevant to the topic, in particular, any information that will inform the critical review of this data source but is not listed in other fields.

Appendix III: Critical Review Considerations

The following guide was used for critical review of data sources.

Sampling:

1. Are there any suspected biases in sampling methodology (design, recruitment, follow-up) for either all included data or for people with I/DD specifically?
2. Are there any perceived strengths or weaknesses in the sampling methodology for people with I/DD?
    a. How likely is the study to include people with I/DD? Does the sampling approach make it more likely that certain subgroups of people with I/DD would be included than others? (i.e. certain age groups, certain levels of I/DD, residential groups (community at home with family or independently, in supported residential settings and/or state services, ICFMR/DDs, nursing homes, incarceration, at home with family or independently)
    b. Does the sampling methodology exclude anyone with I/DD?
3. To what organizational level is the sample powered to estimate reliably (90-95% CI) and meaningfully (precision that is not too broad to be useful)? (i.e. national, region, state)
4. Comment on response rate

Health-related Measures:

5. Which domains does the data source measure?
6. Are there any suspected biases in measurement of indicators?
7. Are there any perceived weaknesses in the collection of information to inform health measures (Accuracy/reliability/validity – any known issues, any studies, potential implications)?
8. Are there any measures that have high applicability to people with I/DD? Are there measures that may have little applicability to people with I/DD?
9. For Primary Data collection:
    a. Are there any aspects of the data collection tool or data collection methodology that would limit information collected from people with I/DD or make the information less reliable/informative for people with I/DD?
    b. Do people with I/DD inform the measures, or is a proxy used?

   c. Did the study include any measures of reliability or validity for the tool? If so, how do the results impact the tool's usefulness for health surveillance?

10. For secondary data collection:
    a. Are there inclusion/exclusion criteria in the source data that would exclude people with ID?
    b. If people with I/DD are included, are there any aspects of the data collection or membership that would that would limit information collected from people with I/DD or make the information less reliable/informative for people with I/DD?

<u>Usefulness:</u>

11. Potential to disaggregate the data by I/DD: Is it possible to disaggregate by both I/DD and other demographic variables?
12. Does the data contain any functional measures or indicators of level of disability that can be paired with other measures?
13. What is the potential for adaptation of this data source for health surveillance for adults with I/DD?
14. Do any of the health-related measures have potential to inform health surveillance of people with I/DD (i.e. to what group(s) are the findings generalizable)? Are certain domains or measures more informative than others?
15. Does this study have any methodology that may be useful for health surveillance for adults with I/DD?
16. Is this information source useful for on-going health surveillance?
17. Does this data source show potential for combination with other data sources to inform health surveillance – either through linkage, or through analytical methods (i.e. in a meta-analysis)?
18. For non-US studies – are there aspects of the methodology that may have application in the US? Are there aspects that limit the applicability?