



# **Compendium of International Data Sources for Parents with Disabilities | 2023**

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## International Data Sources for Parents with Disabilities

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## Introduction

People with disabilities take on many different roles in our societies. One of the common and important roles is being a parent. Globally, an emerging body of research are exploring issues concerning parents with disabilities. Due to the experiences of stigma and discrimination, parents with disabilities experience many disparities related to health, socioeconomic status, etc. Despite significant numbers of disabled people taking on parental roles, global research on this topic remains relatively limited; however, the amount of research is growing. To facilitate more scholarly attention to this topic, the National Research Center for Parents with Disabilities published and updated a compendium of different data sources for Parents with Disabilities in the United States in 2017 and 2022. Seventeen national data sets were compiled in the 2022 United States Data Compendium, providing a valuable source of information for researchers interested in examining issues related to parents with disabilities. Each dataset includes indicators of parental and disability status, meaning that data within each survey allows researchers to determine if a respondent is disabled and/or a parent. Modeling from the 2022 U.S. Data Compendium, this International Data Compendium expands the scope to the international context and describes data sources beyond the United States.

The International Data Compendium is based on the authors' review of literature and web sources, as well as on information sharing by international colleagues. It includes twelve data sources from eight countries/regions. The purpose of this compendium is to provide a preliminary overview of major datasets that collect respondents' disability and parental statuses in international contexts. Due to the nature of an international compendium, some of the data sources included here are in languages other than English, for example, data sources from South Korea and Israel. As a result, authors' ability to extract more detailed information is limited. The authors welcome more information sharing from international colleagues about additional data sources in different countries/regions. We will periodically add to this information to the compendium, making it a more comprehensive hub of current information. The authors can be reached by email at [aggiehu@brandeis.edu](mailto:aggiehu@brandeis.edu) and [miriamheyman@brandeis.edu](mailto:miriamheyman@brandeis.edu).

## Taiwan: National Survey on the Living Conditions of Persons with Disabilities

The [National Survey on the Living Conditions of Persons with Disabilities](#) is an ongoing survey administered by the Ministry of Health and Welfare in Taiwan every five years. The survey gathers basic information on people with disabilities including housing, transportation, living situation, finances, work status, health, medical support and caretaking, leisure activities, social participation, self-determination, primary caretaker's situation, and so forth. The survey aims to provide information for policymaking regarding people with disabilities in Taiwan. The survey includes two questionnaires, one targeted to persons with disabilities and the other targeted to caretakers of persons with disabilities. Prior to the pandemic, the survey was conducted primarily via in-person visits; sometimes, a telephone interview with caretakers was also accepted. Currently, surveys are accepted by video chat and telephone interview, as well as by printed survey filled in and sent by mail.

**Website**      <https://dep.mohw.gov.tw/DOS/lp-5096-113.html>

**Language**      Traditional Chinese

### *Disability indicators*

The questionnaire for persons with disabilities asks respondents to provide the category and severity of their disability/ies. Many categories of disabilities are indicated on the survey, including visual, hearing, orthopedic, speech, intellectual, psychiatric, and multiple, and, in addition, many other disabilities and illnesses.

### *Parental status indicators*

The questionnaire asks whether people with disabilities currently have child(ren), and if they do, how many children they have. This includes foster child(ren).

## Hong Kong: Social Data Collected via the General Household Survey – Persons with Disabilities and Chronic Diseases

The General Household Survey (GHS) survey is administered by the Census and Statistics Department of the Government of Hong Kong Special Administrative Region. It is a continuous sample survey that has been conducted since 1981. Its primary objective is to collect information on the labor force, employment, unemployment, and underemployment. Additionally, special data are collected on an ad hoc basis to obtain specified statistical data on a wide range of social topics such as the one on persons with disabilities and chronic diseases. A territory-wide survey on persons with disabilities and chronic diseases was conducted from August 2019 to December 2020 to estimate the total number of persons with selected types of disabilities and chronic diseases and the prevalence rates. It also collected information on the basic profiles of people

with disabilities and people with chronic diseases as well as information about those who provide care for them. The questionnaire is not shared on the public website, but major data items collected in the survey can be found in a Special Topics Report – Report No. 63.

**Website** <https://www.censtatd.gov.hk/en/EIndexbySubject.html?pcode=C0000055&scode=380>

**Language** English, Traditional Chinese

### *Disability indicators*

The survey asks respondents their level of difficulty in each of the functioning domains listed (restriction in body movement, difficulty in seeing, difficulty in hearing, difficulty in communication, mental illness/mood disorder, autism, specific learning difficulties, attention deficit/hyperactivity disorder) and other diagnosed health conditions (e.g., intellectual disability). The survey asks respondents about their usage of sign language and usage of assistive devices, as well as other information for persons with selected disabilities and those with chronic diseases.

### *Parental status indicators*

There are a series of questions aimed at gathering basic personal information including the number of members in the household and relationship to the head of household. There are also questions about the identity of a respondent's carers, whether carers are a respondent's children/son-in-law/daughter-in-law, domestic helper, spouse, or parents.

## **Israel: The National Insurance of Israel**

[National Insurance of Israel](#) (NII) is one of the pillars on which social policy in Israel rests. It acts as a public social-security institution and operates under the National Insurance Law. The NII aims to provide a financial basis for subsistence to certain populations and families with temporary or long-term need. This includes numerous programs targeting senior citizens and survivors (widows/widowers and orphans of an Israeli resident who dies, except for those who lose their lives in war or due to crime), mothers, children, and those experiencing work injuries, general disability, long-term care, unemployment, bankruptcy, and liquidation of corporations. Periodically the NII publishes research reports, mainly descriptive, on underserved populations, including people with disabilities. Descriptive statistics may include how many people with disability are eligible for disability benefits and how many of them are parents. The NII has a [fund](#) that supports research on these topics. A list of research reports can be accessed via the [NII website](#) (in Hebrew). [Statistics about people with disabilities](#) (in Hebrew) can also be found on the website.

**Website** <https://www.btl.gov.il/English%20homepage/Pages/default.aspx>

**Language** English, Hebrew

## Israel: The Social Survey of the Central Bureau of Statistics (CBS)

The [Social Survey of the Central Bureau of Statistics](#) (CBS) is an ongoing annual survey that has been conducted since 2002 and is commissioned by the Budget Division of the Ministry of Finance. The purpose of the survey is to provide up-to-date information on the welfare and living conditions of the population in Israel. It is based on a sample of persons aged 20 or over, which changes every year. It is intended for a diverse audience: policymakers, government ministries, local authorities, researchers, students, commercial companies, and the general public. The survey questionnaire is made up of two main parts: a permanent core containing about 200 fixed questions on a variety of areas of life, such as health, housing, employment, and financial status; and a variable module, which usually addresses one or two topics each year that are investigated in-depth.

Periodically the CBS publishes social surveys (in Hebrew) about people with disabilities in Israel. Researchers can contact the research units in NII and CBS and ask to get data about sub-groups in the disability community such as parents with disabilities.

**Website** [https://www.cbs.gov.il/en/About/Pages/aboutcbs\\_e.aspx](https://www.cbs.gov.il/en/About/Pages/aboutcbs_e.aspx)

**Language** English, Hebrew

## United States

There are multiple data sets in the United States that collect information on disability and parental statuses. Different data sources are compiled by the National Research Center for Parents with Disabilities and may be viewed on the [NRCPD website](#). One of the major data sources is the American Community Survey (ACS). The ACS is an ongoing yearly survey administered by the United States Census Bureau. Each year, 3.5 million people are contacted to participate. Topics pertain to housing, social history, educational attainment, and occupation; economic indicators such as poverty status and health-insurance coverage; and demographic information.

**Website** <https://www.census.gov/programs-surveys/acs/about.html>

**Language** English

### *Disability indicators*

The survey asks respondents if they have one or more of six disability types: hearing difficulty, vision difficulty, cognitive difficulty, ambulatory difficulty, self-care difficulty, and independent-living difficulty. These are the standard six disability types (see Appendix). If a respondent

has one or more of these disability types, they are considered to have a disability. These questions have been included in the ACS since 2008.

#### *Parental status indicators*

The survey asks for ages of people in the household and asks how each person is related to the focal person, who is defined as “the person living or staying here in whose name this house or apartment is owned, being bought, or rented.” Further, instructions specify, “[i]f there is no such person, start with the name of any adult living or staying here” (with “here” referring to the household).

Relationship options include:

- Opposite-sex husband/wife/spouse
- Opposite-sex unmarried partner
- Same-sex husband/wife/spouse
- Same-sex unmarried partner
- Biological son or daughter
- Adopted son or daughter
- Stepson or stepdaughter
- Brother or sister
- Father or mother
- Grandchild
- Parent-in-law
- Son-in-law or daughter-in-law
- Other relative
- Roommate or housemate
- Foster child
- Other nonrelative

## **Mainland China: Family Income and Living Situation Survey for Persons with Disabilities**

The [Family Income and Living Situation Survey for Persons with Disabilities](https://www.stats.gov.cn/fw/bmdcxmsp/bmzd/202302/t20230215_1907200.html) is guided by the National Bureau of Statistics of China and administered by China’s Disabled Person’s Federation to gather information on families with disabled individuals who are holders of disability certificates in the People’s Republic of China. The survey collects information on family income and other basic information, including the number of people living in the household, family address, name of the person(s) with disability, etc. The survey is conducted via in-person visits.

**Website**      [https://www.stats.gov.cn/fw/bmdcxmsp/bmzd/202302/t20230215\\_1907200.html](https://www.stats.gov.cn/fw/bmdcxmsp/bmzd/202302/t20230215_1907200.html)

**Language** Simplified Chinese

*Disability indicators*

The survey asks whether respondents are holders of the disability certificate, an official documentation in China for persons with disabilities. There are certain criteria and standards for obtaining such a certificate.

*Parental status indicators*

The survey asks about a respondent's relationship to the head of household. Relationship options include:

- Head of household
- Spouse
- Children
- Father or mother
- Brother or sister
- Father-in-law or mother-in-law
- Grandchildren
- Grandparent
- Daughter-in-law or son-in-law
- Other

## **India: Survey of Persons with Disabilities NSS 76th Round**

The Survey of Persons with Disabilities is part of the National Sample Survey (NSS) in India. NSS started to collect information on the number of physically disabled persons during the 15th round (July 1959–June 1960). The latest Survey of Persons with Disabilities was the NSS 76th Round (July 2018–December 2018). It used the interview method to collect data from a sample of randomly selected households and household members. The main objective of the survey is to estimate indicators of incidence and prevalence of disability, cause of disability, age at onset of disability, services available to the persons with disability, difficulties faced by people with disability in accessing public buildings/public transport, arrangement of regular caregiving, out-of-pocket expenses relating to disability, etc. Information on the nature of disability of household members was collected. The survey covers the whole of the Indian Union except the villages in Andaman and Nicobar Islands, which are difficult to access.

**Website** <http://microdata.gov.in/nada43/index.php/catalog/154/study-description>

**Language** English



### *Disability indicators*

The survey asks each household member their type of disability, including locomotor, visual, hearing, speech and language, “mental retardation”/intellectual disability, mental illness, and other disabilities. Further, the survey collects more detailed descriptions of each disability, such as the cause of disability, category of disability, age at onset of a disability, etc.

### *Parental status indicators*

The survey collects demographic information of household members including their relationship to the head of the household, whether the parents are biological parents, etc.

Relation to head options include:

- Self
- Spouse of head
- Married child
- Spouse of married child
- Unmarried child
- Grandchild
- Father/mother/father-in-law/mother-in-law
- Brother/sister/brother-in-law/sister-in-law/other relatives
- Servants/employees/other non-relatives

## **India: National Family Health Survey**

The National Family Health Survey 2019–21 (NFHS-5) provides information on population, health, and nutrition in India. The NFHS surveys are conducted under the stewardship of the Ministry of Health and Family Welfare, Government of India, and provide essential data on health and family welfare, as well as information on important emerging health and family welfare issues. Three rounds of the NFHS have been conducted since the first survey in 1992–93. The NFHS-5, the fifth in the NFHS series, gathered information from 636,699 households, 724,115 women, and 101,839 men. Starting from the NFHS-5, disability was covered among other new topics. Four core survey questionnaires—Household, Woman, Man, and Biomarker—were used in the NFHS-5. The questionnaires were canvassed in 18 local languages using Computer Assisted Personal Interviewing (CAPI), except that the Biomarker Questionnaire was paper-based. In the Household Questionnaire, information was collected on all permanent or usual members of the household and visitors who stayed in the household the night before the interview. Basic demographic information was collected on the characteristics of each person listed, such as age, sex, marital status, schooling, disabilities, relationship to the head of household, etc.

**Website**      <http://rchiips.org/nfhs/>

**Language** Hindi, English

*Disability indicators*

The respondent to the Household Questionnaire provides information for all usual household members on whether they have any disability in specified domains, including hearing, speech, visual, mental, locomotor, and others. The questions include:

Does any usual resident of your household, including you, have any disability?  
What type of disability does (NAME) have? Any other?

*Parental status indicators*

The survey collects demographic information of usual household members, including their relationship to the head of household, etc.

Relationship to head of household options include:

Head  
Wife or husband  
Son or daughter  
Son-in-law or daughter-in-law  
Grandchild  
Parent  
Parent-in-law  
Brother or sister  
Brother-in-law or sister-in-law  
Niece/nephew  
Other relative  
Adopted or foster child  
Domestic servant  
Other not related  
Don't know

## **South Korea: Panel Survey of Employment for Persons with Disabilities, 2016–2021**

The Panel Survey of Employment for Persons with Disabilities (PSED) is conducted every year and collects data related to economic activities and income. Most related documents and publications about this survey are written in Korean.

**Website** <https://kossda.snu.ac.kr/handle/20.500.12236/25954>

**Language** Korean, English

## **South Korea: National Survey on Persons with Disabilities**

The National Survey on Persons with Disabilities (NSPD) is conducted every three years and collects cross-sectional data on persons with disabilities. It has been conducted by the Korea Ministry of Health and Welfare and the Korea Institute for Health and Social Affairs since 1980. Its objective is to estimate the prevalence of disability by disability type and to develop national policies for persons with disabilities. The NSPD interviews household members who have disabilities.

**Website** <https://www.mohw.go.kr/react/jb/sjb030301vw.jsp>

**Language** Korean

## **Australia: Household, Income and Labor Dynamics in Australia (HILDA) Survey**

The Household, Income and Labor Dynamics in Australia (HILDA) Survey is a household-based panel study that has collected information about economic and personal wellbeing, labor market dynamics, and family life since 2001. It aims to tell the stories of one group of Australians over the course of their lives. The HILDA Survey follows the lives of more than 17,000 Australians each year and participants are followed over the course of their lifetime. The definition of disability adopted in the HILDA Survey is as follows: “a person is defined as having a disability if they have any long-term health condition, impairment or disability that restricts the individual in everyday activities and that has lasted, or is likely to last, for six months or more.” This definition of disability is similar to that used in other household surveys, such as the Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers, another data source included in this compendium.

**Website** <https://melbourneinstitute.unimelb.edu.au/hilda>

**Language** English

### *Disability indicators*

Disability severity is defined in terms of restrictions in the core activities of self-care, communication, and mobility. The HILDA Survey does not collect information in each wave on core-activity restrictions, but it collects information on the extent to which health conditions limit the amount of work an individual can do on a 0 to 10 scale, where 0 equals “not at all” and 10 equals “unable to do any work.”

*Parental status indicators*

The survey collects demographic information relationship about family, such as whether respondents are couples with dependent children, single parents, dependent children in couple-parent or single-parent families, etc.

**Australia: Survey of Disability, Aging, and Carers**

The aims of the 2018 Survey of Disability, Ageing and Carers are to: measure the prevalence of disability in Australia; measure the need for support of older people and those with disability; provide a demographic and socio-economic profile of people with disability, older people, and carers compared with the general population; and estimate the number of and provide information about people who provide care to people with disability, long-term health conditions, and older people. The 2018 Survey of Disability, Ageing and Carers (SDAC) was conducted throughout Australia during the period July 2018 to March 2019.

**Websites**     <https://meteor.aihw.gov.au/content/731625>  
<https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release>

**Language**     English

*Disability indicators*

The survey asks respondents questions on disability and carer identification, such as whether they have loss of sight or hearing, speech difficulties, etc.

*Parental status indicators*

The survey collects demographic information of household members, including their relationship to the head of the household.

Relationship to head of household options include:

- Household Reference Person
- Husband
- Wife
- Partner
- Son
- Daughter
- Step Son
- Step Daughter

Father  
Mother  
Brother  
Sister  
Grandson  
Granddaughter  
Nephew  
Niece  
Other  
Not Related

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## Appendix

### The American Community Survey Disability Questions (ACS-6)

*All ages:*

- 1.) Is this person deaf or does he/she have serious difficulty hearing? (Yes/No)
- 2.) Is this person blind or does he/she have serious difficulty seeing even when wearing glasses? (Yes/No)

*Ages 5 years and over:*

- 3.) Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions? (Yes/No)
- 4.) Does this person have serious difficulty walking or climbing stairs? (Yes/No)
- 5.) Does this person have difficulty dressing or bathing? (Yes/No)
- 6.) Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor's office or shopping? (Yes/No)