CRE–DH

Centre of Research Excellence in Disability and Health

DISABILITY AND HEALTH DATA COMPENDIUM

in partnership with

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INTRODUCTION

With the introduction of the National Disability Insurance Scheme (NDIS) and the development of state and local government plans, disability is now a key concern at every level of Australian government. There is a clear need for high quality evidence on the living circumstances of people with disabilities.

The purpose of this compendium is to highlight, raise awareness and illustrate the opportunities that exist for disability researchers in Australia. In this compendium, we outline the main national sample surveys, for children and working age Australians, that include information on disability. All sources of data are either publicly available or readily available to researchers.

These surveys cover a broad range of areas and topic – from surveys specifically designed to capture information on disability, to those specifically focussed on the education and employment opportunities of young Australians, to surveys focussed on various demographic groups including Indigenous people, children, men and women.

We consider each source of data, in turn, outlining a brief introduction, website details, the data available (including important details on disability variables in each source). We also highlight the existing research, strengths and weaknesses of each data base to provide an idea of what is and is not possible with each source.

The data outlined in this compendium is ordered in the following way.

Firstly, the Australian Bureau of Statistics (ABS) data. The ABS have also published a short primer on the sources of disability data they have published **here**

Second we have included longitudinal data sources on:

- young people and children
- income and labour dynamics and housing
- health of women and men.

SURVEY OF DISABILITY AGEING AND CARERS (SDAC)

Introduction

The Survey of Disability, Ageing and Carers (SDAC) is the largest and most comprehensive survey on disability in Australia. The survey was designed to measure the prevalence of disability in Australia and to provide a demographic and socio-economic profile of people with a disability, as well as individuals 65 years or older and carers. The SDAC uses a stratified, multi-stage sample of individuals from households and non-private dwellings, such as care accommodation. Beginning in 1981, data has been collected every 3-6 years. The most recent wave, collected in 2015, included nearly 75,000 Australians, of which over 23,000 are classified as having a disability.

http://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0

Data available

The SDAC uses an in-depth, 152-question disability module based on the International Classification of Functioning, Disability, and Health (ICF). Disability is identified both through specific impairment or condition type, and through functional limitations. Additionally, the ABS classifies disability according to a severity scale on the basis of restriction in core activities. Detailed information is collected about health and assistance needed and received in a wide variety of areas, such as mobility, self-care, household chores, and transport activities. Individuals with disability are also asked about their use of aids and equipment, service usage, NDIS participation, self-rated health, social and community participation, schooling and employment restrictions, access and barriers to health care, and feelings of safety.

Basic demographic and socio-economic information is collected for all individuals within the household, even if they are not part of SDAC's target population.

Strengths

Detailed information on individuals with disability is available across a wide variety of domains, including impairment type and diagnosis, functional limitations, and barriers to participation.

Different years of SDAC are comparable, although caution should be taken as scope and definition for certain populations may change over time.

Weaknesses

As limited information is collected for those not in the target populations, comparability between population groups is restricted. Limited information is likewise collected from individuals living in care accommodation or completing proxy interviews, which may be correlated with severity of disability. Additionally, SDAC excludes certain population groups, such as those living in correctional facilities, very remote areas, or discrete Aboriginal and Torres Strait Islander communities, which may lead to underreporting and bias in disability prevalence estimates. Finally, the SDAC is cross-sectional in nature so cannot be used to evaluate causality.

Research Examples

This data has been used provide evidence for the persistent and increasing socio-economic disadvantage individuals with disability face[2]. SDAC data has also been used to investigate the prevalence and demographic trends in disability-based discrimination[3] and to examine particular impairment types and populations, such as prevalence and demographic data on parents with intellectual disability[4].

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THE CENSUS OF POPULATION AND HOUSING

Introduction

The Census of Population and Housing is a descriptive count of the population of Australia on census night. It is held every five years, and is the best source of data available in Australia for estimating both the size and socio-demographic composition of the usually resident population. The most recent census was held on 9th August 2016. While the census is compulsory, not all questions included in it are.

www.abs.gov.au/census

Data available

The census asks questions on both the socio-demographics (e.g. education, income and country of birth) of individuals and the composition of households. Questions are also asked about the size and type of dwelling people reside in.

There were three main questions on disability in the 2016 census focussing on core activity limitations. These questions were asked in the household component of the survey. They asked whether household members needed someone to help or be with them for: 1) self-care activities (e.g. eating, showering, dressing and toileting); 2) body movement activities (e.g. getting out of bed, moving around at home or at places away from home; 3) communication activities (e.g. understanding or being understood by others). After these three questions, there is a follow-up asking about the reason for the need for assistance. This allows respondents to identify whether it is a short or long term health condition, old or young age or a disability which results in the need for assistance.

Strengths

Currently, the census is the only source of data designed to have total coverage of the whole population and is the best estimate of the usually resident population and its characteristics. It therefore enables detailed analysis at a small geographical area.

Weaknesses

With regard to disability, the census does not capture the complete population of people with disabilities as it mainly identifies individuals with more severe impairments. While gaining the fine grain geographical detail that a total population survey can provide, one loses temporal detail with the census only being conducted on one night every five years.

Research Examples

Examples of recent research using the census includes a study on differences in access to specialist disability services by people from culturally and linguistically diverse backgrounds, when compared to those who were born in Australia[5] and the extent to which the disability status of people born overseas, but who have lived in Australia for periods, has changed over time[6].

Further Information

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NATIONAL ABORIGINAL AND TORRES STRAIT ISLANDER SOCIAL SURVEY

Introduction

The National Aboriginal and Torres Strait Islander Social Survey (NATSISS) was conducted from September 2014 to June 2015 with a sample of 11,178 Aboriginal and Torres Strait Islander people living in private dwellings across Australia. The NATSISS is a six-yearly multidimensional social survey which provides broad, self-reported information across key areas of social interest for Aboriginal and Torres Strait Islander people, primarily at the national level and by remoteness.

www.abs.gov.au/ausstats/abs/4714.0

Data available

The objectives of the NATSISS were to collect data that provides broad information across key areas of social concern. It collects core socio-demographic data (e.g. age, sex, household type), information on education and employment including job security, occupation. There is a range of self-reported health information – including sensory impairments, self-rated health, maternal health, oral health, chronic conditions and co-morbidities. The ABS Disability module is included which asks questions on core activity limitations, impairment type and whether work and/or education is limited. There are also questions on risky health behaviours such as smoking and alcohol intake. Other modules include language and culture, child events and care, access to services and unfair treatment and discrimination.

Strengths

NATSISS collects broad information in one survey, which provides a better picture of the well-being of Indigenous Australians, something that can be lacking in other surveys where Indigenous people make up a small portion of the sample or questions are not specifically designed with Indigenous people in mind. NATSISS can also provide comparisons with the non-Indigenous population using the General Social Survey. It was developed in consultation with a wide range of stakeholders such as Commonwealth and State/Territory government bodies, the Aboriginal and Torres Strait Islander Commission (ATSIC), Land Councils and research agencies. Individuals in both non-remote and remote areas were involved in focus groups and field testing to ensure the questions were relevant and culturally appropriate.

Weaknesses

The NATSISS is a cross-sectional survey and does not allow for study of within-person trends or causality. The survey is only conducted every six years. One has to use alternative surveys to compare the population of Indigenous people to other population groups.

Research Examples

To our knowledge there is no published research that has used NATSISS for research on people with disabilities.

To our knowledge, Australian Health Survey data has not yet been used to examine disability.

Further Information

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AUSTRALIAN HEALTH SURVEY

Introduction

The Australian Health Survey is the largest and most comprehensive health survey ever conducted in Australia. Combining data from the National Health Survey, National Aboriginal and Torres Strait Islander Health Survey, a national nutrition and physical activity survey, and a national health measures survey, the Australian Health Survey provides detailed information on many facets of health, lifestyle, and personal, family, and community circumstances. Data was collected by the ABS using a stratified, multistage sample of private dwellings. One adult and one child were selected from over 25,000 households, for a total of 32,000 participants.

www.abs.gov.au/australianhealthsurvey

Data available

The Australian Health Survey contains detailed information about health-related actions, such as health service use, and risk factors, such as alcohol consumption. The nutrition portion collected in-depth information on food intake and physical activity, using both subjective (e.g. self-report) and objective measures (e.g. pedometer). Physical measurements such as height, weight, BMI, and waist circumference were also taken from the majority of participants.

This survey focuses on specific health conditions that may be associated with disability, such as kidney disease, diabetes, and heart and circulatory conditions. Disability status is obtained from all participants. Individuals who reported a limitation, restriction, impairment, disease, or disorder that lasted, or was expected to last, six months or more and which restricted everyday activities were considered to have a disability. The ABS states that disability data is to be used in the context of comparing service use, risk factors, health behaviours, and health outcomes, as opposed to estimating prevalence.

Strengths

The Australian Health Survey benefits from a large, representative sample with high response rates. Face to face interviews led to higher rates of complete collection and allowed interviewers to take objective measures. Additionally, biomarkers were collected from 11,246 volunteers (37% of sample). There was also representative inclusion of Aboriginal and Torres Strait Islander people through a large, specially selected sample of 12,300 participants.

Weaknesses

Individuals living in non-private dwellings were excluded from this survey. The data is cross-sectional in nature, although some components, such as the NHS, have multiple waves. Disability data cannot estimate prevalence.

Research Examples

To our knowledge, Australian Health Survey data has not yet been used to examine disability.

Further Information

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NATIONAL HEALTH SURVEY

Introduction

The National Health Survey (NHS) is a nationally representative survey conducted every 3-5 years and focused on the health status of Australians and the health-related aspects of their lifestyles. The survey uses a stratified, multistage area sample of private dwellings and interviews one adult and one child aged 0-17 years in each selected household. Data was most recently collected in 2014-2015 and included approximately 19,000 individuals from 14,700 households.

www.abs.gov.au/ausstats/abs/4364.0.55.001

Data available

The NHS collects information on long term conditions, and particular conditions may be selected for more detailed exploration due to policy interests and concerns, such as cancer, kidney disease, and mental, behavioural, and cognitive conditions. Participants' experiences of conditions are broken into five different categories, reflecting an individual's current or ever condition status. Information is also collected on consultations with health professionals and other health-related actions, such as medication use or absences from work. Lifestyle factors that may impact health are also included in the interview, including topics such as tobacco smoking, alcohol consumption, nutrition, physical activity, and physical measurements (height, weight, waist circumference, blood pressure).

Individuals with health conditions are asked if their condition causes difficulties with employment or education, if they ever use aids to assist with tasks or need supervision from others, and if they can complete 4 different functional tasks related to mobility.

Strengths

The NHS provides detailed information on a variety of health conditions, health behaviours, and lifestyle factors. Physical measurements were collected for most participants.

Weaknesses

Limited information is collected on the functional limitations and participation restrictions of people with disability or the health conditions they face. The physical measurements have a decreased response rate and may be prone to bias. Very remote areas, discrete Aboriginal and TSI communities, and non-private dwellings were excluded from the sample, which may underestimate the prevalence of certain health conditions, particularly for the Northern Territory and Aboriginal and Torres Strait Islander individuals.

Research Examples

Recent research using NHS data has concentrated on health behaviours and risk factors, but so far has not included a disability focus. Researchers using NHS data have examined the association between multimorbidity and health service use[7], analysed discrepancies in the health outcomes and behaviour of two different generations[8], found increases in overweight/obesity across Australia[9], and explored the persistent disparities in mental health in Australia based on socio-economic characteristics[10]. NHS data, with its detailed information on health behaviours and risk factors, could be used to delve further into the health disparities experienced by people with disability and long-term conditions.

Further Information

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GENERAL SOCIAL SURVEY

Introduction

The General Social Survey (GSS) is a national, population-based survey conducted by the ABS that collects data on the many factors influencing an individual's social participation, including economic and personal wellbeing, education and labour market participation, and relationships and family life. The most recent wave of the GSS was collected in 2014 from a sample of 12,932 private dwellings across urban and rural areas in all states and territories in Australia, with one person aged 15 years or older providing information for the selected household. The GSS uses a multi-stage sampling strategy and has been repeated every four years since it began in 2002.

www.abs.gov.au/ausstats/abs/4159.0

Data available

The GSS collects data from a core set of topics, such as health and employment, in every wave. Other topics are cyclical and allow for analysis of emerging areas of social concern. Information collected on areas such as mobility and transportation, crime and feelings of safety, attendance at events and cultural venues, and sports and physical activity participation may be especially important for people with disabilities.

The GSS uses the ABS disability module to ascertain disability status. This asks participants if they have any conditions that have lasted, or are likely to last for six months or more and restrict the participants in core activities or in school/employment. Disability is then coded into six different severity categories, and the types of impairment/condition are also noted.

Strengths

The GSS benefits from a good response rate (80.1%). The survey content remains largely (80%) the same from wave to wave, permitting the comparison of different survey waves. The inclusion of new, topical content is valuable in evaluating emerging issues. Multiple years of data collection are available. Finally, the emphasis on recruiting individuals from lower socio-economic areas provides good estimates of this population of individuals, which may be underrepresented in other surveys.

Weaknesses

Although the GSS has multiple years of data collection, it is cross-sectional in nature and can neither evaluate within-person change nor causality. Individuals living in non-private residences, very remote areas, or on discrete Aboriginal and Torres Strait Islander communities are excluded. This may result in an underrepresentation of Aboriginal and Torres Strait Islander people and people with severe disabilities.

Research Examples

2010 GSS data was used to show that individuals with disabilities experienced poorer outcomes in terms of social support, informal and formal support networks, and self-rated health as compared to individuals without disabilities. The researchers found these outcomes were especially poor for people with intellectual and psychological disabilities[11].

Further Information

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PERSONAL SAFETY SURVEY

Introduction

Beginning in 2005, the Personal Safety Survey has collected information on men and women's experiences of violence, abuse, harassment, and feelings of safety. Individuals in all states and territories are included, with information collected through face-to-face interviews with one resident of the selected household. Households were selected through stratified multi-stage sampling, with women overrepresented to allow for state/territory estimates for women. The most recent PSS, conducted from November 2016-June 2017, collected data from approximately 21,250 people, aged 18 years and over. The PSS is conducted by the ABS.

www.abs.gov.au/ausstats/abs

Data available

The PSS questionnaire is divided into mandatory and voluntary topics. Mandatory topics include sociodemographic characteristics, education, labour force participation, personal, family, and economic wellbeing, and health, disability, and perceptions of safety.Voluntary topics include sexual harassment and abuse, physical violence, experiences of witnessing violence as a child, intimate partner violence, emotional abuse, and stalking. Some measures in these areas are lifetime, while others are since the age of fifteen. Disability is assessed using the ABS module, which ascertains if individuals have a health condition which has lasted, or is likely to last, six months or more and leads to restrictions in everyday life. These restrictions are then classified as a core activity limitation, or a school/employment restriction only. Broad impairment types are noted.

Strengths

The PSS is a large, population based survey of violence, a sensitive and challenging topic. The 2016 PSS used specially trained female interviewers to encourage participation, and a response rate of 68.7% was achieved. Prevalence estimates of violence may be estimated for women. The PSS was also conducted in 2012 and 2005.

Weaknesses

The PSS is a cross-sectional survey and does not allow for study of within-person trends or causality. The PSS is not designed to provide state/territory level estimates for men; this data is only at the country-level. Analysts must closely compare variables in previous survey waves, as the PSS is not fully comparable from year to year. There may be selection bias due to non-response, and disability status is based on self-report. The interview had to be performed with no other household members, making proxy or assisted interviews impossible. This likely excluded individuals with communication or intellectual difficulties. Finally, prior to the 2012 PSS disability status was not included in the survey.

Research Examples

Previous research using the PSS has found that there are gender differences in experiences of violence among people with disabilities, although both and women with disabilities were more likely to experience violence than people without disabilities[12]. A further study found that women with disabilities were more likely to experience economic partner abuse than women without disability[13].

Further Information

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LONGITUDINAL SURVEY OF AUSTRALIAN YOUTH (LSAY)

Introduction

The Longitudinal Surveys of Australian Youth (LSAY) focus on the progress of young Australians as they move from their mid-teens to their mid-20s. It includes surveys conducted from the mid-1970s through to the mid-1990s: the Youth in Transition Survey (YITS); the Australian Longitudinal Survey (ALS); the Australian Youth Survey (AYS); and the current LSAY collection, which began in 1995.

The current LSAY collection uses large, nationally representative samples of students at school to collect information about education and training, work, financial matters, health, social activities and related issues. The commencing sample size for each cohort in the current collection ranges from 10,000 – 15,000. Since 2003, the initial survey wave has been integrated with the OECD Programme for International Student Assessment (PISA). Data are initially collected through a combination of school achievement tests and a questionnaire administered at school. Subsequent data are gathered through annual telephone interviews. Since 2012, survey participants have had the option to complete their interview online.

www.lsay.edu.au/

Data available

There are six cohorts in the current collection. Questions on disability are typically asked at three waves for each cohort: 1995 – waves 3, 4 and 7; 1998 – waves 3, 4 and 12; 2003 – waves 3, 7 and 10; 2006 – waves 3, 7 and 10; 2009 – waves 5 and 7; 2015 – not asked yet. Each cohort runs for ten years. The disability questions have remained relatively consistent over time. For example, in the 2006 cohort, at wave three the following question was asked: "Do you have any disability or health problem, which limits the amount or type of work you can do?". This question was later (at wave 7) amended slightly so that it asked about disability and health conditions that have "…lasted six months or more…".

There are four major topic areas – 1) basic demographic information for both the students and parents; 2) education including questions about schooling, students plans for when they leave school and then questions about their progress post-school; 3) employment including questions on wages and benefits and job seeking behaviour and 4) their social characteristics such as living arrangements, household possessions and their general attitudes.

Strengths

LSAY, like HILDA allows users to follow individuals longitudinally. A further clear strength of LSAY is the focus on a particular age-range – 15 – 25 year olds. Normally, conducting analysis for a specific age group in a sample survey is limited by small sample size issues. However, when using LSAY the whole sample is devoted to this younger group of people. There are also detailed questions on work experience, attitudes and aspirations and support young people obtain as they transition from school into emerging adulthood. Questions of this kind are not asked in most sample surveys.

Weaknesses

Questions on disability are not asked at each wave, and questions on other health outcomes are somewhat limited and not asked at each wave. There are also very limited questions on health-related behaviours, such as smoking.

Research Examples

To our knowledge there is no published research that has used LSAY for research on young people with disabilities.

Further Information (green font)

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GROWING UP IN AUSTRALIA: THE LONGITUDINAL SURVEY OF AUSTRALIAN CHILDREN (LSAC)

Introduction

The Longitudinal Survey of Australian Children (LSAC) is a nationally representative longitudinal study following the development of approximately 10,000 children and their families across Australia. Beginning in 2004, a representative sample of children in two age cohorts, 4-5 years and 0-1 years, were randomly chosen from selected postcodes within the Medicare database. Every two years, LSAC collects information from the child (when appropriate), and their parents, teachers, and carers through a combination of face to face interviews and paper questionnaires. Questions address areas such as parenting, family relationships, education, child care, and health and aim to provide information about how a child's social, economic, and cultural environments impact their wellbeing over the course of their lives. The seventh round of data collection was completed in early 2017. LSAC is conducted through the Department of Social Services, the Australian Institute of Family Studies, and the Australian Bureau of Statistics.

growingupinaustralia.gov.au/

Data available

Information about health is included in every wave, with the primary caregiver answering questions regarding medical conditions and disability that have lasted, or are expected to last, for at least 12 months. For children with a medical condition or disability, the type of impairment or condition is recorded and severity for the condition/disability is measured on a three-point scale. Some conditions, such as eczema and allergies, have more detailed question sets. Information is collected on absences related to the condition/disability, restrictions in everyday activity, the use of basic aids/classroom arrangements, injury and hospitalization, sleep, and oral health.

Strengths

LSAC has a good retention rate for both age cohorts. Additionally, the collection of information from several important people in the study child's life, such as parents, teacher, and carer, add depth and richness to the data. For parents who do not live with the study child, interviews are collected by telephone. Finally, the longitudinal nature of the survey permits observation of within person and aggregate change over time.

Weaknesses

The initial response rate was 57% in the infant cohort and 50% for the child cohort. While both parents are interviewed, mothers are more often the primary caregiver, and therefore complete the more detailed interview regarding the child. Disability as reported by parents may be subject to bias.

Finally, children from advantaged households may be overrepresented in the cohort.

Research Examples

A substantial body of work with LSAC data has focused on borderline or intellectual disability as an exposure. Researchers have found that children with intellectual impairment are at increased risk of obesity[14], have higher rates of possible mental health problems[1], and may experience conduct difficulties associated with exposure to environmental adversity[15]. Other researchers have focused on the support needs of fathers of children with Autism Spectrum Disorder[16], analysed the general wellbeing of children who have siblings with disability[17], and investigated recreational participation and social competence among children with disabilities[18].

Further Information

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FOOTPRINTS IN TIME: THE LONGITUDINAL SURVEY OF INDIGENOUS CHILDREN (LSIC)

Introduction

The Longitudinal Survey of Indigenous Children (LSIC) is a longitudinal study of over 1,600 Aboriginal and Torres Strait Islander children, their parents, teachers, and other carers. Beginning in 2008, a non-random, purposively sampled group of Aboriginal and Torres Strait Islander children in two age groups, 6-18 months and 3.5-5 years, were selected from a range of socioeconomic and community environments. Each year, these participants are interviewed on a range of topics, including health, learning and development, and family and community. Interviews are conducted by Aboriginal and Torres Strait Islander Research Administration Officers, with Wave 10 data collection beginning in February 2017. LSIC is conducted through the Department of Social Surveys with guidance from the Footprints in Time steering committee.

www.dss.gov.au/about-the-department/publications-articles/research-publications/longitudinal-data-initiatives/footprints-in-time-the-longitudinal-study-of-indigenous-children-lsic

Data available

Information from both parents/guardians, teacher and child care workers, and the study child is available at each wave. In each wave, the study child completes vocabulary and practical exercises, answers interview questions as appropriate, and has their height and weight measured by the interviewer. Information on socioeconomic and demographic characteristics, parental health, and children's health conditions is also collected in every wave. Detailed information is recorded on the study child's general development, their learning and cognition, and their health as an infant. As the child cohorts grow up, the LSIC includes relevant topical question areas, such as about caring responsibilities, beginning high school, attending school away from home, and social and emotional wellbeing. This data is linked with the NAPLAN.

Strengths

The LSIC has a large sample size with a high retention rate (between 81% and 87% in each wave), and this is due to extensive community engagement and employment of Indigenous interviewers. Face to face interviews provide detailed information from the study child and at least one of their parents, while other informants provide information via telephone or questionnaire. The participants represent diverse geographical areas and socioeconomic circumstances, with in-depth qualitative and quantitative data collected. Core question areas, such as health, are asked in every wave. Other topics appear in waves as relevant to the age of the study child, including experiences of racism, language and culture, relationships, and activities outside of school.

Weaknesses

The use of non-random sampling limits the generalizability of the data to the population of Aboriginal and Torres Strait Islander children. As such, LSIC is designed for internal and longitudinal analyses only. Limited information is available on geographic area in order to preserve privacy. Height and weight are the only physical measurements recorded. Some survey instruments included in LSIC have not been validated in the Aboriginal and Torres Strait Islander population.

Research Examples

There is limited research on disability using LSIC data. The only study using disability as an exposure found that Indigenous children with low cognitive ability were at increased risk of social exclusion compared with their peers[19].

Further Information

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HOUSEHOLD INCOME AND LABOUR DYNAMICS OF AUSTRALIA SURVEY (HILDA)

Introduction

The Household, Income and Labour Dynamics in Australia (HILDA) survey is a household panel study that collects information about economic and personal well-being, labour market dynamics, and family life. It is a longitudinal survey which aims to tell the stories of the same group of Australians over the course of their lives. The sample has gradually extended since the survey began in 2001, including new household members from changes in household composition and a top-up sample in 2001. Face to face interviews collect information on all household members aged 15 years and older.

melbourneinstitute.unimelb.edu.au/hilda

Data available

Since the initial wave, HILDA has ascertained disability status through one question using a definition of disability derived from the ICF: "Do [you] have any long-term health condition, impairment, or disability that restricts you in your everyday activities and has lasted, or is likely to last, for 6 months or more?" Since Wave 3 (2003), HILDA has collected information about impairment type and year the condition developed. Rotating series of questions, asked approximately every 5 waves, collect information about difficulties with education and employment, use of aids, home modifications, and tasks that require assistance.

Major modules in HILDA include wealth, retirement, fertility, health, and education, skills, and abilities. Minor modules include job-related discrimination, intentions and plans, relationships, non-residential adult children, health insurance, youth, literacy and numeracy, diet, and material deprivation.

Strengths

To date, 16 waves of HILDA data are available. The ability to use this data longitudinally allows for the analysis of inter-and intra-personal outcomes over time. HILDA has a high response rate of 90% and 70% for original and newer participants, respectively. HILDA collects in-depth information about socio-economic outcomes.

Weaknesses

Individuals with severe disability, as well as certain impairment types, such as intellectual and psychological disability, are less likely to participate in HILDA. Information on specific impairment types was not collected until Wave 3. Information on functioning, restriction, and assistance for individuals with disability is not collected in each wave and the functional impact of disability is not assessed comprehensively. Finally, not all minor modules are included in each wave.

Research Examples

Multiple recent works have examined disability acquisition as an exposure. This includes an analysis of the impact of social support on mental health for individuals who acquire a disability[20], findings indicating that lower wealth was associated with greater decreases in mental health following disability acquisition[21], and research evidencing that mental health decreases substantially more for socioeconomically disadvantaged individuals who acquire a disability[22]. HILDA data has also been used in the context of employment, with one study finding that individuals with disability were more likely to experience adversity at work[23] and that efforts to increase psychosocial job quality may provide benefits for individuals with disability[24]. Other recent work has examined disability and younger people, including the influences of disability onset on participation[25] and on employment transitions[26].

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JOURNEYS HOME: A LONGITUDINAL STUDY OF FACTORS AFFECTING HOUSING STABILITY

Introduction

Journeys Home was a national survey of Australians who were either homeless or at risk of becoming homeless. Beginning in September 2011, Journeys Home collected information on nearly 1,700 individuals for six waves of data collection over the course of two and a half years, concluding in 2014. Journeys Home was funded by the Australian Government Department of Social Services, and aimed to investigate the pathways leading into and out of homelessness.

melbourneinstitute.unimelb.edu.au/journeys-home

Data available

In each wave of data collection, Journeys Home collected information on personal circumstances, including physical and mental health, family circumstances, housing circumstances, and the use of support services. Detailed questions enabled the creation of an accommodation calendar for participants, to describe their living arrangements.

Participants were asked if they had any long-term condition, impairment, or disability that restricted them in their everyday activities and had lasted, or was likely to last, for six months or more. Following this, participants were asked if they had select mental health conditions, such as depression, anxiety, or bipolar disorder. Participants were also asked if they had been diagnosed with any physical conditions, and were asked to provide information as to the type of condition.

Strengths

Journeys Home was the largest, most comprehensive longitudinal survey of homelessness in Australia. Interviews were primarily face to face, with some telephone interviews conducted. The initial response rate, 61.9%, was sizeable considering the vulnerable population involved and potentially sensitive material discussed. Additionally, over 93% of participants agreed for data linkage to their Centrelink information.

Weaknesses

Journey Home is not a representative survey, and only six waves of data were collected. Aboriginal and Torres Strait Islander individuals are more likely to be excluded due to the clustered sample nature of the survey, wherein clusters had to be within a 10-kilometer radius of major cities and a 20-kilometer radius of regional and rural centres. This sample design was due to financial constraints. Finally, Journeys Home does not ask detailed questions about the type, severity, duration, or restrictions related to disability.

Research Examples

To our knowledge, data from Journeys Home has not yet been used to examine disability.

Further Information

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WOMEN'S HEALTH AUSTRALIA

Introduction

The Australian Longitudinal Study on Women's Health (ALSWH) began in 1996, and included over 58,000 women in three age cohorts, ages 18-23 years, 45-50 years, and 70-75 years. A new cohort of 17,000 women aged 18-23 was recruited in 2012/2013. Women were randomly sampled within each age group, and were randomly selected from the Medicare database. Women complete mail or internet surveys every 3 years, with the older cohort receiving a shortened questionnaire every six months since 2011. The ALSWH collects data on multiple facets of health throughout a woman's life, and is generally representative of the population of Australian women.

www.alswh.org.au/

Data available

The content of the surveys varies from wave to wave, and topics are selected as appropriate to the women's age (e.g. menopause, starting a family). ALSWH focuses on women's physical and mental health, sociodemographic and lifestyle characteristics, and the use of health services.

Disability in the youngest age cohort was most recently ascertained through a multi-response question asking if the participants' health limited them in a number of activities, including climbing stairs, walking, bathing, and dressing oneself. Participants were then asked how much difficulty they encountered with these activities. Using this information, the researcher may create a variable reflecting disability status. In some waves, women are asked to provide the type of illness, condition, or disability.

Strengths

The ALSWH has been following the original three cohorts of women for over twenty years, with good retention rates considering the level of commitment required (ranging from 41%-56% in initial wave). The longitudinal nature of the data allows for within-person comparisons. ALSWH data is able to be linked to other datasets. Women are invited to participate in additional sub-studies, covering topic areas such as violence, menopause, and life plans of young women.

Weaknesses

There is limited information on disability in the ALSWH, and information pertaining to areas such as assistance required due to disability is not collected in every wave. Women with severe disabilities, and/or intellectual or language difficulties, may not have been able to complete the mail or internet questionnaire. Finally, all data collected is via self-report and may be subject to bias.

Research Examples

To our knowledge, ALSWH data has not yet been used to examine disability.

Further Information

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Australian Longitudinal Study on Women's Health

TEN TO MEN: THE AUSTRALIAN LONGITUDINAL STUDY ON MALE HEALTH

Introduction

The Australian Longitudinal Study on Male Health (Ten to Men) is a longitudinal study aimed at understanding the high rates of preventable morbidity and premature mortality experienced by Australian men. Nearly 16,000 men and boys, ages 10-55, supplied data in the initial wave of data collection in 2013/2014. Through questionnaires and face-to-face interviews, the men provided detailed information on health behaviours, personal and family circumstances, life transitions and events, and environmental and social influences. Ten to Men used a multi-stage, clustered random sample design and over-sampled men in rural areas.

www.tentomen.org.au/

Data available

Data is available on a broad range of factors influencing men's lives, covering physical and mental wellbeing, health service use, health risks, education, employment, economic outcomes, housing, and family lives. Topics vary slightly depending on the age of the participant, with life stage questions tailored as appropriate.

Disability status is ascertained through the Washington Group Short Set of questions on disability. This classifies disability into six functional impairment types, with four categories of difficulty. Men may report more than one functional limitation. Detailed information is collected on some long-term conditions, but impairments causing disability are not elucidated.

Strengths

Ten to Men is the only longitudinal study focusing exclusively on Australian men. It is national in scope and has a large sample size, including approximately 2,000 adolescents and boys aged 10-17 years. The second wave of Ten to Men data was released in 2017, and waves are to be conducted every 2-3 years, following men across their lives. Data collected in Ten to Men covers a wide range of factors associated with the social determinants of health. The Washington Group questions permit international comparisons.

Weaknesses

The initial response fraction for Ten to Men was low (35%). Aboriginal and Torres Strait Islander men are under-represented. There may be bias in the self-report questionnaire. Men may have had difficulty or been unable to complete the questionnaire if English was not their first language. Men with visual, intellectual, or cognitive impairments may have been unable to complete the questionnaire, leading to additional under-representation. Finally, the men included in the survey are slightly older, more likely to have been born in Australia, and more likely to live in rural areas than the general population of men they represent.

Research Examples

Data from the initial wave of Ten to Men has shown that men with disabilities experienced significant social and economic disadvantage, as well as poorer health and wellbeing, compared with men without disabilities[27]. Additionally, men with a disability or a mental health condition may be more likely to have sexual difficulties[28].

Further Information

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REFERENCES

1. Emerson, E., S. Einfeld, and R.J. Stancliffe, *The mental health of young children with intellectual disabilities or borderline intellectual functioning.* Soc Psychiatry Psychiatr Epidemiol, 2010. 45(5): p. 579-87.
2. Kavanagh, A.M., et al., *Time trends in socio-economic inequalities for women and men with disabilities in Australia: evidence of persisting inequalities.* Int J Equity Health, 2013. 12: p. 73.
3. Krnjacki, L., et al., *Disability-based discrimination and health: findings from an Australian-based population study.* Aust N Z J Public Health, 2017.
4. Man, N.W.W., Catherine; Llewellyn, Gwynnth, *Prevalence of parents with intellectual disability in Australia.* journal of Intellectual and Developmental Disability, 2017. 42(2): p. 173-179.
5. Zhou, Q., *Accessing disability services by people from culturally and linguistically diverse backgrounds in Australia.* Disabil Rehabil, 2016. 38(9): p. 844-52.
6. Zhou, Q., *Changing disability status of immigrants in Australia: Three case studies.* Journal Review of Disability Studies: An International Journal, 2017. 13(2): p. 1-18.
7. Wang, L., et al., *Multimorbidity and Health Care Service Utilization in the Australian Workforce: Findings From the National Health Survey.* J Occup Environ Med, 2017. 59(8): p. 795-802.
8. Pilkington, R., et al., *Are Baby Boomers healthier than Generation X? A profile of Australia's working generations using National Health Survey data.* PLoS One, 2014. 9(3): p. e93087.
9. Huse, O., et al., *Obesity in Australia.* Obes Res Clin Pract, 2018. 12(1): p. 29-39.
10. Enticott, J.C., et al., *Mental disorders and distress: Associations with demographics, remoteness and socioeconomic deprivation of area of residence across Australia.* Aust N Z J Psychiatry, 2016. 50(12): p. 1169-1179.
11. Mithen, J., et al., *Inequalities in social capital and health between people with and without disabilities.* Soc Sci Med, 2015. 126: p. 26-35.
12. Krnjacki, L., et al., *Prevalence and risk of violence against people with and without disabilities: findings from an Australian population-based study.* Aust N Z J Public Health, 2016. 40(1): p. 16-21.
13. Kutin, J., R. Russell, and M. Reid, *Economic abuse between intimate partners in Australia: prevalence, health status, disability and financial stress.* Aust N Z J Public Health, 2017. 41(3): p. 269-274.
14. Emerson, E. and J. Robertson, *Obesity in young children with intellectual disabilities or borderline intellectual functioning.* Int J Pediatr Obes, 2010. 5(4): p. 320-6.
15. Emerson, E., S. Einfeld, and R.J. Stancliffe, *Predictors of the persistence of conduct difficulties in children with cognitive delay.* J Child Psychol Psychiatry, 2011. 52(11): p. 1184-94.
16. Seymour, M., R. Giallo, and C.E. Wood, *The psychological and physical health of fathers of children with Autism Spectrum Disorder compared to fathers of children with long-term disabilities and fathers of children without disabilities.* Res Dev Disabil, 2017. 69: p. 8-17.
17. Emerson, E. and R. Giallo, *The wellbeing of siblings of children with disabilities.* Res Dev Disabil, 2014. 35(9): p. 2085-92.
18. Phillips, R. and A. Hogan, *Recreational participation and the development of social competence in preschool aged children with disabilities: a cross-sectional study.* Disabil Rehabil, 2015. 37(11): p. 981-9.
19. Gilroy, J. and E. Emerson, *Australian indigenous children with low cognitive ability: Family and cultural participation.* Res Dev Disabil, 2016. 56: p. 117-27.

20. Aitken, Z., et al., *Does social support modify the effect of disability acquisition on mental health? A longitudinal study of Australian adults.* Soc Psychiatry Psychiatr Epidemiol, 2017. 52(10): p. 1247-1255.

21. Kavanagh, A.M., et al., *Mental Health Following Acquisition of Disability in Adulthood--The Impact of Wealth.* PLoS One, 2015. 10(10): p. e0139708.

22. Aitken, Z., et al., *Disability acquisition and mental health: effect modification by demographic and socioeconomic characteristics using data from an Australian longitudinal study.* BMJ Open, 2017. 7(9): p. e016953.

23. LaMontagne, A.D., et al., *Psychosocial job quality in a national sample of working Australians: A comparison of persons working with versus without disability.* SSM Popul Health, 2016. 2: p. 175-181.

24. Milner, A., et al., *Perceived fairness of pay among people with and without disabilities: a propensity score matched analysis of working Australians.* Scand J Work Environ Health, 2015. 41(5): p. 451-9.

25. Emerson, E., et al., *Becoming disabled: The association between disability onset in younger adults and subsequent changes in productive engagement, social support, financial hardship and subjective wellbeing.* Disabil Health J, 2014. 7(4): p. 448-56.

26. Honey, A., Kariouki, M., Emerson, E., & Llewellyn, G., *Employment status transitions among young adults, with and without disability.* Australian Journal of Social Issues, 2014. 49(2): p. 155-170.

27. Kavanagh, A.M., et al., *Inequalities in socio-economic characteristics and health and wellbeing of men with and without disabilities: a cross-sectional analysis of the baseline wave of the Australian Longitudinal Study on Male Health.* BMC Public Health, 2016. 16(Suppl 3): p. 1042.

28. Schlichthorst, M., L.A. Sanci, and J.S. Hocking, *Health and lifestyle factors associated with sexual difficulties in men - results from a study of Australian men aged 18 to 55 years.* BMC Public Health, 2016. 16(Suppl 3): p. 1043.

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