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The importance of welfare data

1. The importance of welfare data

The Coronavirus disease 2019 (COVID-19) pandemic has transformed the way data are thought about and used in Australia and other countries. It has generated an intense interest – in the media; among medical experts, politicians and economists; and among the public – in for example, the daily number of COVID-19 cases. People have become used to seeing data almost in real time. Given the stakes for people's health and welfare and the nation's economy, the demand for timely data has been strong, and this pressure has altered the way that data are used. This will, in turn, have a long-lasting impact on the data system in Australia.

The need for better data has also been a key focus of several recent major inquiries, including the Productivity Commission Inquiry into Australia's mental health system and the Royal Commission into Aged Care Quality and Safety and the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

This article starts by providing some background information on the impact that COVID-19 has had on the data landscape in Australia and the specific role that the AIHW has played in this. It then outlines the current state of welfare data in Australia, highlighting some key data gaps. It concludes by outlining the overall role of the AIHW and how this has changed over time.

Data and COVID-19

From the start of the COVID-19 pandemic in Australia, data have been at the forefront of public discussion. The daily count of new COVID-19 cases quickly became one of the main news stories every day and data-based terminology such as 'flattening the curve' became a part of everyday conversation.

The demand for rapid and close to real-time data since the onset of COVID-19 has been notable – both for data related to the disease itself and for data related to other issues affected by the pandemic.

Data on suspected deaths by suicide

Strong concern had been expressed that any economic downturn caused by the pandemic could have a considerable negative impact on people's mental health and see a consequent rise in the number of deaths by suicide. Monitoring this potential impact required the collation and analysis of data very quickly. Data on deaths by suicide normally have a reporting lag of 12–18 months – clearly not viable in this crisis.

The AIHW began to compile data from several existing suicide registers as part of its work on suicide and self-harm in early 2020 for sharing in confidence, within government. These registers can provide data on the number of suspected suicides within days.

Data from the registers have shown that, despite initial fears, COVID-19 has not, to date, been associated with a rise in the suicide rate. A key goal of the AIHW's work on suicide and self-harm is to establish suicide registers in every state and territory.

Information on suicide and intentional self-harm statistics is available on the AIHW website: https://www.aihw.gov.au/suicide-self-harm-monitoring.

Data on mental health services

The AIHW has been assisting the Australian Government Department of Health since April 2020 to curate, analyse and regularly report to governments on COVID-19 data related to the use of mental health services. Data reported include information from the Medicare Benefits Schedule (MBS), Pharmaceutical Benefits Scheme (PBS), crisis and support organisations funded by the Australian Government (Lifeline, Beyond Blue, Kids Helpline), and analysis of emerging research findings. In addition, the AIHW has facilitated the sharing of detailed data on the use of mental health services with the New South Wales, Victorian and Queensland governments. Importantly, this involves a 2-way sharing of data: the Australian Government shares data in confidence with these jurisdictions and they share their data in return. By sharing these detailed data every fortnight, government agencies can quickly identify emerging trends.

Australian Bureau of Statistics data

The Australian Bureau of Statistics (ABS) has been very active in compiling and releasing timely data since the onset of COVID-19 (Box 1.1).

An important example involves the use of Single Touch Payroll (STP) data. The ABS and the Australian Tax Office (ATO) fast-tracked work to use the new STP data to provide close to real time insights on changes in the labour market. On 21 April 2020, the ABS released weekly payroll jobs and wages indexes for the first time, to complement its existing labour market statistics (ABS 2021a).

The STP data released by the ABS have been invaluable in understanding the impact of the COVID-19 pandemic on employment.

State and territory governments have also used data extensively since the onset of the pandemic that are directly related to COVID-19 and the associated uses of health services, including mental health services.

Box 1.1: Evolving product range of the Australian Bureau of Statistics during COVID-19

From mid-March 2020, the ABS introduced a range of COVID-19-related products as the pandemic escalated. These included new releases on jobs and wages (weekly data published fortnightly), preliminary monthly data on areas such as retail trade and overseas travel (ABS 2021d), as well as new provisional mortality statistics. The ABS also quickly developed 2 rapid turnaround surveys – the Household Impacts of COVID 19 Survey (ABS 2021c) and a survey of business conditions and sentiments (ABS 2021b) – to assess the impacts of the pandemic on businesses, people and households.

Use of STP data for information on changes in jobs and wages

The ABS and the ATO expedited work to use STP data to provide close to real-time information on changes in jobs and wages as pandemic restrictions were implemented. The ABS received the first STP file, containing 351 million transactions, on 2 April 2020, and 19 days later published its first online release of Weekly payroll jobs and wages in Australia (ABS 2021f). This analysis not only provides a national and state/territory picture of changes in jobs and wages during the pandemic – with breakdowns for sex, age group, industry and employment size – but also includes sub-state regional data (from July 2021).

Retail trade estimates

The ABS introduced preliminary retail trade estimates during the COVID-19 pandemic (ABS 2021e), published 2 or 3 weeks after the end of each month. Analysis of supermarket and grocery store scanner data during peak periods in the pandemic backed up stories of some consumers stockpiling for the pandemic, revealing a doubling in monthly turnover at some points for products such as toilet and tissue paper, flour, rice and pasta.

Mortality statistics

From June 2020, the ABS released monthly mortality statistics to provide more timely information on mortality patterns. The monthly provisional information is based on deaths certified by doctors and includes information on the total number of deaths by all key causes of death. The number of deaths was above historical averages for the first 3 months of 2021, including for deaths due to cancer, dementia and diabetes. In contrast, there were no deaths certified due to influenza between late July 2020 and the end of March 2021. The new series also showed that a high proportion of people who died from COVID-19 in 2020 in Australia had pre-existing chronic conditions.

Box 1.1 (continued): Evolving product range of the Australian Bureau of Statistics during COVID-19

Household impacts of COVID-19

The content for the ABS Household Impacts of COVID-19 Survey (ABS 2021c), which ran from April 2020 to June 2021, changed each month. Topics covered over that period included attitudes to vaccination, concerns about health, and psychological distress. The final release from this survey, in June 2021, showed that 1 in 6 people in Australia reported that life would never return to normal. The June survey also showed that 1 in 5 Australians continued to experience high or very high levels of psychological distress.

Business impacts of COVID-19

The ABS survey of the incidence and nature of impacts on business of COVID-19 (ABS 2021b) was introduced in March 2020. As with the ABS Household Impacts of COVID-19 Survey (ABS 2021c), topics changed during the pandemic to capture aspects such as business take-up of JobKeeper payments, operational changes (for example, reduced staff working hours) and other impacts.

Continuing data efforts

Some of these new timely products will continue (including the payroll and jobs release and monthly mortality estimates) and some ceased from July 2021 (such as the Household Impacts of COVID-19 Survey). The ABS is also developing a new suite of monthly indicators tracking household spending, business turnover and employee earnings, which will be released in the second half of 2021.

Private sector data

A range of private sector data has also been very valuable since the onset of the pandemic. For example, aggregate data from mobile phones allows rapid information on mobility, including the extent to which people are using public transport and reductions in trips to central business districts associated with lockdown measures. Rapid information has also been available on changes in spending patterns from, for example, data on spending through bank issued cards and apps. See 'Chapter 4 The impacts of COVID-19 on employment and income support in Australia'.

Another example of the innovative use of data is the CommBank Benefits finder, which uses customer banking data to help the bank's clients identify and access government support that is appropriate to them (Box 1.2).

Box 1.2: Example of innovative use of data

Baker et al. (2010) estimated that in 2007–08, Australians potentially missed out on nearly $5 billion in assistance provided by the government through Centrelink, including to people who have a significant need for these payments and programs. This is a global phenomenon (Bhargarva & Manoli 2014), where citizens find navigating available government programs highly complex, or are not even aware they exist.

There are opportunities to make better use of an individual's own data to improve government service delivery and policy outcomes, particularly to benefit the individual. Data driven experiences across the public and private sectors could create significant benefits for people and governments.

The CommBank Benefits finder uses data to make it easier for customers to access government support. It organises and personalises hundreds of government benefits in one place and makes it easy to claim. It has resulted in more than 1 million new claims since its launch in September 2019 – with half-a-billion dollars going into customer pockets over the last year in reduced energy costs and Centrelink support payments (Collett 2021), and a 45% improvement in satisfaction with government and the CommBank. Of these 1 million claims, 695,000 have been lodged since the start of the coronavirus pandemic (CommBank 2021).

Between September 2019 and February 2021, enabled by the CommBank Benefits finder, there were:

• 31,256 claims for JobSeeker-related payments
• 26,587 claims for the Family Tax Benefit
• 29,863 claims for rent assistance (CommBank 2021).

Many banks capture and use an incredible amount of rich data to provide a valuable and secure banking service. This includes identity checks, geo-location and home address, utilities, concession cards and payments, financial status, family status and business ownership. The Benefits finder uses these attributes to match customers to government rebates or benefits based on eligibility criteria and probability, as well as to alert them to urgent support available in the event of a natural disaster in their geographical location.

Box 1.2 (continued): Example of innovative use of data

Use of this innovative data leads to benefits at the customer/person level by reducing uncertainty and effort and improving outcomes. It also speaks more broadly to the huge potential of sharing analytics and insights from data with service providers and decision makers to help improve operational effectiveness in delivering better public services. For example, looking forward, banks and governments could work together in a safe and transparent way to benefit people – to save millions of hours of time and enable their access to millions of dollars. Many other key corporate entities collect and hold rich data and there may be numerous opportunities for partnerships in the analytics sharing space to benefit the community.

The potential benefits of working together go beyond faster policy response times, empowering individuals and saving them time and money. They extend to greater economic and social benefits, among which is improving the transparency and accountability of governments and partners for improved public trust.

Now may be an opportune time to build on sharing data insights, as the COVID-19 pandemic has meant more people than ever are aware of and attentive to service implementation, and policy makers continue to seek the best evidence to support their decision-making.

Understanding the links between health and welfare

The COVID-19 pandemic has further highlighted the close links between health and welfare. While there is keen interest in the direct health impacts of the pandemic, there is also a strong interest in its broader impacts on wellbeing. The pandemic was associated with large falls in employment in early 2020 and employment is an important determinant of wellbeing. In addition the various restrictions on activity mandated by the pandemic have been associated with psychological distress and loneliness.

Given the need for timely representative data under COVID-19, the AIHW collaborated with the Centre for Social Research and Methods at the Australian National University to include questions on loneliness and levels of psychological distress in the ANUpoll surveys, which collect data from the Life in Australia™ Panel, managed by the Social Research Centre. Importantly, this panel exclusively uses random probability-based sampling methods and covers both online and offline populations (that is, people who do and do not have access to the internet). In addition, as a panel it is possible to obtain longitudinal data from the same respondents prior to the spread of COVID-19, which provides richer information than a series of cross-sectional snapshots. Data from these surveys are included in 'Chapter 3 The impact of COVID-19 on the wellbeing of Australians'.

A person's health and welfare are closely associated. Both determine an individual's ability to fully participate in work, education and training, as well as to engage with their community and its social networks.

On many measures, Australians enjoy good health and welfare. Australians have one of the highest life expectancies in the world as well as years of life lived in full health. The majority of people rate their own health and life satisfaction highly.

Nevertheless, disparities in health and welfare outcomes do exist, particularly for some population groups. It is important to identify these groups as well as the reasons for these disparities. They can be caused by:

• poor outcomes in education, employment, income and housing that can adversely affect health and wellbeing more generally
• participation in behaviours known to cause poor health and welfare, such as tobacco smoking, high levels of alcohol consumption and drug use
• the impact of personal and social behaviours, such as bullying and school truancy, family breakdowns and a lack of social connectedness
• poor access to appropriate health and welfare services.

Some of Australia's health and welfare services are designed to support everyone in the population; others act as a safety net for those in high need. In broad terms:

• the health systems play a role in preventing and treating disease and other ill health and injury.
• the welfare systems support individuals and families with particular needs with a range of government payments (such as income support payments, family assistance payments and other supplementary payments) and by providing a variety of programs and support services, including for child protection, disability support, housing and homelessness, and aged care.

For the most part, welfare systems support people in immediate need. But the objectives of government services in general, especially in education and training, are often to improve the social and economic outcomes for individuals over the longer term. Some programs and services attempt to provide the best possible start in life for all children, with additional support for families and children in need. This focus on early intervention can reduce the future need for additional support.

The age structure, composition and characteristics of the Australian population influence what sort of health and welfare services are needed, when they are needed and for how long and how often. So, the monitoring of changes in the current and emerging population is particularly important to the provision of efficient and effective services. Good-quality and timely data on all Australians form an important part of the evidence base needed to do this.

Key population groups for welfare services

Key population groups with immediate and possible future need for welfare services include:

- young children and families: to prevent the intergenerational transmission of disadvantage to children and young people in vulnerable circumstances
- people with disability: the National Disability Insurance Scheme (NDIS) is a key service for this group but both NDIS recipients and the broader group of people with disability also require access to the full range of mainstream welfare services
- older people: of particular importance is how to provide services that allow older Australians to remain in their homes for as long as possible, with appropriate supports
- those likely to experience economic and social hardship, including a disproportionate number of Aboriginal and Torres Strait Islander people, refugees and ex-prisoners
- people who have experienced intergenerational trauma, including Stolen Generation survivors and descendants
- those who are homeless or at risk of homelessness, including victims of domestic and family violence
- those who live in regional and remote Australia, where access to services can limited
- the long-term unemployed: young people not engaged in education, employment or training; and people on long-term income support
- people who have experienced chronic long-term disadvantage.

Capture of information about these population groups, either through directly asking people at point of service or through data linkage, is important if we are to design policies and services that meet their needs.

Current state of welfare data

High-quality and comprehensive data are critical to inform policy, the delivery of services and the evaluation of services. Better data can help to improve policy formulation and service delivery and so improve outcomes – Figure 1.1 highlights this role.

Figure 1.1: Role of data in policy and service delivery
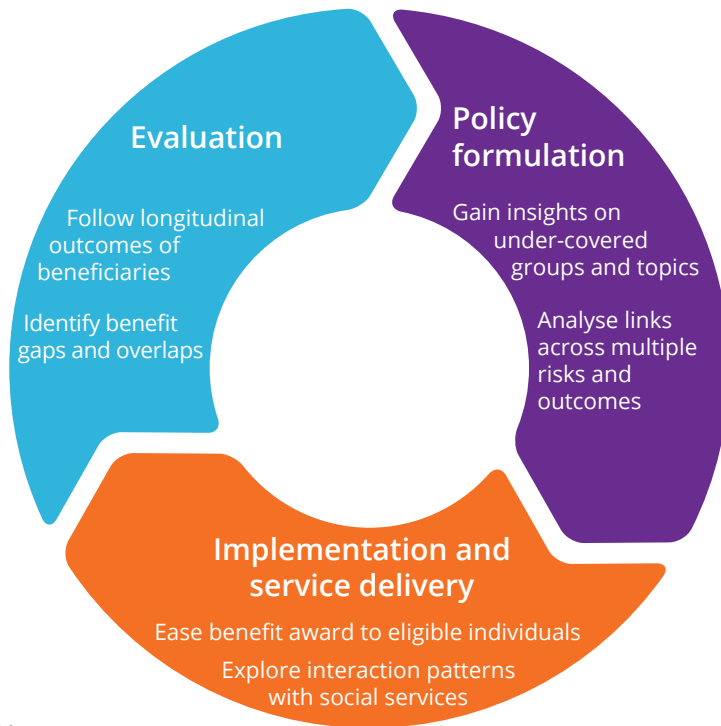
Source: OECD 2019.

Data from non-government organisations

While people have more access to data than ever before, some areas of the Australian data system could still improve. One area where data are sometimes lacking is from non-government organisations (NGOs), including where they are providing services funded by government. Issues with NGO data are not just the responsibility of the NGOs themselves. At times, government agencies ask NGOs to report using requirements that are unique to that agency or specific funding program. This can cause a lack of agreed terminology in the sector and an increase in the reporting burden on NGOs.

In the case of specialist homelessness services (which are NGOs), consistent data are collected across Australia through the AIHW's Specialist Homelessness Services Collection. This type of standardisation of NGO data is a notable gap in several other settings, such as mental health, aged care and family, domestic and sexual violence services.

Mental health

In its 2020 report on mental health, the Productivity Commission reported that little data are collected on NGO activity and performance (Productivity Commission 2020). Furthermore, it noted that, without adequate data on NGO services, it is impossible to monitor, effectively evaluate and research, or plan for mental health care that the NGOs provide. The Commission mentioned that the AIHW has developed the Mental Health Non-government Organisation Establishments national minimum data set but that this has been adopted only by Queensland and Western Australia.

Aged care

Most aged care providers in Australia are NGOs; however, the Royal Commission into Aged Care Quality and Safety (Commonwealth of Australia 2021:76) noted that:

> It remains difficult for people to make informed decisions about aged care services they are likely to receive. Similarly, the Australian Government needs access to comprehensive data to assess the performance and impact of services provided to older people, yet the available information is often surprisingly limited. Difficulties in obtaining reliable information limits the scope for aged care providers to benchmark their performance against their peers, and prevents the community at large from holding governments and service providers to account for the quality of the care they deliver.

Improved data and evidence was the subject of several recommendations in the Royal Commission's final report and in the Australian Government's response to that report. The AIHW will play an important role in improving data from the aged care sector.

Specialist family, domestic and sexual violence services

NGOs are also the main providers of specialist family, domestic and sexual violence (FDSV) services. These services respond specifically to family, domestic and sexual violence and can include crisis support services, counselling, and family violence outreach services. Currently there are limited national data about access to, and impact of, these specialist services, and the extent to which they provide coordinated responses for victims and perpetrators (AIHW 2019). In response to this gap, the 2021 report of the House of Representatives Standing Committee on Social Policy and Legal Affairs Inquiry into family, domestic and sexual violence recommended the development of a national data collection on FDSV specialist services.

Various options for the collection of these data exist, including an approach similar to that used for the AIHW's Specialist Homelessness Services Collection which has been developed through rigorous and extensive stakeholder consultation and has overlap with specialist FDSV services, as some specialist homelessness agencies also provide specialist FDSV services. As part of 2021 Federal Budget commitments, plans are underway for the AIHW to lead this data improvement work, in collaboration with state, territory and commonwealth government agencies.

Data linkage

Data linkage is another area with some room for improvement. Data linkage combines information on the same individuals from multiple data sources, while preserving their privacy. It is a cost-effective and non-intrusive way to build longitudinal data assets, and the mechanisms to protect privacy continue to be enhanced. Although the amount of linked data continues to grow, the linkage of data across the different welfare services, and between health and welfare services, is limited.

Linking such datasets would help to better understand welfare pathways and the relationships between health and welfare. Currently, there is also limited linkage of datasets on welfare services with outcomes such as employment, education and income. Linking administrative datasets enables a much better understanding than is possible by looking at individual datasets in isolation. Data linkage is not new. The AIHW has been linking mortality data with data on the incidence of cancer to estimate cancer mortality rates since 1990; however, the complexity and scale of data linkage projects has expanded substantially in recent years.

Data linkage initiatives

Western Australia led the way in data linkage in Australia through the WA Data Linkage System (WADLS) – a system of linkages within and between health and non-health data collections in the state. Since its inception in 1995, and as reported on its website, the WADLS has 'grown to become one of the most comprehensive, high quality and enduring linkage systems worldwide. Today it contains over 150 million records spanning over 50 routinely linked datasets'. New datasets are imported and linked on a regular basis, including hospitalisations, emergency attendances, births, deaths, electoral enrolments and a variety of other health and non-health information.

For more information on the WADLS, see https://www.datalinkage-wa.org.au/data/wa-data-linkage-system/.

Other jurisdictions, including Victoria and New South Wales, are also forging ahead with data linkage initiatives. The AIHW, along with the Centre for Health Record Linkage (CHeREL) in New South Wales, the Centre for Victorian Data Linkage, Data Linkage Queensland, the Western Australian Data Linkage Branch, the SA–NT Datalink and the Tasmanian Data Linkage Unit are all part of the Population Health Research Network (PHRN), which is designed to bring together existing data from around Australia and make the resultant linked data available for important research.

The ABS is another leader in data linkage through, for example, the Multi-Agency Data Integration Project (MADIP) for people data and the Business Longitudinal Analysis Data Environment (BLADE).

While data linkage is one of the most exciting developments for data in Australia, linkage projects can be time consuming. It is not hard to find examples where it has taken researchers years to access relevant data because of multiple ethical clearances and delays in data provision. That being said, there have been major improvements in recent years through the development of more enduring linkage approaches using linkage keys. As an example, the Victorian Government is developing the Victorian Social Investment Integrated Data Resource (VSIIDR) which is an enduring person-centred dataset to be used for health and social policy research purposes.

Data linkage challenges and possibilities

Linking Australian Government data with state and territory data can be time consuming and could be made more efficient. This is a pressing issue as it is not possible to fully understand many service systems in Australia without linking these data. For example, the states and territories have access to their own hospital data; however, to understand how people use the health system, these data should be linked with Medicare data to better appreciate how people use both primary and tertiary health services. This is why the AIHW created the National Integrated Health Services Information Analysis Asset (NIHSI AA), which brings together de-identified data on hospital admissions, the use of MBS and PBS services aged care and mortality. This asset enables a much better understanding of how people use health services than is possible by looking at individual datasets in isolation.

There are many more examples in which a much better understanding of service systems and how people use services could be gained by regularly linking Australian Government and state and territory data.

- In the housing sector, the states and territories have access to data from homelessness services and social housing but Commonwealth Rent Assistance data is also very important. If de-identified rent assistance data were regularly linked with state and territory data, a much more informed understanding of housing policy and its impacts would be possible.

- While homelessness services data include data on housing outcomes, linking these data with data on social housing and rent assistance would provide a richer picture of what happens when people leave homelessness services. For instance:
   - How long do those who move into social housing stay in this form of housing?
   - How many of those who are still homeless when they stop using homelessness services later move into either community housing or the private rental market? (The answer to this question could be partially gauged with rent assistance data.)

Regularly linking data across Australian Government and state/territory boundaries also has the potential to dramatically improve information available about key population groups, such as people with disability, by enhancing information about their access to specialist and mainstream services, pathways through those services and outcomes. The National Disability Data Asset (NDDA), currently in pilot, has demonstrated that it is possible to bring together a large number of datasets for this purpose. Research findings from the pilot test cases will be available in late 2021. Learnings from the pilot will inform options for an enduring asset, including priority data for inclusion, data integration models, approved uses of the NDDA and asset governance models.

Sources of welfare data

Welfare services are provided by the Australian Government, state and territory governments and NGOs – both for-profit NGOs and not-for-profit NGOs. National data have long been collated across certain service sectors in Australia (for example, disability, drug and alcohol treatment, child protection). But these data may not have been collected consistently and so are not comparable over time or cannot be compared with data from another service provider. This constrains the evaluation of outcomes for people who receive the services across these sectors (and of the effectiveness of different services) and for individuals who receive services from different providers or in different jurisdictions. These service data relate only to those people using the services and do not answer questions which relate to the level of unmet demand or barriers to access.

As well as data collected from welfare services, Australia has a large population survey program, predominantly delivered by the ABS. These surveys provide a wealth of cross-sectional information on the characteristics of potential welfare service users and their experiences (for example, difficulties of access), which can help to provide insights into need based on prevalence estimates.

Australia also has several longitudinal datasets on welfare. Examples include the Household, Income and Labour Dynamics in Australia (HILDA) Survey, the Longitudinal Study of Australian Children (LSAC) and the Longitudinal Study of Indigenous Children (LSIC). These 3 studies are managed by the Department of Social Services' National Centre for Longitudinal Data (see www.dss.gov.au/about-the-department/national-centre-for-longitudinal-data). While Australia has a good range of longitudinal surveys, the use of linked longitudinal administrative data could be expanded.

Data for measuring progress

Evaluations of welfare programs and measuring progress against indicators are necessary to understand and improve outcomes.

A lack of high-quality evaluation restricts the opportunity to improve services and outcomes for individuals. Much of the evaluation work undertaken to date has been short term or piecemeal, which has limited an understanding of which programs work best to improve outcomes for persons most in need. Having better linked, enduring, longitudinal administrative data would facilitate better and more cost-effective evaluations.

Measuring the progress of welfare outcomes, particularly as they relate to health and welfare services, requires consistent measurement against agreed indicators over time. There are opportunities to embed policy evaluation in national plans and agreements that specify performance measures. Given the development of linked and longitudinal data, there is potential to improve the indicators selected for these purposes so that they support more holistic, outcomes-oriented reporting.

The outcomes of programs that aim to bring about changes over a long period of time, or over a generation, cannot be observed while such a program is still in operation. Early childhood education is a good example: some of the main benefits of early childhood education are not apparent until participants are teenagers. But it is possible to observe the subsequent impact of such programs and policies through data linkage, where the individuals who received the service as children are again observed later in their lives.

In Australia, individual states and territories are taking steps to improve the way they build and use data to improve the long-term outcomes for children. An example is the Murdoch Children's Research Institute's Generation Victoria (GenV) research project (see www.genv.org.au for more information). The project, which is open to all Victorian-based babies and their parents, is designed to answer questions on major issues they face today and in the future, including pre-term birth, mental health and illness, obesity, learning, and allergies.

Key gaps in welfare data

Gaps in welfare data exist, where no national data are currently available or where data collected are not comprehensive enough. In the context of welfare data, these gaps include:

- an inability to measure unmet demand for services – for example, those turned away from welfare services, people who 'fall through the cracks' in the welfare system

- a lack of detail on the types of welfare services accessed – for example, supports provided under consumer-directed care models for aged care or services funded by NGOs

- an inability to follow people through the numerous pathways in the welfare systems – for example, the education and employment experiences of vulnerable people as they transition between different services and across different 'systems'

- the long-term effects on individuals and their families of poverty, homelessness or unemployment as well as the intergenerational transmission of risk factors

- an inadequate understanding of risk factors – for example, the causes of homelessness

- the populations of interest for whom information is sparse – for example, Indigenous people who use mainstream services; identifying people with disability and other vulnerable cohorts in data collections

- the geographical location of people of interest – for example, information is often not available on remote Indigenous communities and on locational variation in welfare services and outcomes.

AIHW's role in creating and reporting on evidence

The AIHW is Australia's leading health and welfare statistics agency. Its legislated role is to work with others to develop information standards and collections across health and welfare, and to publish statistics across these areas. It works closely with governments – including state/territory authorities with health and welfare responsibilities, the ABS and other statistics agencies – and with the academic and non-government sector to make this happen.

The AIHW collects and uses data from a range of sources – including from administrative, survey, longitudinal and linked sources as well as from the Census of Population and Housing – to present information on:

- the characteristics of people and their health and welfare needs, and how these change during their lives
- how the health and welfare needs of people differ depending on where they live
- the availability and accessibility of health and welfare services in those places
- how service use changes over time.

The AIHW provides regular information on the health and welfare of the Australian population to assess how outcomes are changing over time. It also provides information on the health and welfare of particular groups, and on how they fare relative to the rest of the population. These population groups include Indigenous people; Australians who live in remote areas; veterans; older Australians in the aged care system; and Australians with disability, mental illness, in the child protection and justice systems, or who are prisoners.

The AIHW validates and standardises the data to allow comparisons to be made between different population groups, different places, and over time.

Where possible The AIHW presents information at the local geographical level, where services and programs are delivered, aiming to assist local decision-makers with planning and policy decisions. The analyses it undertakes highlight areas and groups where program and service delivery efforts should be directed to meet the greatest numbers and the greatest needs.

The AIHW recognises the importance of linked datasets in understanding the relationships between health and welfare outcomes for people. To that end, it is working to expand the availability of longitudinal data by linking the cross-sectional data on individuals that occur in different datasets and over time. Among other things, this approach allows the study of the different pathways people use to access services throughout their lives and can identify those that are most common. It also allows an understanding of whether particular services improve outcomes for individuals over time. This approach may also be useful in identifying the early signs of vulnerability to disadvantage that occur later in life.

All linked datasets used for analysis at the AIHW comply with legislative and regulatory standards, are securely stored and accessed, and meet ethical standards and community expectations. Protocols are in place to prevent privacy breaches or the unauthorised identification of individuals, and to ensure data security and restricted access to information.

A key priority is to build capacity among service providers and to support them in understanding and using health and welfare data. To this end, the AIHW provides secure, accurate, reliable and comparable data to a range of service providers so they can use the data to improve service delivery and outcomes for their clients.

The AIHW strives to make its data and findings accessible to a range of audiences through the release of many products, including summary and detailed reports. It has improved accessibility to information through interactive data visualisation. A significant effort is being directed towards creating more data-driven websites (see, for example, GEN Aged Care Data at www.gen-agedcaredata.gov.au and the suicide and self-harm monitoring website at www.aihw.gov.au/suicide-self-harm-monitoring).

The AIHW will soon launch a new website (Regional Insights for Indigenous Communities) (Box 1.3), which will make it easy to find the regional statistics on a wide range of topics related to Indigenous people and their health and wellbeing that are most important to any community or location of interest.

For more information on the AIHW's current and forthcoming websites, see Box 1.3.

Box 1.3: Selection of key AIHW websites

Suicide and Self-harm Monitoring System

This system, established by the AIHW in collaboration with the Department of Health and the National Mental Health Commission, has improved the accessibility, timeliness, quality and breadth of data available to help identify trends in suicidal and self-harming behaviours and in other emerging areas of concern, and to inform responses. The system comprises several interrelated activities:

• a regularly updated website that presents interactive data visualisation and geospatial analyses of data on suicide deaths and on hospital admissions for intentional self-harm, together with data from the Australian Burden of Disease Study and the National Ambulance Surveillance System developed as part of this project by Turning Point (Monash University)

• work with states and territories to develop the data capture and reporting capabilities on suspected suicides referred to coroner's courts through suicide registers. The existing suicide registers began reporting data on suspected suicides to the AIHW in April 2020 for weekly, then fortnightly, reporting to National Cabinet. A key goal of this project is to establish suicide registers in all jurisdictions

• the development of a secure state and territory information portal to allow sharing of more detailed and potentially sensitive data on suicide and self-harm among jurisdictions

• the modelling of linked data through the MADIP and the NIHSI

• the commissioning of research through collaborating academic institutions such as the Australian National University, Flinders University, Griffith University and The University of Melbourne.

Regional Insights for Indigenous Communities website

This website, which is soon to be launched, will present data and statistics on Indigenous people and their health and wellbeing in accessible and easy-to-use dashboards, with maps and other visualisations. It will include statistics provided by the ABS's Indigenous Regions and, when the robustness and coverage of data allow, by lower-level geographic areas as well. The website will make it easy for users to find regional statistics that are most relevant to their communities of interest through a custom-made search function that matches locations to regions.

> **Box 1.3 (continued): Selection of key AIHW websites**
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> **Indigenous Mental Health and Suicide Prevention Clearinghouse**
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> This website was released in July 2021. Its objectives are to:
>
> - improve the evidence base of what works and does not work relating to Indigenous mental health and suicide prevention, including identifying gaps in the evidence
> - improve access to key information by collating the emerging research, evaluation, program and policy initiatives, and evidence from these initiatives
> - encourage collaboration between researchers and reduce the chance of duplication in research activity, thereby promoting a more coordinated research and evaluation effort.
>
> Content of the Clearinghouse will be regularly updated, with additional publications, data, research and evaluation material, and with news and events added as they become available. The Indigenous Mental Health and Suicide Prevention Clearinghouse website is available at https://www.indigenousmhspc.gov.au/.

A key objective of the AIHW is to fill data gaps as they relate to health and welfare, and to work with data providers to enhance existing collections or to create new ones. One of the key recommendations of the Royal Commission into Aged Care Quality and Safety (Commonwealth of Australia 2021) was to create an aged care national minimum data set and improve data on the interaction between the health and aged care systems. This includes improving the availability of health and aged care data for monitoring, planning and funding purposes.

Another Royal Commission – the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability released its Interim Report in October 2020. A key theme of this report is the lack of useful, and nationally consistent, data on the extent of violence against – or abuse, neglect and exploitation of – people with disability, especially among those who are more vulnerable. The report also notes that there are no public data relating to particular settings such as schools, residential out-of-home care, the youth and criminal justice systems and specialist disability accommodation or segregated work environments (Commonwealth of Australia 2020).

Increasingly, data gaps are filled by creating new linked datasets and facilitating access to linked or other data in secure research environments. The National Integrated Health Services Information Analysis Asset and the National Disability Data Asset are key enduring data linkage projects that aim to rectify these significant gaps.

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