Towards more inclusive research: a guide to inclusive disability research using administrative data

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Preface from the Chair

The Disability-informed Ethical Oversight Panel provides guidance and support to researchers on how they can conduct inclusive research using the National Disability Data Asset (NDDA). The Panel values and encourages collaboration and consultation as an important part of inclusive research.

This inclusive research guide on using administrative data led by panel member Dr Chrissy Antonopoulos aims to educate and support researchers on how to design, conduct, analyse and communicate research using NDDA inclusively. This includes using social and critical models of disability, being trauma-informed and the value of embedding co-design practices throughout linked-data research projects. The guide is also considered to be an evolving body of work.

Both the inclusive research guide and the Disability-Informed Ethical Oversight Panel aim to continue to work collaboratively to build capacity of researchers and people with disabilities in inclusive research with administrative data while reducing the risk of harm to people with disability from NDDA research projects.

Dr Lisa Stafford

Chair Disability-Informed Ethical Oversight Panel

Introduction

Purpose

The National Disability Data Asset will have the capacity to contribute to research needs by combining de-identified administrative data collected by different government agencies. This will provide detailed data and insights into the experiences of people with disability and how government and service providers can better provide support and services to people with disability, their families, and carers.

This guide outlines principles and practices for conducting inclusive research using administrative data. The principles include disability-specific considerations, trauma-informed research, and intersectionality. These principles were chosen as they align with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (1), which Australia ratified in 2008, and the recommendations of the Disability Royal Commission (DRC) to centre people with disability through human rights and intersectional approaches. Disability inclusive research practices are advancing, and guidance will be revised and updated to reflect advancements as required.

Background

Context

Currently in Australia 21.4% of people have disability. Disability is defined as restrictions in daily activities that last for six months or longer, caused by an impairment or restriction (2). The National Disability Data Asset Council defines people with disability to include disabled people's organisations and representative organisations of children and people with intellectual disability. The wider disability community includes families of people with disability, carers, organisations that represent people with disability and allies, as per article 4.3 of the United Nations Convention on the Rights of Persons with Disabilities and the General Comment No.7 (2018).

Historically and presently, people with disability have faced discrimination, harm, and exclusion in all aspects of their lives including in education, employment, and healthcare. This was captured by the Royal Commission into Violence, Abuse, Neglect, and Exploitation of People with Disability (Disability Royal Commission; DRC) (3). The DRC found that people with disability experienced higher rates of violence than people without disability, with First Nations women, young women, and women with intellectual or psychosocial disability experiencing the highest rates. Experiences of violence, neglect, harm, and exclusion can have many consequences including trauma and mental health concerns, physical health effects, social isolation, and financial implications. This creates a need to better understand the experiences of people with disability through research and ethically determined datasets to improve policy and service delivery.

The DRC found a significant gap in data collected about people with disability, including different definitions of disability and inconsistencies of data collected across different datasets. This led to recommending a consistent, nation-wide approach to collecting data (4). Research using administrative data needs to be inclusive, centre people with disability, and consider historical and current marginalisation to prevent further harm to people with disability.

What is administrative data?

Administrative data is data collected from Australian and state and territory governments. Examples of administrative data includes data collected through the National Disability Insurance Scheme, Medicare Benefits Schedule, Pharmaceutical Benefits Scheme, Public Hospitals and Centrelink data. The data is de-identified, which means personal data such as people's names or addresses are not included.

There are many benefits in using administrative data for research. As administrative data includes large groups of people, this can improve the broader applicability of research. This means that research findings can be applied to more people. Another benefit is being able to assess data over long periods of time, which can help to identify and interpret trends and changes. Administrative data can be beneficial for policy development as it can be used to fill data gaps relating to people with disability and programs.

There are some limitations to administrative data. For example, administrative data is not collected for research purposes so it may not address specific research questions or demonstrate causal relationships. Further, some people with disability may not be included in the data due to the linkage processes, or people may be described in the data in ways they do not identify. For example, some people with disability may not identify as having a particular disability type, such as a physical or sensory disability, but they may be recorded this way in the data. Another limitation is that gaps and inconsistencies in data collection across different levels of government can affect its completeness and reliability. While there are many benefits and some limitations to using administrative data for research, it is important that the research conducted is inclusive and respectful of the rights of people with disability. These guidelines are designed as a first reference to assist researchers in conducting inclusive and respectful research.

Principles of Inclusive Research

The principles that underpin these guidelines are disability-specific considerations, trauma-informed research and intersectionality. These principles are interrelated and overlapping.

Throughout this section there are suggestions for further reading and reflective questions, with a comprehensive list provided in the table at the end of these guidelines.

Disability specific considerations

Disability-specific considerations refer to theories and practices that are important when conducting research about people with disability. These considerations relate to how research is conceptualised, designed, analysed, interpreted, and communicated. Each of the below considerations should be reflected on throughout the research process.

Identity and Language: Identity and language preferences can differ between different disability groups as well as between people with disability. Person-first language emphasises the person rather than the disability. An example of this is "people with disability" or "person who is blind". On the other hand, identity-first language can be empowering for people with disability as it centres their disability identity (5,6). An example of this is "disabled person" or "Autistic person". The United Nations Disability Inclusive Language Guidelines suggest using person-first language as this is the language most widely used, including in the UNCRPD. However, it is important to consider preferences of specific disability groups in the language they prefer, such as the Autistic and neurodivergent community, Deaf or Hard of Hearing people, or people with multiple disabilities. Also, consider how language can be reflected throughout the research process including when considering how data sets will be categorised or interpreted and when presenting findings.

Read: ***Inclusive Language Resources***

Neurodiversity affirming: Neurodiversity affirming research and practices respect and acknowledge neurological differences as natural variations that occur between people rather than as deficits. This includes differences in the way people think, feel, and behave. In practice, taking a neurodiversity affirming approach to research considers the conceptualisation of research questions and outcomes to be strengths-based, focused on diversity and differences rather than deficits, while still considering the challenges that neurodivergent people can experience (7). In administrative data research, this can be applied by considering how data sets will be categorised or interpreted for research questions, and how the findings with be presented and shared.

Reflective Question: How can we communicate the purpose and findings of this research using strengths-based language (e.g. no deficit language, limit jargon, medical terminology)?

Models of disability: Models of disability have been used to conceptualise disability, particularly in research and healthcare. The medical model of disability, which has been the dominant theory in research, focuses on a person's impairment as the source of disability. When describing disability, deficit-based language is used, with a focus on overcoming or curing the impairment (8,9). Since the 1990s, there has been a shift from the medical model to the social model of disability. The social model of disability focuses on barriers in the environment around the person with disability, rather than a person's impairment or functioning, as the cause of disability. For example, a person who uses a wheelchair may not be disabled by their condition, rather by the inaccessible built environment where there might not be ramps or accessible bathrooms. Under the social model of disability, social exclusion, attitudes, and inaccessibility are the main causes of disability (8). Australia's Disability Strategy 2021-2031 is based on the social model of disability and sets the framework for all governments (10).

Since 2006, the human rights model of disability, which is an extension of the social model, has been used. The human rights model addresses some concerns about the social model of disability not capturing the entirety of a person's lived experience by only focusing on external barriers (11). The human rights model of disability builds on the social model of disability and underpins the UNCRPD. This model takes into consideration all aspects of a person's experience, both internal and external. The human rights model focuses on the dignity, equality and self-worth of people with disability and their human rights, without emphasising community or economic participatory value of people with disability. Models of disability should be used to conceptualise research projects, with a focus on social and human rights models.

The International Classification of Functioning, Disability and Health (ICF) provides a biopsychosocial framework for understanding disability as the result of interactions between health conditions, personal factors, and environmental influences (12). If using the ICF in research, consider its strengths in capturing multiple dimensions of functioning, however, ensure it aligns with the inclusive research principles outlined in these guidelines, particularly by centring lived experience and avoiding medicalised or deficit-based interpretations.

Co-design and co-production: A key underlying principle of inclusive research is using co-design, co-production and collaborative methods in all aspects of research. This means that people with disability are not only involved in research as participants, but as co-researchers and contributors to knowledge creation. Co-production specifically requires researchers to collaborate and include people with disability in decisions about the research (13). This process allows research to focus and be guided by issues that are important to people with disability. In an administrative data context, co-design principles could be used when devising the research topic, considering what datasets to utilise, analysing and interpreting data, and when sharing accessible findings.

Read: ***Co-Design Resources***

Reflective Question: How is this research centring the voices of people with disability?

Trauma-informed research

Trauma-informed research practices involve empowerment of the group of people that knowledge is being created about, by ensuring there is control over decisions, collaboration, safety, respect, and cultural responsiveness to minimise the potential risk of re-traumatisation and distress (14,15). This is important when conducting research about people with disability who may have experienced high rates of trauma and continue to experience the ongoing effects of trauma, discrimination, and stigmatisation. This means it is important for researchers to understand the underlying impacts of trauma on people with disability. Using trauma-informed practices can increase the sense of control and safety of the community and by involving people with disability throughout the process, outcomes can be improved through increased acceptability, transparency and relevance of research (15). Putting people with disability in the centre of the research project shifts focus from stories that were imposed by others on people with disability to creating stories and research driven by people with disability on their own terms (16).

There are several factors to consider when using trauma-informed practices. Power dynamics should be considered, as perceptions of illegitimate use of power and authority can lead to people being re-traumatised by the research process (17). It is important that research does not ‘other’ or disempower the subjects of the research. For example, this is done by considering the impact of colonisation and violence towards First Nations people both past and present (15). Trauma-informed practices require researchers to understand the impacts of trauma on an individual, community and population level alongside the historical and structural trauma and stigmatisation experienced by the group (14). When trauma-informed principles are utilised, feelings of vulnerability are reduced and a sense of safety increases (15). This is particularly important for administrative data as people within the community may be unsure whether data relating to themselves could have been included in the research. To reduce the risk of re-traumatisation when using administrative data, researchers should involve people with disability in the process including when considering the research topic and selecting datasets for use. Consider together how these decisions may affect people with disability, given the context of increased experiences of trauma.

Reflective Question: How could this research be conducted and findings shared to reduce the risk of re-traumatisation?

Principles of Trauma-informed Research

There are no standardised trauma-informed research principles, and no specific principles related to administrative data. Many trauma-informed principles arise from a social justice lens (15). The principles below have been adapted specifically for use in administrative data from several sources (14, 18, 19).

Safety: Includes creating and disseminating research that creates a sense of safety for people with disability. This includes considering psychological safety and the impacts of the research on the mental health of people with disability. Using clear and accessible communication, openness of the research process, and ensuring privacy and confidentiality can facilitate safety.

Read: ***Disability Background Resources***

Trustworthiness and transparency: Building trust and rapport between researchers and the community that they are researching is essential. This can be achieved through co-design, consultation, and openness in sharing the research process. Any decisions made relating to the research should be communicated to the community in accessible formats.

Collaboration and mutuality: This prioritises reducing power differences between people involved in the research, researcher-participant relationships and relational collaboration. This means that people with disability should be involved in all stages of the research and have decision making power over their own information and data.

Empowerment, voice, and choice: Understanding power differentials and how people may have been affected by historical events that reduced their choice and voice. This is particularly important for people with disability with historical and current experiences of trauma, abuse, neglect, and discrimination. Empowerment can be created through highlighting strengths of the participant group and the language used to communicate findings. Using co-design methods can also increase empowerment and allows for people with disability to make choices in the research.

Read: Communication Resources

Reflective Questions:

What is my/our relationship with the people being researched?

What past experiences have I/we had that are related to the people being researched?

Cultural, historical, and gender issues: Considering intersectionality in the research project and ensuring research is culturally sensitive and researchers have cultural competency relevant to the topic. This includes considerations specific to First Nations people, people from Culturally and Linguistically Diverse backgrounds, Deaf or Hard of Hearing people, people in the LGBTIQ+ community, and other groups.

Intersectionality

Intersectionality theory states that experiences are shaped by multiple social positions that need to be considered jointly rather than on their own (20). At its core, intersectionality can be described as an analytical sensitivity or an approach to thinking about the relationship between identity and power (21). In disability research, intersectionality is important because often people with disability are grouped based only on their diagnosis or disability status, and their other identities and experiences can be ignored. Intersectionality means that other identities of people with disability are considered, and the interactions of these different identities can help to better understand the complexity of experience of people with disability including the impacts of social location and marginalisation (15,22).

Reflective question: What is the role of inequality in the lives of the people being researched?

Benefits to using an intersectional approach can include capturing unique lived experiences of people with disability. Often, these experiences intersect with multiple oppression identities and social positions that may not always be uncovered in research. Using an intersectional lens from early stages of research can help to consider how historical marginalisation may impact people and the research process. This is important because using “outsider” models, where researchers do not have connections to the group being researched, can lead to further marginalisation of groups as the focus can often be linked to deficit based models of health (23).

Reflective Questions:

What biases do I/we have about the people included in the research?

What assumptions have I/we made about the people in this research and the topic?

There are several ways to incorporate intersectionality into research. Reflexivity and identifying bias can be used by researchers to understand their own identities and any biases, and how this may impact research questions, analysis, data interpretation and reporting (23). Like trauma-informed research, including community as co-leaders and having shared input into research, particularly when conceptualising the research, can lead to communities having shared agency in co-creating knowledge they otherwise would not have contributed to, and has the potential to be harmful. This can further build trust and rapport. It is also key for intersectional groups to be part of interpreting, communicating, and determining how research findings can be applied in practical situations.

Reflective Question: How can the results be framed to capture different identities within the group being researched?

There have been discussions about how intersectionality can be applied using statistical methods. (20, 24, 25). While qualitative and mixed methodologies can be utilised to capture intersecting identities and their experiences, using administrative data predominantly does not allow for qualitative analysis. However, there are exceptions when used in mixed methods designs. There is debate as to the best methods of quantitative analysis that can be used to incorporate intersectionality. Statistical analysis that can be used include regression with interactions and cross classified variables or stratification (18). However, this may be beyond the scope of research using administrative data or some research questions. In this case, intersectionality should be applied in a conceptual/ theoretical and practical way. This includes in shaping and conceptualising the research questions and frames of analysis and discussion. When using an intersectional approach, researchers should acknowledge the likelihood that marginalisation has had an impact on people and how this may have shaped their experiences, even if the research question or focus is not on inequality (23).

How to Conduct Inclusive Research

This section provides an overview of reflexivity as a key component of applying inclusive research guidelines, alongside specific strategies and questions to consider throughout the research process.

Discursive and Embodied Reflexivity

Discursive reflexivity is a practice that looks at the influences of power. The practice can help to acknowledge the power dynamics between different stakeholders, including the researchers and the people the research is about. Discursive reflexivity acknowledges multiple truths and diversity of perspectives, making space for voices that have historically been unheard, which is important for people with disability. Further, embodied reflexivity encourages researchers to consider their standpoint within the topic. This includes emotions and beliefs about disability, and how past experiences might shape interpretations and knowledge production (15).

Using reflexivity in research can be both a personal practice and a methodological practice. Methodologically, this practice can help to manage assumptions and beliefs, which can negatively impact people with disability. These assumptions and beliefs can, often unintentionally, influence the way research is conceptualised and designed, how data is analysed and interpreted, and how findings are presented (23).

Table 1: Stages of research – strategies

Note: Stages of research are:

Initial - Refers to the conceptualisation, design, and application stage of the research project.

During - Refers to conducting the research, analysing the data, and creating outputs.

After - Refers to sharing of information and findings from the research project.

Stage of Research	Strategy	Principle/s	Reflective Questions
Initial **During** **After**	Engage in regular conversations, both structured and unstructured, between the research team and members of the disability community (e.g. advisory groups, consultants, Disabled People's Organizations (DPO) etc) about knowledge creation and biases.	Disability-specific considerations Trauma-informed research Intersectionality	• What have we been told is important to the community relating to our topic? • What biases commonly exist relating to this topic or group of people?

Stage of Research	Strategy	Principle/s	Reflective Questions
Initial **During** **After**	Considering co-design and other methods to include people with disability as part of the research process to create collaboration, choice, and voice.	Trauma-informed research Intersectionality	*Read: Co-Design Resources* • How can we facilitate co-design in this research? • What ways can we include people with disability in this research to collaborate? • How is this research centring the voices of people with disability? • How can people with disability be included in the design of this research?
Initial **During** **After**	Collectively, consider connections to disability, and how this shapes your perceptions on policy, research and practices both past and present.	Trauma-informed research Intersectionality	• What assumptions have we made about the community and topic? • What biases do we have about the community and topic? • What ethical or practical implications might these assumptions and biases have?

Stage of Research	Strategy	Principle/s	Reflective Questions
Initial **During** **After**	Individually, consider your standpoint with the group being researched and any emotions, beliefs, or past experiences that might affect the research process.	Trauma-informed research Intersectionality	- What is my identity and privilege? How might this impact my participation in this project? - What is my relationship with the people being researched? - What emotions and beliefs do I have towards the people being researched? - What past experiences have I had that are related to the people being researched?
Initial **During** **After**	Create safety through understanding the impacts of trauma on people with disability by engaging with disability history and current experiences of people with disability. Use this information to identify strategies to reduce the risk of re-traumatisation of people with disability.	Trauma-informed practice	*Read: Disability Background Resources* - What effects could this research have on re-traumatising people with disability? - How could this research be conducted and findings shared to reduce the risk of re-traumatisation?

Stage of Research	Strategy	Principle/s	Reflective Questions
During **After**	Create and share information about the research project and the findings in accessible formats.	Disability specific considerations Trauma-informed research	*Read: Communication Resources* • What formats should be used to communicate findings that are accessible to the group being researched? • What methods can be used to share findings within the disability community?
During **After**	Consider intersectionality during analysis and interpreting the research findings by using reflective practice both individually and as a research team.	Trauma-informed research Intersectionality	• How can the results be framed to capture different identities within the group? • What is the role of inequality in the lives of the group? • What are the commonalities between different identities within the group? • How might power imbalances or marginalisation be influencing the findings from this research?

Stage of Research	Strategy	Principle/s	Reflective Questions
After	Interpret the results and communicate the findings using a social or human rights model of disability, neurodiversity affirming, and strengths based.	Disability specific considerations Trauma-informed research	*Read: Inclusive Language Resources* • How can I communicate the purpose and findings of this research using strengths-based language (e.g. no pathologising language, limit jargon, medical terminology)? • How can I include the voices of people with disability in interpreting and communicating findings? • How can I communicate findings so they are accessible to specific groups of people with disability?

Resource List

Co-Design

Doing Research Inclusively (University of New South Wales; UNSW):

https://www.disabilityinnovation.unsw.edu.au/inclusive-research/guidelines

Guide to Co-Design with People Living With Disability (JFA Purple Orange):

https://purpleorange.org.au/application/files/7416/2510/1861/PO-CoDesign_Guide-Web-Accessible.pdf

Queensland Disability Stakeholder Engagement and Co-Design Strategy (Queenslanders with Disability Network):

https://qdn.org.au/qld-disability-co-design-strategy/

Towards Inclusive Practice (Inclusion Australia):

https://www.inclusionaustralia.org.au/towards-inclusive-practice/

Communication

Good Practice Guidelines for Engaging with People with Disability (Disability Gateway):

https://www.disabilitygateway.gov.au/sites/default/files/documents/2023-10/3826-dess5092-good-practice.pdf

Accessibility Guidelines for Government Communications (Victorian Government):

https://www.vic.gov.au/accessibility-guidelines-government-communications

Factsheet: Accessible and Inclusive Information Provision and Communications (National Disability Services; NDS):
https://nds.org.au/images/resources/EffectiveOrganisationalCommunication/Accessible_and_inclusive_information_provision.pdf

Disability Background

Final Report – Executive Summary, Our Vision for an Inclusive Australia and Recommendations (Royal Commission into Violence, Abuse, Neglect, and Exploitation of People with Disability):

https://disability.royalcommission.gov.au/publications/final-report-executive-summary-our-vision-inclusive-australia-and-recommendations

Conventions on the Rights of Persons with Disabilities (CRPD; United Nations):

https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-crpd

Segregation of People with Disability is Discrimination and Must End (Disabled People's Organisation Australia):

https://dpoa.org.au/wp-content/uploads/2020/11/Segregation-of-People-with-Disability_Position-Paper.pdf

Inclusive Language

Language Guide: A Guide to Language About Disability (People with Disability Australia; PWDA):

https://pwd.org.au/wp-content/uploads/2021/12/PWDA-Language-Guide-v2-2021.pdf

Inclusive Language Guide (Queensland Government):

https://www.families.qld.gov.au/campaign/queenslands-disability-plan/_media/documents/inclusive-language-guide.pdf

Disability Inclusive Language Guidelines (United Nations):

https://www.ungeneva.org/sites/default/files/2021-01/Disability-Inclusive-Language-Guidelines.pdf

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