

# ***Data Set Identification Project***

## ***Report***

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## **Abbreviations and acronyms**

ABS – Australian Bureau of Statistics

ACT – Australian Capital Territory

AHS – Australian Health Survey

AIHW – Australian Institute of Health and Welfare

Census – Census of Population and Housing

COAG – Council of Australian Governments

CURF – Confidentialised Unit Record File

CEDAW – Convention on the Elimination of All Forms of Discrimination against Women

CRPD – Convention on the Rights of Persons with Disabilities

DAC – ACT Disability Advisory Council

DS NMDS – Disability Services National Minimum Data Set

D-SIP – Data Set Identification Project (this current study)

GSS – General Social Survey

NDA – National Disability Agreement

NGO – Non-governmental Organisation

PSS – Personal Safety Survey

SCRGSP – Steering Committee for the Review of Government Service Provision

SDAC – Survey of Disability, Ageing and Carers

SEIFA/I – Socio-Economic Indexes for Areas/Individuals

SET – Survey of Education and Training

SMHWB – Survey of Mental Health and Wellbeing

TUS – Time Use Survey

UN – United Nations

WHO – World Health Organisation

WWDACT – Women With Disabilities ACT

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## Synopsis

In June 2013, the ACT Disability Advisory Council (DAC) commissioned Women With Disabilities ACT (WWDACT) to undertake work to find what survey and data information about women with disabilities in the ACT is available in the areas of services for health and wellbeing and participation in social and economic life. The work was also to investigate how this information can enable the DAC to provide policy advice to the Minister for Disability, Children and Young People.

The first section of the report sets out the objectives of the commission in more detail and includes the underlying rationale for the study. The direction of the study is aligned with the ACT Government's Triple Bottom Line Assessment Framework which examines the economic, environmental and equity impacts of policies. In turn, the ACT Women's Plan 2010 – 2015 contains Economic, Social and Environmental strategic outcomes.

The rationale is in three major areas. Firstly, it examines the complex nature of the intersection of disability and gender, acknowledging the diversity of vulnerable groups and various forms of inequality. Any action to address the challenges of this intersectionality must be based on sound evidence. Secondly, this section establishes the grounds on which public authorities are obligated to respond to the needs of women with disabilities. Thirdly, it stresses the role of information in guiding policies as well as justifications for the participation of public authorities in generation and dissemination of information.

The remainder of the document contains the study methodology, a review of 13 data sets that are identified as relevant to women with disabilities in the ACT, and findings resulting from the review. The main outcome of the study is to provide systematised information regarding available data sources. This information is summarised in a Table (Table 1, page 35). The study recommendations identify some of the current gaps in data collection or where analysis could be expanded in a way that would be helpful to ACT policy makers. It further identifies which body could be responsible for making the suggested data collection changes.

The concluding section explains the central place of statistical evidence in guiding policies and actions, as well as outlining the joint responsibilities of all participants in the ACT community.

## Summary of Recommendations

Recommendations put forward in this report revolve around five areas of opportunity.

The first area relates to the primary purpose of the study, an identification of data sets relevant to women with disabilities in the ACT. It is important that:

1. All stakeholders using data sets identified in this study to research information on women with disabilities should familiarise themselves with the underlying survey structure for guidance on its applicability.

The second area is concerned with enhancing the completeness of the way that the intersectionality is currently depicted in surveys and data sets. Consequently, it is recommended to:

2. Introduce a disability component to surveys dedicated to specific issues, such as has been done with the 2012 Personal Safety Survey, in order to add a new dimension to problem analyses.
3. Expand the question on disability in data sets that cover a wide range of social issues but currently offer only limited usefulness for researching women with disabilities (e.g. Census).
4. Extend the scope of disability information to provide a more comprehensive coverage of social and environmental features of disability, in line with state-of-the-art models of disability, e.g. including information on participation requirements rather than diagnostic details.
5. Prioritise women with disabilities by explicitly targeting the group in data collection and research projects, as well as making statistical facts and their interpretations accessible to a wider range of stakeholders.
6. Consider the use of extended gender definitions in research and data collection that allow for gender identity going beyond the simple twofold male and female identity .
7. Ensure study and understanding of carer needs, especially where women with disabilities are carers, by using opportunities to expand the scope of surveyed information.
8. Make greater effort to increase the level of inclusion of institutionalised persons in surveys, opinion polls, interviews and qualitative studies.
9. Ensure decisions being made with respect to women with disabilities account for the possible underrepresentation of institutionalised populations in data and evidence.

The third area discusses the accessibility of data and possibilities for its improvement.

10. Review the current pricing and conditions of access to data, so that access is not denied to individuals and entities that work in a voluntary capacity to benefit the community.

11. Promote openness, transparency and quality in the use of administrative data sets, such as the Disability Services National Minimum Data Set, for the purposes of statistical analysis and research.

Fourthly, it is recommended that the ACT Government and the ABS support disability sector stakeholders through actions which:

12. Encourage collaboration between the ACT Government and the ABS to enhance the understanding of information needs and strengthen ACT disability policies.
13. Ensure the existence of a strong evidence base despite the small ACT population size. The problem can be minimised by the use of techniques which protect the identity of individuals or make use of qualitative analyses.
14. Identify areas of data priority to ensure key information supporting stakeholders' actions is up-to-date and released in a timely manner.

Finally, the last area looks at the possibility of improving the ABS contributions on the subject of disability. Two relevant opportunities appeared in the process of preparing this report.

15. Work through ABS Advisory Groups to ask for increased clarity of information of the ABS website's disability section, and for upgrading its status to a comprehensive portal on disability.
16. Enrich the Socio-Economic Indexes for Areas/Individuals with information on disability. Alternatively create an equivalent index for disability that allows for further analysis of gender.

## 1. Introduction

This report is an outcome of a study commissioned by the Australian Capital Territory (ACT) Disability Advisory Council (DAC) to Women With Disabilities ACT (WWDACT). The grant was allocated with the purpose of identifying and assessing data sets on disability and their capacity to guide actions that advance the situation of women with disabilities in the ACT. The actions in question, which may originate from government, non-government, or private initiatives, encompass the provision of services for health and well-being as well as participation in social and economic life. To ensure women with disabilities receive equitable, responsive and cost-effective support, actions and policies ought to be based on sound evidence. Responding to needs in a well-informed, evidence-based manner is not only sensible, but also constitutes a step towards meeting the requirement of the ACT Government's Triple Bottom Line Assessment Framework that encompasses economic, environmental, equity impacts. Availability of data is, in turn, a prerequisite for producing evidence reflecting the existing problem areas and thus capable of guiding further actions.

In line with its purpose, the report focuses on data sets available in Australia, paying particular attention to three aspects of information provided: disability, women, and the ACT. The disability aspect allows us to understand and distinguish between various forms of disability. The women aspect relates to the gender disaggregation of data. The ACT aspect demands disaggregation of data by State/Territory and the inclusion of the Capital Territory in surveys. The need for disaggregation while observing the confidentiality requirements translates to a need for sufficiently large sample.

Ultimately, this report aims to identify sources of information relevant for women with disabilities in the ACT, and to suggest ways for enabling the use of these sources to their full potential. Understanding the situation of women with disabilities involves, *inter alia*, understanding the composition of the group, various types and facets of disability, and their implications for health, well-being, and participation in social and economic life. Realising the full potential of data sets requires their development, coordination, as well as facilitating access and dissemination of research outcomes to the benefit of stakeholders.

This study also offers a response to the previous WWDACT report<sup>1</sup> that revealed a number of problem areas with respect to public data. The shortcomings included limited access to data existing in the public institutional sphere, inadequate capacity or support for gender disaggregation of data on social phenomena, scarce or non-existent data on employment conditions and data on group homes for the disabled. In addition inadequate representation of women with intellectual disabilities was identified, reflecting their status as a 'problematic' group in terms of their identification, establishing meaningful interaction, and investigation of their situation. More broadly, the present study conforms to the 2013 Productivity

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<sup>1</sup> Carnovale A. Strong women great city: a snapshot of findings from a survey of ACT women with disabilities. Australian Capital Territory: Women's Centre for Health Matters Inc.; 2012.

Commission Report on Government Services for people with disability, which emphasises, among other things, building the evidence base for disability policies and strategies.<sup>2</sup>

The problem of data accessibility is an important one. Besides government agencies and organisations of substantial research capacity that can ensure institutional access to the data sets under investigation, initiatives that aim at advancing the situation of women with disabilities frequently stem from numerous smaller-scale organisations of the non-governmental and private sectors, as well as from volunteering individuals. The latter contribute greatly to supporting people in need and raising social awareness of the existing problem. Yet, various barriers restrain access to data on disability, including restrictions of purpose of use, fees, and the limited scope of freely accessible analyses.

Consequently, the report aims to make recommendations that would advance the use of identified information assets for the greater benefit of vulnerable and disadvantaged groups. While the recommendations are rooted in findings on the surveyed data sets and relate to identified shortcomings and opportunities, they offer broader improvement insights by tapping into various perspectives, experiences and expertise of the reference group members.

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<sup>2</sup> SCRGSP (Steering Committee for the Review of Government Service Provision). Report on government services 2013 [Internet]. Melbourne: Productivity Commission. Steering Committee for the Review of Government Service Provision; 2013. Available from: <http://www.pc.gov.au/gsp/rogs/2013>

## 2. Background

### 2.1. The challenging intersection of gender and disability

Disability is an umbrella term for a wide range of conditions limiting activity and participation in desired aspects of life. Disability arises at the tangency of an individual's physical or health condition and interpersonal or environmental circumstances. People with disabilities face many barriers to achieving fulfilling and independent lives. These barriers span across physical access to the environment as well as access to the labour market. Over a lifetime, every person will almost certainly have either direct or indirect experience of disability. Historically, societal perceptions and management of disability have been based on segregation (using demonic, charitable and medical models which impute a deficit to the individual). These have been replaced with an inclusion approach which attributes deficit to the structural and social environments. The latter approach continues to account for the medical aspect of disability, however, it also recognises the restrictions that are imposed by the human-made environment rather than the disabling condition per se. The way for this paradigm shift has been largely paved by people with disabilities themselves, through their bottom-up initiatives, and strengthening the human rights perspective on disability.

The state-of-the-art understanding of disability is reflected by the 'bio-psycho-social' model that establishes disability as a constraint on a person's functioning, due to impairments (e.g. blindness), mobility limitations (e.g. wheelchair dependence), or participation restrictions (e.g. discrimination in the form of inadequate facilities of physical access), which are a product of environmental factors (e.g. technology and infrastructure) and personal factors (e.g. self-esteem).<sup>3</sup> This holistic definition suggests the impacts of disability range from having an effect on an individual's health and well-being to their participation in social and economic life.

Manifestations and implications of disability are marked with a strong gender component. Framing the research question with women at the centre naturally poses the question of a relevant comparator group. A number of groups can be proposed for the purpose of the assessment of the situation of women with disabilities. Possible perspectives include the population at large, persons with disabilities, persons without disabilities, all women, non-disabled women, and men with disabilities. Another relevant factor is the geographic scope, in this case referring to the ACT or national samples of the above groups as the most adequate.

While a range of possibilities exist, keeping the objectives of gender equity in mind, it is conventional to examine disparities between women with disabilities and men with disabilities as well as comparisons to non-disabled women. Salthouse provides a number of facts that illustrate differences that persist in Australia.<sup>4</sup> Evidence shows that men with disabilities have higher labour market participation rates, are almost twice as likely to have a job, enjoy higher

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<sup>3</sup> World Health Organization. World Report on Disability. Geneva, Switzerland: World Health Organization; 2011.

<sup>4</sup> Salthouse S. The Status of Women With Disabilities in Australia – A Snapshot. Quebec Conference Proceedings; 2008.

levels of salary, are disproportionate recipients of government programmes, vocational rehabilitation, training, formal care, and similar benefits, and may also have a higher educational attainment at senior secondary or tertiary levels. In addition, women with disabilities, compared to their male counterparts, are less likely to own a house, are more often institutionalised, and report higher levels of unmet needs. Compared to non-disabled women, they are less likely to receive adequate health services and to fully enjoy access to telecommunications, and are more likely to face situations in which their dignity or autonomy is violated.

The above problems extend further to access to justice. Schetzer et al. identify the following attributes as conducive to justice access limitations: (a) intellectual, psychiatric or severe disabilities, (b) disadvantaged urban areas, (c) low levels of education, poor literacy skills or limited relevant knowledge, (d) people suffering systemic discrimination and exclusion on the basis of their ethnicity, gender, sexual preference, age or other grounds, (e) special needs in relation to discrimination, pregnancy, responsibility for children and sexual abuse, (f) older people, (g) low disposable income, (h) being institutionalised, or recently released from institutions such as psychiatric hospitals and nursing homes.<sup>5</sup> Problematically, many women with disabilities have multiple attributes that are likely to be direct or indirect impediments to accessing justice, which magnifies the detriment of their position.

The intersectionality of gender and disability means that women with disability are doubly disadvantaged, as inequalities within disabled groups not only mirror those of general population, but are further aggravated. It is apparent that structural issues that prevent women with disabilities from fully realising their talents and aspirations should be identified and explained. This sets an overarching objective for research on the impacts of gender and disability. In addition, the presence of double disadvantage raises questions about the relevant normative framework. That is because the abovementioned problems may also substantiate the use of special, cross-cutting measures aimed at reducing the negative impacts of both womanhood and disability.

To speak of women with disabilities as a monolithic group constitutes an oversimplification. In fact, it is an ample and diverse group consisting of identifiable more vulnerable or further excluded sub-groups. For this reasons, studying women with disabilities offers a window overlooking various social challenges, including discrimination and inequalities stemming not only from disability, but also from racial, age, educational, economic and other statuses.

A special distinction ought to be made between people living in private residences and institutionalised populations residing in accommodation such as boarding houses, nursing homes, and other institutional settings. The latter are more likely to experience involuntary treatment, abuse, neglect, persistent devaluation, sexual abuse and other forms of violence.

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<sup>5</sup> Schetzer L, Mullins J, Buonamano R. Access to justice and legal needs. Background Paper. Sydney: Law and Justice Foundation of New South Wales; 2002 Aug.

They are also underrepresented in surveys, data sets and studies.<sup>6</sup> Gaps in the collection of data lead to this area of policy being neglected and exacerbate the position of people in the institutionalised setting as voiceless and powerless. As a consequence, the most disadvantaged and vulnerable groups tend to be hidden.

Needless to say, forms of disability also contribute to the group's diversification, resulting in evident differences in the type and intensity of need as well as the severity of consequences for overall well-being. Particularly strong barriers to voicing preferences and improving personal situations arise where there are intellectual disablements. When reaching a group relates to multi-layered difficulties, such as in cases of institutionalised persons with intellectual disability or cognitive impairment, especially when coupled with undiagnosed mental health condition, chances of adequate representation are only slight.

Altogether, there are two complementary perspectives on the problem: the disability lens, and the demographic lens. A deepened understanding of the composition and characteristics of the disabled may reveal specific needs of its sub-groups, leading to design of more effective policies and giving an opportunity to reach those most disadvantaged. In particular, the two combined perspectives permit addressing the problem of gender-disability intersectionality keeping in mind the diversity underlying women in Australia.

A related area of concern is the situation of carers and representation of their needs. Caring is intrinsically tied to the presence of disability, and carers face a multitude of difficulties: material and financial pressures, time constraints and inequalities of workload, stress and other health risks, and exclusion from decision-making by health professionals, to name a few.<sup>7</sup> In addition, caring, both formal and informal, has a strong gender component: women account for 70% of carers.<sup>8</sup> This dual nature has to be highlighted in the context of understanding the problem of caring through the gender lens: on one hand, there are instances of caring for disabled women, on the other, women constitute the majority of carers.

Disability or a long-term health condition, are established determinants of persistent opportunity disadvantage, income poverty, multiple deprivation, and social exclusion. The above considerations show that gender is a central factor in understanding and addressing disadvantages of disability in a meaningful manner. Any equitable policy regarding disability must acknowledge and address the above facts. This implies the necessity to genderise disability policy by distinguishing between the genders and taking adequate, diversified measures. Frohmader substantiates the need for focused, gender-specific steps aimed to

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<sup>6</sup> World Health Organization. World Report on Disability. Geneva, Switzerland: World Health Organization; 2011.

<sup>7</sup> Glasby J. Understanding Health and Social Care. Bristol: The Policy Press; 2012.

<sup>8</sup> McLachlan R, Gilfillan G, Gordon J. Deep and persistent disadvantage in Australia. Melbourne, Vic.: Productivity Commission; 2013. Available from: <http://www.pc.gov.au/research/staff-working/deep-persistent-disadvantage>

decrease the discrimination and ensure full enjoyment of human rights for disabled women and girls.<sup>9</sup>

Finally, actions successful at improving the situation of women with disabilities have to take into account the local (State/Territory, city/urban/rural, district, suburb) context. This means, in particular, awareness of an area's distinguishing features, such as infrastructure and demographics, and idiosyncratic challenges and opportunities. The above may be reflected in local statistics deviating from national outcomes, and may justify exploratory investigations that may reveal such differences, and standalone qualitative and quantitative local studies should such local variation be identified. Findings of a WWDACT report entitled 'Strong Women: Great City' suggest that disparities between local and national averages may be considerable.<sup>10</sup> For example, there are considerable differences in the composition of disability by type, with intellectual and psycho-social disability being considerably more prominent in the ACT than nationally (13% and 20% respectively in the ACT, vis-à-vis 7% and 12% nationally). Other structural differences shown in the Carnovale report include private health insurance coverage, prevalence of health care cards among the respondents, as well as self-assessed physical health and well-being. While differences in sample sizes and compositions have to be kept in mind, to an extent the above values reflect the underlying variation of the ACT from the national standards.

## **2.2. Role for public authorities**

### **2.2.1. Legal obligations**

There are several grounds on which women with disabilities are entitled to an active support from public authorities such as Federal and State/Territory governments as well as their agencies. On one hand, there are laws and legal regulations that bind public authorities to perform certain functions. On the other, there are voluntary, declaratory commitments of public authorities to inform, support and promote activities that advance the situation of women with disabilities.

#### *International laws*

At the basic level, the expectation of public authorities' involvement stems from the human rights perspective on disability. This view is rooted in the observation that a causal link can be established between disability and gender discrimination, and violence, as well as other aspects of exclusion and disadvantage. Consequently, people with disabilities are on average more likely than the non-disabled population to experience discrimination, be denied equal opportunities, and have their dignity and autonomy violated.

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<sup>9</sup> Frohmader C. Gendering the National Disability Care and Support Scheme. Women With Disabilities Australia; 2010.

<sup>10</sup> Carnovale A. Strong women great city: a snapshot of findings from a survey of ACT women with disabilities. Australian Capital Territory: Women's Centre for Health Matters Inc.; 2012.

The United Nations (UN) promotes the use of the gender lens for understanding disability. This is reflected by UN instruments that recognise an overlapping area of the two domains. More specifically, there are two international conventions that specifically warrant policies on women with disabilities in member countries. The conventions provide both frameworks and obligations for States parties to take adequate steps towards ensuring a defined level of protection of vulnerable groups.

First, the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW),<sup>11</sup> obligates States parties to abolish discriminatory laws, promote equality of men and women through legal measures, and put in place mechanisms of the justice system to ensure execution of the above laws. Whilst the text of the Convention does not specifically refer to women with disabilities, the Articles address various problems of relevance to them, such as violence and discrimination, opportunities of social and economic life, equity of educational attainment and access to health services. It was not until 1991, that a specific General Recommendation 18 on women with disabilities was made by the CEDAW Committee. This recommendation requires States parties to provide information on disabled women in their periodic reports, and on measures taken, including special measures, to deal with their particular situation. The obligation to meet this Convention requirement rests with all levels of governments.

Regarding efforts of the Australian Government in this sphere, the Concluding Observations of the Committee on the Elimination of Discrimination against Women<sup>12</sup> make a specific mention of strengthening disaggregated data to reinforce the identification of needs and elimination of gender-based disparities (paragraph 37). With respect to women with disabilities, the Committee expresses its concern regarding the inadequate participation in public life, underrepresentation in political life (paragraph 26), limited job opportunities and overburden of caring (paragraph 38), absence from key leadership and decision-making positions, disadvantage in educational opportunities, and the continued presence of violence particularly in institutions and supported accommodation (paragraphs 42 and 43). Furthermore, the Committee urges that temporary special measures be indispensable for timely improvements (points 26, 35 and 43).

Secondly, the Convention on the Rights of Persons with Disabilities,<sup>13</sup> abbreviated CRPD, contains a number of entries concerning women with disabilities. In particular, in a dedicated Article 6 it recognises that (paragraph 1)

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<sup>11</sup> United Nations General Assembly. Convention on the Elimination of All Forms of Discrimination against Women. United Nations; 1979.

<sup>12</sup> Committee on the Elimination of Discrimination against Women. Concluding observations of the Committee on the Elimination of Discrimination against Women. United Nations; 2010 Jul. Report No.: CEDAW/C/AUS/CO/7.

<sup>13</sup> United Nations General Assembly. Convention on the Rights of Persons with Disabilities. United Nations; 2006.

*‘women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms’*

and that (paragraph 2):

*‘States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention’.*

Other considerations of women’s rights can be derived from the mentions regarding persons with disabilities made within the Convention, including in the context of awareness-raising (Article 8), freedom from violence and abuse (Article 16), health (Article 25), and social protection (Article 28).

#### *Special measures*

Temporary special measures are one of the UN Strategies and Tools for gender equality and empowerment of women, along with gender balance strategies and monitoring, staff selection systems, exit interviews, flexible work arrangements, and policies on organizational culture.<sup>14</sup> The purpose of special measures is to accelerate the advancement of gender parity and their subsequent removal after the goal is achieved. Special measures can include targeted recruitment and promotion of women and training programmes. Data collection can be interpreted as a special measure, in so far it is necessary for the conception, management and assessment of the above strategies, and where the existing data sets do not allow for an adequate disaggregation by gender, disability and location.

Currently in Australia there are a number of targets in place that can be seen as special measures towards women equal opportunities and for people with disabilities. For example, in 2010, the Australian Government set a target of a minimum of 40 per cent women and 40 per cent men on Australian Government boards and committees by 2015. The target applies to each portfolio. In 2012-13, 41% of people on government boards were women, with the 40% target achieved across 7 portfolio areas.<sup>15</sup> In the ACT, the overall representation of women on Boards is 46.7%.<sup>16</sup> In addition, the ACT Public Service Strategy for Employment of People with Disabilities set a target to double the number of people with disabilities in the ACT public service by 2015.<sup>17</sup>

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<sup>14</sup> [www.unwomen.org/en/how-we-work/un-system-coordination/women-in-the-united-nations/strategies-and-tools](http://www.unwomen.org/en/how-we-work/un-system-coordination/women-in-the-united-nations/strategies-and-tools)

<sup>15</sup> Australian Government, Department of Social Services, Office for Women, *Gender Balance on Australian Government Boards Report 2012-2013*

<sup>16</sup> ACT Government, Community Services, *A Picture of Women in the ACT 2013*, Chap.5.,Topic3, p. 67

<sup>17</sup> ACT Government, ACT Public Service, *Employment Strategy for People with a Disability, 2011-2015*

The relevance of special measures in Australia is highlighted by the Committee on the Elimination of Discrimination against Women and the Committee on the Rights of Persons with Disabilities. In their Concluding Observations addressed to the Australian Government, the former Committee recommends the use of temporary special measures, targeted measures, targets and quotas to address the existing issues of inequity.<sup>18</sup> The latter makes a specific mention regarding the situation of women with disabilities and the need for a more comprehensive consideration of their participation in public programmes and policies.<sup>19</sup> Both Committees express their disappointment with the insufficient level of disaggregated data collected and reported publicly. This deficiency obscures the situation of women and girls with disability, in particular those of the indigenous background. Recommendations regarding a development of nationally consistent measures for data collection and reporting follow this observation.

#### *National laws*

At the national level, the Social Security Act (1991)<sup>20</sup> and Social Security (Administration) Act (1999)<sup>21</sup> provide the legal ground for the financing of disability-related benefits, allowances and pensions to eligible groups, as well as define the administrative responsibilities regarding these payments. The needs of people with a disability are acknowledged in the legislation by the Disability Discrimination Act (1992)<sup>22</sup>.

In addition, the Australian Government and State/Territory Governments negotiated and endorsed a National Disability Agreement (NDA) which outlines the responsibilities and apportioning of delivery of disability services as well as income and employment support.<sup>23</sup> The role of the NDA document is to nationally coordinate objectives and outcomes for people with disabilities, their families and carers. Listed as explicit priorities are: (a) building the evidence base for policies and strategies, (b) strengthening family and carer capacity, (c) increasing choice and autonomy, (d) supporting innovative and flexible support models for people with

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<sup>18</sup> Committee on the Elimination of Discrimination against Women. Concluding observations of the Committee on the Elimination of Discrimination against Women. United Nations; 2010 Jul. Report No.: CEDAW/C/AUS/CO/7.

<sup>19</sup> Committee on the Rights of Persons with Disabilities. Concluding observations on the initial report of Australia. United Nations; 2013 Oct. Report No.: CRPD/C/AUS/CO/1.

<sup>20</sup> Parliament of Australia. Social Security Act 1991 [Internet]. 1991. Available from: <http://www.comlaw.gov.au/Details/C2012C00298>

<sup>21</sup> Parliament of Australia. Social Security (Administration) Act 1999 [Internet]. 1999. Available from: <http://www.comlaw.gov.au/Details/C2013C00627>

<sup>22</sup> Parliament of Australia. Disability Discrimination Act 1992 [Internet]. 1992. Available from: <http://www.comlaw.gov.au/Details/C2013C00022>

<sup>23</sup> Council of Australian Governments. National Disability Agreement. 2009.

high and complex needs, and (e) creating employment opportunities for people with disabilities.<sup>24</sup>

Accordingly to the NDA, various aspects of the provision of disability services are divided between the Australian Government and States and Territories. The Australian Government is in charge of the employment services for people with disabilities, including regulation, policy and sector development according to local needs and priorities. State/Territory Governments are responsible for the provision of specialist disability services other than employment, which involves regulation, planning and sector development, ensuring the compliance of their legislation with the national reform directions, and investing in initiatives in support of national priorities. Developing national policy and reform directions, funding and pursuing research to establish a national evidence base in the relevant policy area, the provision of data and improving their quality, as well as developing and implementing policies for Indigenous people with disabilities, are joint prerogatives of the Australian and State/Territory governments.<sup>25</sup>

#### *ACT Laws*

In the ACT a number of laws have direct relevance to women with disabilities: the Discrimination Act (1991)<sup>26</sup>, Disability Services Act (1991)<sup>27</sup>, Human Rights Act (2004)<sup>28</sup>, and Human Rights Commission Act (2005)<sup>29</sup>. In addition, administration of the Guardianship and Management of Property Act (1991)<sup>30</sup> and Public Advocate Act (2005)<sup>31</sup> may be relevant in the lives of some women with disabilities.

#### *Other commitments*

Other than the binding legal acts outlined above, public authorities engage in voluntary plans and declaratory commitments to advance causes discussed in this report. This applies in particular to improving data and building evidence base for policies. For example, in the ACT Women's Plan 2010-2015, the ACT Government commits to improving access to information disaggregated by sex through enhanced data collection and analysis.<sup>32</sup> The National Plan to Reduce Violence against Women and their Children is rooted in sound evidence produced from

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<sup>24</sup> [www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/government-international/national-disability-agreement](http://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/government-international/national-disability-agreement)

<sup>25</sup> Productivity Commission. Report on Government Services 2012. Chapter 14 Services for people with a disability. Canberra: Productivity Commission; 2012.

<sup>26</sup> ACT Government. Discrimination Act 1991. Dec 13, 1991.

<sup>27</sup> ACT Government. Disability Services Act 1991. Dec 24, 1991.

<sup>28</sup> ACT Government. Human Rights Act 2004. Mar 10, 2004.

<sup>29</sup> ACT Government. Human Rights Commission Act 2005. Sep 1, 2005.

<sup>30</sup> ACT Government. Guardianship and Management of Property Act 1991. Oct 31, 1991.

<sup>31</sup> ACT Government. Public Advocate Act 2005. Sep 2, 2005.

<sup>32</sup> ACT Community Services Directorate. The ACT Women's Plan 2010-2015. Canberra: ACT Government; 2010.

data collection and new research activities.<sup>33</sup> The ACT Prevention of Violence Against Women and Children Strategy 2011-2017 envisages development of a national data collection and reporting framework by 2022.<sup>34</sup> In addition, the commitments extend to programmes and policies put forward by political parties, for the purpose of elections or otherwise. Such declaratory statements may include anti-discrimination, violence, disability and aged care, and provide a ground for expectations on the parties' course of action regarding issues concerning women.<sup>35</sup>

### 2.3. Provision of information

The need for data generation and analysis stems from various abovementioned considerations. It can be seen as a means towards achieving social policy objectives. Other than through direct financing or provision of disability care, goals in this area can be accomplished through policy, regulation and enabling non-government actors. Providing reliable and accurate information reinforces consumers', providers', and other sector participants' ability to make informed decisions and actions. Thus, generating and disseminating information in order to influence behaviours of individuals and businesses is a viable government strategy that provides an alternative to traditional 'hard' forms of regulation.<sup>36</sup> The OECD Council for Enhanced Access and More Effective Use of Public Sector Information recommends a wider and more effective use of public sector information.<sup>37</sup> This can be achieved through the presumption of openness, removal of access restrictions, heightened awareness of available information assets, ensuring quality and integrity, fostering the generation of new data uses through public-private partnerships, pricing policies aimed at covering the costs of maintenance and distribution rather than profit-orientated, and supporting the above with adequate copyright policies and the use of state-of-the-art information technologies.

Secondly, regardless of the form of government participation or regulation of the market, the concepts of evidence-based policy and the Triple Bottom Line Framework require comprehensive, high quality data for the assessment of policies and actions. Data and research are essential in policy development, allocation of resources, capacity planning, improving of services, diminishing inequalities, monitoring and assessing cost-effectiveness of programmes.

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<sup>33</sup> [www.dss.gov.au/our-responsibilities/women/programs-services/reducing-violence/the-national-plan-to-reduce-violence-against-women-and-their-children/national-plan-to-reduce-violence-against-women-and-their-children](http://www.dss.gov.au/our-responsibilities/women/programs-services/reducing-violence/the-national-plan-to-reduce-violence-against-women-and-their-children/national-plan-to-reduce-violence-against-women-and-their-children)

<sup>34</sup> [www.dhcs.act.gov.au/\\_\\_data/assets/pdf\\_file/0014/231341/ACT\\_Prevention\\_of\\_Violence\\_Against\\_Women\\_and\\_Children\\_Strategy\\_2011.pdf](http://www.dhcs.act.gov.au/__data/assets/pdf_file/0014/231341/ACT_Prevention_of_Violence_Against_Women_and_Children_Strategy_2011.pdf)

<sup>35</sup> [www.nfaw.org](http://www.nfaw.org)

<sup>36</sup> Organisation for Economic Co-operation and Development. Regulatory policies in OECD countries: from interventionism to regulatory governance. Paris: OECD; 2002.

<sup>37</sup> Council for Enhanced Access and More Effective Use of Public Sector Information. OECD Recommendation of the Council for Enhanced Access and More Effective Use of Public Sector Information. OECD; 2008.

Thirdly, improving data collection is an explicit, standalone objective of policies and recommendations. In the NDA, the task is shared between the Australian and State/Territory governments. In particular, the Agreement obligates State/Territory governments to annually report to the Australian Government information regarding disability services provided under their financing. This reporting provides a basis for the Disability Services National Minimum Data Set (DS NMDS), which in turn is used for the assessment of needs and demands, their satisfaction rating, as well as for planning the supply of disability care. The ACT Women's Plan 2010-2015 aims to improve access to sex-disaggregated data in order to better identify needs of women. Concluding observations of the above-discussed UN Committees place data collection and analysis at the centre of efforts aimed at advancing the situation of women with disabilities.

A policy paper by Frohmader utilises the human rights framework to identify key areas of data and research fundamental for a comprehensive assessment of the situation of women with disabilities in Australia and improving relevant policies. Such an assessment provides a stepping stone for developing successful policies. The identified areas of information include forced sterilisation, abuse in institutions, exploitation, violence and abuse, reproductive freedoms and child removal by authorities, labour participation, standard of living, participation in public and political life, health status, education, access to justice and equal recognition before the law, as well as the intersectionality of the above areas.<sup>38</sup>

At the national level, the tasks of data collection and analysis are distributed between various agencies. To a large extent they are carried out by the Department of Social Services, as well as the Departments of Health, Education, and Employment. The Departments collect and analyse data primarily for internal purposes. The central role in data collection and dissemination for public use toward statistical purposes is played by the Australian Bureau of Statistics (ABS). Disability is a part of the ABS research agenda and reflected in its array of data sets and publications.<sup>39</sup> With respect to informing reforms and policies, an important position is also held by the Australian Institute of Health and Welfare (AIHW). The AIHW is a national agency particularly concerned with producing and publishing high quality data, statistics and analysis on a range of topics covering health and social issues. A considerable number of publications on disability include an annual review of support services provided under the National Disability Agreement.<sup>40</sup> In addition, research outputs that assess and shape the disability sector are produced by the Productivity Commission. Notable publications include the recent inquiry

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<sup>38</sup> Frohmader C. Assessing the situation of women with disabilities in Australia – a human rights approach. Rosny Park: Women With Disabilities Australia; 2011 Jul.

<sup>39</sup> Australian Bureau of Statistics. ABS Sources of Disability Information, 2003-2008. Canberra: Australian Bureau of Statistics; 2010 Aug. Report No.: 4431.0.55.002.

<sup>40</sup> Australian Institute of Health and Welfare. Disability support services: services provided under the National Disability Agreement 2011-12. Canberra: Australian Institute of Health and Welfare; 2013 Jul. Report No.: Bulletin no. 118. Cat. no. AUS 173.

report on Disability Care and Support<sup>41</sup> and a series of Reports on Government Services which include information on disability<sup>42</sup>.

Alongside the above government agencies are a number of non-governmental sector organisations that engage in collection, analysis, and dissemination of data that throw light on the issues around disability. These include focused research institutes such as the National Council of Vocational and Educational Research and the Australian Housing and Urban Research Institute, as well as advocacy groups such as Women With Disabilities Australia, Australian and ACT Councils of Social Service, Women's Centre for Health Matters, and others.

### **2.3.1. The question of data literacy**

Upon discussing the responsibilities for generating and disseminating knowledge, it ought to be emphasised that data literacy is a prerequisite for making meaningful use of data, both raw and processed. Without adequate analytical skills of its users, information is ineffectual regardless of its accessibility and explanatory potential. Therefore, a consideration of data literacy is critical in the context of openness, transparency, and an optimal use for the purposes of policy-setting. This observation extends to all groups of data users, including service providers, decision-makers, politicians, and the general public. Building analytical capacity should thus be considered a worthwhile social goal. The education system, and the higher education sector in particular, perform the key role in this respect. The ABS also holds a number of activities in this area, e.g. providing expertise for government agencies and supporting community groups in their need of quantitative analysis.

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<sup>41</sup> Productivity Commission. Disability Care and Support. Canberra: Productivity Commission; 2011 Jul. Report No.: 54.

<sup>42</sup> SCRGSP (Steering Committee for the Review of Government Service Provision). Report on government services 2013. Melbourne: Productivity Commission. Steering Committee for the Review of Government Service Provision; 2013. Available from: <http://www.pc.gov.au/gsp/rogs/2013>

### 3. Methodology

#### 3.1. Study concept

The study methodology comprised four elements. In line with the objective of the report, its aims were to identify and assess data sets relevant for women with disabilities in the ACT.

The first step concerned an identification of existing data sets. The data sets, and respective surveys through which these data are generated, needed to convey information about participation in social life, economic life, or the provision of services for improving health and well-being. The latter may involve such aspects as availability, accessibility, degree of utilisation or satisfaction with such services.. The data sets were identified through a search strategy that combined online and literature searches coupled with indications and feedback from experts in the project reference group.

Secondly, the identified resources were assessed in terms of the data they generate. This stage primarily concerned the scope of information that is collected in the process of surveying. For the purposes of this study, emphasis was placed on data which enabled: : (a) the opportunity to distinguish between various categories of disability, e.g. physical, intellectual, ; (b) the representativeness of the disabled population, in particular any ability to identify people in institutional settings, as opposed to household dwellers who are more readily included in data collection; (c) the support of sex disaggregation of data; (d) geographic information in particular regarding state or territory residence.

The third step provided an assessment of whether the data generated by the above-identified surveys is available to the public either partially or in its entirety. Consequently, this assessment included general availability, accessibility conditions such as exclusions and limitations, forms of access, and the mode of presentation of data. Also considered was processed data made available in the form of research publications. If shaped according to information needs, in-house research published by major data set providers (e.g. ABS, AIHW) has the potential to direct disability sector stakeholders' actions without them having to engage in statistical analysis.

Finally, the fourth step appraised the overall relevance of a particular data set for describing the situation of women with disabilities in the ACT. This included an identification of gaps and areas where gender or disability disaggregation of data is needed, as well as an exemplification of the information source applications.

In line with the above, each identified data set was particularly assessed with respect to (a) the general profile, (b) the depth of disability characterisation, (c) groups excluded from the sample, (d) the opportunity for disaggregation by gender and (e) by State/Territory, (f) conditions of access to raw data and the comprehensiveness of analyses that accompany the data set release. A summary evaluated the usefulness and applicability of each source for enabling actions in support of women with disabilities in the ACT.

## **3.2. Notes on survey comparison**

### **3.2.1. Presentation**

Data sets are presented in an order loosely reflecting the comprehensiveness of information they convey in relation to the problem area.

### **3.2.2. Relevance of data set profiles**

Survey descriptions are representative of the most recent survey, but may be applicable to previous editions.

### **3.2.3. Basic demographic information**

Surveys routinely collect information about such socio-economic and demographic characteristics as gender, age, and area of usual residence. The latter typically includes the State/Territory, and dwelling characteristics such as Accessibility and Remoteness Index of Australia (ARIA). To avoid redundancy, in presenting data set profiles, the above are referred to as basic demographic information. Any deviation from thus defined basic information is detailed and discussed.

### **3.2.4. Usual exclusions**

Survey scope definitions reveal certain patterns regarding sample properties. First, only usual residents of private dwellings are represented in surveys, while non-usual residents are omitted. Secondly, populations residing in very remote areas are excluded, as opposed to those living in urban and rural areas. Thirdly, ABS surveys exclude diplomatic personnel of overseas governments, persons whose usual residence is outside Australia, and members of non-Australian defence forces stationed in Australia. In discussing survey scopes, the above are referred to as usual exclusions. Samples with alternatively defined scopes are discussed taking the usual exclusions as a point of reference.

### **3.2.5. Forms of access to ABS data sets**

Confidentialised Unit Record Files (CURFs) enable researchers to perform their own analysis and investigation of a wide range of factors. The practice of confidentialisation is rooted in both legal requirements of privacy protection and maintaining the public trust in the ABS that is instrumental in obtaining truthful answers to survey questions. CURFs can be delivered on a physical drive (Basic CURF) or accessed remotely via Remote Access Data Laboratory (Expanded CURF). In addition, the ABS enables analyses of its data sets through online tools, Survey Table Builder and Analysis Service. The tools are part of the Remote Execution Environment for Microdata project that enables researchers to perform analyses in a secure environment of the ABS and includes confidentiality routines to ensure compliance with the relevant legislative requirements.

Accessing CURFs is subject to restrictions. These include a justification of use that has to constitute a valid statistical purpose, a requirement of responsible use, and a payment of fee.

In the case of Basic or Expanded CURF, the fee is \$1,680 per organisation per CURF, while the use of data through the Table Builder online tool attracts a fee of \$925 per organisation.<sup>43</sup>

Non-ABS data are available in a variety of systems, online or otherwise. Details of access are specified in each case.

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<sup>43</sup> [www.abs.gov.au/websitedbs/D3310114.nsf/home/Microdata+prices](http://www.abs.gov.au/websitedbs/D3310114.nsf/home/Microdata+prices), accessed on November 17, 2013.

## 4. Survey of data sets

### 4.1. Survey of Disability, Ageing and Carers

The Survey of Disability, Ageing and Carers (SDAC) includes a comprehensive study of disability tailored to accommodate a wide range of conditions.<sup>44</sup> It was carried out in years 1981, 1988, 1993, 1998, 2003, 2009 and most recently in 2012. The survey identifies and targets individuals living in households and cared accommodation locations. Data are collected through individual or proxy interviews, from persons aged 5 or more with a disability, and those aged 60 or more irrespective of their disability status. The 2012 edition covers 68,802 household and 10,362 cared-accommodation respondents, corresponding to approx. 27,400 private and 500 non-private dwellings, and 1,000 health establishments. The distinction between the two groups of respondents is reflected in the survey design, which consists of two parts. The household component and the cared accommodation component use different methods of data collection and processing appropriate for the different settings.

The survey contains the basic demographic information, and the usual exclusions apply in the surveyed population (see page 22). Because one component of the SDAC is a dedicated disability study, its capacity to identify conditions is the highest among surveys considered in this report. A number of levels of analysis attest to this comprehensiveness. At the household level, SDAC identifies numbers and roles of persons with disabilities and restrictions, carer functions, and eligibility for allowances and pensions. At the personal level, it captures needs, the availability of aids, the level of needs met through assistance, the level of community-related activities, ability to perform core activities, types of disability, education attainment and employment participation as well as their restrictions, housing situation and modifications, long-term health conditions and impairment, the situation of the primary carer<sup>45</sup>, self-perceptions, and transport-related issues. Moreover, at the personal level carer status and related activities are identified. The questionnaire also gathers detailed information regarding the condition, restrictions, broad and specific forms of activity, and use of service providers.

The SDAC microdata are available in the form of Basic CURF and via Table Builder, and follow the standard restrictions of access. Survey outcomes are communicated to the public in a number of ways. The survey release is complemented with the publication of estimates, summaries, and discussions of findings. Secondary tables with additional information are added after the initial publication and include tabulations of variables representing compositions of State/Territory populations with respect to various facets of disability. Additional tabulations can be requested in addition to release publications and standard products, however, these are considered special data services and thus attract fees.

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<sup>44</sup> Australian Bureau of Statistics. Disability, Ageing and Carers, Australia: Summary of Findings, 2012. Canberra: Australian Bureau of Statistics; 2013 Nov. Report No.: 4430.0.

<sup>45</sup> The SDAC defines primary carers as the people who provide the majority of the informal help needed by a person with a disability.

The SDAC is a large and focused survey whose collected data are highly relevant to understanding the situation of women with disabilities in the ACT. This is in particular due to a comprehensive approach to describing disability as well as a full reach of the ACT population that includes both private household and cared-accommodation residents.

#### **4.2. Disability Services National Minimum Data Set**

Disability Services National Minimum Data Set (DS NMDS) is a comprehensive, nation-wide survey of the disability services sector primarily concerned with the structure of utilisation, the composition of users, unmet needs and planning.<sup>46</sup> The data have been collected and released annually since 2003-04. The survey execution is done through service outlets, which comprise a wide range of residential settings, including private residences, domestic-scale supported, supported accommodation facility, and the 'other' category. These categories are assumed to reflect the existing range of residential options, such as boarding houses and retirement villages. Because of the way the survey is conceived, the sample only represents users of NDA-funded services, which in the most recent data set 2011-12 total 317,616 persons.

There are three levels of analysis in DS NMDS. The first level contains the provider characterisation. This encompasses types of supplied services, various forms of provider identification, the time dimension of operation, the number of staff hours, and the number of service users. In addition to the information of the State/Territory responsible for data collection, data items such as service type outlet postcode, funding jurisdiction, and statistical local area, enable a close approximation of the service area. Secondly, at the user level, basic demographic characterisation is gathered, disability type selected from 12 categories including physical and intellectual conditions, support needs selected from nine groups, details on the informal carer arrangement (presence, primary status, residency status, relationship to user, and age group), the receipt of carer allowance, labour force status, main source of income, and individual NDA funding status. Thirdly, at the service level, the start and exit dates, hours of service received, and the reason for exit are described.

Information contained in the DS NMDS data set is available through three venues. An interactive online tool available with no restrictions enables the presentation of counts in customised tabulations. Disaggregation of data going beyond the capacity of this simple tool can be made on request, and a charge may apply to cover the costs of preparation. Finally, AIHW offers a collection of publications covering various aspects of disability and based on the DS NMDS data.

DS NMDS is a unique survey in that it targets service users rather than the general population. In addition, the data are collected by tapping into the databases of NDA funded agencies. It should thus be seen as a catalogue of NDA providers and clients. Compared to other surveys, this approach has both strengths and limitations. The former relate to an accurate depiction of disability service usage and its year-on-year dynamics. On the other hand, the data does not

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<sup>46</sup> Australian Institute of Health and Welfare. Disability Services National Minimum Data Set: data guide. Canberra: Australian Institute of Health and Welfare; 2013 Jul. Report No.: DIS 62.

contain a component that would enable evaluation of the supplied services, excludes services funded through means other than NDA, estimates of unmet need are confined to information gathered by service providers and does not tell anything about needs of the population at large.

With respect to data access, the online tool offers a narrow range of variables for the customisation of cross-tabulations. In particular given the focus of this report, it does enable disaggregation of users by sex, primary disability, existence of informal carer, and residential setting, however, it does not give the opportunity to create a sub-national geographic breakdown of the above. Thus, it does not have the capacity to inform researchers interested in the State/Territory or postcode layout of the matter. This can be done through a customised data request, giving DS NMDS the potential to characterise women with disabilities from the perspective of service users .

### **4.3. Census of Population and Housing**

The Census of Population and Housing (Census) provides information on the population's characteristics and housing issues, focusing on small geographic areas. The latest 2011 release was preceded by the 2006, 2001, and 1996 editions. The Census offers a wealth of demographic and socio-economic information, which can in particular be disaggregated by sex and by geographic areas.

However, its usefulness for understanding issues of disability is limited by the narrow scope of the relevant questionnaire section that results in a basic description of disability. More specifically, the Census' depiction of disability is limited to taking a note on the number of people with a profound or severe disability. The latter group is defined as 'people needing help or assistance in one or more of the three core activity areas of self-care, mobility and communication, because of a long-term health condition (lasting six months or more), a disability (lasting six months or more), or old age'.<sup>47</sup> Consequently, there are only two variables pertinent to disability, namely a binary 'Core Activity Need for Assistance' and 'Unpaid Assistance to a Person with a Disability' that identifies the interviewee as carer.

The latest Census data are available in the ABS online tool Table Builder, and the 2006 and 2001 editions also as Basic CURF and Expanded CURF. The 2011 and 2006 data can be accessed free of charge via the Basic version of Table Builder. A variety of publications follow the Census release and include: accessible analytical articles and simple statistics, as well as intermediate and complex information products such as community profiles, Socio-Economic Indexes for Areas, and others.

#### **4.3.1. Socio-Economic Indexes for Areas/Individuals**

Socio-Economic Indexes for Areas (SEIFA) is a collection of indicators based on Census data that represents areas' relative position in socio-economic terms. At present, it comprises the

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<sup>47</sup> Australian Bureau of Statistics. Census Dictionary. Canberra: Australian Bureau of Statistics; 2011 May. Report No.: 2901.0.

Index of Relative Socio-Economic Disadvantage, Index of Relative Socio-Economic Advantage and Disadvantage, Index of Economic Resources, and Index of Education and Occupation. The indexes identify the magnitude of relative local advantage/disadvantage taking into consideration education, income, employment and housing. Based on the above dimensions, SEIFA applies weights to statistical districts, which may in turn be used to direct funding, develop services, identify business opportunities, and for various forms of socio-economic research. Related to SEIFA are Socio-Economic Indexes for Individuals (SEIFI) that enable identification of socio-economic inequalities at the individual level.<sup>48</sup> A recent report published by the ACT Government applied SEIFI in a study of socio-economic diversity of suburbs in the ACT.<sup>49</sup> Compared to SEIFA, SEIFI emerged as a method of heightened sensitivity that reveals a more complex structure of disadvantage by tapping into the within-area heterogeneity.

Currently, due to its limited attention to information on disability, the Census has only a basic capacity for supporting the evidence base on women with disabilities. Still, the disadvantage profiles of SEIFA and SEIFI have a considerable potential to strengthen our understanding of the structure of disability. For instance, a disability index could be added to the SEIFA and SEIFI collections, and its comprehensiveness would only be constrained by the scope of information on disability gathered by the Census.

#### **4.4. Survey of Education and Training**

Survey of Education and Training (SET) throws light at various circumstances influencing the level of educational participation, attainment and learning.<sup>50</sup> In the most recent 2009 edition, the sample of complete responses reached 23,807 individuals in 13,200 households. Previous editions were carried out in 1989, 1993, 1997, 2001, and 2005. Target survey participants are aged 15-74 years and reside in private dwellings. Disaggregations of data by State/Territory and sex are enabled through the basic demographic content.

Disability is characterised with binary variables that capture the presence of disability, five categories of severity, type of condition encompassing 13 broad categories, educational or employment restrictions, complemented with a five degree self-assessed health status.

Survey data is released in the form of microdata, available as Basic CURF and Expanded CURF and subjected to the usual access restrictions, as well as a written report supplemented with tables and stand-alone State/Territory tabulations. Customised presentations of data can be requested but attract charges.

In sum, educational attainment is an important factor contributing to the socio-economic status achieved by an individual. The survey has the capacity to link educational outcomes with

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<sup>48</sup> Wise P, Mathews R. Socio-Economic Indexes For Areas: Getting a Handle on Individual Diversity Within Areas. Canberra: Australian Bureau of Statistics; 2011 Sep. Report No.: 1351.0.55.036.

<sup>49</sup> ACT Government. Detecting Disadvantage in the ACT. Canberra: ACT Government; 2012.

<sup>50</sup> Australian Bureau of Statistics. Education and Training Experience, 2009. Canberra: Australian Bureau of Statistics; 2010 Mar. Report No.: 6278.0.

disability also allowing for State/Territory and sex layouts. This is valuable knowledge, especially given the intermediate characterisation of disability.

#### **4.5. General Social Survey**

General Social Survey (GSS) is a multi-dimensional social survey exploring a wide array of social aspects of life that among other things include health and disability, employment and education, housing and mobility, income and financial stress, use of technology and transport, and social capital.<sup>51</sup> The survey was carried out in 2002, 2006, and 2010. The most recent 2010 edition's survey sample comprised 15,028 private dwellings, with the qualifying age of at least 18 years, with the usual exclusions of diplomatic personnel and non-residents.<sup>52</sup>

Compared to other data sets, the GSS emerges as a source of intermediate comprehensiveness in terms of understanding disability. The disability profile employs the variables of severity (profound, severe, moderate, mild), disability type (sight, hearing or speech; physical; intellectual; psychological), and educational and employment restrictions. In addition, it identifies Centrelink disability support pensioners, disability as a major stress factor, and as an obstacle in accessing service providers. The GSS also identifies carers by gathering information on time spent providing care, help or assistance related to disability, long-term illness or old age, as well as additional caring activities provided to relatives outside the household.

The GSS data are available as Basic and Expanded CURFs. Moreover, the release is accompanied by the publication of a summary of results and complementary tables that present simple tabulations of selected social phenomena.

In summary, the general socio-economic profile and geographic information on residence, coupled with the intermediate characterisation of disability, make the GSS a valuable contribution to the evidence base regarding women with disabilities in the ACT.

#### **4.6. Time Use Survey**

Time Use Survey (TUS) is a source of information on time allocation and its determinants.<sup>53</sup> More specifically, the survey aims to establish the patterns of unpaid work, daily life activities, issues of labour force, voluntary work, leisure activity, and transport issues. Up to date there have been three editions: 1992, 1997, and 2006. The 2006 edition's final data set comprises 3,816 households and 6,961 individuals aged 15 and over. In scope were all usual residents of private dwellings. Non-private dwellings are excluded, and the typical sample exclusions apply. The survey supplies ample information on socio-demographic characteristics and place of residence, thus establishing the possibility of disaggregation by sex and State/Territory.

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<sup>51</sup> Australian Bureau of Statistics. General Social Survey: User Guide, Australia, 2006. Canberra: Australian Bureau of Statistics; 2007 Dec. Report No.: 4159.0.55.002.

<sup>52</sup> Australian Bureau of Statistics. General Social Survey: Summary Results, Australia, 2010. Canberra: Australian Bureau of Statistics; 2011 Sep. Report No.: 4159.0.

<sup>53</sup> Australian Bureau of Statistics. Time Use Survey: User Guide, 2006. Canberra: Australian Bureau of Statistics; 2008 Feb. Report No.: 4150.0.

A particular form of unpaid service provision that the survey throws light on is caring for people with disabilities and aged persons. This is accomplished through a series of sets of questions. The first set identifies persons with disability or long-term health condition within the household, also distinguishing between receiving/not receiving assistance and, in case of children, two levels of severity. The second set of questions details the family profile with respect to children with disability, including their number, age, placement among all children, gender, severity of condition, and restriction in everyday activities. At the personal level, the third set of questions inquires about disability status, severity on a five item scale, employment and education restrictions, and details the forms of received assistance. Regarding the carer, the survey finds about the nature of relationship and household sharing. It also identifies individuals who are institutionalised due to chronic medical condition, old age or disabling conditions, conditions that exclude from the labour force, forgoing labour force participation due to caring for another person, disability support pension recipients, and the perception of spare time in relation to a disabling condition. At the episode level<sup>54</sup> the survey inquires but does not detail activities aimed at helping sick, frail or disabled persons in own household and outside of it.

The TUS data are available for researchers' use in the form of Basic and Expanded CURFs. Processed data are shown and discussed in a number of complementary publications, including a summary report and tables.

The TUS offers a fairly comprehensive view of disability with the focus on caring activities and relationships between disabled persons and their carers. This is a welcome addition to the perspectives of disability provided by other data sets, although it has to be noted that little is known about subjective perceptions of persons involved in the analysed situations.

#### **4.7. Survey of Mental Health and Wellbeing**

The 2007 Survey of Mental Health and Wellbeing (SMHWP) is a focused study of mental disorders, with information collected from approximately 8,800 Australians aged 16-85 years and living in private dwellings.<sup>55</sup> Its focus was on anxiety, affective disorders, and substance use. The survey followed the 1997 precursory survey of Mental Health and Wellbeing: Profile of Adults.

The survey has narrowly defined objectives, over and above the basic socio-demographic characteristics. The data set gathers detailed information about instances of agoraphobia, panic disorders, social phobia, anxieties, obsessive-compulsive disorder, post-traumatic stress, depression, mania, bipolar affective disorders, and substance use. This information is complemented by an assessment of functioning and health service utilisation, as well as

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<sup>54</sup> The TUS has 6 groups of data items: household, family, person, day, episode, and activity. The 'episode' group relates to the length of time an activity is undertaken. The 'activity' group describes what was being done during that segment of time.

<sup>55</sup> Australian Bureau of Statistics. National Survey of Mental Health and Wellbeing: Users' Guide, 2007. Canberra: Australian Bureau of Statistics; 2009 Nov. Report No.: 4327.0.

disability, social networks and caregiving profiles. Disability is characterised by the disability status, severity, type of condition causing restriction and whether it affects daily activities, employment, and education, as well as a series of questions scoping the degree of reliance on assistance. The caregiving profile identifies the types of disabilities and long-term conditions among the interviewee's family members, as well as the status, nature, associated cost, extent of and attitudes toward their caregiving role.

Survey data are released as Basic and Expanded CURFs. Relevant publications supplied by the ABS offer summary commentaries based on descriptive statistics as well as tables presenting selected aspects of mental health and well-being of the Australian population.

SMHWB provides detailed information within its focus, and thus is a valuable addition to the evidence base on women with disabilities. It offers insights into the mental health dimension of disability that are outside the capacity of other surveys. The downside of the SMHWB's narrow scope is a limited usefulness in explaining social or economic issues that may stem from the mental health conditions well-described in the study. Moreover, because the survey is not recurring, the applicability of the data will decline in time.

#### **4.8. Australian Health Survey**

The Australian Health Survey (AHS) is a comprehensive study of health matters, nutrition, and physical activity and provides information on the health status of the population, lifestyles and risk factors relevant to health, as well as the utilisation of services and activities aimed at improving health.<sup>56</sup> The most recent edition of AHS was conducted in 2011-12 and consisted of three components: the National Health Survey (ca. 20,500 individuals of all ages, with a guardian proxy for persons aged below 15 years), National Nutrition and Physical Activity Survey (ca. 12,000 persons, adults and children aged 2-17 years), and National Health Measures Survey (ca. 11,000 participants aged 5 years and over). The survey included private dwellings, and the typical exclusions in the sample apply. However, overseas visitors staying in Australia for 12 months or longer are included. Previous editions were completed in 2008, 2005, 2001, 1995, and 1990. Similar studies were also carried out in 1983 and 1978. The basic socio-demographic information collected permits various breakdowns of data including disaggregations by sex and by the geographic context of the household.

In the AHS survey, disability constitutes a part of a broader health status. Disability is described with the following aspects: status and severity (five grades), type (sight, hearing, or speech; physical; intellectual; psychological; head injury, stroke or brain damage; other), as well as educational/employment restriction or difficulty. Serious disability may also be identified as a family stressor. In addition, the survey notes recipients of the Centrelink disability support pension and other disability pensions.

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<sup>56</sup> Australian Bureau of Statistics. Australian Health Survey: Users' Guide, 2011-13. Canberra: Australian Bureau of Statistics; 2013 Jul. Report No.: 4363.0.55.001.

The AHS data can be accessed as Basic CURF and Expanded CURF. An overview of the survey topics comprising tables of basic statistics and their interpretations is published by the ABS.

The AHS offers up-to-date information on the health status of the Australian population with a notable inclusion of its disability aspect. As such, and also because of its sample size, it has the capacity to show the prevalence of disability and its dynamics, also among women in the ACT. However, the survey's concern with across-the-board health issues results in disability being somewhat marginalised, which is reflected with its basic characterisation. In addition, the survey does not contribute towards explaining the situation of institutionalised disabled groups.

#### **4.9. Household Income and Labour Dynamics**

Household Income and Labour Dynamics (HILDA) is a year-on-year panel study of social issues that was first completed in 2001. It is mainly concerned with well-being, economic status, labour market, and family dynamics. The first wave sample consisted of 7,682 households, corresponding to 19,914 individuals. By the 11th wave, the sample size was expanded by 2,153 households, or 5,477 persons. The survey is household-based and thus excludes residents of institutions. Data are collected at the household level, regarding its composition, and at the personal level from persons aged 15 and more. Other usual exclusions in the sample also apply. The survey supports the sex and geographic disaggregation of phenomena.

The HILDA survey conveys a considerable amount of disability information. Although not exhaustive in every cross-section, the questionnaire details the presence and year of onset of a disability or a long-term health condition, their type, impacts on work, difficulties arising as a consequence, and need for assistance. The use of aids, home modifications, employment/education difficulties, and the utilisation of health services are also identified. Furthermore, the carer status is established, inside or outside the household (Summerfield et al. 2012).<sup>57</sup>

The HILDA data set can be ordered on a physical drive in Stata, SAS and SPSS formats.<sup>58</sup> Accessing the data set hinges on obtaining an approval from Melbourne Institute of Applied Economic and Social Research, observing detailed lists of responsibilities and requirements. Access attracts a fee of \$330 (organisations) or \$77 (individuals). The data set is summarised in HILDA publications that include statistical reports and discussion papers, and has also sprouted a sizeable body of literature comprising journal articles, book chapters, and dissertations, including analysis on the topic of disability.

To summarise, HILDA provides a considerable data set in terms of size, comprehensiveness of disability depiction, topics range, and the possibility to infer information about the

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<sup>57</sup> Summerfield M, Freidin S, Hahn M, Ittak P, Li N, Macalalad N, et al. HILDA User Manual – Release 11. Melbourne Institute of Applied Economic and Social Research, University of Melbourne; 2012 Nov.

<sup>58</sup> [www.melbourneinstitute.com/hilda/data](http://www.melbourneinstitute.com/hilda/data) accessed on November 29, 2013.

relationships between disability and various facets of socio-economic status. Consequently, it offers an attractive venue for researching the situation of women with disabilities in the ACT.

#### **4.10. National Council of Vocational and Educational Research**

The National Council of Vocational and Educational Research (NCVER) provides intelligence on the participation and outcomes of students with disabilities in vocational education and training. The Council explores various perspectives, including course completion, barriers and facilitators, and pathways from welfare to work. More specifically, the NCVER manages three data sets, all of which contain information on disability: Students and Courses, Apprentices and Trainees, and Student Outcomes Survey.<sup>59</sup> The data sets are updated annually, or quarterly in the case of Apprentice and Trainees, with 2012 being the most recently published edition. The demographic variables enable disaggregation by sex and State/Territory, as well as other characteristics of interest.

The disability status is described with a binary variable, and also distinguishes between nine disability categories (hearing, physical, intellectual, learning, mental illness, acquired brain impairment, vision, medical condition, other).

The data set can be accessed online and manipulated using an interactive user interface. The access is subject to terms and conditions, including confidentiality requirements, as well as a fee aimed to cover the marginal cost of managing the data base.

The dataset enables exploration of the impacts of disability on the aspects of education and training such as participation, attainment and outcomes. The composition of variables enables applicability to the research area of women with disabilities in the ACT. However, the depth of analysis is constrained by a crude approach to quantifying disability.

#### **4.11. Indigenous population surveys**

The ABS run two surveys dedicated to the Indigenous population of Australia: the National Aboriginal and Torres Strait Islander Health Survey (NATSIHS) and the National Aboriginal and Torres Strait Islander Social Survey (NATSISS).

In the 2004-05 NATSIHS edition,<sup>60</sup> the sample size was ca. 10,500 adults and children (aged 0-17) representing both remote and non-remote areas living in private households. The sample size was considerably expanded since the previous 2001 and 1995 releases, when Indigenous samples were only supplementary to the National Health Survey. By definition, the survey excluded the non-Indigenous persons. Moreover, it included populations living in remote and very remote areas. The remaining usual exclusions applied. The demographic information gathered enables disaggregation by sex and by State/Territory.

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<sup>59</sup> National Centre for Vocational Education Research. VOCSTATS fields: terms and definitions. Release 1.0. 2010. Available from: [www.ncver.edu.au](http://www.ncver.edu.au)

<sup>60</sup> First results of the 2012-13 edition were published while this report was being completed, on November 27, 2013. The publication excluded technical information on the survey sample.

For a health-themed survey, NATSIHS collects surprisingly little information regarding disability. More specifically, there is information regarding disability pension recipient status (Centrelink, Department of Veterans' Affairs) and disability as a personal or family stress factor. In addition, the study does gather information on long-term health conditions such as cancer and diabetes.<sup>61</sup>

More comprehensive information regarding disability among indigenous populations is supplied by the two editions (2002, 2008) of the NATSISS.<sup>62</sup> The more recent edition covered approximately 13,300 persons living in private dwellings.<sup>63</sup> The collected information included a range of basic demographic characteristics. The disability profile includes status and severity (three levels), type of disability (six categories), type of restriction (18 categories), the presence of educational or employment restriction and its characteristics (five and seven categories, respectively).

Both surveys' microdata are available from the ABS servers in the form of Expanded CURFs, and are accompanied by a summary discussion based on descriptive statistics. Tables presenting the State/Territory breakdown of variables are only available for the 2002 NATSISS edition, however, even they do not cover the topic of disability.

Overall, the Indigenous population surveys have a limited applicability to research on women with disabilities in the ACT. Especially in the case of NATSIHS, the available disability variables do not allow for a meaningful analysis. NATSISS, on the other hand, can be used to explore the impacts of disability on Indigenous women's lives.

#### **4.12. Personal Safety Survey**

Because of the matter it is primarily concerned with, the 2005 Personal Safety Survey (PSS) is an important asset in the consideration of women's issues. Given the acknowledged disproportionately high rates of violence experienced by women with disabilities (Section 2.1), the PSS also has the potential to investigate its prevalence and nature and thus could be instrumental in guiding policy and responses to violence. Problematically, in its 2005 form, the PSS did not contain any information regarding the disability status of surveyed persons.<sup>64</sup> However, the 2012 survey included a broad measure of disability status, comprising a binary disability variable, and variables of disability type (six categories) and severity (five levels plus schooling/employment restriction). It also included amended content on many aspects of the

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<sup>61</sup> Australian Bureau of Statistics. National Aboriginal and Torres Strait Islander Health Survey: Expanded Confidentialised Unit Record File, Technical Manual. Canberra: Australian Bureau of Statistics; 2006 Aug. Report No.: 4715.0.55.002.

<sup>62</sup> Likewise, the first results of 2012-13 edition of NATSISS were published on November 27, 2013.

<sup>63</sup> Australian Bureau of Statistics. National Aboriginal and Torres Strait Islander Social Survey: Users' Guide, 2008. Canberra: Australian Bureau of Statistics; 2010 Feb. Report No.: 4720.0.

<sup>64</sup> Australian Bureau of Statistics. Personal Safety Survey, Australia: User Guide, 2005. Canberra: Australian Bureau of Statistics; 2006 Oct. Report No.: 4906.0.55.003.

survey which enable greater understanding of non-physical violence or abuse, feelings of safety and the availability of supports or social connectedness.

The 2012 survey targeted individuals aged 18 years and more residing in private dwellings, with the usual sample exclusions. The final survey sampled ca. 17,050 respondents. The scope of generated demographic information enabled disaggregation by State/Territory as well as by gender.<sup>65</sup>

#### **4.13. Small Scale Studies**

In addition to the above-described, there exist data sets generated through non-recurring independent research, e.g. in academic projects, that explore various aspects of disability. For example, a study of learning support needs of post-secondary students with a psychiatric disability (394 participants),<sup>66</sup> and on the attitudes of people with disability to undertaking vocational education and training (104 respondents).<sup>67</sup> Contacting authors of such surveys may yield relevant, if fragmented, information on women with disabilities in the ACT.

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<sup>65</sup> Australian Bureau of Statistics. Personal Safety, Australia, 2012. Canberra: Australian Bureau of Statistics; 2013 Nov. Report No.: 4906.0.

<sup>66</sup> McLean P, Andrews J. The learning support needs of students with psychiatric disabilities studying in Australian post-secondary institutions. Australian National Training Authority; 1999 Aug.

<sup>67</sup> Nechvoglod L, Griffin T. The attitudes of people with a disability to undertaking VET training. National Centre for Vocational Education Research; 2011.

**Table 1: Comparison of data sets available**

Survey	Comprehensiveness of disability description	Disaggregation S/T*	Sex	Sample definition	Sample Size	Conducted	Data Access	Applicability
SDAC	Highest	Y	Y	Ages 5 and more, private dwellings and institutions	79,164 persons/ca. 28,900 households and health establishments	1981, 1988, 1993, 1998, 2003, 2009, 2012	Basic CURF, Table Builder	In-depth understanding of population disability profile
DS NMDS	Comprehensive, focused on disability services use	Y	Y	All service users	317,616 persons	Annually since 2003-04	Simple online interactive table, customised data request	Understanding disability through the lens of disability services supplied nationally
Census	Basic	Y	Y	Full population	Full population, approx. 9.8 million households	1996, 2001, 2006, 2011	Basic CURF, Expanded CURF, TableBuilder	Detecting the presence of disability, and carer status, and linking them to socio-economic, demographic and geographic features of the Australian population
SET	Intermediate	Y	Y	Ages 15-74, private dwellings	23,807 persons/13,200 households	1989, 1993, 1997, 2001, 2005, 2009	Basic CURF, Expanded CURF	Disability in the context of educational attainment
GSS	Intermediate	Y	Y	Ages 18 and more, private dwellings	15,028 private dwellings	2002, 2006, 2010	Basic CURF, Expanded CURF	Provides an opportunity to link disability to various aspects of social life, including health status, employment and education, housing and mobility, income and financial stress, use of technology and transport, and social capital
TUS	Intermediate	Y	Y	Ages 15 and more, private dwellings	6,961 persons/3,816 households	1992, 1997, 2006	Basic CURF, Expanded CURF	Disability and carer status as determinants of time use
SMHWB	Comprehensive, mental disorders only	Y	Y	Ages 16-85, private dwellings	Approx. 8,800 persons	2007	Basic CURF, Expanded CURF	Detailed population profile with respect to mental disorders
AHS	Intermediate	Y	Y	All ages (main survey component), private dwellings	Approx. 20,500 persons (main component)	1990, 1995, 2001, 2005, 2008, 2012	Basic CURF, Expanded CURF	Disability in the context of health status
HILDA	Comprehensive	Y	Y	All ages (household level), ages 15 and more (personal questionnaire)	25,391 persons/9,835 households	Annually since 2001	Order a physical drive, in a number of popular data formats	Disability in relation to well-being, economic status, labour market, and family dynamics (data available may depend on wave)
NCVER	Basic to intermediate	Y	Y	Students, all ages	Approx. 20,000 records every Quarter (Apprentices and Trainees component)	Quarterly or annually, depending on component	A range of options, from summary tables to CURFs	Participation and outcomes of students with disabilities in vocational education and training
NATSIHS	Basic	Y	Y	All ages, private dwellings	Approx. 10,500 persons	1995, 2001, 2005, 2013	Expanded CURF	Disability in the Indigenous population, however disability description inadequate
NATSISS	Intermediate	Y	Y	All ages, private dwellings	Approx. 13,300 persons	2002, 2008	Expanded CURF	Disability in the Indigenous population, meaningful disability description available
PSS	Intermediate	Y	Y	Ages 18 and more, private dwellings	17,050 persons	2012	not yet released	Disability in relation to personal safety, including the problems of violence, stalking, and abuse
Small scale studies					Variable, depending on the scope and purpose of study			

Note on comprehensiveness of disability description: 'basic' identifies the presence of disability but does not specify its type; 'intermediate' identifies the presence, type and severity of disability; 'comprehensive' conveys extra information in describing disability, restrictions, caring, or perceived quality of life; 'highest' indicates the most detailed characterisation of disability available among the surveyed data sets.

\* State/Territory

## 5. Findings and recommendations

The following sub-sections provide summaries of findings collated by topic, and put forward recommendations that aim to enable the best use of the existing assets or indicate possible extensions. The holistic examination of the data landscape emerging from this report is an indispensable step toward enabling an improved understanding of women with disabilities and their life circumstances. Thus, diverse directions for action are considered. Making a better use of available resources may hinge on fine-tuning the scope of collected data, its dissemination, analysis and presentation, ensuring the capacity of organisations, including government and non-government, as well as individuals to make more meaningful and effective use of data. A number of other opportunities are presented below.

### 5.1. Sources of information on women with disabilities

The study identified data sets which provide information on women with disabilities for the reference of the WWDACT, the DAC, the ACT government, and other bodies and individuals having interest in the topic. The survey of disability data sets in Section 4 of the present report showed a variety of themes combined with different levels of comprehensiveness in disability characterisation. The SDAC stands out as the major data sets that provide comprehensive information on disability in Australia. However, due to its focused approach, it does not permit the investigation of causal relationships between aspects of disability with well-being and social and economic life participation. This is enabled by the GSS and the TUS but at the expense of precision in describing disability. Additionally, these latter two surveys are particularly useful in studying the situation of carers.

The main strength of the HILDA survey is a balanced accommodation of the disability profile and other characteristics, which make it an attractive venue for researching the socio-economic situation of women with disabilities in the ACT.

Further still, the Census offers a broad view of social issues and a full population sample, however, with only cursory information on disability. Other data sets offer narrowed-down perspectives: DS NMDS assumes the lens of service users, the SMHWB – of mental health conditions, the SET and the NCVER – of educational outcomes, and the NATSISS – of the Indigenous population. These fragmentary views can be seen as complementary sources of information that can enhance our understanding of issues beyond the scope of the generalist data sets. The sources of data should be utilised accordingly to the breadth and depth of problem analysis, and combined in order to maximise the relevance and comprehensiveness of evidence. Table 1 presents a summary of key data sets' characteristics that can guide data set choices for the purpose of addressing specific issues concerning women with disabilities.

#### *Recommendation 5.1*

1. All stakeholders using data sets identified in this study to research information on women with disabilities should familiarise themselves with the underlying survey structure for guidance on its applicability.

## 5.2. Enhancing the comprehensiveness of intersectionality depiction

This section contains suggestions for improving and expanding information on women with disabilities. The suggestions are rooted in the overview of data sets, which provided an opportunity to reflect on the strengths and weaknesses of existing sources. Recommendations that follow represent directions for action desirable from the perspective of women with disabilities. Therefore, they can inform advocacy objectives of WWDACT and the DAC, even though the actual actions may be outside of the bodies' scope of authority.

### *Descriptions of disability*

Four categories emerged in terms of the comprehensiveness of disability description. First, the PSS exemplifies a study that has the capacity to shed light on an important problem relating to women with disabilities. However, until the 2012 survey, the PSS conveyed no information whatsoever about disability status. It thus represented a major missed opportunity for informing resource allocation, policies and voluntary actions. Secondly, there are surveys such as the Census and the NATSIHS that have the potential to address a broad range of issues. Problematically, this potential is hindered by only basic treatment of disability in their respective questionnaires, which indicates the presence of a disability but fails to supply any description thereof. Thirdly, surveys such as HILDA, the GSS and the AHS convey an intermediate level of information on disability, including type, severity, and an indication of its consequences. Finally, the SDAC, the TUS, and to some extent the SMHWB, provide comprehensive views of disability that go beyond factual description to include a subjective assessment of the burden of condition, quality of life and satisfaction with the living environment. The latter three surveys are predominantly dedicated to studying disability, and this exclusive focus diminishes the space for linking aspects of disability to other socio-economic outcomes.

The data sets have a joint capacity to explain different aspects of disability, including its implications for health and wellbeing, as well as social and economic life participation. It is notable, however, that for the most part they are rooted in the obsolete models that treat disability as a medical and personal condition. Consequently, they largely fail to adequately reflect the social and environmental contexts, including such dimensions as social networks, support group participation, and environmental restrictions and amenities, e.g. housing modifications.

### *Prioritising women with disabilities*

For reasons discussed in Section 2, women with disabilities can be seen as a disadvantaged group. This well-established fact justifies the use of special measures, which among other things may apply in the area of data collection and research. Strengthening the position of women in the research agenda can be attempted in a number of ways exemplified below.

The ABS website contains sections devoted to a number of disadvantaged groups, including children with disability, families with a disabled child, Indigenous Australians, working people, and aged persons. However, women are not identified as a target disability group. The Council of Australian Governments' (COAG) 2008 Reform Council includes both Gender Equity and Disability among its themes, and the Australian Gender Indicators Project was instigated in 2010. In addition, an ABS Gender Portal (Topics @ a Glance – Gender) has been set up. These initiatives put greater emphasis

on sex disaggregation of results. A section dedicated to women with disabilities could provide a profiled source of information as well as signal its priority.

Disaggregation by sex and by State/Territory could significantly improve our understanding of the situation of women with disabilities in the ACT. While these types of data disaggregation are currently performed, they rarely take place jointly and are usually serve as an analysis' ends rather than a means for explaining other characteristics or phenomena.

Prioritising this area would also require additional resources. For instance, the ACT Women's Plan 2010-2015 makes specific mention of improving data collection,<sup>68</sup> however the ACT Office for Women does not have a dedicated staff member with expertise in data collection. The task of coordinating data collection and management in the area of women with disabilities, or other disadvantaged groups, may require an officer specifically employed for this purpose.

### *Definitions of gender*

With respect to gender identity, the identified surveys rely on the traditional definition based on the exclusive disjunction of either female or male. This dichotomous choice may inadequately reflect the way some persons perceive their gender.

### *Understanding carers*

Carers represent an essential part of the disability sector, due to the materiality of labour, support and expertise they provide. About 2.7 million Australians identify themselves as carers, including 770 thousand primary carers. Women constitute 56% of all carers and 70% of primary carers.<sup>69</sup> Therefore, having a research focus on carers is central to understanding the situation of women in the context of disability. A number of existing data sets identify aspects of carers. Notably the SDAC, DS NMDS, and the TUS provide comprehensive information about the scope and nature of caregiving. Carers are a risk group exposed to stress, work-life imbalance, health risks, financial pressures, and other problems. In addition, many women with disabilities are themselves primary carers of children with disabilities or older people, and understanding of their situation requires knowledge of both disability and care-giving. Full advantage should be taken of existing and enhanced data to evidence carer well-being, socio-economic life participation, and needs.

### *Institutionalised populations*

The main disability data sets, SDAC and DS NMDS, account for persons that reside in private dwellings as well as those who live in institutionalised setting such as boarding houses and retirement homes. Hence, these surveys come the closest to reflecting the actual structure of the Australian population with respect to its disability-related needs. The remaining surveys, however, are predominantly household-based and thus only represent the private residence part of the population. This poses an important constraint on understanding disability, as institutionalised groups are arguably the most disadvantaged given the magnitude of disadvantage and

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<sup>68</sup> ACT Community Services Directorate. ACT Women's Plan 2010-2015. Canberra: ACT Government; 2010.

<sup>69</sup> Australian Bureau of Statistics. Disability, Ageing and Carers, Australia: Summary of Findings, 2012. Canberra: Australian Bureau of Statistics; 2013 Nov. Report No.: 4430.0.

discrimination they experience, especially violence and abuse in both the domestic and community environments, with high levels of unmet needs, accompanied by the lack of voice and an environment which engenders complete or near-complete dependence.

From the disability data standpoint, this gap is a consequence of practical difficulties in ensuring survey coverage of individuals residing in the institutional setting. The challenges of targeting, accessing, and interviewing also extend to people with intellectual, cognitive and communication impairments.

There are two courses of action that can help to alleviate these issues. First, the fact that the two groups may be overlooked or underrepresented should be accounted for and compensated with intelligence from other sources, quantitative or qualitative. Secondly, opportunities should be identified and taken to ensure a more adequate representation of the two groups in equity studies.

### *Recommendations 5.2*

2. Introduce a disability component to surveys dedicated to specific issues, such as has been done with the 2012 Personal Safety Survey, in order to add a new dimension to problem analyses.
3. Expand the question on disability in data sets that cover a wide range of social issues but currently offer only limited usefulness for researching women with disabilities (e.g. Census).
4. Extend the scope of disability information to provide a more comprehensive coverage of social and environmental features of disability, in line with state-of-the-art models of disability, e.g. including information on participation requirements rather than diagnostic details.
5. Prioritise women with disabilities by explicitly targeting the group in data collection and research projects, as well as making statistical facts and their interpretations accessible to a wider range of stakeholders.
6. Consider the use of extended gender definitions in research and data collection that allow for gender identity going beyond the simple twofold male and female identity .
7. Ensure study and understanding of carer needs, especially where women with disabilities are carers, by using opportunities to expand the scope of surveyed information.
8. Make greater effort to increase the level of inclusion of institutionalised persons in surveys, opinion polls, interviews and qualitative studies.
9. Ensure decisions being made with respect to women with disabilities account for the possible underrepresentation of institutionalised populations in data and evidence.

### **5.3. Facilitating access to data**

Organisations representing the interests of women with disabilities, such as WWDACT and the DAC, may want to promote facilitated data access with the goal of strengthening the evidence base. Stemming from the present survey of data sets are the following considerations.

#### *Conditions of access to data*

All data sets considered in this report are subject to access restrictions and responsible usage policies that ensure the use of data for statistical purposes and to help maintain its confidentiality.

Moreover, accessing the systems typically demands a fee payment. While the report does not attempt to assess the adequacy of particular policies, requirements and prices, it encourages their periodical revision so as to ensure support of the accessibility and openness goals outlined in the previous paragraph. This is also relevant to special product services and customised data requests offered by the ABS and the AIHW. Provision of affordable and flexible data services may be seen as a form of support given to entities such as NGOs that require a specific knowledge of their domain to perform effectively.

#### *Wealth of administrative data*

In addition to data sets collected for statistical purposes there exists an abundance of administrative data that are generated as a by-product of statutory tasks performed by public agencies and public or private sector organisations, e.g. Centrelink, Medicare, Child Support Agency, health insurers. The main purpose of these data sets is to support the operations of the respective organisations. While there have been cases of successful use of these data sets for research purposes, for instance a study of welfare dependency and income support time periods that relied on Centrelink data,<sup>70</sup> for the most part administrative data remain underutilised. As far as policy-relevant statistical evidence is concerned, this is a missed opportunity. For example, the untapped data could shed light on the equity of treatment of disabled women by the child protection authority thus revealing a previously undocumented form of disadvantage. Data generated in the course of the justice system operation could provide a ground for testing hypotheses regarding the existence of inequalities in access to justice and legal outcomes.

A related issue is the presence of sizeable redundancies in data collected independently by organisations. Emerging from this report is the fact that surveys duplicate basic disability information, in particular inquiring about the disability status, type, and educational/employment restrictions. While this is done to ensure the possibility of linking the presence of disability to other socio-economic characteristics of interest, the question remains whether this redundancy could be managed and reduced.

Coordination at the national level could help address the two above issues, as well as provide basic compatibility between presently unlinked data sets. The Statistical Clearing House operated by the ABS has the potential to occupy the central place for disability data generated in Australia and improve the utility of existing and future data sets for the purposes of scientific research.

Finally, a policy action could be considered to encourage openness, transparency, access, and utilisation of administrative data for valid statistical purposes. Such disclosure of non-sensitive public data is recommended by the OECD Council for Enhanced Access and More Effective Use of Public Sector Information<sup>71</sup> which was discussed more broadly in Section 2.3. Yet, without legal or economic incentives, opening up of administrative data sets is unlikely to occur spontaneously due to relevant costs and legal risks coupled with the lack of immediate benefits to data owners.

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<sup>70</sup> Gregory RG, Klug E. A Picture Book Primer: Welfare Dependency and the Dynamics of Female Lone Parent Spells. 2003.

<sup>71</sup> Council for Enhanced Access and More Effective Use of Public Sector Information. OECD Recommendation of the Council for Enhanced Access and More Effective Use of Public Sector Information. OECD; 2008.

*Recommendations 5.3*

10. Review the current pricing and conditions of access to data, so that access is not denied to individuals and entities that work in a voluntary capacity to benefit the community.
11. Promote openness, transparency and quality in the use of administrative data sets, such as the Disability Services National Minimum Data Set, for the purposes of statistical analysis and research.

**5.4. Supporting the disability sector stakeholders**

The ACT Government and the ABS share responsibilities for supporting the disability sector operation and development. The former can shape the sector through its legislative powers. The latter plays a central role in providing intelligence informing the sector operation, including the ACT Government itself. Therefore, a form of collaboration between the two bodies is desired in carrying out their supervisory and guidance roles. This section concludes with recommendations to be considered in the process of two bodies' interaction.

Tabulations of data that present within-State circumstances are helpful in customising policies. With respect to women with disabilities in the ACT, they could throw light on the structure of disability relative to that of men, especially in relation to assessing whether the support needs are met equally for both sexes. Despite high utility of such statistics, the depth of data disaggregation is limited by the confidentiality requirement and data quality considerations.

The ACT faces specific limitations in this regard, due to the size of its population. The ACT accounts for 1.66% of the Australian population.<sup>72</sup> This translates proportionately into its share of the sample size of nationally representative survey studies. This in turn limits the possibility of making statistical inferences based on the ACT sub-sample. In the case of SDAC that exemplifies a large study sample of 73,683 individuals, the ACT accounts for approx. 1,221 persons. Restraining the sub-sample to women halves the number of observations. This leaves little space for a statistical exploration of the social, demographic, and economic compositions of this sub-group, and their interaction with various forms of disability.

Perhaps for the above reason, the ABS publications shun away from in-depth problem analyses at the State/Territory level. To the contrary, they rest at presenting across-the-board national characteristics. In the case of SDAC, gender breakdowns are supplied regarding the need for assistance, source of personal income, carer status by age and by the level of remoteness. The consolidated set of tables thus gives a fragmentary view of issues. In the SET, tables accompanying data release provide disaggregations by sex and by disability status, however only disjointly and without making the full use of disability information contained in the survey data. Similarly, the ABS website offers little material applicable directly to the ACT.

The ABS is thus limited in guiding policy and other within-state developments. It is especially important for this limitation to be considered in the ACT context because of its legal status and the fact that Federal laws override laws made within the Territory. This requires the ACT Government to be careful in recommending and implementing policy, and to seek partnership and cooperation with

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<sup>72</sup> Australian Bureau of Statistics. Australian Demographic Statistics, March 2013. Canberra: Australian Bureau of Statistics; 2013 Sep. Report No.: 3101.0.

the Federal Government. Therefore, collaboration and coordination by the ABS regarding ACT information needs can be instrumental in seeking evidence-based policy consensus.

The ABS practice of publishing secondary tables some time following the data set release gives an opportunity for addressing information needs going beyond the primary publication of basic statistics and findings summary. The process of producing secondary tables by the ABS could be opened up to include specific needs of the ABS data stakeholders. The ACT Government and individual stakeholders could use their access to the various ABS advisory groups<sup>73</sup> to better voice these needs, and would be a significant step towards improving the use of public data owned by the ABS, one potentially leading to a better use of already available resources in support of evidence-based policy and toward the Triple Bottom Line Assessment Framework.

A timely availability of up-to-date information on disability is essential in supporting the sector stakeholders. A number of data sets are in place which inform actions and policies with respect to disability. However, their applicability is constrained by the frequency of new releases and timing of publication. Data sets updated annually, such as DS NMDS, have the highest relevance to informing about the current situation and recent dynamics. In contrast, some key data are obsolete or only seldom updated. For instance, the usefulness of TUS and SMHWP in understanding carers and the mental health profile of the population is limited by their latest releases dating 2006 and 2007. The discontinuation of the TUS is regarded to have wide-ranging negative impact on development of policies which affect women. Given the demographic dynamics and the rapidly evolving structure of needs, data aged five years or more may be insufficient for the purposes of current planning of budgets and grants. A revised approach to data release relying on an identification of high priority areas would strengthen the adequacy of resource allocation, policy-making, and voluntary action.

#### *Recommendations 5.4*

12. Encourage collaboration between the ACT Government and the ABS to enhance the understanding of information needs and strengthen ACT disability policies.
13. Ensure the existence of a strong evidence base despite the small ACT population size. The problem can be minimised by the use of techniques which protect the identity of individuals or make use of qualitative analyses.
14. Identify areas of data priority to ensure key information supporting stakeholders' actions is up-to-date and released in a timely manner.

#### **5.5. Reinforcing ABS contributions**

In the course of reviewing disability data sets, this report identified issues with the ABS online resources as well as opportunities for improving existing products. While this report is addressed to bodies that do not have power over ABS strategies and practices, in performing their advocacy functions, e.g. through Advisory Groups, they may consider making the following recommendations.

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<sup>73</sup> Information on ABS Statistical Advisory Groups are at:  
[www.abs.gov.au/websitedbs/c311215.nsf/web/States+and+Territories+-+Services+for+State+and+Territory+Government+-+Advisory+Groups](http://www.abs.gov.au/websitedbs/c311215.nsf/web/States+and+Territories+-+Services+for+State+and+Territory+Government+-+Advisory+Groups)

*Tidying up ABS online*

While not exclusive, the position of the ABS is central in the area of disability data. This is because of its statutory obligations, the range of statistical products, and the range of stakeholders that includes the Federal and State/Territory governments, the National Disability Insurance Scheme, research institutes, and others. The investigation of data sets presented in this report to some extent highlights the centrality of the ABS in generating, processing and disseminating data and evidence that may inform disability policies.

The ABS website is the key channel of communication with its stakeholders; consequently, it is also a go-to source of information on disability for both the Australian and international public. The website currently offers a wealth of content on various aspects of disability. Yet, the form of the contents' presentation is often unclear and navigating between resources unintuitive. Examples include: publishing some reports as web pages while some others are published as PDF documents; certain documents are only available for download indirectly and are thus not readily accessible (e.g. data item lists for the SDAC are available in the 'downloads' section of the main publication); to access corresponding data item lists in the case of the SET, one must access 'related information', follow a link to a technical manual publication, and then go to 'downloads'); relevant information is missing (e.g. SMHWP is not listed among disability surveys); non-uniform structure of documents and hyperlinks between products and publications; in-text references to chapter numbers without having the numbers designated in the contents list or in-text headers; relevant downloadable files scattered across various sub-pages; non-uniform documentation for different editions of a survey and publishing two versions of a document without a clear indication of the more recent one (e.g. NATSISS data items lists).

While the above problems do not constitute a major obstacle in accessing the ABS materials, an updated layout and organisation of the existing and future contents would greatly increase the useability of the website as a major source of disability-themed information.

*SEIFA/I inspired disability index for areas and individuals*

SEIFA and SEIFI provide examples of an excellent use of statistical data to identify areas of priority, streamline resource allocation, and guide policy. A similar index of disability could reveal unmet needs and environmental/infrastructural deficiencies, as well as distinguish their perceived levels between the sexes. The information could be provided at the levels of statistical district and individual, corresponding to SEIFA and SEIFI respectively, or perhaps more adequately, at the level of household.

Such an index could be added to the SEIFA/I collections or built independently. The former possibility is currently obstructed by the poor disability content of the Census, which would first require a considerable expansion of the section on disability and caring. A new index could be based on the rich information conveyed by the DS NMDS or another large registry possibly derived from administrative databases such as Centrelink's. The sample size and the degree of representativeness of the disabled population would be the main challenges in pursuing this option. This cross-linking between currently disparate administrative data-sets could be useful in evidence building for the NDIS.

The inclusion of disability-related advantage/disadvantage indicators in small area holistic measures would be a major step toward an improved understanding of women with disabilities in the ACT, their wellbeing and sources of day-to-day struggle. An enhanced index would be instrumental in directing resources towards areas of highest need or priority, thus increasing the marginal benefit of each dollar spent on addressing disability with considerable impacts on disabled persons' lives.

*Recommendations 5.5*

15. Work through ABS Advisory Groups to ask for increased clarity of information of the ABS website's disability section, and for upgrading its status to a comprehensive portal on disability.
16. Enrich the Socio-Economic Indexes for Areas/Individuals with information on disability. Alternatively create an equivalent index for disability that allows for further analysis of gender.

**Table 2: Summary of recommendations**

Problem area	Relevant to	No.	Recommendation
Sources of information on women with disabilities	WWDACT, the DAC, the general public	1.	All stakeholders using data sets identified in this study to research information on women with disabilities should familiarise themselves with the underlying survey structure for guidance on its applicability.
Enhancing the comprehensiveness of intersectionality depiction	WWDACT, the DAC, through their advisory functions  Other participants of the disability sector	2.	Introduce a disability component to surveys dedicated to specific issues, such as has been done with the 2012 Personal Safety Survey, in order to add a new dimension to problem analyses.
		3.	Expand the question on disability in data sets that cover a wide range of social issues but currently offer only limited usefulness for researching women with disabilities (e.g. Census). Extend the scope of disability information to provide a more comprehensive coverage of social and environmental features of disability, in line with state-of-the-art models of disability, e.g. including information on participation requirements rather than diagnostic details.
		4.	Prioritise women with disabilities by explicitly targeting the group in data collection and research projects, as well as making statistical facts and their interpretations accessible to a wider range of stakeholders.
		5.	Consider the use of extended gender definitions in research and data collection that allow for gender identity going beyond the simple twofold male and female identity .
		6.	Ensure study and understanding of carer needs, especially where women with disabilities are carers, by using opportunities to expand the scope of surveyed information.
		7.	Greater effort should be made to increase the level of inclusion of institutionalised persons in surveys, opinion polls, interviews and qualitative studies.
		8.	Ensure decisions being made with respect to women with disabilities account for the possible underrepresentation of institutionalised populations in data and evidence.
		9.	Review the current pricing and conditions of access to data, so that access is not denied to individuals and entities that work in a voluntary capacity to benefit the community.
		10.	Promote openness, transparency and quality in the use of administrative data sets, such as the Disability Services National Minimum Data Set, for the purposes of statistical analysis and research.
Facilitating access to data	WWDACT, the DAC, through their advisory functions	11.	Encourage collaboration between the ACT Government and the ABS to enhance the understanding of information needs and strengthen ACT disability policies.
		12.	Ensure the existence of a strong evidence base despite the small ACT population size. The problem can be minimised by the use of techniques which protect the identity of individuals or make use of qualitative analyses.
Supporting the disability sector stakeholders	The ACT Government in collaboration with the ABS	13.	Identify areas of data priority to ensure key information supporting stakeholders' actions is up-to-date and released in a timely manner.
		14.	Work through ABS Advisory Groups to ask for increased clarity of information of the ABS website's disability section, and for upgrading its status to a comprehensive portal on disability.
Reinforcing ABS contributions	ABS, other stakeholders through ABS Advisory Groups	15.	Enrich the Socio-Economic Indexes for Areas/Individuals with information on disability. Alternatively create an equivalent index for disability that allows for further analysis of gender.
		16.	

## 6. Conclusion

Australia has a long-standing commitment to the prosperity of its population, and a strong agenda for improving the well-being of its disadvantaged groups. This report has suggested improvements in the area of social policy by presenting a scoping study of data sets relevant for women with disabilities in the ACT. Other than identifying sources of information, it has assessed opportunities and shortcomings of the disability data landscape and put forward ways of making the most of its potential. It has also shown that review of primary data collection to enable better extraction of gender and disability interactions is warranted..

Data collection is an essential component of generating evidence to guide decisions and policies. Building an evidence base is found to rely on the three pillars of data literacy: the availability of quality data, its accessibility and dissemination, and the capacity to make meaningful use of it. These three pillars support the capacity to satisfy the Triple Bottom Line Assessment Framework of equity, economic and environmental impacts. Furthermore it ought to be recognised that supporting informed decisions is a cost-effective and unintrusive government strategy to foster sector development.

A number of idiosyncratic issues relevant to the area have arisen in the discussion. These include defining characteristics of women with disabilities; their status as a disadvantaged group; the exclusion or underrepresentation of the institutionalised and people with psychosocial disability, and the particular situation of the ACT population size in terms of suitability for statistical analyses. All the above have been put in the context of data, which is instrumental for assessing and addressing needs of women with disabilities. The needs should be seen in both absolute terms and relative to a highly relevant comparator group of men with disabilities. Carrying out principles of equity, i.e. narrowing gender gaps with the end goal of closing them, may require special measures as recommended by the CEDAW Committee and the CRPD Committee. The use of special measures is politically controversial, however, and thus highly reliant on sound evidence. The flip side of the argument is that a lack of data will result in deficient evidence, which will in turn perpetuate if not exacerbate gender-based inequalities. In addition, any special measures must be undertaken as research in which women with disabilities are partners rather than subjects of the investigation.

That being said, this report is by no means intended to suggest a diminished commitment to other disadvantaged groups. Instead, it observes the need to understand challenges of particular groups and calls for tailored policies. Indeed, following the report's recommendations would expand the information capacity across-the-board, clarifying the situation of all disadvantaged groups and enable information stakeholders to make better service decisions for their beneficiaries. Stakeholders who could take advantage of more accurate data include the Federal Government, States and Territories, agencies such as the NDIS, NGOs, support groups, volunteering individuals, and socially-aware businesses. This would result in improving the quality of policy debate and policy-making; better planning and development of services and infrastructure; ensuring funding more accurately targets areas of need, and an overall improved allocation of resources within the public and private sectors.

The recent WWDACT Canberra Hypothetical brought together various groups of stakeholders with an interest in advancing the status of women with disabilities, to discuss what broad consensus is

needed in order to address underlying causes of disadvantage.<sup>74</sup> The meeting reflected the fact that governments, policy-makers, academics, NGOs, volunteers, and women with disabilities themselves, are equal partners in the ongoing debate. A human rights framework has been put forward as a means to bring together the questions of dignity and legal considerations. Putting arguments in the form of statistical evidence represents another possibility: clearly defined, factual, and constructive. This present report is conceived as a contribution toward establishing data and evidence as a platform for understanding and describing the issues of women with disabilities. Observing its recommendations may help to improve the evidence and further enhance capacity of data to describe the intersectionality and environmental aspects of disability.

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<sup>74</sup> 'The Canberra Hypothetical: A conversation on Gender and Disability' was held on the 20th of November 2013, from 2pm to 4pm, at the Conference Room, Level 4, National Library of Australia. The meeting's aim was to bring together academic, government and community experts and to find a common ground on which to talk about the impact of the intersection of disability and gender.

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