Harmonisation and Standardisation of Disability Data and Statistics in South Africa

Final Report

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Submitted by

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Abstract

This report provides an overview of how disability data is collected in South Africa, compares it to international standards, and suggests a framework for harmonising administrative and survey data in a way that will enable different data sources to be used in conjunction with one another and allow for greater clarity in understanding the disability-related findings of various data sources. It is the product of a joint project by Statistics South Africa, the South African Department for Women, Youth and Persons with Disabilities, and the World Bank. It sets forth a series of practical recommendations that can move the system towards greater harmonisation.

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<td>Department of Public Service Administration</td>
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<td>DWS</td>
<td>Department of Water and Sanitation</td>
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<td>DWYPD</td>
<td>Department of Women, Youth, and Persons with Disabilities</td>
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<td>GDDS</td>
<td>General Data Dissemination System</td>
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1. Introduction

Statistics South Africa (Stats SA) in partnership with the South African Department for Women, Youth and Persons with Disabilities (DWYPD) and supported by the World Bank (WB) initiated a research project aimed at harmonizing disability definitions and classifications across different data sources for better production and use of disability data and statistics in the country.

The project addressed challenges in the harmonization of disability survey and census data with administration data within government departments.

Initiatives such as the 2001, International Seminar on the Measurement of Disability held in New York were crucial in the process of managing a credible component of the value chain related to disability statistics. Participants agreed that there was a need for common definitions, concepts, standards and methodologies in the production of statistics about persons with disabilities. The need for accurate and internationally comparable data on disability and standard indicators on disability/population-based measures of disability for country use and for international comparisons was also agreed upon.¹

Because of this meeting, the Washington Group on Disability Statistics (WG) was formed as a United Nations Statistical Commission City Group to promote and coordinate international cooperation in the area of statistics focusing on censuses and national surveys. The main objective is to provide basic necessary information on disability that is comparable throughout the world.

Efforts to mainstream disability in statistical systems were supported by the need to:

1. Review methodologies and instruments used to measure disability;
2. Explore the use of the International Classification of Functioning, Disability and Health (ICF) as the conceptual framework for collecting and classifying data on disability;
3. Provide guidance on planning for the collection and utilization of policy relevant data on persons with disabilities.
4. Address the growing need for harmonization of data collection tools across different sectors of government and society.

The World Bank appointed an international consultant to lead the study with the support of a local expert to execute the research deliverables. The results of the Stats SA research reported here contribute to the harmonization process within and among South African government departments at all tiers, all with different approaches and needs for disability statistics, referencing the Washington Group Set of questions.

¹ Source: [http://www.washingtongroup-disability.com/about/history/](http://www.washingtongroup-disability.com/about/history/)
2. **Background**

2.1. **International Policy Instruments**

The strengthening of the implementation of policies impacting on disability (2009–2013) was enhanced with the ratification, by South Africa, of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol without reservation in 2007. This ratification meant that South Africa was/is still obliged to implement CRPD **Article 31 on Statistics and data collection**, which states that:

1. *States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention. The process of collecting and maintaining this information shall:*  
   a. Comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities  
   b. Comply with internationally accepted norms to protect human rights and fundamental freedoms and ethical principles in the collection and use of statistics.

2. The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties’ obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.

3. *States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.*

The 2030 Agenda for Sustainable Development Goals (SDGs) and its 17 SDGs provide a powerful framework to guide local communities, countries and the international community toward the achievement of disability-inclusive development. The 2030 Agenda pledges to leave no one behind, including persons with disabilities and other marginalized groups, and has recognized disability as a cross-cutting issue, to be considered in the implementation of all of its goals. While all SDGs are relevant to persons with disabilities, the Agenda includes seven targets and 11 indicators explicitly making reference to persons with disabilities, covering access to education and employment, availability of schools sensitive to students with disabilities, inclusion and empowerment of persons with disabilities, accessible transport, accessible public and green spaces, and building capacity of countries to **disaggregate data by disability**.

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2 United Nations Convention on the Rights of Persons with Disabilities (CRPD), Article 31 on Statistics and data collection  
The Protocol to the African Charter on Human and Peoples Rights on the Rights of Persons with disabilities (popularly known as the African Disability Protocol or ADP) adopted on 29th January 2018 has Article 32 on Statistics, Data and Other Surveys. This article states that:

1. **States Parties shall ensure the systematic collection, analysis, storage and dissemination of national statistics and data covering disability to facilitate the protection and promotion of the rights of persons with disabilities. Towards this end,**

2. **States Parties shall:**
   a. Disaggregate statistics and data, as appropriate, on the basis of disability, gender, age and other relevant variables, including by ensuring that national population census and other survey captures data on disability
   b. Disseminate statistics and data in forms accessible to all persons including persons with disabilities
   c. Ensure that the collection, analysis, storage and dissemination of statistics and data on persons with disabilities comply with acceptable ethical, confidentiality and privacy standards.
   d. Ensure effective involvement and participation of Persons with Disabilities in the design, collection and dissemination of data.⁴

The ADP’s Article 32 is supported by the Model Disability Law (MDL) adopted by the Pan Africa Parliament (PAP) on 19 October 2019. **Article 36: Statistics, Data and Other Surveys** states that:

1. **The State shall ensure that continuous data gathering on the causes and prevalence of disabilities, the types of disabilities, disaggregated regarding gender and age, participation of women, children, youth and with disabilities in education, health care, labour market, vocational skills training are available.**

2. **The collection, analysis and processing of statistical data relating to disability shall be in accordance with the Pan-African Parliament’s Methodology, which can be adapted to the country specificities.**

3. **The State shall:**
   a. Establish inter-ministerial epidemiological surveillance system on disabilities to gather evidence for consideration by National Disability Councils, policy bodies and relevant Government Ministries
   b. Provide indicators on disabilities in national census questionnaires and other national surveys
   c. Stimulate research and conduct surveys to collate disability data from health, education, and tertiary and labour statistics regularly and publish regular reports on the situation of disability and persons with disabilities in the country.

⁴ AU Protocol to the African Charter on Human and Peoples Rights on the Rights of Persons with disabilities, 2018
In South Africa, the national strategies are linked to efforts at continental level. African countries are dealing with a myriad of challenges and problems across all sectors of society. The growing population is not matched by a corresponding or significant growth in political, social and economic sectors.

In many African countries human rights and development are compromised and compounded by factors such as corruption, poor management, global environments that are not controlled by Africa and the effects of climate change. In the field of the development of statistics, key historical and contemporary challenges exist and can be summarized as:

1. A decline in the quality and quantity of African Statistics towards the end of the 1970s and throughout the 1980s
2. Economic, political, social, human rights crises that had led to cuts in public expenditures, diminished growth and under-development
3. Low priority attached to quantitative information in development planning
4. Low status of statistical services vis a vis many other government/public services
5. Poor management of statistical services and
6. Competition between external and internal demands for statistical data.

Other continental initiatives were developed to address old and new challenges which include:

a. Low societal awareness of the role of statistical information accompanied by poor definitions/assignment of funded stakeholder roles;
b. Capacity of most countries in the region remains weak, and there is little use of data by policy-makers. This contributed to the need for the formation of the Reference Regional Strategic Framework (RRSF) which sets out a coherent framework to build this capacity.
c. Lack of coordination, monitoring/evaluation strategies
d. No harmonization of statistical systems and data sets across Africa
e. National statistical systems are faced with a shortage of funds thus contributing to poor performance and low-quality statistics, which in turn create a negative view/further lack of support/funding for statistical operations and development. For instance, as at 2006, about $73 million a year in additional external assistance was needed to implement the Reference Regional Strategic Framework (RRSF) throughout Africa, about $60 million of which was required by low-income countries.\(^5\)

These challenges were viewed in a serious light, causing the African Union to adopt the Addis Ababa Plan of Action for Statistical Development in Africa (AAPA) in the 1990s. However, a review of AAPA noted slow levels of implementation, low stakeholder participation at all levels, lack of means to respond to new results-based demands for information, no strategies at national, sub-regional and regional levels for enhancing statistical capacity, no strategy to

\(^5\) ECA, Reference Regional Strategic Framework (RRSF), 2006
address the plight of countries emerging from war and other crises, and inadequate or no mechanisms of continuous monitoring and evaluation.

Other continental initiatives in which South Africa played a crucial role include:

b. The General Data Dissemination System (GDDS)
c. The National Strategy for the Development of Statistics (NSDS)
d. The African Symposium on Statistical Development (ASSD)
e. The establishment of the African Statistical Coordination Committee (ASCC)
f. The Strategy for the Harmonization of Statistics in Africa (SHaSA)

These policy instruments present opportunities and indicate interest in mainstreaming disability statistics in Africa’s statistical systems. However, there are challenges. The global, regional and local reporting demands necessitates improved disability measures related to data demands, but also the creation of opportunities for national, regional and international statistical cooperation. The sheer magnitude of the task within the context of limited resources means that existing data, regardless of whether it is sourced from administrative or survey data, has to be used to the fullest.

2.2. South African Policy Interventions

In 1994, the new democratic government inherited a society that understood disability to be a personal tragedy that required a health and welfare response to “fix” the person and the situation. The ongoing difficulty and debate in measuring disability is reflected in the changing methodologies adopted over the past 20 years. At the centre of the debate lies the need for disabled people to be recognised as a distinct group of people with rights and responsibilities like any other citizen of a country, while they continue to experience high levels of exclusion and discrimination. Debates are centred on, among other areas, definitions, measures and categories.

National statistics are an instrument for assessing progress or otherwise towards achieving set goals and targets. There is a recognition that South Africa belongs to the community of nations which requires adherence to global and international practice. The Constitution of South Africa imposes a major responsibility on measurement and national statistics to inform planning and measurement of progress in an impartial manner. In South Africa, policy development work is in line with the provisions of the Bill of Rights in the Constitution of the Republic of South Africa, Act 108 of 1996 and the National Development Plan (NDP) 2030.

The right to equality guaranteed in the 1996 Constitution includes social and political equality at all levels. This means, in part, that persons with disabilities should enjoy equal access to fundamental rights, even if the exercise of these rights involves removing barriers

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7 Stats SA Background Document, 2019
and creating enabling mechanism. Disability rights policies were included in government legislation (2001–2008) within the context of the revision and redesign of the country’s policies. The development of several white papers served to inform legislation reform as South Africa moved into the new millennium.

South Africa has a 5-year Strategic Plan 2019-2024 with a new direction for Stats SA in order to increase the supply and use of official statistics by enabling the state to conduct its business in a transparent and accountable manner and enabling the state to make results-based decisions to drive transformation.

The strategy acknowledges existing holdings of organisational strengths as strategic assets and takes deliberate advantages of opportunities presented to enhance production efficiency. It outlines strategic outcomes for the next five years to drive the establishment of a sound national statistical system in response to the statistical demands emanating from, among others, the National Development Plan (NDP) and the Medium-Term Strategic Framework (MTSF).  

**The period 2001 to 2020 entrenched disability rights in government legislation.** Within the context of the revision and redesign of the country’s policies, the development of several white papers served to inform legislation reform as South Africa moved into the new millennium. This phase also put focus on the development of strategies and programmes to guide the implementation of legislation that had already been promulgated.

As the understanding of disability at the policy level moved beyond a health and welfare construct, this new approach had to be conceptualised in the process of addressing the residual effects of apartheid within the health, social development, education, transport, communication and employment sectors, which are the core areas of service delivery for persons with disabilities.

To ensure that these historical/contemporary policy values are entrenched in all sector-wide policies, legislation and strategies such as the National Development Plan (NDP), the South African government adopted the White Paper on the Rights of Persons with Disabilities (WPRPD), 2015. The WPRPD reiterates that the primary responsibility for disability equity lies with national, provincial and local government; and other sectors of society but also allocates responsibilities to persons with disabilities and their families. The vision of the WPRPD is the creation of free and just society inclusive of all persons with disabilities as equal citizens. The WPRPD commits duty bearers to realising the rights of persons with disabilities by (among other measures):


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8 Stats SA Strategic plan 2015/2016 – 2019/2020
ADP), with South Africa’s legislation, policy frameworks and the National Development Plan (2030)

3. Endorsing a mainstreaming trajectory for realising the rights of persons with disabilities
4. Providing clarity on and guides the development of standard operating procedures for mainstreaming disability
5. Guiding the review of all existing, and the development of new, sectoral policies, programmes, budgets and reporting systems to bring these in line with both Constitutional and international treaty obligations
6. Stipulating norms and standards for the removal of discriminatory barriers that perpetuate the exclusion and segregation of persons with disabilities
7. Broadly outlining the responsibilities and accountabilities of the various stakeholders involved in providing barrier-free, appropriate, effective, efficient and coordinated service delivery to persons with disabilities, and

With a rights-based approach, effective action for development moves from the optional realm of charity into the mandatory realm of law, with identifiable rights, obligations, rights-holders and duty-bearers.

Pillars seven and nine of the WPRPD specifically focusses on building a disability equitable state machinery.¹¹ These two pillars include strong references to the importance of evidence-based policy and program development as well as the establishment of monitoring and evaluation systems that can measure progress with regards to the implementation of the directives of the WPRPD and its associated programs.¹² In relation to pillar nine of the WPRPD, there are several directives that fully or indirectly pertain to the mandate of Statistics South Africa. The most important within the context of this research work is:

a. Standardisation of disability data and statistics;
b. Strengthening reporting systems to include disability related reports;
c. Disaggregating disability data to reflect gender and age statistics.

All these national imperatives fit together with the current international policy agenda through the Sustainable Development Goals (SDGs) and Africa Agenda 2063 (AA 2063) which are also aimed at leaving no one behind and calls for the general improvement of the statistical measurement of disability related aspects.

Countries are required to develop a National Strategy for Development of Statistics (NSDS) as an instrument used to strengthen and develop the national statistical system (e.g. Strategic Plan 2019-2024). Statistics South Africa (Stats SA), as the national statistical body, was, among other strategies, mandated to establish a Disability Statistics Advisory Group on disability to guide the research, development, testing, validity and analysis of disability question(s) and responses to provide acceptable disability data for inclusion in the national census, household, labour and other socio-economic surveys. Membership of the Advisory Group was to include, among others, national government departments, the South African

¹¹ ibid
¹² Ibid
Local Government, disability organisations, research institutions and institutions of higher education.

3. **Problem statement**

Accomplishing such harmonization faces a variety of challenges. These include:

a. Disability is a complex and multidimensional issue that poses a number of challenges for data collection and measurement.

b. The lack of a uniform definition to be used by different organs of state when gathering disability data whether through surveys, censuses or at service points result in statistics from these data sources not being consistent.

c. Data collection on disability prevalence through national surveys does not provide an accurate reflection of actual incidence, mainly due to the fact that these surveys are often done through proxy responses, where one family member responds on behalf of the entire family;

d. Limitations in the number and type of questions which can be asked;

e. Difficulties posed by language barriers and other traditional beliefs associated with disability.

f. Definitions of disability that is aligned with the mandate of government departments that can make data more relevant to budgeting, planning, implementation and performance tracking.

4. **Objectives**

The research study aims to find strategies for:

a. Standardisation of disability administrative/survey data and statistics; and

b. Strengthening reporting systems to include disability inclusive reports.

5. **Defining Disability**

To disaggregate coverage and outcome indicators by disability status it is necessary to identify people with disabilities in the surveys used to generate those indicators. Past methods of doing so have often been found to be inadequate and to generate confusing and inconsistent results.\(^3\) Before addressing the methodology for identifying disability status through quantitative instruments, it is worthwhile to review the conception of disability in the CPRD, which South Africa has ratified.

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According to Article 1 of the CRPD:

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.¹⁴

This approach is based on the social model of disability, which maintains that disability is not lodged solely within the person, but emerges from the interaction of functional limitations linked to impairments with barriers in the environment, as shown in Figure 1.

**Figure 1: Social Model of Disability**

People bring to the world a set of characteristics. These include gender, age, and ethnicity, but impairments, such as paralyzed legs. This alone does not make them disabled. What disables them is the lack of supports or the presence of barriers that impede their ability to participate in society, such as go to school, go to work, participate in civic events, start a family, etc.¹⁵

Identifying disability by impairments or medical conditions is not consistent with the social model. While they are a contributing factor to disability, they do not determine disability. Two people with the same impairment may have very different experiences. First, an impairment can affect their functioning differently. Someone with cerebral palsy may have a lot of difficulty doing things like speaking and walking or may have minimal difficulty. More important, their ability to function in the world will be very different depending on their environment. If they have access to assistive devices and rehabilitation, accessible transportation and infrastructure, and

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¹⁴ UN Convention on the Rights of Persons with Disabilities, Article 1
a lack of stigma, for example, their right to be full participants in society may be fully realized. If not, they may face significant exclusion.

The challenge for developing a statistical framework that encapsulates this model is that it is complex and involves a variety of interactions. It is not possible to have a single question on a survey or administrative form that can accurately identify people as having a disability. To confront this challenge, the UN Statistical Commission convened the Washington Group on Disability Statistics (WG). UN Statistical Commission city groups (named after the first city in which the meet) comprise representatives from the national statistical offices of UN member states. Over the course of its lifetime, dozens of national statistical offices – including Stats South Africa – have taken part in the development, testing, and implementation of statistical tools designed to identify people with disabilities.

The WG began its deliberations using the WHO’s International Classification of Functioning (ICF) as the basis of developing its questions. The ICF is represented below in Figure 2. According to the ICF there are three levels of functioning: body function and structures, activities, and participation. A body function is something like being able to move one’s legs. An activity requires the combination of body functions to perform a task, like walking. To walk you must use your legs, your cardiovascular system, your sense of balance, etc. Participation is fulfilling a social role, like going to work. To work, you must combine a bunch of activities like walking, seeing, remembering, communicating, etc. Health conditions, like impairments, can affect these levels of functioning, but the relation between them – for example, personal resources, barriers, and facilitators in the general environment impact how an activity limitation like not being able to walk affects the ability to work.

**Figure 2: International Classification of Functioning, Disability and Health**

Once again, capturing these relationships with quantitative data is complex. Therefore, the WG decided to choose that portion of the model that most related to the reason behind disability
data collection in censuses and surveys. The decision was to focus on activity limitations, i.e. people with activity limitations who are at risk of not being able to participate in an environment because of barriers. By disaggregating data by disability defined in this manner, it is possible to see the extent to which barriers may be restricting participation. If people with disabilities are half as likely to be working (controlling for other factors, like age and gender) then people without disabilities, that is evidence that there are barriers in the environment restricting work.

Focusing on activities has other advantages.

a. People with the same impairments often face very different activity limitations. For example, two people may be autism, but their ability to function in the world can be very different.
b. While there are many, many impairments and diseases, the number of core activities is smaller.
c. People – especially poor people with little access to health care – may not know their diagnoses, but are very aware of their activity limitations
d. Forms and expectations of participation vary a lot by country, culture, and other characteristics and so it is hard to create questions that are internationally comparable – or even comparable across some sub-populations. Basic activities are more universal

Conceptually those with activity limitations are the people of most concern to policymakers wanting to remove barriers to participation and to fulfil the goals of the CRPD. They are the people at risk of facing barriers to participation. According to the ICF, there are eight main categories of activities.

a. General tasks and demands
b. Communication
c. Mobility
d. Self-care
e. Domestic Life
f. Interpersonal interactions and relationships
g. Major life areas
h. Community, Social and Civic Life

Within each of the areas, the ICF lists many specific codes. Once again, even focusing on just activities would yield a definition that is too extensive and hard to conceptualize for quantitative identification of people with disabilities. This was especially true for the WG whose first task was to come up with a set of questions for identifying people with disabilities in censuses.

Therefore, the WG developed a short set of six questions that can be used to identify the majority of people with disabilities in an internationally comparable manner. As stated above, the WG comprises representatives from a large number of national statistical offices of UN member states, with adjunct members from international development agencies and civil society.\textsuperscript{16} A growing consensus has emerged across producers and users of disability data of

\textsuperscript{16} For a full description of the WG and its work, see their website at washingtongroup-disability.com
the WG short set being the preferred methodology for such disaggregation.\textsuperscript{17} The WG Short set can be found below in Box 1.

The advantages of the WG questions are that:

1) They identify the large majority of people with disabilities in an internationally comparable manner
2) Being only six questions, they can be added to existing data instruments at low cost, and then used to disaggregate all indicators generated by that survey
3) Being functional measures, they can easily fit into an analysis framework consistent with the social model of disability\textsuperscript{18}

\begin{center}
\textbf{Box 1 -- WG Short Set Questions}
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1. Do you have difficulty seeing, even if wearing glasses?
2. Do you have difficulty hearing, even if using a hearing aid?
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty (with self-care such as) washing all over or dressing?
6. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?

Response categories: No – no difficulty, Yes – some difficulty, Yes – a lot of difficulty, Cannot do at all

A person is identified as having a disability if he or she answers Yes- a lot of difficulty or Cannot do at all to at least one question. For more information see: washingtongroup-disability.com

However, there are limitations to the WG short set (WGSS). First, they do not adequately identify children with developmental disabilities.\textsuperscript{19} Second, they do not capture a significant percentage of people with psychosocial disabilities. To address these problems, the WG

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\textsuperscript{18} See this blog for a explanation of how the WG questions are designed for use in an analytical framework based on the social model: http://www.washingtongroup-disability.com/washington-group-blog/washington-group-questions-consistent-social-model-disability/
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worked with UNICEF to create a Child Functioning Module (CFM)\textsuperscript{20}, and also developed the Washington Group Extended Set (WGES) of questions that includes questions on anxiety and depression that are shown in Box 2\textsuperscript{21}. The CFM is being used on the latest round of the Multiple Indicator Cluster Survey (MICS) which is UNICEF’s quantitative instrument for assessing the well-being of children.

The WGES extends the WGSS in two ways. First, it adds functional domains by asking questions on anxiety, depression, pain, fatigue, and upper body mobility. Secondly, it adds additional questions to the functional domains in the WGSS. For example, instead of just asking about difficulty walking, it asks about walking shorter and longer distances.

The CFM also adds domains and more detailed questions within domains. Some of these are specific to children, such as playing, behavior and staying on task. In addition, the wording is a bit different because parents are being asked about children. For example, they are asked to provide levels of difficulty compared to children of the same age. In addition, there is a module for 2-4 year-olds and a different one for 5-17 year-olds because the expectations of what children can do varies with age. For example, it does not make sense to ask a 2 year old about self-care.

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**Box 2** WG Extended Set questions on anxiety and depression

How often [do/does] [you/he/she] feel worried, nervous or anxious? Would you say…?

a. Every day  
b. A few times a week  
c. A few times a month  
d. A few times a year  
e. Never

Thinking about the last time [you/he/she] felt worried, nervous or anxious, how would [you/he/she] describe the level of these feelings? Would [you/he/she] say…?

a. A little  
b. Somewhere in between a little and a lot  
c. A lot

How often [do/does] [you/he/she] feel depressed? Would [you/he/she] say…?

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\textsuperscript{20} For full question set, see https://data.unicef.org/resources/module-child-functioning/

\textsuperscript{21} For question set, see http://www.washingtongroup-disability.com/washington-group-question-sets/extended-set-of-disability-questions/
Thinking about the last time [you/he/she] felt depressed, how depressed did [you/he/she] feel? Would you say… [Read response categories]

a. A little
b. Somewhere in between a little and a lot
c. A lot

A person is considered to have a disability if they feel a lot of anxiety or depression on a daily basis. For more information, see washingtongroup-disability.com

Adding the CFM and the anxiety and depression questions from the WGES to household surveys could make up for the limitations of the WG Short Set, but due to the added length of those questions, national statistics offices are generally resistant to do so. They definitely are too long to be added to censuses, where space is very expensive.

This framework for identifying people with disabilities was designed for quantitative data collected through statistical tools like surveys and censuses. But focusing on people who have difficulties doing activities, it identifies people at risk of not participating. The focus in on an activity like “walking,” not on the impairments that might affect a person’s ability to walk, such as a stroke, an amputation, intense vertigo, spinal injury, etc. While impairment information is important for health professionals in designing medical treatments, it is not important for identifying people whose participation may be affected by barriers in the environment. A ramp and an elevator, for example, helps all of these people.

The framework, though, applies equally to administrative data, another potential source of information about the environment. Administrative data are data routinely collected on an ongoing basis as part of operating and managing a government program. As such, they contain information considered necessary for running and monitoring government programs, and thus reflect the requirements and characteristics of those programs. These programs may be disability specific, such as a disability pension system, but they can also be general programs not primarily related to disability but collecting information relevant to disability issues, such as education management information systems (EMIS) or Health Management Information Systems (HMIS).

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22 This discussion on administrative data is drawn from Mont, D. “The Use of Administrative Data in Disability Inclusive Policies,” Working Paper 32., University College London
For some of these data systems, other information may be important that goes beyond activity limitations. For example, a health system definitely wants to record information about impairments because that is important for treatment purposes. But if all statistical and administrative data systems have a similar core of activity limitation data, then the different data sets can be used and understood together, as explained further below.

There are several advantages to administrative data compared to statistical data, namely:

1. **Sustainable.** Budgeting for administrative data is generally part of program delivery. As long as a program exists, data will be available. In addition, administrative data is usually cheaper to collect than surveys because it is included in program administration.

2. **Timely.** Administrative data is usually collected on an ongoing basis, so unlike surveys (and especially censuses) there are generally no time gaps in data collection. However, it should be noted that because data often needs to be processed there can be lags as to when that data is available.

3. **Universal for program recipients.** There are no issues related to sampling or sample sizes because all people being served by a program are necessarily included in the data.

4. **Less response error on programmatic data.** For example, administrative data on service delivery is probably more likely to record exactly the amount and nature of benefits received – and when they were received – than a person responding to a questionnaire.

5. **Ministry owned.** Agencies are sometimes more willing to accept and act upon data that they are collecting themselves and that they are familiar with, as opposed to a survey conducted elsewhere, especially if it is not conducted by the government but by independent researchers.

However, relative to surveys they also have several disadvantages. These include:

1. **Definition of disability is often program based.** There is a difference between a person being eligible for disability benefits and being considered to have a disability when it comes to the Convention on the Rights of Persons with Disabilities. For example, eligibility for a disability benefits may be means-tested, targeted only to a working-age population, or only meant for people with severe disabilities.

2. **Less detail on non-programmatic data.** Because of the burden on administrative staff, administrative systems tend to only collect data that is of direct use in program administration. Therefore, less information is collected on personal and household characteristics and factors outside the program.

3. **No data on people not receiving services.** To enter an administrative data base, a person must be receiving services (or at least has applied for services). Thus, people’s experiences that are not in a program are unavailable.

4. **Not representative.** A result of point (3) is that since people are systematically excluded from administrative data, the data are not representative of the entire population.

Sometimes there are ways to lessen the problem of the lack of data on people not in a program by linking administrative data sets. For example, in Armenia, children who are identified as having a disability for the purposes of disability benefits are automatically entered into the EMIS (Armenian Ministry of Education, 2019). Thus, the EMIS has records of children who are out of
school, where they live, their type of disability and other information. However, this does not completely solve the problem because there are no data on children with disabilities who are neither in school nor in the disability benefit system. Also, for the purposes of disability, if different systems have a different definition of what constitutes a disability, it may not be possible to link data on people with disabilities across systems.

Of course, when using any type of data, the quality must be assessed. Are the data concepts clearly defined? Are they directly relevant to the purpose for which they will be used? However, with administrative data two further issues arise. First, if particular data fields are not used routinely in the administration of a program there may be little incentive for that data to be collected accurately, even at all, and even if collected the data may not be processed or cleaned. Thus, while it might appear that such data exists when looking at administrative forms, in actuality it may not be usable.

Second, unlike some characteristics, like birth date, it is necessary to update information on disability, as functioning is not a static state. This adds to the reporting burden and will probably not be re-collected it does not have direct relevance to program administration. Thus, collecting data on disability status in an administrative data system for a program that does not directly deal with disability may yield out of date information. wider and more detailed indicators.

The purpose of this project is to see how links can be made in methodologies to harmonize the data to an extent where data from different sources can be used jointly to combine their strengths.

6. Methodology

The methodology of this report consisted of four components.

1. A desk review of Stats South Africa material, regional policy interventions, and South African interventions
2. A series of meetings with central departments and provincial governments, and subsequent review of documents and survey responses provided by participants
3. Workshops with stakeholders
4. An analysis of Washington Group responses to disability certifications by SASSA.

Regarding this final component, the test on the use of social/functioning methods against the medical/functional limitation methods currently being used by the South African Social Security Agency (SASSA) was conducted. That test would entail conducting an experiment to determine the extent to which people applying for disability benefits would be identified by the Washington Group Extended Set of questions as having a disability, and if the concordance with the SASSA disability determination procedure varies by type of disability or other personal characteristics. The idea was that a better understanding of the relation between those deemed eligible for benefits by SASSA and those identified as having a disability by the Washington Group questions can help in the administration of SASSA programs.
Due to challenges emanated by Covid-19 pandemic, the extent of the testing had to be scaled down. In the end, phone interviews were conducted with people certified as having a disability by SASSA over the previous six months, asking them the full Washington Group Extended Set of questions. This provided information on how many of those newly certified as having a disability by SASSA would have been identified by various disability measures based on the WG questions. Prior to the test, a training for interviewers was conducted on 17 November 2020 to ensure better understanding of the questionnaire content and data collection methodology.

7. Limitations

1. Due to Covid-19 pandemic, final mission and workshop were not able to take place. Some meetings, however, could be set up virtually.
2. In the design of the test with SASSA that resulted from restrictions related to Covid19 that led to cutbacks in the design of the study.
3. In relation to examining administrative data on disability determination was that most of the fields collected for that determination process are not maintained in their administrative system once the determination is made.

More generally, due to privacy and time constraints it was not possible to actually examine the administrative data first-hand, but only data forms and information that could be obtained through interviews.

8. Data collection

8.1 Bilateral and stakeholder meetings

The first step after the desk review was to map out how different agencies collected data and for what purposes. To do so, the team conducted two missions in Gauteng with available institutions on October 2019 and March 2020. The consultants and officials from Statistics South Africa (Stats SA) and the Department for Women, Youth and Persons with Disabilities (DWYPD) met with a broad cross section of departments/agencies. The list of agencies participating are included in Table 1.

<table>
<thead>
<tr>
<th>Departments</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Labour and Employment</td>
<td>October 2019</td>
</tr>
<tr>
<td>Higher Education and Training</td>
<td>October 2019</td>
</tr>
<tr>
<td>Public Service and Administration</td>
<td>October 2019</td>
</tr>
<tr>
<td>Social Development</td>
<td>October 2019</td>
</tr>
<tr>
<td>Home Affairs</td>
<td>October 2019</td>
</tr>
<tr>
<td>DPOs</td>
<td>November 2019</td>
</tr>
<tr>
<td>Transport</td>
<td>March 2020</td>
</tr>
<tr>
<td>South African Police Service</td>
<td>March 2020</td>
</tr>
<tr>
<td>Basic Education</td>
<td>March 2020</td>
</tr>
<tr>
<td>Planning, Monitoring and Evaluation</td>
<td>March 2020</td>
</tr>
<tr>
<td>Human Settlements</td>
<td>March 2020</td>
</tr>
</tbody>
</table>
In addition, a questionnaire was distributed to provincial governments. That questionnaire contained in Appendix 1, asked questions similar to those that took place in the face-to-face meetings. The onset of the Covid-19 pandemic precluded further face-to-face meetings at both the national government and provincial government levels.

8.2 Stakeholder workshops

A project initiation and stakeholder consultative meeting with relevant departments on the harmonization and standardization of disability measurement research project was held on 10 October 2019.

A stakeholder consultation workshop was held during the October mission, to explain the purpose and the importance of undertaking this project. Moreover, the workshop was also meant to sensitize all stakeholders who were critical to the success of the project by highlighting the crucial role they were expected to play in ensuring that the project achieves the desired results. Most importantly, this consultation workshop afforded various stakeholders an opportunity to engage robustly among themselves and with the consultants on disability data and statistics challenges they counter as they conduct their day-to-day business. The workshop was attended by representatives from some of the government agencies which were interviewed during the bilateral engagements, and some which were to be interviewed at a later date. Presentations were made describing both African and other international efforts to standardize disability data collection consistent with the Convention on the Rights of Persons with Disabilities.

A second stakeholder meeting with representatives from the disability sector was held on 20-21 November 2019. The purpose of the meeting was to consult and share information on the project and explore how the disability sector is impacted and affected by the collection of disability related data and statistics.

The last stakeholder meeting was convened with provincial governments in August 2020. The provincial government are responsible for coordination of disability programmes and data collection within the provincial sphere of government. Originally, it was planned to have an additional mission, including a final workshop, but that was cancelled because of the COVID-19 pandemic.
8.3 Questionnaires

The questionnaires - Measure of Disability and Disability Monitoring and organised the Consultative & Capacity Development Workshop on Disability Statistics for Disability Sector were analysed. Questionnaires from the South African Human Rights Commission (SAHRC) and organisations of/or persons with disabilities were received/analysed.

Table 2: Analysis of Submitted Questionnaires-Measure of Disability and Disability Monitoring

<table>
<thead>
<tr>
<th>November 2019</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Planning work and study drafts of questionnaire</td>
<td>11th</td>
</tr>
<tr>
<td>South African National Deaf Association</td>
<td>14th</td>
</tr>
<tr>
<td>South African Human Rights Commission and study SAHRC Monitoring Tool for Places for People with Disabilities</td>
<td>15th</td>
</tr>
<tr>
<td>Blind SA</td>
<td>14th</td>
</tr>
<tr>
<td>SA Federation for Mental Health plus Statistical Template</td>
<td>13th</td>
</tr>
<tr>
<td>National Council of and for Persons with Disabilities (NCPD)</td>
<td>22nd</td>
</tr>
</tbody>
</table>
9. Findings

9.1 Department Interview Findings and Specific Recommendations

This section of the report lists the findings from the departmental interviews and recommendations specific to those agencies. The team had intended to interview more institutions, however a number of departments could not be scheduled within the timeframe of the project, especially given the limitations created by Covid-19. A general conclusion and set of recommendations stemming from interviews is included at the end of the report.

9.1.1 Statistical Data versus Disability Determination

South African Social Security Agency (SASSA)

The eligibility for adult disability benefits is based on work ability combined with an asset and income test. The assessment tool is administered by a doctor and is based on his/her judgment and reporting on the level of severity of difficulties in body systems – cardio, respiratory, neurological, GI/metabolic, musculoskeletal, sight, hearing, mental, and other. The doctor doing the assessment provides a medical diagnosis, and records whether there are any activity limitations and what assistive devices the applicant requires. There is no coding system for those limitations; the response is written out. The doctor then reports on whether the limitations are permanent and whether they preclude work in the applicant’s current occupation. If the answers to those two things are “yes” the applicant is certified as having a disability. They then go to SDS for the means-test for final approval. There is an appeals process.

For children the threshold is not “work ability” but whether the child has permanent care needs. The determination includes the same medical based information but unlike with adults there is a list of functional categories, as well (e.g., crawling, standing, walking) that include domains like communication and social behavior.

Unfortunately, none of this information is entered into a dataset. The only information in the dataset related to disability is whether the applicant is certified as having a disability, their medical diagnosis, and whether they were approved. The SASSA dataset also includes workflow information – date of initial contact, date of assessment and name of doctor and health clinic, and date of application determination.

SASSA reports that the diagnosis data is not reliable. Doctors often report N/A to save time, as the diagnosis is not important for certification. They just have to determine that there is some medical reason that the person cannot perform their duties at work. As this is a contributory program, all applicants have a reference job to make such a determination.

SASSA Recommendations: For the purpose of data harmonization, it would be good if the SASSA system were expanded to record types and levels of difficulties in the examined functional domains. That would serve at least two key purposes. First, it would provide the SASSA system information pertinent to the level and type of support needs of their recipients.
Second, by comparing that data to Stats SA’s data it could give insight into how the program is meeting the needs of persons with disabilities in the general population. However, as the data system is very new, SASSA did not seem hopeful that the department would be willing to update it at this time.

9.1.2 Other government department findings and recommendations

The rest of the departments reported on fall into three groups.

1. Those who collect data based on self-identification as being “disabled”
2. Those who collect detailed information on functioning
3. Those who do not collect information on functioning, but who report it would be useful.

The recommendations at the end of this report correspond to these groupings. It is assumed that departments that we were not able to reach in the time we had available would also fall into these three categories and so be given the same recommendations.

9.1.2.1 Group 1: Departments using self-Identification as being “disabled”

- Department of Employment and Labour
- Department of Public Service Administration
- Department of Transportation
- Department of Human Settlement
- Department of Water and Sanitation
- South African Revenue Service

In general, self-identification as being “disabled” greatly undercounts the number of people with a disability. Asking even the WGSS to all people may require too many resources. The general recommendation is that for those people who do identify themselves as “disabled” on the forms mentioned below, then be asked the WGSS so they can be better understood relative to the statistical data collected.

9.1.2.1.1 Department of Employment and Labour (DEL)

The Employment Equity Act aims to eliminate discrimination in the workplace (race, gender, and disability) and support affirmative actions that promote the employment of vulnerable groups. The definition of disability was updated in 2014 to be consistent with the Convention on the Rights of Persons with Disabilities, namely

Persons with disabilities include those who have perceived and or actual physical, psychosocial, intellectual, neurological, and/or sensory impairments, which, as a result of various attitudinal communication, physical and information barriers are hindered in participating fully and effectively in society on an equal basis with others. (WPRPD)

DEL must collect data on employees with disabilities from designated employers, who consist of those firms employing 50 or more employees and passing industry specific turnover
thresholds. All employees, when hired into a designated firm must fill out an EA1 form where they are asked to voluntarily disclose their disability status. They may choose not to disclose. The form simply asks them to check off if they “have a disability.” No documentation is required to prove they have a disability.

The EA1 forms are kept by the employer and not passed on to the DEL. Instead, they aggregate the data into an EA2 form that reports the percentage of their employees who have a disability. The EA1 form can be changed if a person’s disability status changes. While the EA1 form asks the employee to specify the nature of their disability, this information is not included in the EA2 form. There are no response categories included in EA1 on the nature of disability. That is simply an open question. The DEL does not verify the EA2 form unless there is some reason that instigates an audit.

The following two major issues were highlighted by DEL. First, was the degree of underreporting. From studies of survey data, it is known that asking if a person “has a disability” greatly under-identifies persons with disabilities. DEL indicated that the misidentification goes the other way. People might say they have a disability so that firms can come closer to meeting their quota. Experience from both other countries and among the disability community in South Africa suggests this is unlikely. AK Dube said that in his experience working with disabled people organizations he finds that people under-report. Besides, while a firm would benefit from a “false positive,” the individual worker would not, so it was unclear what would be his/her incentive to misreport. The only way to know, however, would be to undertake a study. For example, Stats SA’s Labor Force Survey (LFS) asks the WG questions on disability. If people employed by designated employers were asked if they disclosed their disability status to their employers, then the degree of under-reporting could be estimated.

When asked if including the WG or similar questions on the EA1 form was possible, the DLE said that logistically it would be possible, but they did not see the need because according to their statutes they were not supposed to collect data on the type of disability.

The concern of the consultants was that the question they are using “do you have a disability” is not in line with the definition of disability in the statute.

**DEL Recommendation:** The WG Short Set (WGSS) of questions should be added to the EA1 form. The data would be most useful if all people filling out the form answered them. People could then be considered to have a disability if they either report “having a disability” or they meet the criteria based on the WGSS. If DEL considers this too burdensome, they could at least ask those self-identifying as having a disability to answer the WGSS so that the distribution of type of disability could be compared to the statistical data to see if people with difficulties in certain functional domains are under- or over-represented among employees.

### 9.1.2.1.2 Department of Public Service Administration (DPSA)

The DPSA collects disability data, and similar to DEL and DHET, it is based on people self-disclosing they have a “disability.” Such data is collected on the Z83 form when people apply
for a job, the EA1 form when they are hired, and the Persal data system that manages the human resource data for the department.

In addition, employees participating in all trainings and other institutional mechanism are asked to report their disability status – again, whether they “have a disability.” The type of disability is then recorded if the disability is considered permanent. Another database tracks what assistive technologies and reasonable accommodations are made. Reasonable accommodations are only given with medical certification of the employee’s condition.

DPSA suspects that many people with disabilities do not disclose, especially those with “invisible disabilities.” For example, data from the Government Employee Medical Scheme reports many more people receiving medication for psychosocial conditions than are registered as having psychosocial disabilities in the personnel database. The same with medications for other chronic conditions.

Under-reporting is especially expected on the Z83 form because applicants are afraid that their disability status will be considered to disqualify them for employment – even though the department has a disability quota that they are not meeting.

They suspect under-reporting after a person is hired may result from people in human resources not having a human rights perspective and not being proactive about telling them about the possibility of receiving reasonable accommodations.

It was pointed out by the Stats SA working group that when Stats SA compared their personnel database and reasonable accommodation database they did not match. A number of employees who did not declare they had a disability when hired, later went to the disability Desk to declare their disability and get reasonable accommodations. This was not reported to the personnel database. It seems likely the same thing is the case at DPSA and other departments, as well.

DPSA indicated that it would be useful to know – for each position – how many applicants said they had a disability, how many were short-listed, and then how many were hired. The consultants suggested also reporting on how many disclosed a disability after they were hired. DPSA and the consultants believe the current Integrated Financial Management System (IFMS) could be modified to allow for such reporting.

DPSA also thinks that the Leave Management System should also record reasons for leave taking by persons with disabilities. They believe there is a myth that absenteeism is higher for persons with disabilities, and such data would a) dispel that, and b) record accessibility related leave-taking (e.g., a lift being out of service).

DPSA Recommendation: People self-identifying as having a disability during the application process should be asked the WGSS so that the distribution of types of disabilities for those applying compared to the general population can be examined. It will probably be seen as too
intrusive during an application process to ask the WGSS to all applicants, and there will probably be too big of an incentive to hide difficulties, leading to false negatives.

9.1.2.1.3 Department of Transport (DOT):

DOT collects a variety of information, including traffic fatalities and payouts to people who become disabled as a result of an accident. There is also a complaint system that persons with disabilities use to report on transportation barriers they have faced.

Currently people are identified as having a disability either by self-reports in the complaint system or if post-accident they receive disability benefits from the government. The disability focal point at DOT had previously suggested a data collection template for collecting better data on disability but received significant pushback. She said that the national survey that Stats SA conducts about every 10 years includes data on disability that has been very helpful, but it is not harmonized with the data collected by DOT.

*DOT recommendation:* People self-identifying as having a disability during the complaint process should be asked the WGSS so that the distribution of their types of disabilities can be compared to the general population can be examined

9.1.2.1.4 Department of Human Settlements (DHS)

When people register on the waiting list for housing they self-identify as having a disability, provided they have a medical certificate that can be obtained from any doctor. People are asked, “Do you have a disability?” If they answer in the affirmative, they are asked to categorize that disability, according to a list of conditions associated with subsidies. This qualifies them for extra funds to support adaptations to housing based on the expected needs from their type of disability (e.g., doorbell linked to flashing lights for deaf people). Also, people using wheelchairs are allotted an extra 5 square meters for the construction of an accessible bathroom. Because there are no subsidies associated with intellectual or psychosocial disabilities or some other conditions, people with those types of difficulties do not register. Also, as it is usually the head of household registering, it is not clear how many persons with disabilities who are not heads of household are registered as having a disability.

When persons without a disability living in a settlement acquire one, they can apply for subsidies. There is a program, the Informal Settlement Upgrading Program (ISUP), which conducts socio-economic surveys in various areas to discover unmet needs. If they identify persons with a disability who have not gotten a subsidy they are referred to apply for that subsidy. This can occur when the person who registered on the waiting list was not a person with a disability and neglected to mention their disabled relative, or because their disability started after they got their house.

*DHS Recommendation:* The initial registration form should explicitly ascertain if anyone in the household has a disability, not just the person registering. People self-identifying or listing their relative as having a disability during the registration process should be asked the WGSS so
that the distribution of their types of disabilities can be compared to the general population can be examined.

9.1.2.1.5 Department of Water and Sanitation (DWS)

DWS considers people with disabilities as those having a long-term or recurring physical or mental impairment that substantially limits their ability to gain employment or access services. However, the way they identify them – similar to other departments – is by having them list themselves as having a disability on employment and attendance forms, or to self-identify when they make requests for accommodations. However, once they self-identify they fill out a disability disclosure form that incorporates some of the WG questions. As their mandate is not monitoring, they have no simple way of comparing the information they collect with other departments. Nevertheless, at the beginning of the financial year, the Annual Performance Plan is analyzed, and they update the Operational Plan of the Gender and Disability Mainstreaming Directorate. The standards used are from JobAccess Strategy, Gender Strategy, Youth strategy, and White Paper on the rights of persons with disabilities implementation matrix.

DWS Recommendation: The disability disclosure form should contain the full list of WG short set questions, being sure to use the full set of response categories. This form should be distributed to all people who report having a disability on any form, including attendance at meetings, However, not each time they report so. For example, the attendance sheet can ask them to check if they have previously filled out such a form. If not, they can then fill it out. This will allow a comparison of people with disabilities interacting with DWS and the general population via Stats SA data.

9.1.2.1.6 South African Revenue Service (SARS)

Persons with disabilities receive certain tax breaks that they claim on their tax forms. That information is self-reported, and only validated if the person’s taxes are audited, in which case they must have a disability certificate. Any data on the people receiving such tax breaks can thus be compared to data on people certified by SASSA. However, SARS felt it inappropriate to ask WG type questions on a tax form. The bureaucratic barriers to doing so were very high. Therefore, there are no recommendations for SARS.

9.1.2.2. Group 2: Departments using detailed Information on Functioning

The two education departments collect more extensive information on functioning than the WGSS, much closer to the WGES and CFM. The overall recommendation for departments such as these is to map their data to the WGSS, WGES and CFM so cross department comparisons can be made.
9.1.2.2.1 **Department of Higher Education and Training (DHET)**

DHET collects extensive information on students with disabilities. Public universities collect data on students who self-identify as having a disability. They record whether these students have difficulties in the following domains:

- Communication
- Emotional (behavior and psychological)
- Hearing (even with aid)
- Intellectual
- Physical (move, stand, grasp)
- Sight
- Unspecified
- Multiple

As with DEL data, students are asked if they have a disability and then specify the nature of that disability. They must provide medical records confirming their disability, which then qualifies them for reasonable accommodations. When asking for such accommodations the disability rights staff asks probing questions to determine the nature of those accommodations which then might affect the student’s classification.

Some students with disabilities – even those supported by NSFAS (a funding scheme for students at tertiary institutions) – do not self-identify. Moreover, the DHET suspects that many students with disabilities do not self-disclose if they a) would feel stigmatized, b) feel they do not need reasonable accommodations, c) they come from rich families that provide all the assistive technology or personal assistance they need, or d) are unaware that reasonable accommodations would be available to them.

Community colleges must report on the disability status of their students based on the following categories which are based in part on medical diagnoses:

a. Attention deficit disorder with/without hyperactivity
b. Autism spectrum disorder
c. Behavioral/conduct disorder
d. Blindness
e. Cerebral Palsy
f. Deafness
g. Deaf-blindness
h. Epilepsy
i. Hard of hearing
j. Mild to moderate intellectual disability
k. Partial sightedness/ Low vision
l. Physical disability
m. Severely intellectual disabled
n. Specific learning disability
o. Psychiatric disorder
p. Albinism
However, DHET then re-classifies the students based on how these medical conditions align with the functional domains used in the WG questions taking into account the degree of disability. For example, students with hearing difficulties are grouped into three categories - those who are Deaf (no hearing), deaf (little or no hearing but does not use sign language), hearing impaired (little or no hearing but uses verbal communication/lip reading).

Data is used not only for identifying who qualifies for reasonable accommodations, but it is also aggregated to produce reports needed for planning and budgeting. To that end, the consultants raised the issue of the appropriateness of a “multiple disability” category, since it hides the nature of a student’s difficulties and what type of accommodations such a student would need.

According to DHET, compliance with reporting on students’ disability status is not complete. Also, if a student doesn’t declare themselves as having a disability when they enter the school, but then at a later date asks for reasonable accommodations, they will not necessarily end up in the school’s reports on students with disabilities. The reasonable accommodations data base is separate from the data base of incoming students and their declared disability status.

The DHET does not collect data on the environment, for example the accessibility of structures. They feel this data would be very useful, but it would require accessibility audits and the participation of universities. For this reason, they feel it would be difficult. They were advised by the consultants on one option they could pursue is an app-based accessibility rating system that students with disabilities could use on their smart phones. Such apps are being developed.

A strong conclusion was that the DHET needs data at a much more detailed level than DEL needs or Stats SA could be expected to collect through household surveys. However, it would be useful if students could be classified by broader categories and then more detailed information within those categories could be added. That way there could be a mapping between Stats SA data and DHET data.

**DHET Recommendation:** People reporting “multiple disabilities” or those identified based on a medical condition, such as cerebral palsy, autism, or albinism, should also be asked functional questions. If this were done, then all of the people in their database could mapped to the WGSS of questions. DHET reports could then also report data based on those domains so they could be easily compared with statistical data collected by Stats SA. It should be noted that the DEHT data is more detailed so it identifies people with psychosocial or neurological issues that may be missed by the WGSS. Identifying those people will help Stats SA better understand who the WGSS is missing in their data collection.

### 9.1.2.2 Department of Basic Education (DBE)

DBE collects detailed information on learner’s difficulties and support needs. If teachers feel that a child has support needs, she lists the child’s problems and needs on a form that is entered into the EMIS. If the teacher is unsure of how to support the child, she consults with a multi-disciplinary support team. If that is not sufficient then the child is sent to a district hospital for a full assessment.
The functional domains – and degrees of difficulty – on the district assessment form can be mapped directly on to the WG Child Functional Module and so is already in harmonization with such data collected by Stats SA. However, the form used for students not referred to the district hospital for assessment is not. Teachers have discretion in how they describe things and can even simply list diagnoses. The focus on those forms is for support needs, which is the appropriate focus at the school level, but for statistics to monitor the system it would be important to have a standardized set of questions that capture functional limitations as captured by Stats SA and hopefully other administrative data. It would not be difficult to incorporate those questions on the current form.

**DBE Recommendation:** DBE reports based on their assessment forms should include tables showing the breakdown and experience of children based on the functional domains included in the WG’s Child Functioning Module. This will not require the collection of any new data, just reporting it in a way that can be aligned with Stats SA data reports. In addition, that coding should also be included on forms not referred to district hospitals for assessment.

### 9.1.2.3. Group 3: Departments with greater need for functional questions

Some departments expressed a greater need for functional questions, in general, or in specific areas. It is recommended that when they add question on disability they are consistent with the WGES and CFM.

#### 9.1.2.3.1 Disability Welfare Services Programme (DWSP)

DWSP is located within the Department of Social Development (DSD). It serves two functions. The first is overseeing a set of disability programs (residential facilities, protective workshops, funding of NGOs delivering services, care centers for children, and respite centers). The second is advocating and advising for mainstreaming of persons with disability in general DSD programs, many of which are run at the provincial level. DWSP administers a form for registering for residential facilities, the assessment tool for protective workshops, and the forms for their care centers. They also recommended we obtain the provincial forms for general services from a couple provinces, especially from Gauteng Province which is particularly good at data collections.

**DWSP Recommendation:** Given the focus on disability, it is recommended that their forms use the WG extended set of question for adults and the UNICEF/WG Child Functioning Module for Children. These forms can be easily mapped to the disability questions in Stats SA data. This data would be helpful in identifying the demand for different types of supports.

#### 9.1.2.3.2 Department of Home Affairs (DHA)

The DHA does not currently collect any disability data. A discussion ensued about the usefulness of putting disability status on birth certificates. The rate of visible disabilities among infants is quite low, but such data could pick up environmental causes of disabilities occurring at birth. For example, some pesticides or pathogens can cause birth defects and so if a region
was an outlier in newborns with disabilities the government could investigate potential causes. It was noted that there are some big regional differences in disability in South Africa. For example, the rate of blindness is high in Limpopo because of contaminants in the soil, and the North West region has a high rate of deafness, possibly because of bacteria in bathing water. Birth certificates could also track the incidence of albinism, which is a big issue in the country.

Including disability on death certificates could be used to see if survival rates of people with disabilities varied by region, suggesting differences in the availability of health care. Collecting such data from doctors filing death certificates, though, would be difficult.

The DHA noted that everyone in South Africa has a unique identification number that is used in all data sets, so it will be possible to link data across data sets.

DHA recommendation: Disability status should be added to birth certificates. This will not be in harmonization with other disability data but would still be useful in highlighting trends in congenital conditions or regional patterns. In a similar vein, disability status should be added to death certificates.

9.1.2.3.3 South Africa Police Service (SAPS)

The SAPS has two disability focal points, one in their Human Resources department that deals with staff issues and one that focuses on victims and perpetrators.

Crime victims self-identify as having a disability. Upon self-identification they are asked to choose which category of disability applies to them. Data are entered into the Crime Administration System (CAS). The same thing happens when people are imprisoned. For more information on them, however, we need to consult the Department of Corrections.

We discussed the possibility of including the Washington Group (WG) questions on their intake forms, and whether police officers would be willing to collecting that information. One important point with the SAPS is that a major issue they deal with is persons with psychosocial disabilities which is a weakness of the WG short set of questions – only about half of persons with psychosocial disabilities are identified as having a disability, and none of them are explicitly categorized as such. A possible option is adding further questions on mental health.

SAPS Recommendation: Crime victims should be asked the WGSS enhanced set of questions, and afterwards asked if they have any other mental health issue. The enhanced set includes four questions on anxiety and depression that could be used in Stats SA data collection in a special disability module at some point. A good deal international research shows that persons with disabilities have much higher rates of being victims of violence, and it is important to document this in a way that can be compared to national statistics.
9.1.2.3.4  Department of Planning, Monitoring and Evaluation (DPME)

DPME is responsible for the Medium Term Strategic Framework (MTSF) which includes a set of indicators for monitoring outcomes across all department in the GoSA. The specification of these indicators includes guidelines for how the indicators should be produced. As the MTSF is currently being revised, DPME suggested that the disability indicators that it requires departments to report on should be harmonized with the Stats SA data.

Currently disability indicators are not easily compared. For example, one indicator is the number of people receiving personal assistance. Another is the number of people receiving grants in aid. In fact, many persons with disabilities are not receiving grants, not all receiving grants require personal assistance, and not all people requiring personal assistance obtain it. So, while these populations overlap, they are not the same. If administrative data used the same functional questions, then the GoSA could better analyze them in conjunction with one another.

One of the indicators used across departments is how many persons with disabilities attend various meetings. Attendees sign in on an attendance sheet and check off on their gender and whether they have a disability. It was deemed too burdensome every time someone signed an attendance sheet to fill out a short survey on their functional status – and could be seen as intrusive. On the one hand, this will lead to an under-estimate of how many persons with disabilities are attending a meeting. However, if the goal is to have disability issues represented in the meeting, it may be that the more important thing is how many people attending the meeting self-identify as having a disability.

DPME Recommendation: DPME joins Stats SA and DWYPD on the data harmonization working group and supports the agreed upon recommendations that result from this report.

9.1.2.3.5  Department of Health (DoH)

DoH has a centralized Health Information System (HIS) that captures data from district clinics, hospitals, and tertiary services, including teaching, psychiatric, and rehabilitation hospitals as well as TB clinics. The HIS has data on people, clinical information, and services used. They can count how many people have a medical condition, but they do not label people as having a “disability”, per se. They record information on who requires and is issued a wheelchair, as well as hearing aids.

For a while, DoH used an assessment tool based on Washington Group questions but stopped doing so because they felt the data being collected was redundant since it is based on the same type of information already being collected by SASSA in their determination of disability. DoH simply uses that certification for their records. In addition, case files contain a lot of functional information related to the referral to services and assistive devices. This data is updated as patients’ conditions change.
There is also a provincial system, PIDS, that collects data on service interventions, assistive devices, and the number of health care recipients determined to be disabled by SASSA.

DoH noted that often functional questions are more useful to them than knowing particular diagnoses, because their emphasis is on outcomes, not conditions. A person’s outcomes can improve even if their condition (e.g., cerebral palsy) remains the same.

DoH said it would be useful to have a standard operating protocol that health systems could use for assessing disability. All the necessary information is in case files, but it is not standardized, nor is it available in a database. Right now, the data is collected and kept in a way needed for health professionals delivering services.

**DOH Recommendation:** DOH casefiles, using either data from SASSA or from their own functional assessments should clearly label the type of disability according to the functional domains delineated by the WG questions: Vision, Hearing, Mobility, Cognition, Communication, Self-care. Persons with multiple disabilities should have all the domains affected recorded. In doing so, the distribution of their types of disabilities can be compared to the general population can be examined.

### 9.2 Provincial Questionnaires

All provinces except the Western Cape responded to the questionnaire. Only one province, Northern Cape answered ‘yes’ to the question: **Does your institution make use of the Washington Group Set (WG) of Questions?**

The definition of disability is not the same for all of the different provincial offices. Provinces take the definitions that emanate from the different national government departments and the definition of disability in the White Paper on the Rights of Persons with disabilities (WPRPWD) which is aligned to the UNCRPD.

The final report of responses from provinces is available at:


### 9.3 Stakeholder workshops

Stakeholders from Stats SA and other departments convened for a workshop at the Stats SA office. First, government representatives explained the goal of the project and how it was developed. This was followed by a presentation by AK Dube setting the context for disability data collection in Africa. Daniel Mont then made two presentations, first an overview of the Washington Group questions and how to collect data on disability in surveys and censuses. Then, a presentation on the purposes and challenges of taking what was learned from the WG questions to adapting administrative data systems.

There was an extensive discussion focusing on four questions:
What type of information are you not getting from your current data systems that would be useful for you?

How could analyses of census and survey data collected by Stats SA provide you with information that can help the monitoring and evaluation of your programs?

What is the feasibility of matching functional data collected by your data systems to the domains in the WG questions?

What is the feasibility of adding the WG questions or other similar functionally based questions to your data collection?

Stakeholders were informed that while the consultants will take the lead in writing this report and proposing a terms of reference for future studies, that it will be very important to continue to have communication to better address department needs and to draw on their knowledge of the local context.

10. Data Analysis and Interpretation

The team approached SASSA, suggesting that understanding the relation between those deemed eligible for benefits by SASSA and those identified as having a disability by the Washington Group questions can help in the administration of SASSA programs in several ways.

- First, comparing the distribution of type of disabilities between SASSA data and Stats SA, as well as personal characteristics such as sex, age, and area of residence, data could give SASSA insight to what barriers may be inhibiting access to the disability benefits by looking at the population of people whose functional limitations are similar to SASSA benefit recipients but who are not receiving benefits. This will also help Stats SA to better understand what persons with disabilities may be missing in our data collection. These comparisons could be made at the provincial level, since data shows that the rates of disability (and types of disability) are not uniform across the country.

- Second, if the relation between SASSA eligibility and Stats SA identification are better understood, then the Stats SA data can be used to make projections about trends in people applying for benefits, as the population ages or as the economy changes.

- Third, if SASSA were contemplating changes in their procedures as to who was eligible for benefits, the Stats SA data would be more useful in making estimates of what the impact of those changes would be on programs outcomes and costs.

Before reporting the results of the test, it is important to stress that the WG questions were not designed for disability determination but for statistical purposes. Nevertheless, the expectation is that disability as identified by the WG questions and by DG program are correlated. However, they are also expected to not completely overlap. We expect, as in the diagram below, that there will be some people identified as having a disability through both procedures but others through only one.
People might be in the DG circle but not the WG circle as a result of:

1) Having conditions that can be missed by the WG questions, such as:
   a. Psychosocial conditions when the WGSS is used
   b. Conditions (like chronic medical conditions or short stature) that may be missed by the WG questions
2) The DG program using a threshold below “a lot of difficulty,” at least for certain functional domains
3) False negative errors inherent in responses to survey questions

Unfortunately, due to the scaling back of the study design we are not able to examine people who may be in the WG circle, but not the DG circle. It should be noted that might occur for a number of reasons:

1) They did not have knowledge of our access to the DG procedure
2) They did not want to go through the DG procedure because they did not self-identify as having a disability, were concerned about stigma, or some other reason
3) They are elderly and were receiving old age benefits that were at least as good as the disability benefits they could receive
4) They do not qualify as having a disability under DG procedures
5) False negative errors inherent in responses to survey questions

In the end, the only data collected was from people who were newly certified as having a disability by SASSA over the previous six months. They were interviewed by phone using the Washington Group Extended Set (WGES) of Questions.

There were two sets of respondents – those adults identified under the Disability Grant (DG) program and those children identified under the Care Disability Grant (CDG) program. Using the WGES, four different measures of disability were constructed:

1) WGSS – based on the WG short set of questions, which are a subset of the WGES. A person was considered to have a disability if they answered “a lot of difficulty” or “cannot do” to at least one of the six questions. This is the measure used by Stats SA for its statistical analyses of disability
2) **WGSS Enhanced** – This adds the six WGSS questions four questions on psychosocial issues. The WGSS is known to miss many people with psychosocial issues. People are identified as having a disability by the questions on anxiety and depression if they report having a lot of difficulty in either of those areas on a daily basis.

3) **WGES minus pain and fatigue** – The WGES minus its pain and fatigue questions does not add additional functional domains but asks additional questions on the nature of difficulties people have in several of the WGSS domains. The questions on pain and fatigue are left out because they are often considered more controversial in the determination of disability.

4) **WGES** – The full set of WGES questions, including those on pain and fatigue. Pain and fatigue qualify someone as having a disability if it causes them a lot of difficulty on a daily basis.

Table 3 shows the percentage of recent DG recipients who also fall within the WG circle. Over 62 percent would have been identified as having a disability using the WGSS. The addition of the psychosocial questions and pain and fatigue questions add very few additional people, but the other extended set questions that probe deeper into difficulties in the functional domains in the WGSS do add a significant number.

Nearly 77 percent of DG recipients are identified as having a disability using the full WGES. It is expected that the more questions you can ask to uncover various types of difficulties the more people will be identified. The DG determination procedure, of course, is even more in-depth.

Table 3 shows no significant differences by gender. Large differences emerge when looked at by province, however care should be taken in drawing any strong conclusions because of the sample size. Still, those differences warrant further examination to see if the disability determination procedures as employed by SASSA are being administered evenly across provinces.

Table 4 shows similar figures from the CDG program. Surprisingly, there is much more overlap with the WG questions. We say "surprisingly" because the WG questions are known to under-identify children with disabilities, which led to the development of the UNICEF/WG Child Functioning Module.

No gender comparisons are possible because nearly all the respondents were female. This may have been because the interviewers recorded the gender of the respondent – typically the mother – and not the child.

A further study that examines those in the WG circle but not the DG (or CDG) circle would provide significantly more information about the relation between the two measures.
Table 3: Percentage of Disability Grant respondents identified as having a disability according to different measures

<table>
<thead>
<tr>
<th></th>
<th>WGSS</th>
<th>WGSS plus Anxiety and Depression</th>
<th>WGES minus pain/fatigue</th>
<th>All WGES</th>
<th>Number of cases</th>
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<tr>
<td>All</td>
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<td>65.5</td>
<td>76.2</td>
<td>76.8</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>64.4</td>
<td>71.2</td>
<td>76.7</td>
<td>76.7</td>
<td>73</td>
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<tr>
<td>Male</td>
<td>61.1</td>
<td>61.1</td>
<td>75.8</td>
<td>76.8</td>
<td>95</td>
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<tr>
<td>Province</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eastern Cape</td>
<td>64.8</td>
<td>64.8</td>
<td>75.9</td>
<td>75.9</td>
<td>54</td>
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<tr>
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<td>50.0</td>
<td>75.0</td>
<td>75.0</td>
<td>4</td>
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<tr>
<td>Gauteng</td>
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<td>57.1</td>
<td>85.7</td>
<td>85.7</td>
<td>7</td>
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<tr>
<td>KwaZulu-Natal</td>
<td>69.6</td>
<td>71.7</td>
<td>78.3</td>
<td>78.3</td>
<td>46</td>
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<td>Limpopo</td>
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<td>Mpumalanga</td>
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<tr>
<td>North West</td>
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<td>61.5</td>
<td>76.9</td>
<td>84.6</td>
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<tr>
<td>Northern Cape</td>
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<td>10</td>
</tr>
<tr>
<td>Western Cape</td>
<td>28.6</td>
<td>42.9</td>
<td>50.0</td>
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</table>
Table 4: Percentage of Care Disability Grant respondents identified as having a disability according to different measures

<table>
<thead>
<tr>
<th></th>
<th>WGSS</th>
<th>WGSS plus Anxiety and Depression</th>
<th>WGES minus pain/fatigue</th>
<th>All WGES</th>
<th>Number of cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>All</td>
<td>87.5</td>
<td>89.6</td>
<td>90.6</td>
<td>90.6</td>
<td>96</td>
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<tr>
<td>Gender</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>87.1</td>
<td>89.2</td>
<td>90.3</td>
<td>90.3</td>
<td>93</td>
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<tr>
<td>Male</td>
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<tr>
<td>North West</td>
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<tr>
<td>Northern Cape</td>
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<td>100.0</td>
<td>100.0</td>
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<td>80.0</td>
<td>80.0</td>
<td>80.0</td>
<td>5</td>
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</tbody>
</table>

Adding the WGES – or even the WGSS – to the data collected by the determination procedure could serve several purposes. First, it allows better understanding of the two populations and how they relate to one another, which is important for comparing statistical and administrative data. Second, it would provide some insight into who are accessing the DG system, especially if the overlap between the WG and DG circles are different depending on gender, area of residence, income or other characteristics. Third, it could help determine who the WG questions may be missing who are still in need of supports. We will revisit this issue below.
11. Recommendations

11.1. Framework for harmonization

The proper framework for harmonization should be connected to the conception of disability embodied in the CRPD. The recommended framework for identifying people with disabilities is to identify those people with activity limitations that put them at risk of restrictions to their participation in society upon encountering environmental barriers.

In a world with unlimited resources, the full range of activities in the ICF could serve as such a basis, but that is unrealistic. The WGES and CFM provide the basic, core functional domains that can identify a large majority or people with disabilities. Even these questionnaires, however, may be seen as too long – definitely too long for a census and often for administrative forms.

Therefore, the recommendation is to use the core activities encapsulated in the WGSS as the core upon which to connect various data sets. This is consistent with the approach to disability embodied in the CRPD and with the ICF.

The WGSS are the questions already adopted by Stats SA through their work with the WG. They consist of the main core functional domains. While they are not complete (they under-identify people with psychosocial disabilities, for example), they identify most people with disabilities and can be used as a base. For various purposes (for example, eligibility for disability benefits) or for departments with specific concerns (for example the police service’s focus on people with mental health issues) data collection can be expanded or made more detailed, but that core set of questions applied throughout the system will allow for a better understanding of disability data and allow data from different sources to be used together.

The framework does not necessitate the use of the WG questions. For example, DHET collects more detailed data. But it does require that data collected in a manner and reported on in a fashion where the identification of functional difficulties in various domains can be mapped on to the core functional domains of the WG questions.

Complete and total harmonization of data would require major revision and expansion of data collection, as discussed in the conclusion of this report. The departmental recommendations included earlier in this report are considered to be practical first and important steps in this direction. For ease of reference, all of the individual department recommendations are copied in Appendix 2.
11.2. Recommendations for Provincial Governments

South Africa has nine provinces that are aligned to national government departments. The local government sector has a direct interface and interaction with persons with disabilities. It is recommended that the local and provincial government departments use the WG extended set of question for adults and the UNICEF/WG Child Functioning Module for Children.

It is further recommended that a capacity-building programme be planned and implemented for the benefit of local and provincial government departments.

12. Conclusion

Disability data is collected and used throughout the South African Government, but often it is collected by simply asking people to self-identify as having a disability. This undercounts the rate of disability and also provides no information on the type of disabilities, so it is impossible to use the data in conjunction with Stats SA data to determine with people with different types of disabilities are experiencing different levels of barriers to participation.

Asking departments to administer the WG questions– or similar questions – in all instances to identify people using their services would provide useful information by both identifying more people who have a disability, and by being able to categorize the type of disability. This is not recommended, however, for two reasons. First, it would impose a significant data collection burden which would probably be resitited. Second, while the WG questions have proven to be useful for statistical purposes, they are not adequate for making disability determinations at an individual level for the purposes of administering programs. This is clearly stated on the WG website. The rate of false positives and false negatives would be problematic for administrative purposes. For example, a person identified as having a disability on a Department of Human Settlements form using the WG questions, may not qualify for disability benefits. It would be wrong to give an applicant the impression by how they answer the WG questions that they are eligible.

Therefore, for departments that currently ask about self-identification of disability using a question such as “Do you have a disability?” It is recommended that those people self-identifying as having a disability be asked the WG questions as a way of better understanding that population in relation to the data collected by Stats SA. As these people have already self-identified as having a disability and as they are a small percentage of the population, this would not pose a significant burden but would provide useful and important information.

Other departments are already collecting detailed data on human functioning, most notably the education departments, the Department of Health and SASSA. In those instances, it is recommended that they map their data to the WG categories in their reporting so that their data can be better understood in relation to Stats SA data. Also, in instance where that data is categorized by medical diagnosis and not functioning (e.g., cerebral palsy in DHET data) that functional data is also collected.
If departments collect and report on data in this way, it will enable a deeper understanding of the lives of persons with disabilities and how government programs are serving them. That understanding could be used to design occasional studies or surveys (or survey modules) to further explore issues that arise from that understanding.
References

AU Protocol to the African Charter on Human and Peoples Rights on the Rights of Persons with disabilities, 2018

ECA, Reference Regional Strategic Framework (RRSF), 2006


Stats SA Background Document, 2019

Stats SA Strategic plan 2015/2016 – 2019/2020


UN Convention on the Rights of Persons with Disabilities (CRPD), Article 31 on Statistics and data collection

UN Flagship Report on Disability and Development, 2018
Appendix 1: Provincial Questionnaire on Measure of Disability and Disability Monitoring

For responses, refer to this link: https://documentcloud.adobe.com/link/review?uri=urn:aaid:scds:US:06c67afe-1bfd-4b7b-b8fb-2af1ec7037d4

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</tr>
<tr>
<td>1.2</td>
<td>What is the mandate of your institution?</td>
<td></td>
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<tr>
<td>1.3</td>
<td>How do you define disability for your programmatic purposes?</td>
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</tr>
<tr>
<td>1.4</td>
<td>What disability data does your institution collect?</td>
<td></td>
</tr>
<tr>
<td>1.5</td>
<td>How do you identify persons with disability in your data collection? Do you identify them by type and/or degree of disability?</td>
<td></td>
</tr>
<tr>
<td>1.6</td>
<td>What is your disability data collection methodology?</td>
<td>(please attach copies of forms if applicable)</td>
</tr>
<tr>
<td>1.7</td>
<td>Do you make use of other data sources eg. STATS SA, government, academic, private?</td>
<td>If yes, which? Provide examples.</td>
</tr>
<tr>
<td>1.8</td>
<td>Do you have problems with inconsistencies between disability information from different departments? If so, please explain</td>
<td></td>
</tr>
<tr>
<td>1.9</td>
<td>What do you use disability data for?</td>
<td></td>
</tr>
<tr>
<td>1.10</td>
<td>Are there information gaps in the data sources that you use?</td>
<td></td>
</tr>
<tr>
<td>1.11</td>
<td>Does your institution make use of the Washington Group Set of Questions?</td>
<td></td>
</tr>
<tr>
<td>1.12</td>
<td>What are the opportunities and constraints related to disability data / statistics?</td>
<td></td>
</tr>
<tr>
<td>1.13</td>
<td>Does your institution make use of data on youth and gender as it intersects with disability?</td>
<td></td>
</tr>
<tr>
<td>1.14</td>
<td>How does your organisation use disability data to monitor progressive realisation of rights for persons with disabilities?</td>
<td></td>
</tr>
<tr>
<td>1.15</td>
<td>How can government and disability sector collaborate in disability data collection and usage?</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 2: Consolidated Departmental Recommendations

Department of Basic Education

Reports based on their assessment forms for children referred to district hospitals for assessment should include tables showing the breakdown and experience of children based on the functional domains included in the WG’s Child Functioning Module. This will not require the collection of any new data, just reporting it in a way that can be aligned with Stats SA data reports. In addition, that coding should also be included on forms not referred to district hospitals for assessment.

Department of Employment and Labour

The WG Short Set (WGSS) of questions should be added to the EA1 form. The data would be most useful if all people filling out the form answered them. People could then be considered to have a disability if they either report “having a disability” or they meet the criteria based on the WGSS. If DEL considers this too burdensome, they could at least ask those self-identifying as having a disability to answer the WGSS so that the distribution of type of disability could be compared to the statistical data to see if people with difficulties in certain functional domains are under- or over-represented among employees.

Department of Health

DOH casefiles, using either data from SASSA or from their own functional assessments should clearly label the type of disability according to the functional domains delineated by the WG questions: Vision, Hearing, Mobility, Cognition, Communication, Self-care. People with multiple disabilities should have all the domains affected recorded. In doing so, the distribution of their types of disabilities can be compared to the general population can be examined.

Department of Higher Education and Training

People reporting “multiple disabilities” or those identified based on a medical condition, such as cerebral palsy, autism, or albinism, should also be asked functional questions. If this were done, then all of the people in their data base could mapped to the WGSS of questions. DEHT reports could then also report data based on those domains so they could be easily compared with statistical data collected by Stats SA. It should be noted that the DEHT data is more detailed so it identifies people with psychosocial or neurological issues that may be missed by the WGSS. Identifying those people will help Stats SA better understand who the WGSS is missing in their data collection.
**Department of Home Affairs**

Disability status should be added to birth certificates. This will not be in harmonization with other disability data but would still be useful in highlighting trends in congenital conditions or regional patterns. In a similar vein, disability status should be added to death certificates.

**Department of Human Settlements**

The initial registration form should explicitly ascertain if anyone in the household has a disability, not just the person registering. People self-identifying or listing their relative as having a disability during the registration process should be asked the WGSS so that the distribution of their types of disabilities can be compared to the general population can be examined.

**Department of Planning, Monitoring and Evaluation**

DPME joins Stats SA and DWYPD on the data harmonization working group and supports the agreed upon recommendations that result from this report.

**Department of Public Service Administration**

People self-identifying as having a disability during the application process should be asked the WGSS so that the distribution of types of disabilities for those applying compared to the general population can be examined. It will probably be seen as too intrusive during an application process to ask the WGSS to all applicants, and there will probably be too big of an incentive to hide difficulties, leading to false negatives.

**Department of Social Development**

For the purpose of data harmonization, it would be good if the DSD system were expanded to record types and levels of difficulties in the examined functional domains. That would serve at least two key purposes. First, it would provide the DSD system information pertinent to the level and type of support needs of their recipients. Second, by comparing that data to SSA’s data it could give insight into how the program is meeting the needs of people with disabilities in the general population. However, as the data system is very new, DSD did not seem hopeful that the department would be willing to update it at this time.

**Department of Transport**

People self-identifying as having a disability during the complaint process should be asked the WGSS so that the distribution of their types of disabilities can be compared to the general population can be examined.
**Department of Welfare Services**

Given their focus on disability, it is recommended that their forms use the WG extended set of question for adults and the UNICEF/WG Child Functioning Module for Children. These forms can be easily mapped to the disability questions in Stats SA data. This data would be helpful in identifying the demand for different types of supports.

The disability disclosure form should contain the full list of WG short set questions, being sure to use the full set of response categories. This form should be distributed to all people who report having a disability on any form, including attendance at meetings. However, not each time they report so. For example, the attendance sheet can ask them to check if they have previously filled out such a form. If not, they can then fill it out. This will allow a comparison of people with disabilities interacting with DWS and the general population via Stats SA data.

**South Africa Police Service**

Crime victims should be asked the WGSS enhanced set of questions, and afterwards asked if they have any other mental health issue. The enhanced set includes four questions on anxiety and depression that could be used in Stats SA data collection in a special disability module at some point. A good deal international research shows that people with disabilities have much higher rates of being victims of violence, and it is important to document this in a way that can be compared to national statistics.