Creating Harmonized Disability Data Systems: The Example of South Africa

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Why Harmonize?

- **To avoid confusion**

Why does one source say the prevalence is 2% and another source says it is 10%? Who is right?

- **To be able to use different data sources together**

For example
- how are people NOT applying for disability benefits different from the ones who are?
- How can we connect data about kids in school and their schools with what is going on in their households?

Challenges to be Addressed/Noted

1. Disability is a complex and multidimensional

2. Agencies lack of a uniform definition of disability and way of collecting disability data

3. Different purposes in collecting disability data

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

Must every department collect data the same way?

Each department has different needs

- "work ability" vs. employment quotas
- Cash benefits directed at extra costs of disability vs. inclusive services

Each department has different resources for data collection

- Full-length surveys
- In-take forms
- Disability assessments

Framework for Use By All Departments

1. Move toward functional definition of disability, in line with CRPD

   Identifying people who because of functional limitations are at risk, because of barriers in the environment, of exclusion.

2. This approach is embodied in Washington Group Questions, recommended by US Stats Division and Stats South Africa.

Goal: Create a bridge between all data sets

Create a core set of information so that we have better understanding of how people identified as having a disability from one data source relate to the other data sources: statistical and administrative

Challenge: Difference between disability identification and eligibility determination

1. For CRPD compliance and SDGs, we want to identify everyone who because of functional limitations is at risk of being disabled by barriers in the environment

2. For eligibility determination, we are identifying people who meet a programmatic definition aligned with the specific purpose

3. Self-identification as "disabled" historically greatly undercounts

Different Approach Identify Different People

"do you have a disability"

WG   DG
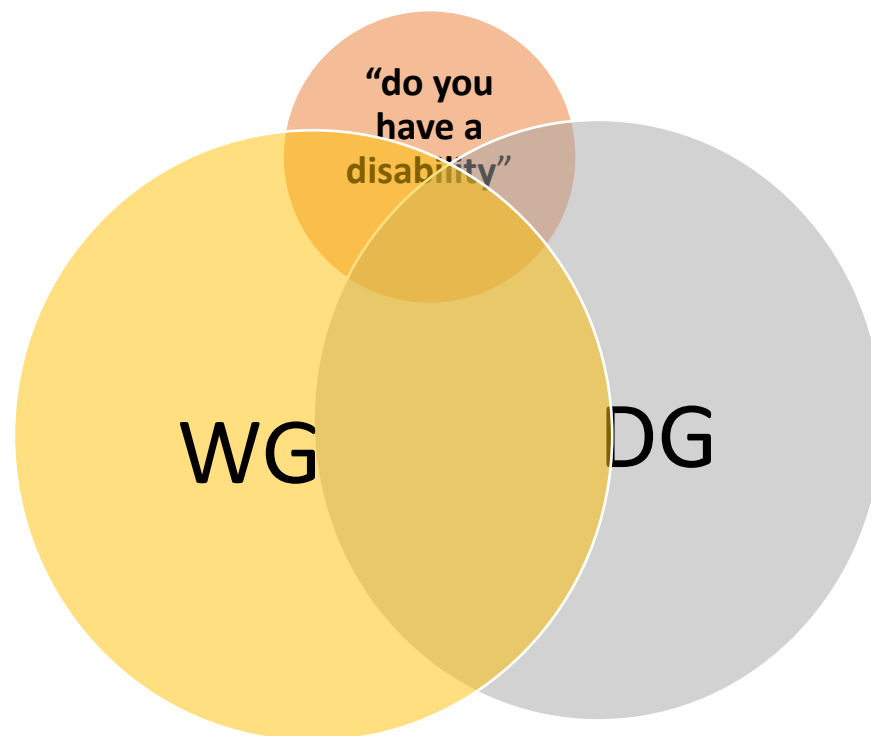
We don't expect a complete overlap of WG and DG (Disability Grant)

In DG, but not WG

- Conditions that can be missed by WG
    - Psychosocial conditions when the WGSS is used
    - Conditions (some related to chronic medical conditions or short stature)
- The DG program using a threshold below "a lot of difficulty," at least for certain functional domains
- False negative errors inherent in responses to survey questions

In WG, but not DG

- No knowledge or access to the DG procedure
- Did not self-identify as having a disability, were concerned about stigma, or some other reason
- Elderly and were receiving old age benefits that were at least as good as disability benefits
- They do not qualify as having a disability under DG procedures
- False negative errors inherent in responses to survey questions

Methodology

- Reviewed questionnaires and administrative forms to see how disability data was collected

- Interviewed a wide group of departments to ask them:
  - Are they collecting data on disability?
  - Why are they collecting it?
  - How are they collecting it?
  - How they intend to use it?
  - If they are not collecting it, what tools do they have where it would be most feasible to add questions on disability?

- Study on how new disability benefit recipients answer WG and CFM questions

SASSA and Stats SA

1. The Washington Group (WG) questions cannot function as eligibility determination

2. The key is to understand the relationship between (WG) and people certified by SASSA as eligible for a disability grant (DG)

3. This can help us understand the relationship between the two populations, who the DG is and isn't reaching and who the WG questions are identifying

Percentage of Disability Grant respondents identified as having a disability according to different WG measures

	WGSS	WGSS plus anxiety and depression	WGES minus pain/fatigue	All WGES
All	62.5	65.5	76.2	76.8
Female	64.4	71.2	76.7	76.7
Male	61.1	61.1	75.8	76.8

Percentage of Carerers Disability Grant respondents identified as having a disability according to different WG measures

	WGSS	WGSS plus anxiety and depression	WGES minus pain/fatigue	All WGES
All	87.5	89.6	90.6	90.6
Female	87.1	89.2	90.3	90.3
Male	100.0	100.0	100.0	100.0

Recommendations for SASSA

1. SASSA records levels of difficulty in WG functional domains.

2. Keeps them attached to individual records.

3. When reporting on beneficiaries, reports on breakdown.

4. If possible, use the full WGES domains – including psychosocial, pain and fatigue.

What is the state of data dis/harmonization in South Africa now?

Other departments fall into three groups

Group 1: Those already collecting functional information

Group 2: Those using "do you have a disability?"

Group 3: Those requiring more data on functioning

Recommendations for Group 1

1. These departments are **already collecting functional information** directly analogous to the WG questions.

2. Answers to questions already asked should be mapped on to corresponding WG questions.

3. All records should have information on WG domains.

4. Best if it includes domains in WGES.

Recommendations for Group 2

1. Not practical to have all these forms replace the "do you have a disability question" with WG questions

2. However, people self-identifying as having a disability should then be asked the WG questions

3. All reports should show disaggregation by type of functional limitations

Group 3: Departments to add functional questions

1. **Department of Social Development**– should add functional questions

2. **South Africa Police Service** – should specifically note mental health

3. **Department of Health** – should add checklist of WG functional domains to records

Results of Recommendations

1. Moves all disability data reporting towards the functional limitation approach embodied in the WG questions while minimizing extra data collection burden

2. Allows disability data from each source to be compared relative to WG domains

3. Ability to understand how the various populations of people identified as having a disability relate to each other

THANK YOU