

THE LIFE OF PEOPLE WITH DISABILITIES  
AN INTRODUCTION TO THE SURVEY ON THE NEED  
FOR SOCIAL ASSISTANCE PROGRAMMES FOR  
PEOPLE WITH DISABILITIES (SNSAP-PWD 2012)

JAN PRIEBE AND FIONA HOWELL

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TNP2K WORKING PAPER 08 - 2014  
*May 2014*

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Support for this publication has been provided by the Australian Government through the Poverty Reduction Support Facility (PRSF).

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**Attribution:** Priebe, J. and F. Howell. 2014. 'The Life of People with Disabilities: An Introduction to Survey on the Need for Social Assistance Programmes for People with Disabilities (SNSAP-PWD 2012)', *TNP2K Working Paper 08-2014*. Tim Nasional Percepatan Penanggulangan Kemiskinan (TNP2K), Jakarta, Indonesia.

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# The Life of People with Disabilities in Indonesia: An introduction to the SNSAP-PWD 2012

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**Jan Priebe and Fiona Howell<sup>1</sup>**

May 2014

## **ABSTRACT**

In 2012, the Demographic Institute of the University of Indonesia conducted on behalf of TNP2K a unique survey on disability that sheds new light on the needs and living conditions of people with disabilities (PWDs) in Indonesia. This new dataset is called the Survey on the Need for Social Assistance Programmes for People with Disabilities (SNSAP-PWD 2012) and is available free of charge from TNP2K and PRSF\*.

This paper provides an introduction into the SNSAP-PWD 2012 by describing its sampling design and the topics covered.

*Keywords: Disability, survey, Indonesia.*

*JEL Classification: C46, I1, I3, J1*

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The authors would like to thank the survey team at the Demographic Institute of the University of Indonesia without whom this survey would not have been possible. We also wish to gratefully acknowledge Melvin Wong for his editorial assistance. Any remaining errors are solely our responsibility.

Support for this survey and publication has been provided by the Australian Government through the Poverty Reduction Support Facility (PRSF).

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## 1. Introduction

Little is known about the life of People with Disabilities (PWDs) in Indonesia. Currently, researchers need to rely on data from Susenas and Riskesdas<sup>2</sup> to explore living conditions of PWDs in the country. While these datasets are important, their usefulness in addressing many questions around the issue of disability is limited. First of all, Susenas and Riskesdas lack a specific disability focus since they are designed to provide information on many other socioeconomic indicators. Therefore these datasets contain very few questions that can be used to specifically measure the socioeconomic circumstances of PWDs. Secondly, both datasets can be difficult to obtain for researchers, which limits their usefulness for general research.

In light of the lack of data on disability, TNP2K commissioned the Demographic Institute of the University of Indonesia<sup>3</sup> to conduct a unique survey of PWDs. This new dataset was collected in the year 2012 and is called the *Survey on the Need for Social Assistance Programmes for People with Disabilities* (SNSAP-PWD 2012). The SNSAP-PWD 2012 can be obtained free of charge from TNP2K and PRSF<sup>4</sup>.

By providing a description of the SNSAP-PWD 2012, TNP2K seeks to make the general public and interested researchers better understand the dataset and its potential for use within their own analysis. Increased information and awareness about the living conditions of PWDs in Indonesia, will provide more evidence to better inform the policies that address the specific needs of PWDs.

The remainder of this paper is organized as follows. Section 2 describes the main topics covered in the SNSAP-PWD 2012 while section 3 discusses the sample design of the survey. In section 4 we present examples in terms of what can be analyzed from the SNSAP-PWD 2012 while section 5 summarizes and concludes.

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<sup>2</sup> Susenas = Survei Sosial Ekonomi Nasional (National Socioeconomic Survey) conducted by BPS; Riskesdas = Riset Kesehatan Dasar (National Basic Health Research) conducted by the Ministry of Health.

<sup>3</sup> The team involved by the Demographic Institute (University of Indonesia) included Tara B. Suprobo, Sri Moertiningsih, Merry SW Kusumaryani, Elda Pardede, Zainul Hidayat, Ratna Indrayanti, Rosya, Mercoledi Nikman, Dwindi Andaninggar, Dicky Sugandi, Hendra Ahmidi, Tunggul Budiarto, Wahyu Donor, Redha Sutarna, Sonny Wibisono, Diah Arlinawati, Anis Khurniawati, Akbar Nikmatullah, Aang Jatnika, Riswandha, Heru Hendrastio, Armanto Sulistiono Zawaqui, Glen Peter, Sansila Amrul, and Quamila. Additional technical assistance and guidance was provided by Professor Irwanto (Puska Disabilitas) and Daniel Mont (consultant).

<sup>4</sup> TNP2K refers to the National Team for the Acceleration of Poverty Reduction (Tim Nasional Percepatan Penanggulangan Kemiskinan) while PRSF refers to the Poverty Reduction Support Facility.

## 2. Topics in the SNSAP-PWD 2012

The SNSAP-PWD 2012 was designed to complement disability information from Riskesdas and Susenas. Therefore, certain topics that are covered in those datasets do not feature in the SNSAP-PWD 2012. However, in general the SNSAP-PWD 2012 includes a variety of topics and themes with a special focus on social assistance needs and the living and livelihood arrangements of PWDs and their families. The main topics are listed below.

Topics:

- General
  - Household demographics (household composition, educational attainment, labour market attachment, etc.)
  - Source of income
  - Dwelling characteristics
- Access to social assistance programs (Raskin, PKH, microcredits, etc.)
- Disability
  - Type, degree and cause of disability (including physical and mental disabilities as well information on activity limitations)
  - Implications of disability on family members and degree and extent of family support
  - Services and assistive devices
    - Knowledge and need
    - Usage
    - Accessibility

### 3. Survey Design of the SNSAP-PWD 2012

The SNSAP-PWD 2012 was conducted in March 2012 and follows a purposive sampling design. Due to the sampling strategy, the SNSAP-PWD 2012 is not representative of the general population of PWDs. As explained below, the sampling strategy leads to a higher number of persons with severe disabilities being included in the sample, which allows for a better understanding of socioeconomic issues concerning this particular group of PWDs. In general, the SNSAP-PWD 2012 only interviewed PWDs.

The sampling design followed a 2-stage process. In stage 1, two districts (*kabupaten/kota*) were chosen from each of the pre-selected provinces (11 provinces in total). Based on information from the 2010 Population Census in each of the 11 provinces, the districts with the largest number of PWDs were selected to be included in the SNSAP-PWD 2012. In stage 2, PWDs were selected from each district. A list of PWDs (by name and address) in each district was compiled by drawing on information from a) PWDs who receive Social Assistance for Severely Disabled People (*Asistensi Sosial untuk Orang Dengan Kecacatan Berat* or ASODKB), a cash-transfer program from the Ministry of Social Affairs, b) members of civil society organizations such Indonesia's Disabled People's Association (*Persatuan Penyandang Cacat Indonesia* or PPCI) or the Organization of PWDs with Visual Impairment, and c) Village Heads and community member information. On average, about 100 PWDs per district were randomly selected and interviewed which leads to a total sample size of about 2,200 PWDs<sup>5</sup>. Table 1 provides a snapshot of the SNSAP-PWD 2012.

**Table 1. Snapshot information on the SNSAP-PWD 2012**

Survey period	March 2012
Province coverage (see Appendix for more details)	3 in Western Indonesia (Sumatra and Kalimantan) 5 on Java 3 in Eastern Indonesia (Sulawesi, East Nusa Tenggara, Maluku)
Total number of districts	22 (two districts in each province)
Total number of PWDs	2,211
Sampling method	Purposive sampling based on census 2010 and availability of organizations for disabled people; snowball sampling
Age of respondents	10 years and above

Source: SNSAP-PWD 2012.

<sup>5</sup> 2 districts in each of the 11 provinces means that the survey took place in 22 districts. With 100 interviews per district (on average) the total sample size amounts to approximately 2,200 PWDs.

Table 2 describes the SNSAP-PWD 2012 sample in more detail. The sample consists of 1,238 men and 973 women allowing for approximately equal numbers of PWDs in each age group. The majority of PWDs interviewed live in rural areas (1,349 PWDs) compared to 862 PWD who live in urban areas.

**Table 2. Characteristics of Individuals by Type of Disability**

Individual Characteristics		Mild Disability	Severe Disability	Total
		%	%	N
Sex	Male	18.30	81.70	1,238
	Female	15.00	85.00	973
Age of respondent (in years)	10–14	9.44	90.56	180
	15–19	14.83	85.17	209
	20–24	17.39	82.61	207
	25–29	19.57	80.43	184
	30–34	23.12	76.88	199
	35–39	22.46	77.54	187
	40–44	16.93	83.07	189
	45–49	22.30	77.70	139
	49–54	18.79	81.21	165
	55–59	24.11	75.89	141
	60–64	10.00	90.00	80
	65+	8.36	91.64	299
Region	Urban	20.00	80.00	862
	Rural	14.90	85.10	1,349
Education	No Schooling	9.17	90.83	971
	Primary Level	18.65	81.35	622
	Religious Boarding School	27.78	72.22	18
	Junior High School	21.61	78.39	236
	Senior High School	35.04	64.96	234
	High Education	39.39	60.61	33
Total		16.90	83.10	2,211

Source: SNSAP-PWD 2012.

## 4. Examples from the SNSAP-PWD 2012

In this section we would like to illustrate the kind of information that can be obtained from the SNSAP-PWD 2012.

### *Example 1: Causes of disability*

Similar to Riskesdas and Susenas, the SNSAP-PWD 2012 provides information on the type of disability. In addition, the SNSAP-PWD 2012 asks respondents about the perceived origin of their disability. Table 3 shows the respective statistics by type of disability and by self-reported cause for the disability.

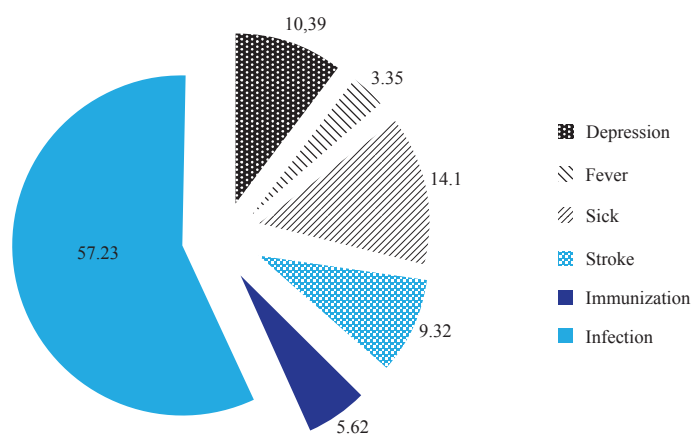
**Table 3. Self-Reported cause of disability (%) by first type of disability experienced**

Cause of disability	All Types (%)	Vision (%)	Hearing (%)	Cognitive (%)	Communication (%)	Mobility (%)	Psycho-Social (%)
At birth	36.32	18.86	44.62	36.92	44.33	31.03	35.10
Illness	34.64	27.58	18.78	32.33	28.12	30.43	31.66
Injury	17.73	12.52	9.79	9.69	7.78	16.69	11.57
Cursed	3.44	2.22	0.64	4.23	3.28	3.27	4.23
Aging	16.37	31.38	22.15	10.66	8.43	8.43	8.66
Do not know	1.45	0.79	0.96	0.70	0.66	0.75	0.33
Other	17.59	6.66	3.05	5.46	7.40	9.39	8.46
<b>TOTAL</b>		100.00	100.00	100.00	100.00	100.00	100.00

*Source: SNSAP-PWD 2012.*

As one would expect, the causes of the first disability are very different by domain. For vision, aging is the primary cause. For hearing and communication however, the primary cause is associated with birth although it is not known whether this finding is related to congenital aspects or to birth trauma. When it comes to psychosocial and mobility issues, illnesses seem to cause as many disabilities as those that occur at birth. Not surprisingly, a small percentage of people blame supernatural causes ('cursed') for their disability, most commonly for cognition.

**Figure 1. Types of Illnesses Reported as Cause of Disability**



Source: SNSAP-PWD 2012.

Figure 1 depicts the types of illnesses that people report causing their disability. Infection is clearly the largest cause, and includes those citing ‘fever’ and ‘immunization’ as well as those people who responded with the more general term, ‘sickness.’ Strokes and depression are also mentioned. Therefore, according to the SNSAP-PWD 2012, infections and other illnesses play a major role in causing disability which adversely affects PWDs’ personal lives, economic activity such as schooling and work as well as social and political participation.

### ***Example 2: Participation in community activities***

Participation in religious or political activities, festivals, and sporting events are important parts of an individual’s life. However, the inaccessibility of transport and of venues to PWDs as well as stereotypes and negative attitudes towards PWDs can become barriers to PWDs’ participation in community events. The SNSAP-PWD 2012 provides information on the restrictions in community participation as experienced by PWDs. The results are shown in Table 4. According to the SNSAP-PWD 2012, many PWDs experience participation restrictions. Furthermore, the survey allows for differentiating between severity of disability. For example, only 12 percent of men with mild disabilities felt restricted in terms of participating in community organizations, but nearly 63 percent of men with more severe disabilities felt limited. Women with disabilities felt more restricted across the board. The differences between rural and urban areas are not as uniform. Among people with mild disabilities, the only area of difference was in recreation, sports, and culture, in which urban residents felt more restricted from participating. Among people with more severe disabilities, urban residents also felt more restricted from participating in community and religious organizations but not in political activities.

**Table 4. Restrictions in Participation in Community Activities, by Degree of Disability, Age, Gender, and Type of Residence**

	Mild Disabilities				More Significant Disabilities			
	Comm. Or- ganisations (%)	Recreation, Sports, and culture (%)	Religious (%)	Political (%)	Comm. Or- ganisations (%)	Recreation, Sports, and Culture (%)	Religious (%)	Political (%)
<b>Age (years)</b>								
10–19	27.08	10.42	8.33	41.86	74.85	50.74	47.65	75.16
20–29	8.33	5.63	2.78	8.33	64.44	53.94	45.14	55.27
30–39	17.05	18.18	3.41	11.36	60.94	64.86	48.82	55.25
40–49	3.17	20.63	4.76	7.94	60.31	66.29	47.17	57.74
50–59	13.85	33.85	7.69	10.77	61.67	69.29	48.96	48.33
60+	45.45	56.25	15.15	36.36	80.12	85.47	60.06	72.75
<b>Gender</b>								
Men	12.00	17.86	3.56	11.76	62.94	60.26	46.91	58.38
Women	23.45	27.08	9.66	22.22	73.77	70.85	53.40	65.64
<b>Area</b>								
Rural	15.29	16.57	7.06	16.87	62.52	57.10	43.94	61.14
Urban	17.50	25.63	5.00	15.08	71.03	69.76	53.37	62.00

Source: SNSAP-PWD 2012.

## 5. Conclusions

There is still limited information available on the life of PWDs in Indonesia. In 2012, the Demographic Institute of the University of Indonesia conducted on behalf of TNP2K, a new survey that explores the socioeconomic environment and living conditions of PWDs. In total about 2,200 PWDs were interviewed in 22 districts in 11 provinces throughout Indonesia.

The SNSAP-PWD 2012 collected data on a variety of topics that are relevant to the life of PWDs which can contribute to the development of policies that address the specific needs of PWDs. This paper documents and describes the SNSAP-PWD 2012 in more detail.

TNP2K expresses its hope that by making the SNSAP-PWD 2012 available to the general public and the research community, that further analyses of the dataset will contribute to obtaining a more accurate understanding of the life of PWDs.



## Appendix

**Table A1: List of Provinces, Districts, and Sub-districts included in the SNSAP-PWD 2012**

Province Code/ BPS	Province	District	Subdistrict
13	West Sumatra	1 Cab. Agam	1 Lubuk Basung
		2 Kab. Padang Pariaman	2 Palupuh
16	South Sumatra	1 Palembang City	1 Nan Sabaris
		2 Lahat	2 VII Koto
31	DKI Jakarta	1 East Jakarta	1 West Ilir II
		2 North Jakarta	2 East Ilir I
32	West Java	1 Kab. Bandung	3 Kertapati
		2 Kab. Sukabumi	1 West Merapi
33	Central Java	1 Kab. Sragen	2 South Merapi
		2 Magelang City	1 Cakung
34	DI Yogyakarta	1 Kab. GunungKidul	2 Pulo Gadung
		2 Kab. Bantul	1 Cilincing
35	East Java	1 Kab. Nganjuk	2 Koja
		2 Kab. Sidoarjo	1 Ciparay
53	East Nusa Tenggara	1 Kab. Central South Timor	2 Pameungpeuk
		2 Kupang City	1 Cikidang
63	South Kalimantan	1 Banjarmasin City	2 Cisolok
		3 Barito Kuala	1 Gemolong
73	South Sulawesi	1 Makassar City	2 Sukodono
		2 Takalar	1 South Magelang
81	Maluku	1 Central Maluku	2 Central Magelang
		2 Ambon City	1 Palian
			2 Saptosari
			2 Imogiri
			2 Gondang
			2 Sidoarjo
			2 Boking
			3 Alak
			2 West Banjarmasin
			3 Cerbon
			3 Marabahan
			2 Tamalate
			2 North Polongbangkeng
			2 Salahutu
			2 Baguala





In 2012, the Demographic Institute of the University of Indonesia conducted on behalf of TNP2K a unique survey on disability that sheds new light on the needs and living conditions of people with disabilities (PWDs) in Indonesia. This new dataset is called the Survey on the Need for Social Assistance Programmes for People with Disabilities (SNSAP-PWD 2012) and is available free of charge from TNP2K and PRSF.

This paper provides an introduction into the SNSAP-PWD 2012 by describing its sampling design and the topics covered.

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