

Original research

Statistics on disabled people in Japan

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Abstract

In Japan, the central government has not implemented a comprehensive statistical survey of the disabled. The results of some surveys have been compiled and published, but the objectives, definitions and procedures are somewhat different between surveys, and the results do not seem accurate or reliable. Furthermore, it appears that estimated values that are calculated from these results (e. g., the number of disabled) are inadequate. In this paper, problems and improvements are explained with respect to statistics on disabled people. Although issues related to the disabled are sensitive and difficult to survey, there is no doubt that the statistical system for the disabled in Japan is deficient and unsatisfactory. Therefore, the central government should review and reconstruct the statistics of people with disabilities. Especially, the survey items on health and disability need to be added to the census questionnaire as soon as possible.

Key words: statistics on disabled people, number of people with disabilities, investigation of actual situation with children and persons with physical disabilities, Basic Investigation of actual situation with children and persons with intellectual disabilities, Washington group on disability statistics

Introduction

According to the 2008 Annual Report on Government Measures for Persons with Disabilities, the total number of disabled is estimated at about 7,238,000 in Japan. That number is equivalent to 5.6% of the total population and has been increasing recently. Details of the numbers are provided in Table 1. The numbers of children and persons with physical disabilities, intellectual disabilities, and mental disorders are 3,663,000, 547,000, and 3,028,000, respectively.

The term “persons with disabilities” is defined as those with physical disabilities, intellectual disabilities, or mental disorders who have trouble coping with daily life and social life on an ongoing basis. “Children with disability” refers to those disabled persons who are under 18 years of age.

Statistics on the disabled in Japan have been compiled from several surveys, but the definition, classification, method of estimation, and other factors are somewhat different for each survey. At the same time, the coverage of

Table 1 The number of persons with disabilities in Japan (thousands)

Type of disability	Total number	Persons living at home	Residents of facilities
Children and persons with physical disabilities	3,663	3,576	87
Children and persons with intellectual disabilities	547	419	128
Persons with mental disorders	3,028	2,675	353

Source: Ministry of Health, Labour and Welfare: Annual health, labour and welfare report 2008–2009.

disability in Japan is narrower than that required by international standards and the number of disabled persons tends to be underestimated. As a result, the interpretation of results requires special attention. Although there have been extensive discussions about the disabled in Japan, little attention has been paid to the statistics. Consequently, the survey methodology for statistics on persons with disabilities does not appear to be either accurate or reliable. This paper describes the statistical system, points out problems with

this system, and recommends improvements.

The system of gathering statistics on disabled people in Japan

In Japan, the central government has not implemented a comprehensive statistical survey for disabled people. Some local governments (for example, Tokyo), however, carry out extensive surveys in order to determine the number of disabled people within their constituency and study the current status of this subset of the population. However, most surveys are carried out only partially and irregularly. The objective, time, definition, and procedure varies according to local government. It is difficult to compare the results published by each local government.

One of the reasons there is no comprehensive survey of disabled people is the government's vertical administrative structure. Initially, the Department of Health and Welfare for Persons with Disabilities in the Ministry of Health and Welfare (currently Ministry of Health, Labour, and Welfare) merely collected information and took charge of implementing the related policies. Because the other departments and ministries were not interested in the problems of people with disabilities, the Department of Health and Welfare for Persons with Disabilities carried out small surveys and collected data when necessary. Even the other departments of the Ministry of Health and Welfare did not attach much importance to the issues of people with disabilities. This attitude resulted in an undeveloped statistical system for disabled people.

The second reason is that issues related to people with disabilities deal with personal information and privacy. Thus, the surveys are fraught with many challenges and it is difficult to ascertain facts. For example, people with disabilities—or their families—tend to conceal the presence of disability.

The National Livelihood Survey has sometimes been recognized as a comprehensive statistical survey of disabled people. This survey investigates fundamental issues (e.g., health, medical welfare, and pension) related to the lives of citizens. It also aims at collecting the necessary material for planning and implementing not only public welfare policies but also labor policies. The first survey was conducted in 1986. Since then, a

survey has been conducted every year. However, the survey items on health are only investigated once every three years.

In the 2007 National Livelihood Survey, people aged 65 or over account for 94.8% of people who need care. Among the major diseases of people who need care, cerebrovascular (stroke) accounts for 23.3%. Following this are dementia (14.0%), senile deterioration (13.6%), and arthritic disorders (12.2%), all of which account for large proportions. In the strict sense, people that need care are not the same as those with disabilities. Specifically, the central government does not consider senile deterioration part of the welfare for the disabled.

In addition, the total number of people who have difficulty with daily activities is 106.8 per 1,000 people. This number has decreased since the 2004 survey (110.2). Among those above 65 years of age, the number of people who have difficulty with daily activities is 226.3 per 1,000 people. This number has also improved since the 2004 survey (246.1). These data are not sufficient, however, to investigate the improvement in national health over the three intervening years. In this survey, patients in hospitals have been included, but residents of welfare institutions for the elderly have been excluded. Therefore, the improvement has been viewed superficially.

The purpose of the National Livelihood Survey is not limited to a study of the disabled. The definition of "disabled people" is ambiguous and somewhat different from that of the Basic Act for Persons with Disabilities. Furthermore, the relationship between disability welfare and care is not clear. Consequently, it is unreasonable to utilize the National Livelihood Survey as a substitute for statistics on the disabled.

Generally, representative surveys of statistics on the disabled in Japan include Investigation of Actual Situation with Children and Persons with Physical Disabilities and Basic Investigation of Actual Situation with Children and Persons with Intellectual Disabilities. Additionally, Investigation of Social Welfare Facilities and Investigation of Patients are utilized as supplements. The results of these four surveys are compiled and published in each report and article; they also contribute to policy design. Next, it is important to explain the contents of these surveys.

The Investigation of Actual Situation with Children and Persons with Physical Disabilities has been conducted every five years since 1951. The objective of this survey is to determine the current status and needs of physically disabled persons and physically disabled children at home and to collect the necessary information for planning and implementing future welfare policies. The subjects of the survey include holders of the Identification Booklet for the Physically Disabled (and, for those who do not hold the booklet, persons qualified under the Appendix of the Act on Welfare of Physically Disabled Persons).

In the 2006 survey, a sample size of 10,725 households was chosen from census enumeration districts. First, the survey takers visited each household within their enumeration districts, explained the contents of the survey, and confirmed the presence or absence of persons with physical disabilities. If a subject was present, the survey takers distributed a questionnaire and requested a response by mail. Basically, the subjects needed to fill out the forms by themselves.

The number of physically disabled persons and children was estimated based survey data. As of July 2006, the number of physically disabled persons and children in Japan was 3,483,000 and 93,100, respectively. The number of physically disabled persons has increased by 238,000 (7.3%) since June 2003. Orthopedically impaired people accounted for 50.5% (1,760,000). Hearing and speech disorders, and visual disability accounted for 343,000 (9.8%) and 310,000 (8.9%), respectively.

The Basic Investigation of Actual Situation with Children and Persons with Intellectual Disabilities applies to intellectually disabled persons and children. The purpose of the survey is largely similar to that of the Investigation of Actual Situation with Children and Persons with Physical Disabilities. In 1990, the survey was conducted for the first time in two decades and has been conducted every five years since then. The term "intellectually disabled" includes persons and children who require special support due to an intellectual disability that occurred at an immature stage (before 18 years of age).

In the 2005 survey, a sample size of 2,584 people was chosen from census enumeration districts. The collection rate and response rate

were 80.3% and 82.2%, respectively. This survey includes intellectually disabled persons who live at home, but excludes those who live in social welfare facilities, rehabilitation centers, and vocational aid centers. The survey procedure is the same as that of the Survey on Physically Disabled Persons and Children.

As of November 2005, the total number of intellectually disabled persons and children in Japan was estimated at 419,000. The number of intellectually disabled persons increased by 89,800 (27.3%) compared to estimates made earlier five years. It was estimated that the numbers of intellectually disabled under and over 18 years of age were 117,300 (28.0%) and 289,600 (69.1%), respectively. With regard to the severity of impairment, the rates of profound, severe, moderate, and low-level disability were 14.9%, 24.4%, 25.5%, and 23.3%, respectively.

The Investigation of Social Welfare Facilities surveys the number of social welfare facilities, the current status of users and workers, and collects necessary information for social welfare policy promotion. The subjects of this survey are all social welfare facilities (except for those that have been temporarily closed) in Japan. The survey forms are classified into two types: those for welfare facilities and those for business places providing welfare services for persons with disabilities. Both survey forms cover name, address, business entity, description of business, quota, numbers of users and workers, etc. The survey forms are sent by mail to every facility from welfare office or the Ministry of Health, Labour and Welfare. The chief administrator of each facility is responsible for filling out the form.

Because the targets of the survey include support centers for people with disabilities, the results have been published individually. In 2007, the number of residents in rehabilitation facilities for the physically disabled, for the intellectually disabled, and for those demonstrating mental disorders was 49,085, 175,971, and 19,194, respectively. The number of residents in welfare facilities for children was 38,458. With regard to the change between 2000 and 2007, welfare facilities for children decreased by 2.4%, while the number of rehabilitation facilities for physically disabled people remained the same. However, rehabilitation facilities for intellectually disabled

people increased by 16.6%, and rehabilitation facilities for people with mental disorders rose to more than twice the number in 2000.

The Investigation of Patients focuses on exploring the injuries and diseases of patients at medical facilities (hospitals and clinics) and on collecting the necessary information for medical policies. The respondents to this survey are patients at medical facilities on a stated day; samples of 332,100 people are chosen by stratified random sampling. The survey items include sex, birth date, address, whether inpatient or outpatient, and the contents of medical service (remedy, treatment, examination, etc.). The chief administrator of each facility needs to fill out the questionnaire.

The results of the Investigation of Patients are utilized to clarify the current status of people with mental disorders. The definition of "mental disorder" in the Investigation of Patients includes dementia (including Alzheimer's disease), mental and behavioral disorders caused by substances that affect mental function, integration disorder syndrome, delusional disorders, mood disorders, neurotic disorders, epilepsy, and other disorders. Nevertheless, mental deficiency is excluded from the definition of mental disorder.

In the 2007 survey, the numbers of hospital inpatients and outpatients with mental and behavioral disorders were 301,400 and 232,300, respectively. Compared with the 2004 survey, the number of hospital inpatients fell by 24,800 (7.6%). However, the number of outpatients rose by 7,800 (3.4%).

Problems with the statistics on disabled people in Japan

The contents of the four surveys have been described in the previous section (Investigation of Actual Situation with Children and Persons with Physical Disabilities, Basic Investigation of Actual Situation with Children and Persons with Intellectual Disabilities, Investigation of Social Welfare Facilities, and Investigation of Patients). This section clarifies many problems with the statistics on disabled people.

1. Lack of survey of people with mental disorders

As illustrated in Table 1, the number of people with mental disorders is estimated at 3,028,000, which represents more than 40% of all disabled people. Despite this high propor-

tion, few surveys have been conducted among people with mental disorders. Alternatively, the Investigation of Patients is utilized to learn more about their current status and needs.

Until 1983, the National Survey on Mental Health had been carried out four times (1954, 1963, 1973, and 1983) by the Ministry of Health and Welfare. The 1954 and 1963 surveys were nationwide sampling investigations. Thus, survey takers visited each household and interviewed subjects. However, due to issues of human rights and privacy, the methods of subsequent surveys needed to be revised. In the 1973 survey, the door-to-door survey, which required an interview by the survey takers, was abolished. In the 1983 survey, the subjects were sampled not on the basis of region, but on the basis of hospital. In addition, some cities were opposed to the survey and did not participate in it. Because the regional execution and collection rates varied considerably from year to year, comparisons between years require special attention.

Ironically, it has been pointed out that the results of the 1963 survey were the most reliable. At that time, the number of people with mental disorders was estimated at 1,240,000 and the number per 1,000 people was 12.9. Until 1992, this figure was utilized as a benchmark for estimating the number of people with mental disorders.

Because there have been more patients with mental disorders such as depression, mental deficiency, and so on, mental disorder emerges as a major social issue. It is impossible to resolve such problems without official extensive surveys. The Investigation of Patients counts the number of patients at medical organizations. In some instances, people with mild emotional distress due to overwork may be counted as patients. However, the survey does not include people with mental disorders who do not consult medical facilities but stay at home all day long (namely, those with social withdrawal). Consequently, it is suggested that the central government should restore a nationwide sampling investigation such as the National Survey on Mental Health. Moreover, it is expected that specialists interview the subjects in order to prevent fraud.

2. Problems related to the low collection rate and estimation techniques

The official collection rate of the Investi-

Table 2 Data on questionnaire collection in the Investigation of actual situation with children and persons with physical disabilities 2006

The circumstances of the survey	The number of children and persons with physical disabilities
The number of survey subjects: A	10,725
The number of those to whom the questionnaire was not distributed: B	3,145
The number of those to whom the questionnaire was distributed: C (A-B)	7,580
The number of questionnaires that were collected: D	5,136
The official collection rate: D/C	67.8%
The actual collection rate: D/A	47.9%

Source: Investigation of actual situation with children and persons with physical disabilities 2006

gation of Actual Situation with Children and Persons with Physical Disabilities is calculated as approximately 67.8%, as illustrated in Table 2 (which is shown as D divided by C). The sample size was originally 10,725. Only 7,580 questionnaires were distributed, however, due to long-term absence, refusal to participate, and so on. Consequently, the actual collection rate was calculated as being approximately 47.9% (which is shown in Table 2 as D divided by A), and accounts for less than half. This collection rate is too low from the perspective of government statistics.

As well as a low collection rate, the techniques used to estimate the number of Children and Persons with Physical Disabilities are doubtful. In the 2006 survey, the estimated number was calculated using the ratio estimation method. However, the problem seems to lie in the assumption that the levels of disability in the collected questionnaires are representative of those in the uncollected questionnaires (which were uncollected to death, long-term absence, refusal to participate, and so on). This assumption is valid if the collection rate is high, but it is difficult to ensure the accuracy of the estimated result if the collection rate is low. In fact, it is natural to assume that the low rate can be attributed to issues of personal information and privacy, and that the results of the collected questionnaires are different from those of the uncollected questionnaires. What seems to be lacking is a variety of survey biases such as selection bias, information bias, and so on. For example, in the 2006 survey, there were very few people who do not possess a physical disability certificate. At the same time, the report does not provide any explanation for sampling errors and standard errors resulting from survey biases.

In the Basic Investigation of Actual Situation with Children and Persons with Intel-

lectual Disabilities, the collection rate (80.3%) and response rate (82.2%) have been described, but the estimation method was not explained in the brief overview of the survey.

The credibility of the statistical data is discussed in more detail in the next section. At least, it is necessary to revise the survey procedure and estimation method in order to improve the collection rate and accuracy of the estimated results.

3. Credibility of the statistical data

If there are problems related to the low collection rates and estimation techniques, the shortcomings of the statistical data are fairly obvious. In other words, it seems correct to assume that the statistical findings are not accurate or reliable. For example, the number of people with mental disorders was estimated at 1.08 million in 1992, and at 1.57 million in 1993, demonstrating an increase of 45.4%.

This drastic increase was due to a change in the estimation method. Until 1992, the estimate was based on results from the National Survey on Mental Health. In particular, the prevalence of mental disorders in the 1963 results—namely, 8.7 per 1,000 people—had been utilized for a long time: 1.08 million people were estimated to have mental disorders, using the calculation of 124 million (the population estimate at the time) x 8.7 per thousand. Since 1993, that estimate has been calculated based on the results of the Investigation of Patients.

In addition to the problem of the number having risen by about 500,000 in one year, there is another issue. The estimate based on the results of the Investigation of Patients does not seem accurate or reliable. According to the Investigation of Patients 2005, the number of outpatients with mental disorders except amnesia was estimated at 255,000 a day. However, the number in Table 1 is

estimated at 2,675,000. While the results of the Investigation of Patients refer to the number on one specific day, the results of Table 1 indicate the number over a certain period. Therefore, it is understandable that there is no agreement between these figures.

Under standard statistical methodology, there is no straight forward explanation for the calculation of the "2,675,000" result. Although this estimate is being used by the Ministry of Health, Labour and Welfare, it is impossible to judge whether the estimation method is correct. It is necessary for the government to publish the details of the estimation method used.

4. The absence of environmental factors in the statistics

The International Classification of Functioning, Disability, and Health (ICF) was adopted as a new classification of health and health-related domains by the World Health Organization (WHO) Member States in May 2001. ICF is the revised version of the International Classification of Impairments, Disabilities, and Handicaps (ICIDH), which was established in 1980. While ICIDH classifications are based on impairment, disability, and handicap, ICF includes a list of environmental factors and classifies domains along the lines of body, individual, and society using the interaction between two factors (body functions and structure as one factor, and domains of activity and participation as the other factor).

There have been numerous discussions on the ICF, but this concept is not reflected in the statistics of persons with disabilities in Japan. Even in the twenty-first century, conventional surveys have been conducted and have shown problematic results. In particular, statistical surveys of environmental factors are carried out mainly by the Ministry of Land, Infrastructure, and Transport. The purpose of these surveys, however, is to understand the current status of infrastructure improvement, rather than the environments of persons with disabilities. The central government needs to implement statistical surveys of environmental factors from the perspective of ICF.

5. Treatment of developmental disability

The definition of "developmental disability" is stipulated not in the Basic Act for Persons with Disabilities, but in Services and Support

for Persons with Developmental Disability. This includes pervasive developmental disorders (autism, Asperger's syndrome, etc.) and brain dysfunction (learning disability, attention-deficit hyperactivity disorder, etc.) that occur at an early age. It is difficult to clearly diagnose the type of developmental disability because the characteristics of individual diseases partially overlap. Hence, it is difficult to separate developmental disability from other kinds of disability such as physical, intellectual, or mental.

The number of persons and children with developmental disabilities has increased recently. Not only the medical field but also communities face serious problems regarding this issue. The central government promotes overall policies that consolidate health, medical, welfare, education and labor, but that do not survey the current status and needs of people with developmental disabilities in terms of personal information, privacy, and difficulty of classification. Exceptionally, the Ministry of Education, Culture, Sports, Science and Technology publishes the number of students with special needs (112,334 in FY 2008). Naturally, this number does not include those over 18 years of age. Consequently, persons and children with developmental disabilities should be included in the statistics on the disabled. At the same time, it is necessary to discern the types of disabilities.

Improvement of the statistics on disabled people in Japan

In the preceding section, problems on the statistics of disabled people have been discussed, including some suggestions for refinements. Subsequently, this section suggests some major improvements. First, international movements need to become better understood.

Currently, statistics on the disabled have been studied progressively throughout the world. The leading organization to emerge is the Washington Group on Disability Statistics. That group was formed by the United Nations in 2001. As of 2009, representatives from 116 countries and areas participate in the Washington Group. The purpose is to develop and promote definitions, methods, and approaches to statistics on disabilities in order to facilitate the comparison of data at the international level. The Washington Group

holds meetings at regular intervals and publishes its findings and recommendations.

The main achievements of the Washington Group are as follows:

- (1) Development and endorsement of a short question set intended for use on national censuses, accompanying rationale, and test implementation protocols
- (2) Instruction to countries conducting Washington Group tests and, more generally, on disability data collection methods
- (3) Survey by standardized Washington Group tests for a short set of questions in 15 countries
- (4) Development of extended question sets to be used as components of population surveys, as supplements to surveys, or as the core of a disability survey
- (5) Implementation of standardized cognitive testing of the extended question sets in nine countries
- (6) Implementation of field testing of extended question sets in six countries

It is beyond the scope of this paper to explain every achievement in detail. An important point about achievements is two question sets, namely short and extended. The Washington Group has developed question sets intended for use on national censuses, population surveys, and disability surveys. In addition, the group analyzes survey results and revises the question sets as needed. Figure 1 illustrates the content of the short question set.

The Washington Group hopes that many countries will utilize short or extended question sets for statistical surveys such as census. In fact, 80 countries and areas have adopted questions on disability for use in censuses between 1995 and 2004. Some countries have introduced the Washington Group's question sets in total, and others have modified these question sets. Furthermore, the number of countries that have adopted the use of those questions in population surveys and disability surveys seems to be on the rise.

Contrary to the international trend, Japan

The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM	
1. Do you have difficulty seeing, even if wearing glasses?	2. Do you have difficulty hearing, even if using a hearing aid?
a. No – no difficulty	a. No – no difficulty
b. Yes – some difficulty	b. Yes – some difficulty
c. Yes – a lot of difficulty	c. Yes – a lot of difficulty
d. Cannot do at all	d. Cannot do at all
3. Do you have difficulty walking or climbing steps?	4. Do you have difficulty remembering or concentrating?
a. No – no difficulty	a. No – no difficulty
b. Yes – some difficulty	b. Yes – some difficulty
c. Yes – a lot of difficulty	c. Yes – a lot of difficulty
d. Cannot do at all	d. Cannot do at all
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?
a. No – no difficulty	a. No – no difficulty
b. Yes – some difficulty	b. Yes – some difficulty
c. Yes – a lot of difficulty	c. Yes – a lot of difficulty
d. Cannot do at all	d. Cannot do at all

Figure 1 Short set of questions

Source: Washington group on disability statistics, Recommended short set of questions
 (http://www.cdc.gov/nchs/data/citygroup/WGhort_Measure_on_Disability.pdf).

has not adopted the Washington Group's question sets either in the census, or in other statistical surveys. At the same time, there has not been any attempt to investigate current situations regarding health and disability in the census. The survey items of the census are classified into three sections: household (number, type, age, etc.), housing (kind of residence, area of floor space, etc.), and labor (occupation, employment status, hours of work, etc.). Because there are no questions about health and disability, it is impossible to examine the adequacy and reliability of sampling. As a result, estimated values do not seem correct. In conclusion, the central government should introduce survey items on health and disability in the census. Naturally, the Washington Group's international standard needs to be utilized. In view of aging population, it is hoped that this suggestion will be implemented as soon as possible.

Conclusion

The objective of this paper is to introduce a system for statistical survey of people with disabilities, point out the problems, and suggest improvements. Because a comprehensive statistical survey of disabled people is not carried out in Japan, the objectives, definitions, procedures, and so on among existing surveys contain differences, and the results do not seem accurate or reliable. This situation leads to inappropriate estimations such as that for the number of disabled people. Therefore, survey items related health and disability should be adopted in the census as soon as possible.

The number of people with disabilities in Japan appears considerably lower than international levels due to the narrow coverage and inadequate estimation method. It is consid-

ered that this underestimation results in indifference, negligence, and budget cuts for the disabled. In other words, the deficiency of these statistics suggests that the government intentionally neglects people with disabilities.

The issues related to disabled people are sensitive and difficult to survey. After carefully considering the difficulties, there is no doubt that the statistical system for the disabled in Japan is deficient and unsatisfactory. These circumstances deprive not only the disabled but also the healthy individual of safety and security. Therefore, the central government should review and reconstruct the statistics on people with disabilities.

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