Asian Journal of

# HUMAN SERVICES

Printed 2011.0901 ISSN2186-3350
Published by Asian Society of Human Services

September 2011
VOL. 1

Asian society of Human services

ORIGINAL ARTICLE 7

# Causes of Transition from Institution to Group Home for the Persons with Intellectual Disability, Analyzed with the ICF

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## ABSTRACT

The Ministry of Health, Labor and Welfare has formed a scientific research study group to clarify factors inhibiting social participation of persons with mental retardation, and to develop methods to improve such participation. The group conducted the present survey with the aim of identifying the causes preventing such participation at present, and clarifying the types of measures needed to resolve these issues. To enable future international comparisons with some of the results, they were rated using the common international language in the International Classification of Functioning, Disability and Health (ICF). Surveys were sent to the chief staff of 506 institutions (welfare facilities for mentally retarded) nationwide in Japan, and valid responses were received from 224. Each institution was asked to recall one member each from among those transited or residing in institutions, and rate them on each of the ICF levels. The factors producing differences in the career path treatments for transition to community life and institutional residence were then analyzed. The transited group of members had a mean score of no higher than 2 for any item evaluated by the ICF criteria. The institutionalized group, on the other hand, had this score on 1 body function item and 12 activity and social participation items.

Received
June 10,2011

Accepted
August 22,2011

Published
September 1,2011

＜Key-words＞
Transition, Group home, WHO, ICF
Asian J Human Services, 2011, 1: 100-111. © 2011 Asian Society of Human Services

# Ⅰ. Introduction

The popularization of normalization is changing policy toward the intellectually disabled, with the emphasis shifting from institutional placement to community life. In Japan, however, most people with intellectual disabilities who are employed by a company live with their parents. There are many people with intellectual disabilities unable to live by themselves, making them dependant upon their parents for daily life.

In Europe and America the development of group homes, which serve as a basis for transition to community life, has spread rapidly. The development of such facilities lags in Japan, however. There is an unequivocal shortage of support and societal resources for people with intellectual disabilities living in communities. We are then left to wonder if anything else is preventing the transition from institutions to community life.

A nationwide investigation was conducted by a welfare, labor and science group entitled "Research for the promotion of social participation in persons with intellectual disability by identifying and resolving obstructive factors." The two objectives of the study were as follows.

(1) To identify the factors which prevent such participation by people with intellectual disabilities.
(2) To clarify the types of measures needed to resolve these issues.

To enable future international comparisons with some of the results, graduates were rated using the common international language in the International Classification of Functioning, Disability and Health (ICF). ICF belongs to the “family” of international classifications developed by the WHO for application to various aspects of health. The WHO family of international classifications provides a framework to code a wide range of information about health and uses a standardized common language permitting communication about health and health care across the world in various disciplines and sciences. ICF is a multipurpose classification designed to serve various disciplines and different sectors (WHO, 2001).

The components of functioning and disability in Part 1 of ICF are interpreted by

Received
June 10,2011

Accepted
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means of four separate but related constructs. These constructs are operationalized by using qualifiers. Body functions and structures can be interpreted by means of changes in physiological systems or in anatomical structures. For the Activities and Participation component, two constructs are available: capacity and performance2). The definitions of ICF components are given in Table 1. Badley (2008) described that A key area left open in the ICF was the distinction between activity and participation.

ICF has two parts, each with two components. Each component can be expressed in both positive and negative terms. Each component consists of various domains and, within each domain, categories, which are the units of classification. Health and health-related states of an individual may be recorded by selecting the appropriate category code or codes and then adding qualifiers, which are numeric codes that specify the extent or the magnitude of the functioning or disability in that category, or the extent to which an environmental factor is a facilitator or barrier (WHO, 2001).

Bruyere, Van Looy, Peterson (2005) reviews the literature since the ICF's endorsement, focusing on those articles that discuss (a) what the ICF means and how it can be used. Research and clinical implementation efforts suggest that the ICF is a useful and meaningful public health tool (Peterson, 2005). Jette, Norweg, & Haley (2008) reviewed the strengths and weaknesses of two different approaches to assessing ICF concepts: coding versus quantitative scales. They concluded ICF codes provided a useful approach for classifying easy-to-interpret health-related information on individuals that can be incorporated into administrative records and databases.

Schneidert, Hurst, Miller, & Ustun (2003) provides a framework for understanding the impact of environmental factors on functioning when a person has a health condition. They said the ICF was a classification that allows a comprehensive and detailed description of a person's experience of disability, including the environmental barriers and facilitators that have an impact on a person's functioning. Howard, Nieuwenhuijsen, & Saleeby (2008) discussed how the ICF could be useful in enhancing social change through health promotion and health education for all people, in particular those with disabilities and chronic conditions. Excepting the reports mentioned above, there are many ones affirm the ICF in clinical experience ( Maeda, Kita, Miyawaki, et. al., 2005; Slebus, Sluiter, Kuijer, et. al., 2007; Mullis, Barber, Lewis, et. al., 2007; Gabl , Krappinger, Arora, et. al., 2007; Osteras, Brage, Garratt, et. al., 2007; Starrost, Geyh, Trautwein et. al., 2008; Mittrach, Grill, Walchner-Bonjean et. al., 2008; Paul, Leitner, Vacariu et. al., 2008;

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Jonsson, Ekholm, & Schult, 2008; Martin, Burtner, Poole et. al., 2008; Soberg, Finset, Roise et. al., 2008; Coster & Khetani, 2008; Wright, Rosenbaum, Goldsmith et. al., 2008; Okawa, Ueda, Shuto et. al., 2008 ).

**<Table 1> The definitions of ICF components**

| |
|---|
| In the context of health:<br>Body functions are the physiological functions of body systems (including psychological functions).<br>Body structures are anatomical parts of the body such as organs, limbs and their components.<br>Impairments are problems in body functions or structures such as a significant deviation or loss.<br>Activity is the execution of a task or action by an individual.<br>Participation is involvement in a life situation.<br>Activity limitations are difficulties an individual may have in executing activities.<br>Participation restrictions are problems an individual may experience in involvement in life situations.<br>Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives. |

WHO (2001)

In this investigation, the transition from institutions to community life was considered to be a concrete form of participation. Each institution was asked to recall one user with intellectual disabilities each from among those sifted to group homes or residing in institutions, and to rate them in accordance with each ICF criterion. From comparison, the factors behind these differences in career path handling (i.e., transition to community life and institutionalization) were then analyzed.

## Ⅱ. Methods

### 1. Subjects

Replies to the survey investigation were requested from the chief staff of 506 institutions (welfare facilities for mentally retarded) nationwide in Japan. Although the director at each institution was in charge of filling out the return questionnaire

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Accepted
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in principle, it was presumed that other teachers were also allowed to do so in cases requiring detailed evaluation.

## 2. Procedure

1) Investigation method (Mail survey)

The survey questionnaire recipients were asked to mail back the completed stamped, self-addressed reply forms using the previously enclosed return envelope.

2) Contents of questionnaire

A stamped, self-addressed return envelope containing the request letter and a set of survey forms was mailed out to the chief staff at each institution. The questionnaire survey items covered the group home's conditioning, system, ICF comparison, and opinion.

Here we present the results of the ICF comparison. One member each from the institution was to be chosen for the following categories: "Member transit to a group home" and "Member entering institution for more than 3 years". The respondent was to select members whose informations were sufficient to rate them on each of the ICF levels. They were to remember how the member of their choice seemed as, and then to evaluate him according to the ICF criteria. A member transit to a group home was called A, and a member entering institution for more than 3 years was called B.

They were to be evaluated by each of the main 3 ICF factors of body functions, activity and participation, and environment. However, since body structure was difficult for an on-site teacher to distinguish clearly from psychosomatic function, it was included in the body function analysis.

The ICF uses two ways to score activities and participation; performance and capacity. The scoring (evaluation) of capacity is defined as the level of an individual's ability to execute a task or given action at a given time. Since evaluation involves the past in the present survey investigation and the person doing the evaluation does not do so in a uniform manner, the evaluation in a uniform or standard environment is virtually impossible. For this reason we decided to use only performance as a criterion to evaluate activity and participation. Moreover, the evaluation of activity and participation was to be made in detail by further subdividing the "education" factor into 3 categories; "informal education," "school education," and "vocational training."

"Relationship and support" in the environmental factors was also to be evaluated in detail using further classifications because one's relationships and the type of support provided key information for devising measures to address certain issues.

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Accepted
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Specific examples of the above criteria items were provided in each case in the questionnaire. Use of only ICF expressions would be presumably difficult to understand and thus make it difficult for the respondent to reply. The respective standards used by the ICF to rate difficulty, etc. were adopted for the evaluation criteria. Among the environment factors, the "facilitation level" was evaluated for "Member transit to a group home", and the "hindrance level" was evaluated for "Member entering institution for more than 3 years".

## Ⅲ. Analysis

After checking the original forms of the returned questionnaires, Excel was used to finally sort out the raw data from valid replies. SPSS was used for the statistical analysis.

## Ⅳ. Result feedback

The plan is to e-mail a summary of the survey results to any person requesting it.

### 1. Results and Discussion

1) Response Rate

Some 224 valid replies were obtained from the survey questionnaires sent out to the chief staff of 506 institutions nationwide in Japan. This amounts to a response rate of 44.3%.

2) ICF comparison of transit to group home and residing in institutions members

(1) Severity of body function and functional impairment

Figure 1 presents a comparison of body functions between those who transit to group homes (A) and those who reside in institutions (B). The severity was significantly greater in the transit group than the residing group on all items using t-test. In both groups "mental functions" were highest, followed by "voice and speech functions." Both groups evidenced virtually the same tendencies for all items evaluated. According to the ICF evaluation criteria, a score of 2 was defined as a moderate degree of functional impairment, and only the "mental functions" item of the residing group exceeded this level.

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June 10,2011

Accepted
August 22,2011

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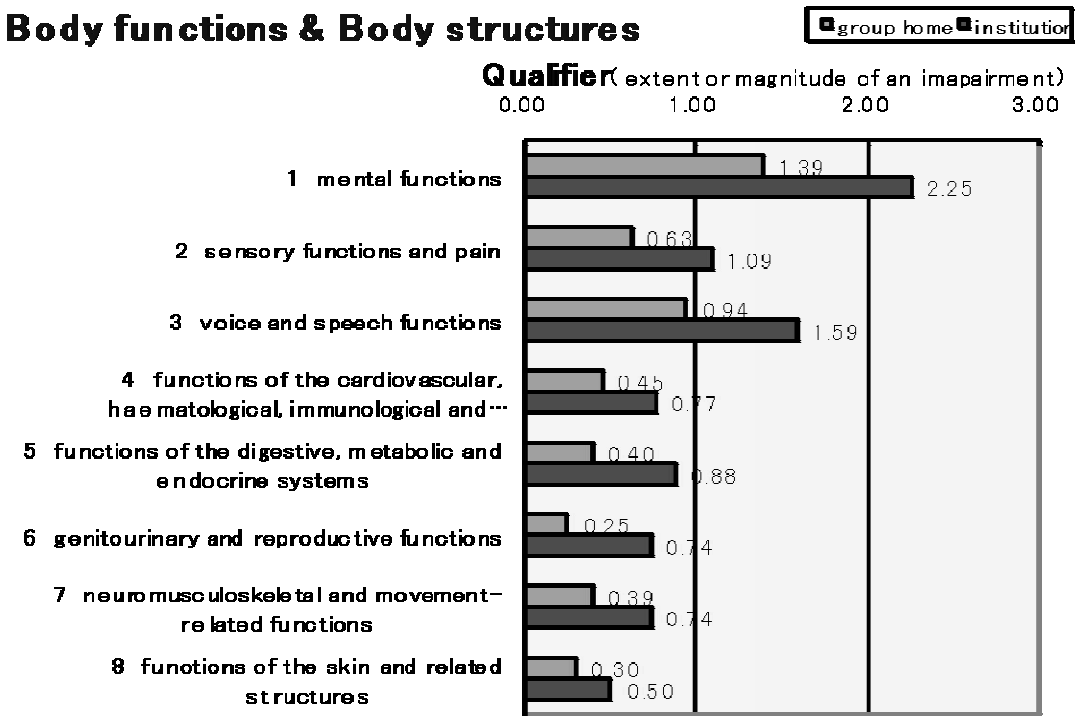
<Fig 1> Impairment of body functions




(2) Degree of difficulty associated with activities and participation

Figure 2 shows a comparison of the transited (A) and institutionalized (B) groups in terms of their activities and social participation. Members (B) residing in institutions scored significantly higher than transited members (A) on every item based on the t-test results. In the residing group, scores were higher in the order of "vocational training," "economic life," "community life," "interpersonal interaction and relationships," and "school education".

According to the ICF criteria, a score of 1 indicates mild difficulty while a score of 2 denotes moderate difficulty. The mean score of the institutionalized group proved to be over 2 in 12 of the 14 evaluation items. The transit group, on the other hand, had a mean score of more than 1 on only one item, "informal education." This suggested that the "activation and social participation" item is very important as a factor distinguishing the two groups here.

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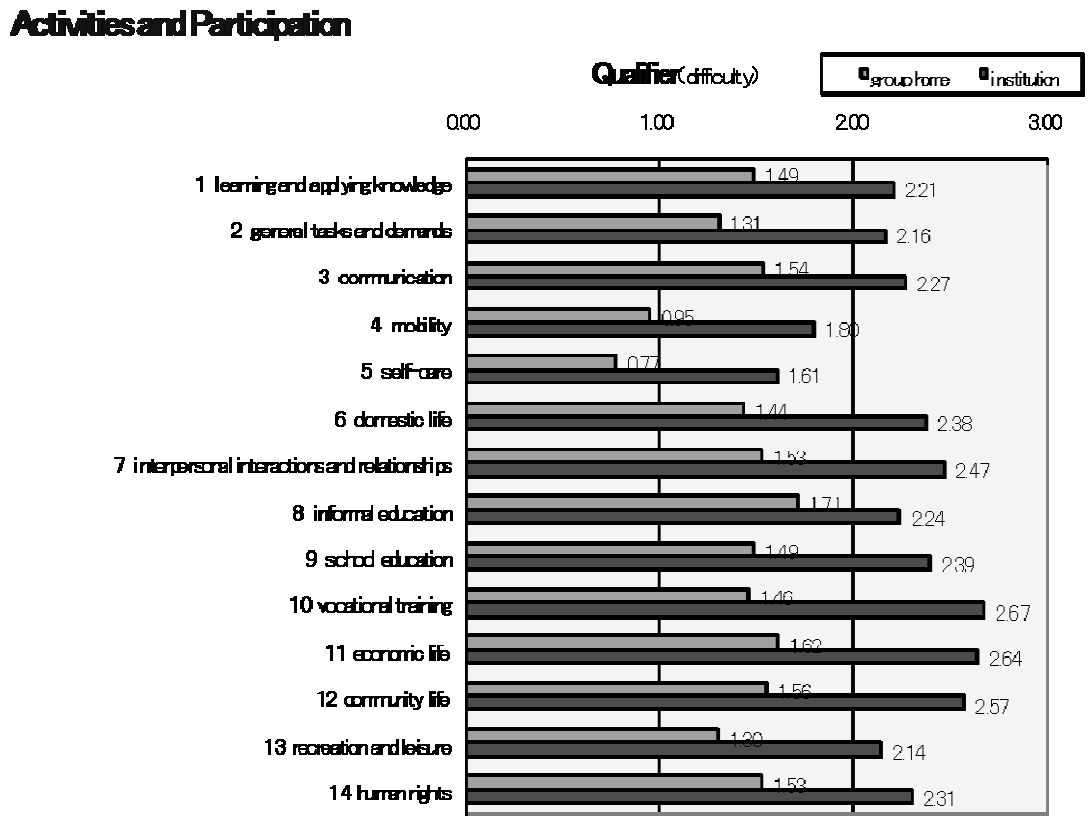
<Fig 2> The degree of difficulty of activities and participation




(3) Facilitation and impairment levels

Figure 3 shows the facilitation level as an environmental factor in the transited group (A) of members. For those in this group, it was clear that the facilitation level was highest for "support and relationships; personal care providers and personal assistants," reflecting the importance of teachers.

Figure 4 shows the hindrance level as an environmental factor in the institutionalized group (B). The highest hindrance levels were for "support and relationships; immediate family" in the institutionalized group. It was clear that the reasons they were forced to enter institutions was the little support from their families.

The ICF evaluation criteria define a score of 1 as a mild facilitation/hindrance factor, and a score of 2 as a moderate facilitation/hindrance factor. Neither group had a mean score of more than 2.

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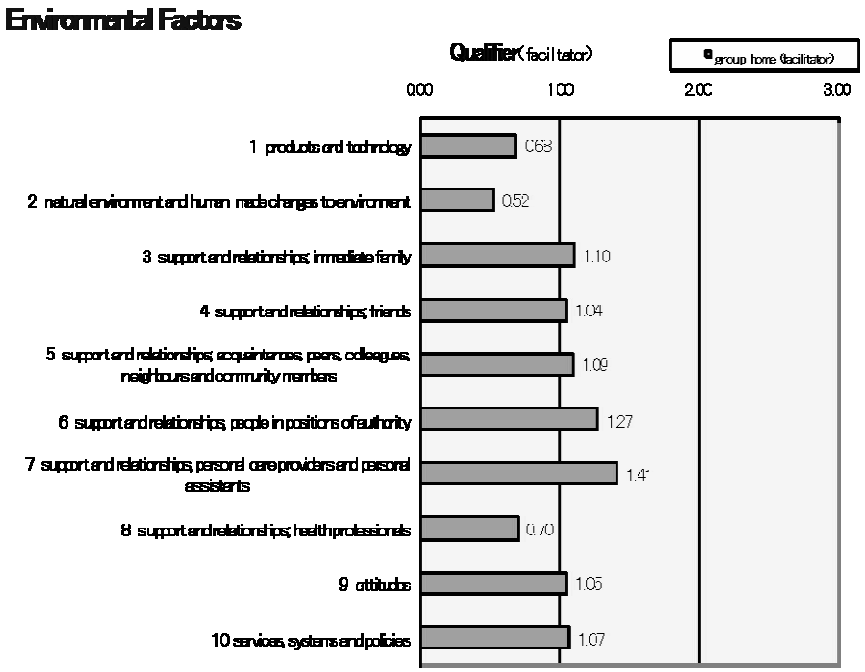
June 10,2011

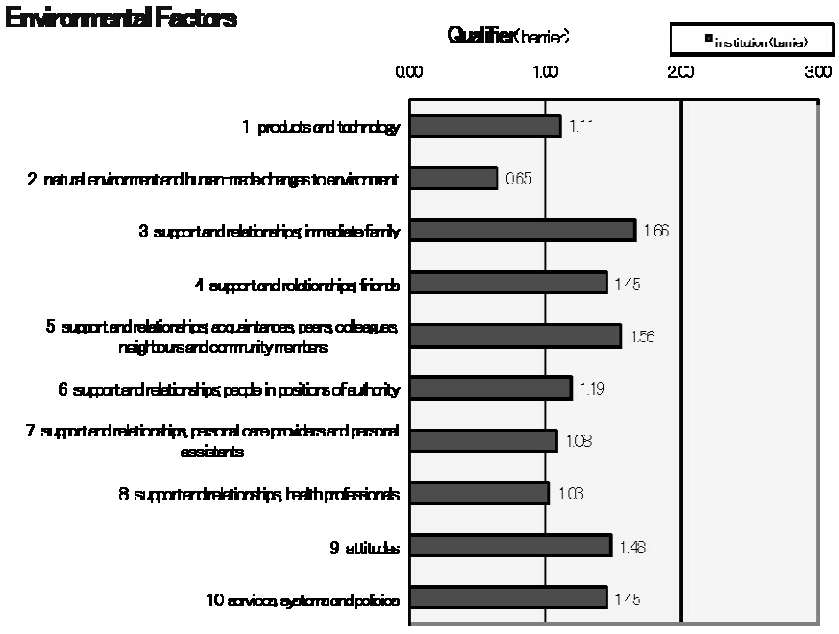
Accepted
August 22,2011

Published
September 1,2011

<Fig 3> The degree of facilitator of the environmental factor of an employment group (the A)




<Fig 4> The degree of barrier of the environmental factors of the institution group (the B)




Received
June 10,2011

Accepted
August 22,2011

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September 1,2011

(4) Overall comparison

The transit group had a mean score of no higher than 2 for any item evaluated by the ICF criteria. The institutionalized group, on the other hand, had this score on 1 body function item and 12 activity and social participation items. It was suggested that these 13 items were important factors for distinguishing between the transited and institutionalized members in terms of career path approaches. We plan to conduct further analyses using detailed statistical processing.

**2. Additional remark**

This research was performed as a welfare, labor and science research group project entitled: "Research for promotion of the social participation in persons with intellectual disability by identifying and resolving obstructive factors" (representative: Masumi Inagaki) in Japan. We are deeply grateful to the professors of the research group, and to the institution staffs who cooperated in our investigation.

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June 10,2011

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Received
June 10,2011

Accepted
August 22,2011

Published
September 1,2011

Asian Journal of Human Services
VOL.1 September 2011

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Published by
Asian Society of Human Services
8-24-25 Shinmachi, Ome, Tokyo, Japan