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Original Paper

Medical-Welfare System Caring for People with Severe Intellectual Handicapps in Japan

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Abstract

The purpose of this paper is to summarize a historical perspective of social-welfare for Japanese with a severe intellectual handicap and to present the major characteristics of the care system at hospital-homes in Japan as compared with the system in Denmark. In addition, this paper describes Japan's unique system for the care of "Jusho-shinshin-shogai-ji" (people with a severe physical and mental handicap). This includes its history and functions, particularly the important role of hospital-homes as community-based centers. Also, we propose a plan for the role of a community-based medical-welfare system for the severely intellectually handicapped based on the concept of "normalization". Introduced is a model for community-based care of "Jusho-shinshin-shogai-ji" in a city of one million people.

Introduction

Since the end of World War II, the Japanese social welfare system for the care of the handicapped has been improved by studying the advanced models of the United States and Europe. Rather than simply imitating the western models, Japan has developed her own unique system based on its own medical-welfare history and the Japanese characteristic of strong family-bonding.

The purpose of this paper is to summarize a historical perspective of social-welfare for

Japanese with a severe intellectual handicap and to present the major characteristics of the care system at hospital-homes in Japan as compared with the system in Denmark, where the concept of "normalization" was born. This paper also describes Japan's unique social welfare concept of "Jusho-shinshin-shogai-ji" (people with a severe physical and mental handicap) and the important role of hospital-homes for these people. A model for hospital-homes as community-based medical-welfare centers is introduced and their functions are discussed.

A historical perspective of social-welfare for the severely intellectually handicapped in Japan

Japan's welfare system for the intellectually handicapped began with non-profit private institutions. Takinogawa-Gakuen was built in 1891, and there were about 20 facilities all over Japan before World War II,

Since the end of World War II, this welfare system has been progressively improved, including by legislation. Japan enacted the Law of Child Welfare in 1947 and the Law of Welfare for People with Mental Retardation in 1960 (Fig. 1).

In 1967, for the first time ever, a statute called the "Revised Law for Child Welfare" provided that children who have both a profound mental handicap and a severe physical handicap would be called "Jusho-shinshin-shogai-ji". Since then, the number of hospital-homes for these people has increased.

In the meantime, similar laws were enacted for people with physical, visual and auditory handicaps. More than 20 years after World War II, Japan enacted the Fundamental Law of Action for the Intellectually and Physically Handicapped. Its purpose was to reorganize and rearrange existing laws and promote more effective networking among people with different handicaps.

In 1993, the above Law was revised as the Fundamental Law for the Handicapped to promote the United Nation's 10 Years campaign of "Perfect Participation and Equality for the Disabled". In 1995, under the name of the Fundamental Law for the Handicapped, a National Action Plan for the Handicapped was announced for the coming seven years. The Japanese Government showed a clear commitment to a definite number of care providers and day-care centers so that the handicapped would be able to participate, work and live in a community-oriented life (Fig. 1).

A historical perspective of hospital-homes for the intellectually handicapped in Japan

The quality of care for the intellectually handicapped at institutions has been improved by the above-mentioned laws. As far as the severity of handicap is concerned, the criteria for institutionalization has changed from a mild degree of severity to a moderate and severe degree. At present, even the most severe cases of handicapped are accepted

Fig. 1 Laws Related to the Intellectually Handicapped in Japan

1947	The Child Welfare Law
1960	The Law for the Welfare of Mentally Retarded Persons
1976	The Revised Child welfare Law (Hospital-Homes for "Jusho-ji")
1970	The Fundametal Law for People with Disabilities
1993	The Fundamental Law for the Handicapped (Revised)
1995	The Plan for People with Disabilities (Seven-year-strategy for Normalization)

(Fig. 2).

Regarding age ranges, at first institutions only accepted school-aged children, from preschool children to adult. Recently, they have begun accepting the whole range of the population, including the aged.

With special regard to the types of services, the functions of the institutions have expanded from inpatient services to outpatient, day-care, short-stay, and visiting services in support of the home-based medical-welfare system. The institutions are not large, with room for about 50 to 100 residents. The trend is toward downsizing to small sized institutions and group homes where only 4 to 6 residents live together.

Major characteristics of institutions for the intellectually handicapped in Japan (Fig. 3)

Figure 3 shows the major characteristics of the facilities for the intellectually handicapped in Japan, in comparison with those in the western countries. First of all, our facilities are mostly founded by non-profit private organizations. According to a survey by the Association for Care of People with Mental Retardation in 1996, there were 13 non-profit private facilities for every two National or Prefectural Government facilities.

Second, as shown in the comparison between Japan and Denmark described later, it is clear that the facilities are, as previously mentioned, mainly medium sized. There are no large facilities that can accommodate 1,000 to 2,000 residents as was the case in the United States in the early years.

Third, the facilities in the western countries are mainly under a hospital-based management system. In contrast, the facilities in Japan place an emphasis on the day-to-day

Fig. 2 Changes and Expansion of the Role of Facilities for the Intellectually Handicapped

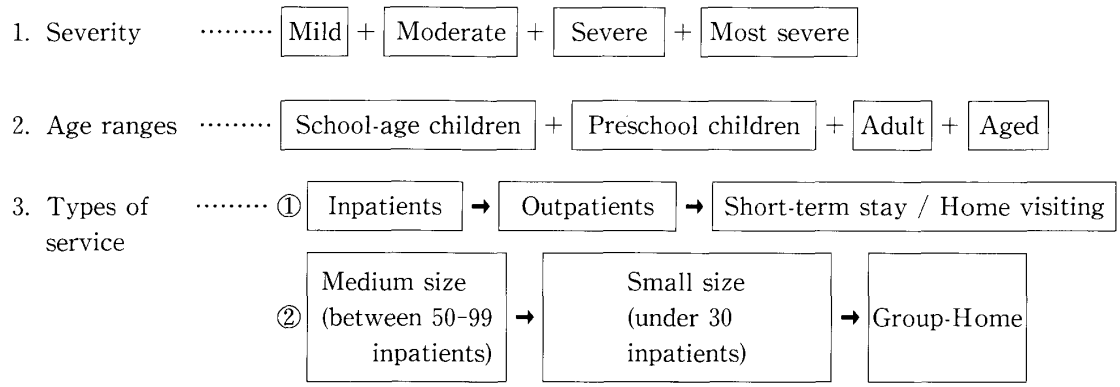


Fig. 3 Major Characteristics of Facilities for the Intellectually Handicapped in Japan

1. Non-governmental organization.
2. Medium-sized facilities. (between 50-99 inpatients)
3. Not hospital but community and family oriented. (except children with autism and "Jusho-shinshin-shogai-ji")
4. Plays a major role as a community-based center.
5. Hospital-home in Japan for "Jusho-shinshin-shogai-ji" is an unprecedented service systdm in the world.

activities performed by various staff members such as nursery nurses, care providers and teachers. Among 2,700 facilities, only about 50 have medical doctors as directors. Only hospital-homes for "Jusho-shinshin-shogai-ji", which will be described in detail in a later chapter, are managed by medical hospitals. They are the exception, however, and comprise only about 5 % of all the facilities. Because of the geographical characteristics of Japan, our facilities are closer and much more connected to the communities in comparison with those in the western countries.

Fourth, the high educational level of the staff members, mainly college and university graduates, makes it possible to extend services from residents to people who live in the community.

Last but not least, we have developed the unique concept of "Jusho-shinshin-shogai-ji" and their hospital-homes, which does not exist anywhere else in the world. Also developed was a support system with integrated medical, educational and welfare services. We also help these people in home-based living.

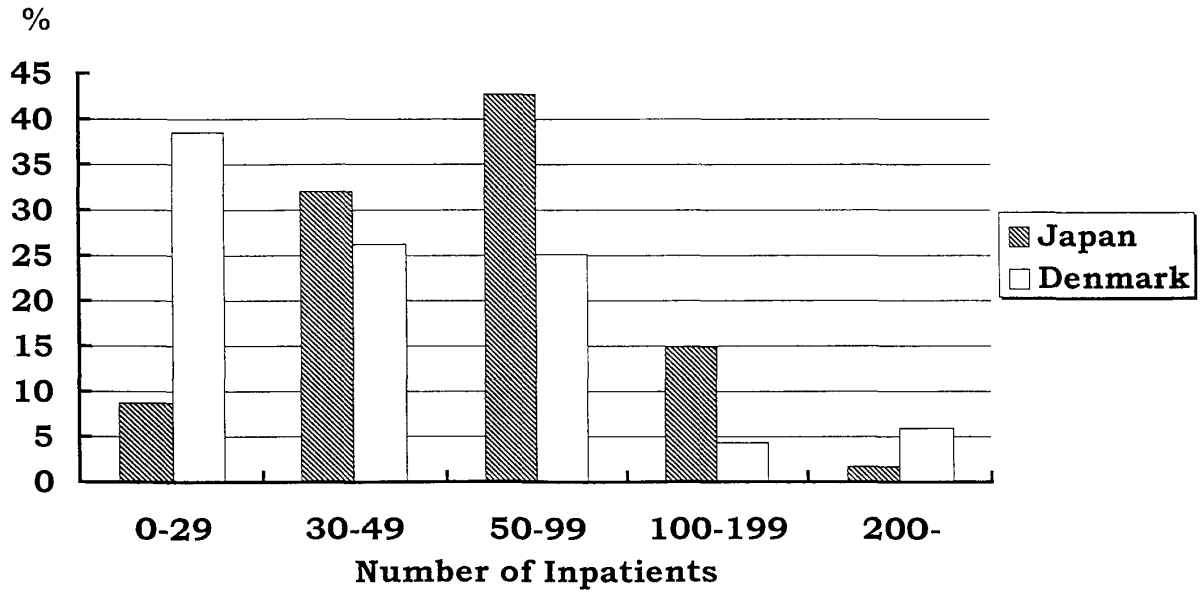
Comparisions between Japanese and Danish Institutions

In 1984, there was a comparative investigation of the size of the facilities for the intellectually handicapped between Japan and Denmark, where the concept of "normalization" was born. This comparative investigation was done in Japan at a time when there were no such concepts as "normalization" and group-homes.

As shown in Table 1, medium-sized facilities where 50 to 99 residents were living were the most popular in Japan. Following in order were facilities with 30 to 49 residents, 100 to 199 residents, and under 29 residents.

In contrast to this, facilities with under 29 residents are the most popular in Denmark. Following in order were facilities with 30 to 49 residents, 50 to 99 residents, and 100 to 199 residents. This means that the larger the

Table 1 Comparison of the Size of the Facilities for the Intellectually Handicapped between Japan and Denmark (1984)



facility, the fewer the number of such facilities. In the case of facilities with over 200 residents, there were less than 2 % in Japan while Denmark had 6 %. The average number of residents in such large size facilities in Denmark was 300 to 400 while in Japan, it was around 200 residents.

Table 2 shows the distribution according to size of the facilities in Japan in 1995, 10 years after the first investigation. The number of large-sized facilities with 100 to more than 200 residents had decreased while the facilities with 30 to 49 residents and less than 29 residents had increased. The number of group homes were not included in this investigation. There were 767 group homes in Japan in April, 1996, and the number is increasing (Table 2).

A historical perspective and current conditions of "Jusho-shinshin-shogai-ji"

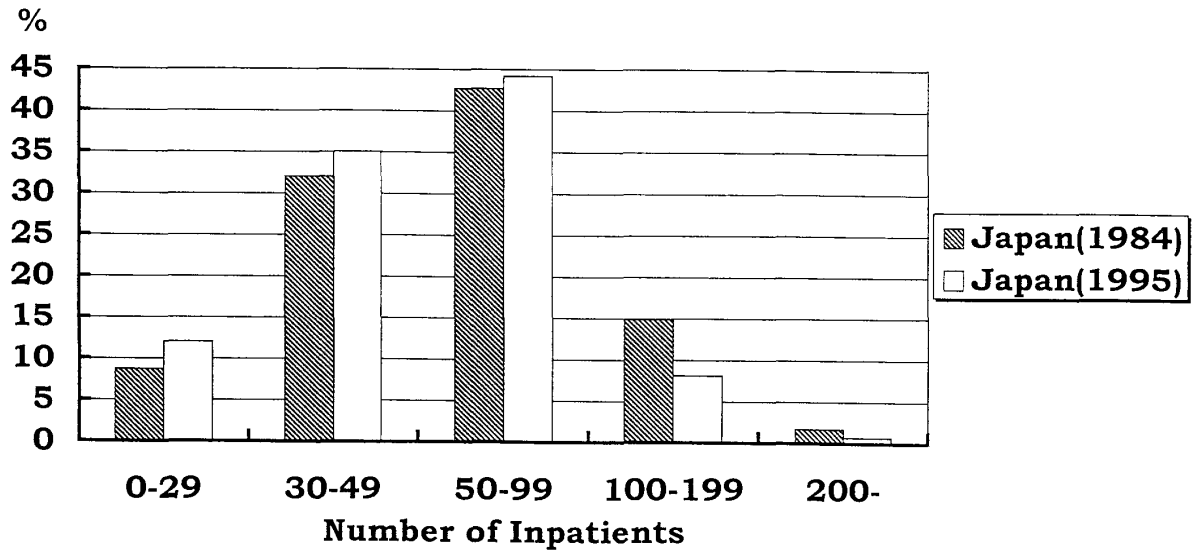
As previously described, Japan's unique concept of "Jusho-shinshin-shogai-ji" was legally accepted as a social welfare term in 1967. This term literally means a child who has both a severe physical disability and profound mental retardation, as shown in Figure 4. Groups 1 through 4 are called "Jusho-shinshin-shogai-ji" and groups 5 through 9 are children on the borderline. The incidence of "Jusho-shinshin-shogai-ji" in Japan was 0.99 per 1,000 children in the 3 to 7 year old range. The number of "Jusho-shinshin-shogai-ji" in the total population has been estimated at around 37,000 "Jusho-ji" in Japan (total population: 120,000,000). Of these, 12,000 are in hospital-homes. It is assumed that the remaining 25,000 live in their homes (Figs. 4^{-1} & 4^{-2}).

The purposes and the significance of the system for the care of "Jusho-shinshin-shogai-ji"

From the previous discussion, it should be clear that the legal acceptance of "Jusho-shinshin-shogai-ji" and their hospital-homes was very significant. The following is a brief summary of the accomplishments (see details in previous articles by the author).

First of all, legal acceptance made it possible to save lives and preserve the dignity of "Jusho-shinshin-shogai-ji". Previously, these people were neglected by society. It was difficult for families to raise these children on

Table 2 Changing Panorama of Facilities for the Intellectually Handicapped in Japan



their own. Therefore, whole family suicides occurred often in families with "Jusho-shinshin-shogai-ji". Legal acceptance relieved the pressure on the families and made it possible to extend the basic concept of the dignity of life to "Jusho-shinshin-shogai-ji", the weakest and most delicate children of all.

Second, it made possible new interdisciplinary approaches for "Jusho-shinshin-shogai-ji" in connection with medical, nursing, welfare and educational services.

Third, new procedures were developed which greatly improved medical diagnosis, treatment and nursing care. Rehabilitation programs, including respiratory physical therapy and feeding therapy, have progressed and we have been developing and improving our services for both inpatients and home-stay "Jusho-shinshin-shogai-ji" and their families (Fig. 5).

Fig. 4-1 Classification of "Jusho-Shinshin-Shogai-ji"

Ability / IQ	Able to Run	Able to Walk	Walking Disturbance	Able to Sit	Bedridden
70-80	21	22	23	4	25
50-70	20	13	14	15	16
35-50	19	12	7	8	9
20-35	18	11	6	3	4
0-20	17	10	5	2	1

*Classifications (1) through (4) are called "Jusho-shinshin-shogai-ji".

Fig. 4-2 Classification of "Jusho-shinshin-shogai-ji"

1. Definition : "Jusho-shinshin-shogai-ji"

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Children who both a profound mental handicap and a severe physical handicap and who were untreated in their early years or failed to procure medical services.

2. Incidence : 0.99 / 1,000 children
3. Inpatients : 12,000 out of 120,000,000 people (total population)
   Home-stayed : 25,000 out of 120,000,000 people (total population)

Changes of the role of hospital-homes

Before 1967, institutionalization was the primary goal for all "Jusho-shinshin-shogai-ji". However, because of developments in caring techniques and improvements in the welfare and educational settings, the prospects for "Jusho-shinshin-shogai-ji" have been changed dramatically. Currently, institutionalization is thought to be the last solution and home-based or community-based care have become the priority for "Jusho-shinshin-shogai-ji". Caring at group homes with medical backup is now under investigation. Hospital-homes are now providing comprehensive services such as short-term stays, day care centers, outpatient clinics, rounds clinics in rural areas, home visiting, supervision by coordinators and screening services for early detection. The hospital-homes for "Jusho-shinshin-shogai-ji" are now expected to play an important role as community-

Fig. 5 The Outcome and the Purposes for the Medical-Welfare Service System for "Jusho-ji"

1. Respects the lives of the vulnerable and severely handicapped.
2. Expands the multidisciplinary and comprehensive services for covering all people with handicapps.
3. Enriches the nursing and specialized medical care program for the most severe "Jusho-ji".
4. Develops specialized rehabilitaion programs (such as respiratory physical therapy and feeding therapy) for "Jusho-ji".
5. Enriches caring programs both for inpatients and the home-stayed.

Fig. 6^{-1} Merits of "The Plan for People with Disabilities" (1)

1. Increases the number of day care centers, sheltered workshops and group-homes.
2. Increases the number of day care centers for persons with severe handicapps.
   (300 centers ➡ 3,000 centers)
   Increases the number of branch centers for children with severe handicapps.
   (25 centers ➡ 300 centers out of the above 3,000 centers)
3. Increases the number of specialized nursing staff for children with handicapps. (40,000)
   Increases the number of specialized nursing staff for elderly people. (170,000)
4. Creates a new Department of Health and Welfare in the National Welfare Ministry to make possible an integrated service plan for people with intellectual, physical and mental handicapps.

Fig. 6^{-2} Merits of "The Plan for People with Disabilities" (2)

1. Enriches the program for the home-stayed.
2. Expresses clearly the numerical goals for services for "Jusho-ji" such as day care centers and volunteers.
3. Delegates responsibility to local community (city, town and village) governments from the national and prefectural governments.

based centers and are also being asked to offer high quality therapy services.

Major characteristics of The Action Plan for the Handicapped

Figure 6 shows some of the characteristics of The Action Plan for the Handicapped, from a "normalization" point of view. It states clearly that day care centers, small-sized workshops and group homes in the community should be increased and medium-sized facilities should be retained or even increased. There will be 3,000 day care centers for people with severe handicaps in 7 years. There are only 300 at the present time. Among these, day care centers for "Jusho-shinshin-shogai-ji" will be increased from 25 sites to 300 sites.

An increase in the number of careproviders is also planned. At the present time, 170,000 careproviders for aged people are planned with an additional 40,000 to be added later.

A restructuring of the National Organization for the Handicapped was also executed in the form of integration. The Department of Health and Welfare for All kinds of Handicapped started in July, 1996.

As mentioned above, various types of home-based services and the policy for "Jusho-shinshin-shogai-ji" are now rapidly improving, both in quantity and quality. And the responsibility for administration is now shifting from the national government to local governments, which will make possible the promotion of more community-based services (Table 3).

A model of community-based care by hospital-homes

In conclusion, Table 4 shows the ideal model of a community-welfare system for "Jusho-shinshin-shogai-ji", which came about as a result of integration among medical, welfare and educational services under the national policy. To be precise, one hospital-home is needed for each one million people of the population and it should have various services such as outpatient clinics, day-care centers, short-term stays, supervision by coordinators, and home visiting. And if at least 2

Table 3 Shifting Roles of Hospital-Homes

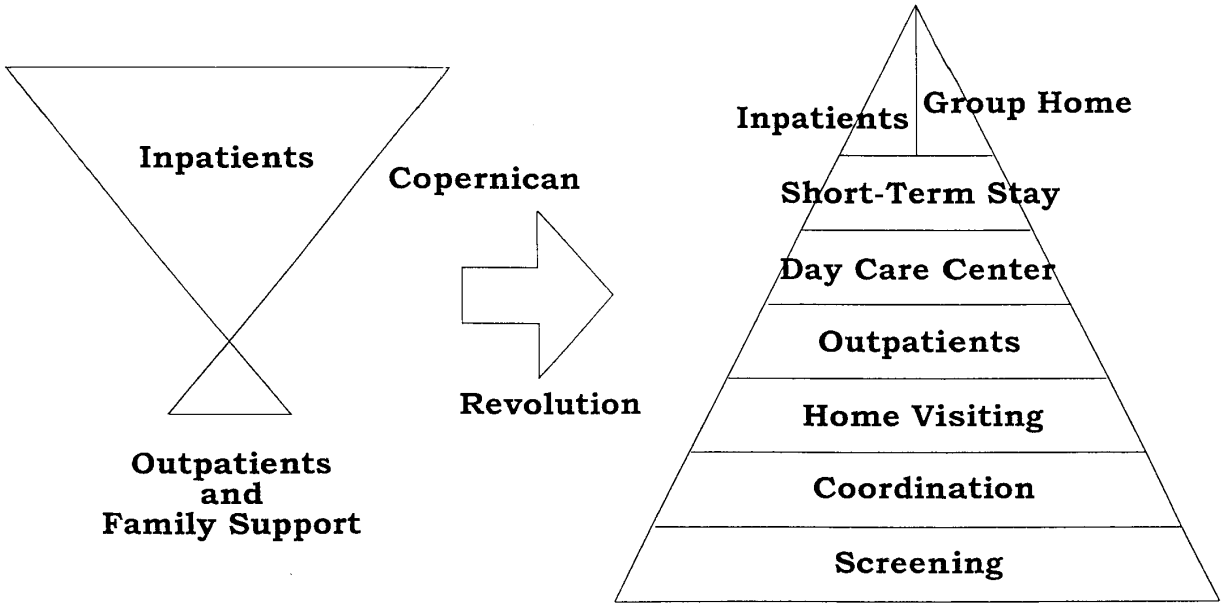
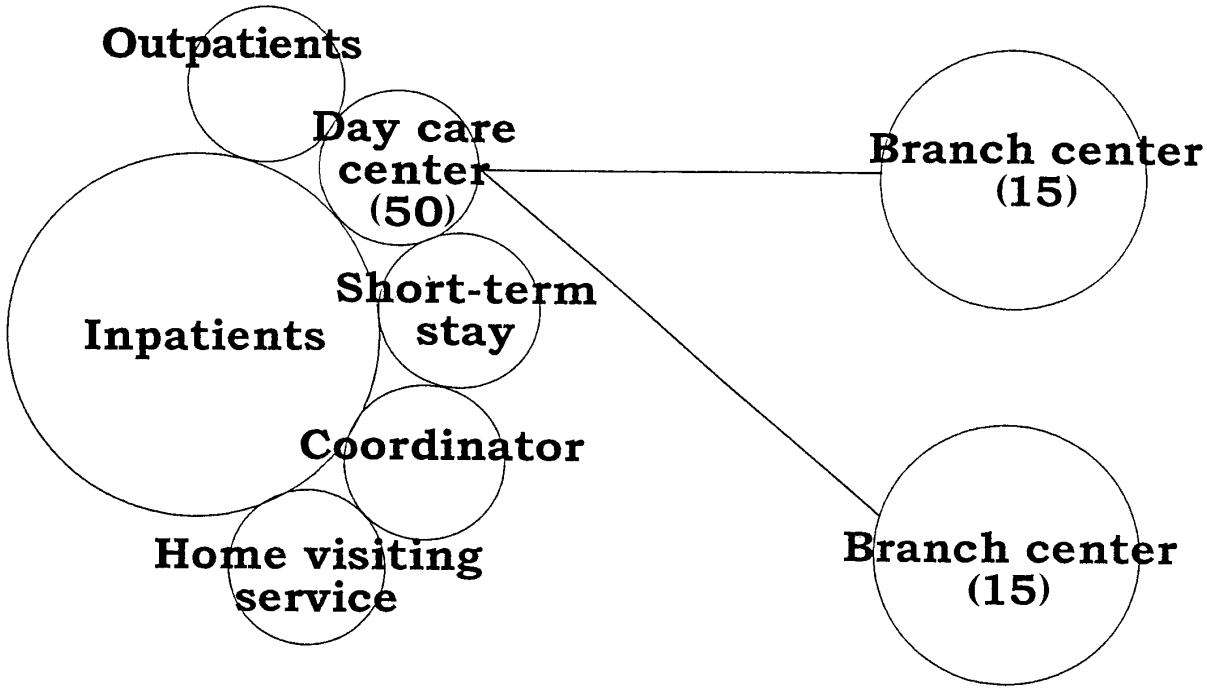


Table 4 Hospital-Home for "Jusho-ji" as a Community-Based Center



small-sized day-care centers for "Jusho-shinshin-shogai-ji" are located in the area of the hospital-home and are supported medically by that hospital-home, it is possible to say that we can support every "Jusho-shinshin-shogai-ji" in that area. These children will be able to have a life of high quality.

In summary, this paper gives a historical perspective of the social-welfare system for the severely intellectually handicapped in Japan and compares it with the system in Denmark. In addition to that, this paper reports on Japan's unique system for the care of "Jusho-shinshin-shogai-ji", with its history and current conditions. Also, we propose a model for community-based care of "Jusho-shinshin-shogai-ji".

References

1) Eiji H, et al. (1969) A study of the etiology sign and pathology of the severely mentally and physically handicapped children. *The journal of the Japan pediatric society*. **55**: 10 pp 1656-1671 (in Japanese).
2) Hagberg B, et al. (1972) The dysequilibrium syndrome in cerebral palsy. Acta Paediatrica Scandinavica, Suppl., **226**: 5.
3) Suemitsu S (1988) Regional care through the institutions for the profoundly mentally and physically handicapped. 16th World Congress of Rehabilitation International (in Tokyo).
4) Suemitsu S (1992) Methods of classifying profound multiple physical and mental disabilities. Handbook of care and training for developmental disabilities, Japan league for the mentally retarded, pp 14-16.