

Case Study on the Improvement of Living Environment for Intellectually Disabled Person at Home -When it Focus on the Increase of the Independence of Bathing Act-

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Abstract

This study presents a discussion, based on various case studies, on whether it is effective to improvement of living environment with intellectually disabled person at home to enable them to cope with difficulties regarding bathing.

The results of the study reveal that improvement of living environment have encouraged intellectually disabled person's independence, reduced the burden of having to provide bathing support for them, and resulted in positive effects such as safety, mental and economic well-being. It also confirms that improvement of living environment have contributed to bettering the quality of life for both intellectually disabled person and their families.

Key Words : Intellectual Disability, housing adaptations, Community Life, Family Relation, Public Support System

1. Introduction

1-1. Background and Objective of the Research

In order to develop a residential environment where everyone can live comfortably, several research initiatives related to the improvement of living environment for the elderly and physically disabled person are under way. Various measures and policies such as financial aid for improvement of living environment, facilities upgradation, and home care are continuously implemented^{1)~3)}. Moreover, research related to improvement of living environment for elderly person with dementia has also recently started^{4)~7)}.

However, so far hardly any research has been done on improvement of living environment for the intellectually disabled person. Delay in this field is quite prominent if we compare it with the previous year's status of overall support available for the elderly and physically disabled person, which has grown rapidly over the past few years.

There are many intellectually disabled person who face difficulties in daily living because of physical and mental growth retardation. For example, they find it difficult to independently perform daily living activities

like bathing for several years. Moreover, it is quite stressful for other family members because of the grim future and physical and mental fatigue due to the burden of providing day to day assistance⁸⁾⁹⁾.

Therefore, in the present study, we undertook actual case research to examine the effects of the improvement of living environment and whether they help in lessening the difficulties faced by the intellectually disabled person and their family members, supporting the intellectually disabled person in becoming self-reliant, and reducing the burden of family members.

1-2. Research Method

In the present study, we researched the following cases.

1) Method of selection of Cases for the Research

We conducted interview-based surveys to understand whether any improvement of living environments have been done in the families with an intellectually disabled person to deal with various difficulties faced in bathing. Persons interviewed during the survey were counseling staff members and governmental officials (around 30 person) responsible

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for consultations related to improvement of living environments and executive officers of family associations(around 10 person).

During the above survey, a few cases were observed where improvement of living environments undertaken for dealing with the difficulties faced in bathing had generated positive results. We selected few distinctive and typical cases, and researched them in the following manner.

2) Content of the Cases Study

While studying these cases, we conducted interview-based surveys of government officials in charge of supporting the improvement of living environments. After that, they also showed us the drawings and pictures and reenacted the various aspects of life of the intellectually disabled person by body language and hand gestures. Topics covered during the interview were same as ①–④described below.

In addition, in the cases where we could get the permission of the families, we visited and interviewed them at home. Items covered in the survey were as follows:①details of improvement of living environments and their results, ②status of living difficulties related to bathing activities, ③details of improvement of living environments related support provided by an expert, ④ bathroom fixtures, etc.

The survey was conducted between August 2002 and March 2004.

Table 1 Outline of This Case Study

No	Sex Age	Disease, and the like	Family members	Outline of house
1	Woman 19	Cerebral Palsy	Father, Mother, Elder& Younger Brother	Wood 2F their own house
2	Man 9	Hyperactivity Disorder・SMEI	Father, Mother, Elder Brother	Wood 2F their own house
3	Man 44	Down syndrome	Mother	Wood 2F their own house
4	Woman 11	Autism	Father, Mother	Steel 4F public housing

3) Method of Analysis

The method of data analysis was as follows.

- We analyzed various living activities with focusing on activities like bathing.
- After carefully considering the situation of intellectually disabled person and their families, we analyzed the process and the background until the positive effects from improvement of living environments were realized
- We examined the relationship between (1)contents of improvement of living environments, (2)living difficulties, and (3)effects of improvements.

2. Survey Results

2-1. Case 1

1) Details of Living difficulties

The subject's standing position was unstable and he was unskillful with his fingers. Before improvements of living environment had been made, he was assisted by his family for almost all bathing activities since his childhood. However, considering the growth of the subject, family members and persons involved in facilities management felt that he can become little more independent in various bathing activities like (a) opening and closing the bathroom door, (b) entering and coming out of the bathtub, and (c) filling the pail with water from the bathtub and pouring it over the body.

Family members encourage the subject to perform the abovementioned activities such as (a)–(c) without any assistance from other family members. In the beginning, he responded positively to the expectations of the family and showed his willingness to somehow perform these activities independently.

However, he could not do them successfully, and there were several instances where he was unable to fill

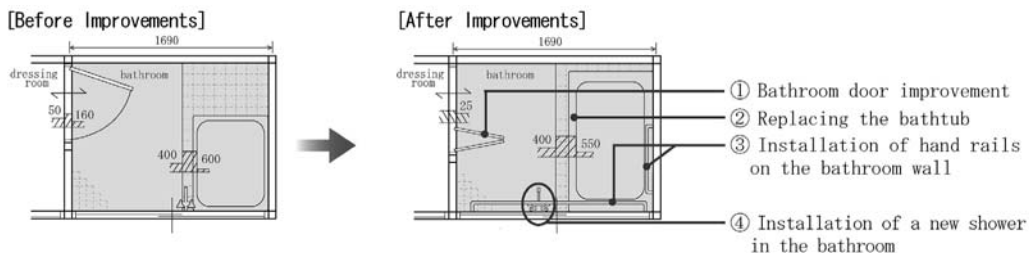


Figure 1 : Conditions before and after improvements of Bathroom (Case 1)

the pail with water or he fell down while opening the bathroom door or while entering the bathtub. As a result of the repetitive failures, he lost his confidence. Although other family members tried to cheer him up, he did not show any willingness to perform the abovementioned activities, and in fact, he became even more dependent on the family.

2) Details of improvements of living environment and their effects

As a result of such adversities, family members consulted the officer of O City. Officer visited the home and conducted a detailed interview-based survey. Officer affirmed that the repetitive successful experience of bathing activities will increase the motivation to live independently. Officer considered various improvements of living environment and assisted with the following improvements:

- ① Bathroom door improvement (heavy hinged door → light folding door)
- ② Replacing the bathtub (depth of the bathtub: 600mm → 550mm)
- ③ Installation of hand rails on the bathroom wall
- ④ Installation of a new shower in the bathroom

The above-listed improvements produced the following results:

- ① The subject was able to successfully open and close the door without any assistance. In addition, the number of instances where he fell down while opening the door decreased significantly.
- ② Since the new bathtub was shallower and equipped with hand rails, the number of instances where the subject fell down while entering or coming out of the bathtub decreased.
- ③ By using the shower, he was able to pour water on his body and take a bath without any assistance.
- ④ As a result of the above, he was very happy as he

became capable of performing more and more activities related to bathing on his own. He regained confidence and started putting efforts for learning other bathing related activities (such as cleaning the body) independently. For other family members also, the burden of cheering him up to make efforts for learning reduced significantly.

2-2. Case 2

1) Details of Living difficulties

The subject was hyperactive and prone to frequent attacks. Before improvements had been made, the subject was brought along into the bathtub along with other family members, who provided assistance in the form of, for example, watching over the subject in order to prevent the subject from falling. The living difficulties associated with the improvements of living environment (to be discussed later) are as follows:

First, there were problems associated with attacks occurring while bathing. The subject becomes more susceptible to attacks as his body temperature rises, which means that attacks were quite common in the bathtub. During these attacks, there have been hazardous occasions in which the subject has, for example, slipped under the surface of the water, lost consciousness, and nearly drowned. In situations such as these, the other family members immediately came to the subject's aid. It has also occurred that, while bathing, the subject has moved the lever of the hot-water heater control panel located near the bathtub to ON; however, there were almost no cases in which the subject subsequently moved the lever to OFF, even after the water had reached the desired temperature. At that time, the control panel was not equipped with the function by which the hot-water heater is automatically shut off when the water has reached the desired

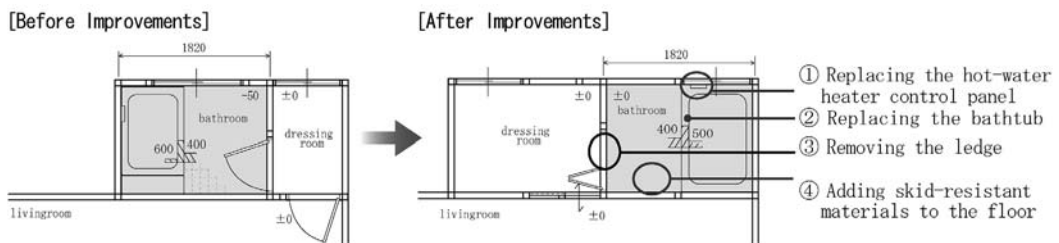


Figure 2 : Conditions before and after improvements of Bathroom (Case 2)

temperature.

Other members of the subject's family entered the bathtub with the subject, adjusted the temperature of the bathwater so that the subject's body temperature would not rise too high, and watched over the subject so as to be able to render immediate assistance in the case of an attack. However, the subject enjoyed bathing very much, and would often enter the bathtub alone (even in the middle of the night). The family members were concerned about the subject drowning because of entering the bathtub alone.

Second, there were many instances in which the subject fell while bathing. The subject is hyperactive, and it happened quite frequently that the subject would run full-speed into the bathroom, trip on the ledge of the bathroom door, slip on the floor, and fall into the bathroom. The family members would tell the subject not to run and jump in the bathroom, and would also physically restrain the subject, preventing him from doing so. As the subject grew older, however, it became more and more difficult for the family members to provide assistance.

2) Details of improvements of living environment and their effects

The family members consulted with officer of O City concerning the abovementioned difficulties. Officer visited the home and conducted a detailed interview-based survey, and assisted with the following improvements:

- ① Replacing the hot-water heater control panel
- ② Replacing the bathtub(depth of the bathtub: 600mm→500mm)
- ③ Removing the ledge at the entrance to the bathroom (50mm→0mm)
- ④ Adding slip-resistant materials to the floor around the bathtub

The above-listed improvements produced the following results:

- ① The temperature of the bath water does not rise above the level that has been pre-set by the family, even when the subject operates the control panel by himself. Attacks while bathing have also decreased.
- ② The bathtub is now shallower, which lessens the risk of drowning.
- ③ The ledge has been removed and the floor has been made skid resistant, falls while bathing are less

frequent, and injuries have decreased. The family is also less often required to physically restrain the subject to prevent him from running in the bathroom.

- ④ As outlined above, attacks and falls while bathing have decreased, and the subject is now easily able to bathe, even by himself.

2-3. Case 3

1) Details of Living difficulties

The subject is living with his mother. Before improvements had been made, when the subject was having a bath, the mother would also go with him in the bathroom and assist him in adjusting the water temperature of shower (several times a day). In addition, the subject would bath several times a day and take 1–2 hours for every single bath. The living difficulties associated with the improvements of living environment are as follows:

First, the monthly water bill was very high, putting great financial strain on the family. When the subject was bathing, shower faucet would be fully open and large quantity of hot water used to flow continuously. Moreover, apart from washing the body while bathing, the subject would play with water by splashing the water on the wall and the door and by forming large quantities of froth.

As a result, since sometimes the monthly water bill used to be more than ¥70,000, the mother had several times asked the subject to reduce the frequency as well as the time spent on bathing. However, there was no improvement in the subject's behavior as she could not win his support. Moreover, whenever the mother forced him to come out of the bathroom, he used to shout and resist strongly.

The second difficulty is related to the difficulties faced in adjusting the water temperature of the shower. Although the subject was trying to adjust appropriate temperature of water flowing from shower, he was unable to adjust the temperature (operation of the faucet), and many times he would end up pouring boiling hot or chilled water on his body by mistake. At that time, he would create a ruckus by yelling loudly and hitting and kicking the bathroom door. Ultimately the mother would assist him in adjusting the temperature.

2) Details of improvements of living environment and their effects

Due to such difficulties, the family consulted the counseling staff during housing improvement consultation activities conducted by S Disabled Persons Association of K city. Counseling staff members (comprising of specialists in the fields of public health, nursing, medical, architecture, construction, etc.) visited the home, interviewed the family in detail from various technical viewpoints, and assisted with the following improvements:

- ① Adjusted the valve of main water tap in such a way that even if the shower faucet is fully open, the quantity of water flow will be approximately 70%.
- ② Closed the water mixing valves of the shower of water supply side so that only the hot-water supply side is used (adjusted such that water will flow from the shower at around 38°C only.)

In addition, the following points were noticed as a result of the interview of the family and their behavioral observation by the counseling team.

In this case, the shower was newly installed just few months before the abovementioned improvements, and the subject had almost no experience in operating the shower before that. After the shower installation, although he practiced adjusting the temperature several times with his mother, he could not fully understand the method of temperature adjustment, and several times he ended up pouring boiling-hot or chilled water over his body by mistake. Moreover, considering the learning capabilities of the subject, it would have been difficult for him to acquire adequate skills in future as well.

Based on these findings, a proposal for improvements was deliberated and improvements mentioned above were implemented.

The above-listed improvements produced the following results:

- ① Even if the shower faucet was left open for a long time, the quantity of water flow would be around 70%, which helped in reducing the water bill. As a result, there were fewer instances where the mother would restrict the bathing. This also decreased the number of instances where the subject would shout and resist strongly.
- ② The subject was able to operate the shower for appropriate water temperature (around 38°C). As a result, there were no more instances of bathing with extremely hot or cold water by mistake. This also mitigated the burden on the mother as it enabled the person to have a bath without any assistance.

2-4. Case4

1) Details of Living difficulties

The subject is hyperactive and unable to stay still even for short periods of time. The subject moves her body even while in the bathtub; because the bathtub is small, the subject's back or buttocks often comes into contact with the hot-water spigot, causing burns. According to the accounts of other family members, when the subject's body comes into contact with the hot-water spigot, the subject shouts and cries very loudly, but by the next day seems to have forgotten about the injury and thus repeats the same mistake.

The family members used to watch the subject constantly while the subject was bathing, never taking their eyes off of the subject for even an instant so that they could prevent the subject from coming into contact with the hot-water spigot. At that time, there was no shower in the bathroom; water from the bathtub was used to wash one's body, water was added to the bathtub and reheated while one was immersed in the

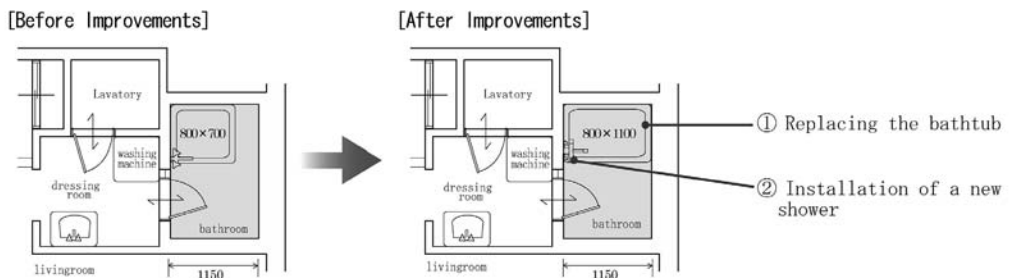


Figure 3 : Conditions before and after improvements of Bathroom (Case4)

bath water, and hot water flowed from the hot-water spigot while bathing.

2) Details of improvements of living environment and their effects

Family members consulted with an ombudsman of K City concerning the abovementioned difficulties. A team led by the ombudsman visited the family's home, conducted an in-depth interview, and assisted with the following improvements:

- ① Replacing the bathtub
- ② Installing a shower in the bathroom

The above-listed improvements produced the following results:

- ① The bathtub is now larger, so that the subject's back and buttocks come into contact with the hot-water spigot less frequently than before, even when the subject moves his/her body while bathing. Further, it is now possible to wash one's body using water from the showerhead and to bathe without having to reheat the bathwater, thus virtually eliminating the flow of hot water from the hot-water spigot while bathing.

2-4. Conclusion

As a result of the case research, we found that in many cases, improvement of living environments undertaken for dealing with the living difficulties faced by the intellectually disabled person in bathing activities had been very effective. This proves that as a strategy for dealing with various living difficulties faced in bathing activities, improvement of living environments are quite effective.

In addition, details of the positive results are also noticed. We realized that in all the cases, benefits from the hygiene viewpoint like reduced burden of toileting assistance and fostering self-reliance in excretion activities were realized. Apart from this, in many cases, safety-related advantages, moral effects, and financial benefits were also realized.

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