Review article

Care management for people with disabilities: Institutional ideals and issues

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Abstract

As disability welfare services shift toward contract operation, equal standing between welfare service business operators and their beneficiaries is increasingly essential. Among other things, such equality protects the users' right to appropriate care management. This paper first presents some representative definitions for "care management," as proposed by the Ministry of Health, Labor and Welfare and by Takeuchi and Moxley. I prefer the definition "organizing the network of activities" because it emphasizes "cooperation among supporters." I will then report the results of my questionnaire on the degree of cooperation between care plan preparers, that is, guidance officers and service management officers. I will also explore several responses concerning the elements other than "cooperation of supporters" that constitute "good care management." The questionnaire results suggest that, at present, guidance officers and service management officers "cooperate almost not at all" and typically have low awareness of the importance of such cooperation. I draw the following conclusion: as care management in disability welfare services is currently widely implemented, quantitative gains have been achieved; however, qualitative improvement, especially with regard to personal support of users, is still needed.

Introduction

Over the years since the assistance benefit supply system was introduced in 2003, welfare service organizations for persons with disabilities have shifted away from a measure-oriented structure to a contract-oriented one. One clear and practical difference between these structure types is that, for the contract structure to work well, the beneficiary and the business operator must be of equal status. Two steps must be taken to correct status disparity and ensure the success of contract-oriented disability welfare services. First, the system must protect beneficiary rights by providing appropriate care management. Second, the administration must prevent businesses from engaging in illegal and excessive pursuit of profits by offering guidance and conducting audits.

In my previous paper, I examined the importance of guidance and audits from the perspective of my long-held position as the employee in charge of guidance and audits in the disability welfare service office of the Osaka prefectural government [1]. Here, I will review appropriate means of care management, this time from the perspective of the users. Compared with the number of studies focusing on elderly people,

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less than one-tenth of previous studies have focused on welfare for people with disabilities. This reflects the low level of concern regarding care management for persons with disabilities. In addition, previous studies have tended to focus on examples of care management for subdivided specific disorders, whereas few studies address the overall system organization and philosophy or analyze such issues in detail. This paper aims to correct this neglect to some degree.

In order to achieve the above objectives, I will first discuss some representative definitions of care management proposed by the Ministry of Health, Labor and Welfare and by Takeuchi and Moxley. The definition that I adopt, i.e., "organizing the network of activities," emphasizes "cooperation among supporters." Accordingly, I will then report the results of my questionnaire regarding how much cooperation actually occurs between people who prepare care plans, that is, guidance officers and service management officers. Next, I will present the opinions of several respondents regarding the elements other than "cooperation among supporters" that constitute "good care management" and examine these concretely. Finally, I will consider the current problems related to care management in the disability welfare services system.

Definition of Care Management

Care management for those with disabilities has many definitions. One of these, proposed by The Ministry of Health, Labor and Welfare, defines care management as "An important support method that respects the intentions of the disabled person so that people with disabilities living in the community can effectively utilize the many services in the area and connect to various welfare, health, medical care, education, employment, and social resources." The predominant characteristic of this definition is that it focuses on "people with disabilities living in the community" [2]. An alternate definition proposed by Takeuchi interprets care management for people with disabilities as a means of comprehensive aid that assesses, understands, and responds to needs and accordingly provides services promoting independence and quality of life (QOL) improvement [3]. A third definition proposed by Moxley states that care management for people with disabilities consists of "activities of people (or a team) who cooperate to organize, coordinate and maintain a network of formal and informal support with the aim that people with disabilities who have various needs will maximize their function and their capacity for healthy living" [4].

These three definitions have three aspects in common: all of them mention "understanding needs," "aiming to meet needs," and "connecting users with appropriate social resources". Nevertheless, I do not accept the definition of The Ministry of Health, Labor and Welfare because it tends to disregard people with disabilities who live in facilities rather than in the community, and these people should also be considered. Moreover, Takeuchi's definition is too simple and does not clarify the purpose and contents of care management. Instead, in this article, I adopt the definition proposed by Moxley. The distinguishing feature of Moxley's definition is its observation that as a means of "organiz[ing] the network of activities," "cooperation among supporters" is included as an element. As this point is very important, I will discuss it in detail in Chapter 4, Section 2. In the next section, I will shed some light on the philosophy underlying contemporary care management by reflecting on the history of care management in disability welfare.

Introduction to the History of Care Management

1. Treatment program in the measure-oriented era

In the measure-oriented care management era, users received uniform support related to treatment programs at their facilities (i.e., the businesses offering the care they received), regardless of user status. Tsuda has pointed out that in that era, daytime programs at these facilities were referred to as “training,” whether they were related to daily assistance with leisure activities, work activities, meal assistance, bathing assistance, tooth brushing instruction, or health care. Furthermore, the long-term intentions of these training courses were based on the experts’ point of view and were inadequate [5]. In addition, facilities aimed to control, regulate, and protect users’ lives because they were required to maintain the safety of their users and the quality of their lives through control by the administration, which also controlled the measures [6]. In all aspects of care management, facilities emphasized that they could not “accept an exception for only one person because [that person would then] become inequitable with other users.” Instead of focusing on the individual, these facilities created a climate that focused on the group. It is said that there were few cases where the intention of the user was reflected; rather, treatment plans were uniform and users had to adapt to existing daily routines and programs [7].

2. Emergence of a philosophy of care management

Individuals have various requirements; however, it is almost impossible to satisfy all of their needs at a single place of business. In acknowledgment of this fact, the concept of care management emerged in the 1990s with a focus on discovering the needs of individuals and linking them to multiple social resources. Regarding consultation support for persons with disabilities, the goal shifted toward implementing projects with a target density of approximately two for every 300,000 people, which would provide comprehensive consultation, life support, and information to people with disabilities in familiar areas, based on the policy titled “Improvement of comprehensive support system” in “The Government Action Plan for Persons with Disabilities- A Seven-Year Normalization Strategy-” published in 1995.

In 2003, the assistance benefit supply system was introduced, and welfare service organizations for persons with disabilities moved from a measure-oriented structure to a contract-oriented one. This transition process is referred to as the social welfare foundation structural reform.

3. Institutionalization of care management

Satoh and Ozawa have suggested that if the welfare office is a specialized social work organization, care management should be handled by the administration as well. In their words,

> “The actual welfare office is far from a specialized user-centered social work organization, and the work is vertically divided in the social welfare system. Therefore, the background of creating “reform of the social welfare foundation structure” can also be regarded as a fundamental problem of welfare administration which has not been considered primarily by users” [8].

The backdrop for such administrative limitation includes not only the Service and Support for People with Disabilities Act of 2006 but also the philosophy of care management, which clearly supports institutions as consultation support businesses. In order to provide planned community life support, designated consultation support business operators were obliged to prepare plans including service mediation, coordination, and monitoring. At the 2008 Social Security Council Disability Subcommittee, the possibility of reviewing Services and Supports for Persons with Disabilities Act was discussed 3 years later and recommendations were made that we should improve consultation support from the following viewpoints so that people with disabilities can live peacefully and independently in the community while utilizing various services and regional resources: (1) strengthening the consultation support system in the community, (2) enhancing care management, (3) strengthening the independence of persons with disabilities through a support council [9].

This intention is also communicated in the "Law to support the everyday life of the person with a disability and a social life generally," which came into force in 2013. According to this law, which concerns the enhancement of care management, starting in the year 2015, it is necessary to submit a draft of service utilization program whenever a grant decision is made [10]. According to a survey by the Ministry of Health, Labor and Welfare in December 2015, 95.9% of the surveyed municipalities reported that "70% or more" of disabled welfare services users take advantage of the service utilization programs thus created [11]. From this result, it can be said that the initial goal of 2015 was almost achieved quantitatively. The reason being that the number of consultation support business operators has increased about threefold in the three years from April 2012 to April 2015.

In the next section, I will clarify how care management is related to and involved in actual businesses.

Care Management System and Actual Conditions

1. Relationship between the two types of plans (service utilization programs and personalized support planning)

There are two major types of care plans available to each user of disabled welfare services, as depicted in Figure 1. The first type is a "service utilization program," which is prepared by a guidance officer before and after a grant decision. The second is "personalized support planning," which is created by the service management officer assigned to each place of business when the user begins to use the services as agreed upon in the "service utilization program."

Personalized support planning may occur multiple times for each user depending on the user's needs. For example, if someone's "service utilization program" is "lives in community, the user receives job training during daytime on weekdays, asks home helpers for housework at night, and occasionally goes shopping with a helper on weekends." This would involve three service management officers, one at each of the three businesses where this user receives disability welfare services (transition support for employment, home help service, and transportation support service), each of whom would create a personalized support plan for the user. Since these plans must be consistent with each other, guidance officers and service management officers need to communicate regularly at meetings "organized by the person in charge of the service" and exchange their aims and opinions.

2. Current situation with regard to cooperation among supporters

As mentioned in the previous section, since users are likely to have multiple plans made for them according to their individual needs, the most important element in successful implementation of these plans is cooperation among the various supporters, especially those who prepare the various plans. Ministerial ordinance (2012, MHLW Ordinance No. 28. Item 10 in paragraph 2 of Article 15) stipulates that

> "The guidance officer must revise the draft of service utilization program based on grant decision (omission), contact designated welfare service business operators for persons with disabilities etc. or other people, hold meetings organized by the person in charge of the service (omission) etc., and explain the contents of the draft of service utilization program and exchange opinions with service management officers etc. from a specialized viewpoint."

Thus, preparing a draft of the service utilization program and explaining the contents and exchanging opinions are legal requirements for consultation support business operators to receive compensation from the administration.

In practice, however, it is not known how

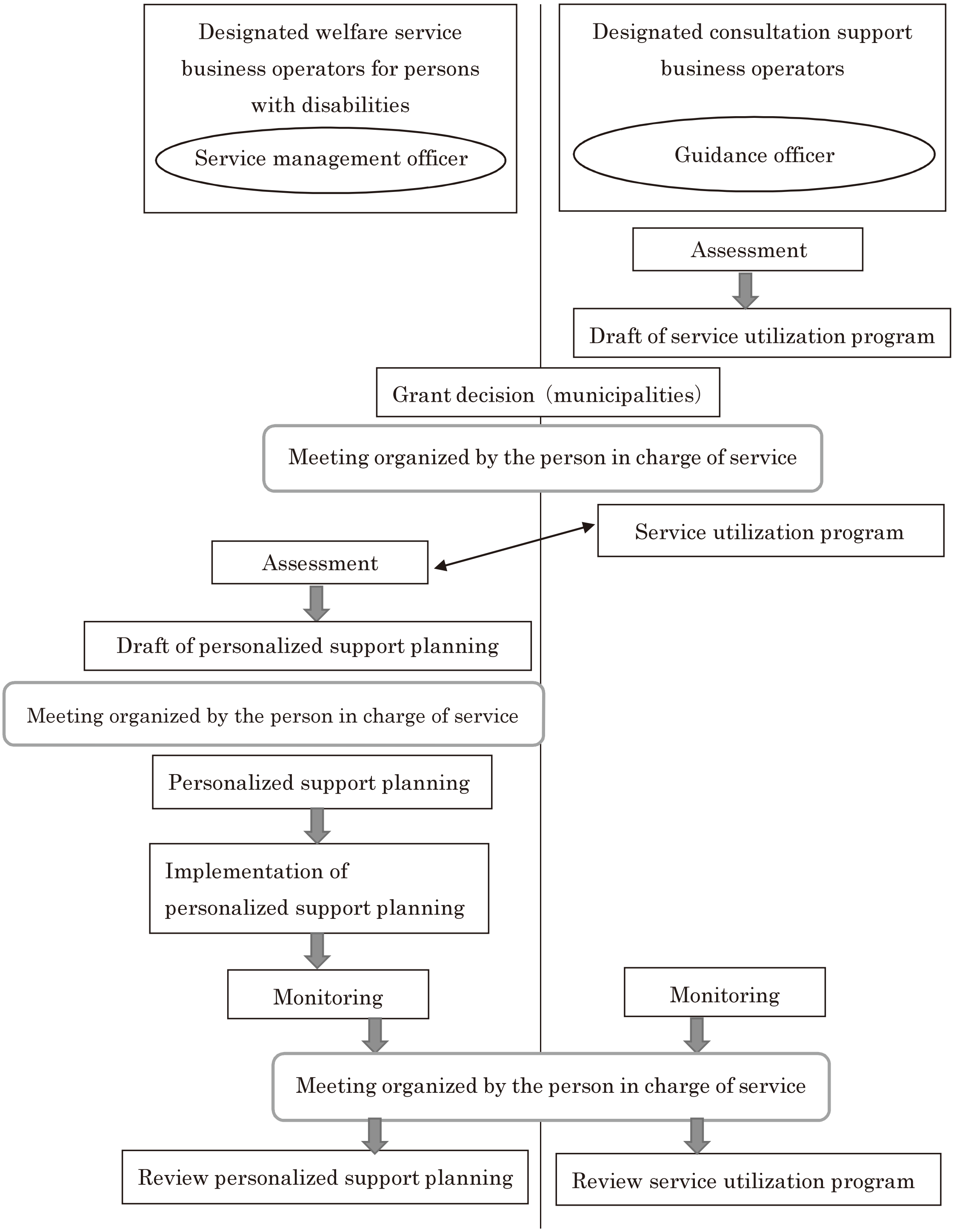

Figure 1. Relationship between guidance officers and service management officers [12].

closely these two officer types (the guidance officer and the service management officer) work together. Honna et al. conducted a survey of 487 consultation support business operators in Kanagawa Prefecture in 2017. From the target, excluding 23 survey forms returned due to change of address etc., the number of implementations was 464 business operators. Among them, they obtained responses from 107 operators (response rate 23.1%). In addition, 105 business operators excluding those with insufficient answers were analyzed. [13]. Out of these, 71.4% responded “always” or “to a great extent” to the question “do you examine the personalized support planning after creating a service utilization program?”, whereas only 7.6% responded affirmatively to the question “do you give advice for personalized support planning?” This suggests not only that the provision of such advice is contrary to the philosophy of the institution but also that illegal compensation requests are widespread, although Honna et al. did not draw attention to that interpretation.

In the same survey, Honna et al. also asked “Are you devising measures for cooperation with service management officers?” To this question, 58.1% of establishments answered that such measures were “being implemented” or “performed to some extent.” However, this does not include the specific content that must be part of any consultation support task such as “Sharing support content at meetings organized by the person in charge of the service” or “Discussing monitoring scenes etc.” If a guidance officer regards such tasks as uncommon and requiring special skills, their suitability for their role must be questioned.

Elements of Fine Care Management

In this section, I will explore several statements concerning the elements other than “cooperation of supporters” that go into “good care management.”

1. Understanding life challenges

In care management, the needs of users should be understood and planned for first. This may involve focusing on activities that are difficult for that person to perform in daily life rather than on specific medical disorders or diseases [14]. Kondoh provided a simple example of this [15].

> Do not simply write schizophrenia or Asperger’s syndrome or the name of a diagnosis or disorder in the disease column. For example, a person has been diagnosed with schizophrenia, and she relapses when she stops her medicine, as has happened in the past. This means that medication management is clearly necessary to support the patient. Also, for Asperger’s syndrome, life challenges are important, such as “weakness in understanding situations” or “being troubled by clumsiness and slowness of work speed.”

2. Supporting the beneficiary's emotions (self-determination support)

Even if all challenges of daily life, as outlined in the previous section, have been successfully responded to, unless the plan reflects the emotions and hopes of the user, it cannot be considered to promote self-determination, which is a human right guaranteed to all citizens in Article 13 of the Japanese Constitution. This also extends to people with severe intellectual disabilities. In the era of measure-oriented care management, these natural rights were restricted by the paternalistic approach of care institutions. As Nonaka et al. have noted, constitutional scholars define “paternalism” as an attitude that justifies a nation’s actions when “the nation interferes with the behavior of private persons in the way that parents interfere in order to take care of a child who does not have independent ability” [16]. In this definition, “the nation” is the subject; examples of paternalistic rules include restrictions on the voting rights of minors and on their access to alcohol and tobacco. The concept of “measure-oriented care” is also reflected this attitude.

In contrast, Sawanobori does not restrict the subject of paternalism to “the nation” but rather defines paternalism as “to interfere by saying ‘stop this because such acts will do you no good’ or ‘do it more like this’, although the act being restricted does not infringe upon the interests of others” [17]. For example, acts such as restraining the body of a person with severe intellectual disability so that the person does not engage in self-injurious behavior corresponds to paternalism under this definition. However, anyone about to engage in such restraint must always check whether there is really a sufficiently serious danger that requires the restriction of human rights, and of course, the restraint must be minimal. The supporter must fully recognize that such restraint corresponds to abuse if human rights are restricted beyond a minimum limit.

Tsuda believes that support should be based on empowerment and the promotion of each person’s capabilities even for persons who are severely intellectually handicapped and have difficulty indicating their intentions. Therefore, Tsuda recommends the behavior change approach [18]:

> Operant conditioning, the fundamental theory of the behavior change approach, consists of three factors: a prior stimulus, a behavior, and the result of a certain action. By presenting results that analyze smaller gestures and expressions of a patient in daily life, draw conclusions about the user’s feelings from these, and generate responses, users’ communication of their intentions will be strengthened. Supporters who behave like this will eventually become prior stimuli for inducing manifestations of the users’ intentions. … Repetition of that process triggers higher-dimensional manifestations of intention and self-determination.

Closer Consideration

The perspectives introduced above will be consolidated and reconsidered in this section.

In the course of my work in providing guidance and audits on behalf of the Osaka prefectural government, I often heard, for example, that an individual played with their own feces and therefore “had to” wear overalls. This regulation was deemed necessary because supporters wanted to prevent such users from touching their own diapers and feces and therefore required them to wear clothes that they could not open at the waist. The “goal” of this intervention was simply to prohibit the filthy act of touching the feces. Such responses are neither supportive of these individuals' feelings nor grasp any of their true needs. Therefore, even in the context of maintaining cleanliness, this is not appropriate care management. Instead, an analysis must be conducted to understand why each individual who touches his or her own feces does so. This feeling or desire can be understood only by offering close emotional support in everyday life. Patients who desire to handle their own feces may do so because they feel that the feces are dirty or shameful, and for this reason, they may prefer to use the toilet rather than diapers. Patients who touch their own feces out of boredom, on the other hand, may cease doing so if they are allowed to develop another interest. Working in this manner will eventually lead to a more detailed understanding of the intentions of the beneficiary.

Thus, in the current system, behavioral problems should not be addressed paternalistically. Needs should be understood and support should be provided through expert knowledge, as described in the previous section, in a context of full cooperation between the guidance officer and the service management officer. In such a state of care management, users can be empowered to move from managed existence to self-determination as well as self-assertion, ultimately becoming a full contracting party and an equal with the consultation support businesses that assist them.

Successfully “supporting the beneficiary’s emotions” depends not on the personality traits of supporters, such as affection or kindness, but rather on their professional expertise. Many supporters think that “there is no other way” than paternalism and thus rush to prohibit certain behaviors of the beneficiary “for the sake of the beneficiary himself/herself.” In order to improve such situations, it is necessary for the supporters to make efforts to share their expert knowledge and cooperate while noticing their emotions. Also, this approach must be incorporated in service utilization programs and personalized support planning. Such professional expertise is truly highly specialized and is still in the research stage.

Conclusion

In this article, I have outlined some “ideal” aspects of care management in disability welfare, which, from my point of view, are really required. In Section IV, I summarized the results of a survey reported in another study, which found a lack of coordination between guidance officers and service management officers. There is presently a great need to analyze the causes of this lack of cooperation in detail, to strengthen cooperation among all relevant parties, and to increase the professional knowledge of the officers. Also, it must be recognized that the performance quality of those who work in care management should be re-evaluated in terms of these updated care standards.

Currently, to become a guidance officer or a service management officer, no qualifications or tests are imposed, although those who wish to become elderly care managers must pass a national exam. For guidance officers and service management officers, in contrast, anyone with experience working directly in support of persons with disabilities (physical assistance, meal assistance, etc.) for over 10 years or in consultation support for over 5 years who goes through a training course is eligible to hold a job. Furthermore, until fiscal 2018, the training duration to become a guidance officer was only 31.5 h and that to become a service management officer was only 30.5 h in the beginning. However, it was decided that the training curriculum will be fundamentally changed since the Social Security Council of the Ministry of Health, Labor and Welfare issued opinions such as “The difference in training content is large depending on each prefecture, and the difference in the quality of training is expanding.” or “We should change the training system, including the introduction of on the Job Training, for securing human resources such as guidance officer and improving quality.” As a result, from 2019, when becoming a guidance officer, training of 42.5 hours (extended 11 hours than before) will be initially imposed and a further training curriculum (30 hours) will be newly established to become the “chief guidance officer” who will play a leading role. In addition, in case of becoming a service management officer, training of 45 hours (extended 14.5 hours than before) will be imposed and a further practical training (16.5 hours) will be newly established so that one can step up with repeated practical experience [19]. Nevertheless, it is still obviously short, compared with the 87 h of training required to become an elderly care manager.

As introduced in Chapter 2, Section 3, the care management system in disability welfare is now being implemented at a high rate, so it can be said that quantitative gains have been achieved. Our next task is to improve the quality of guidance officers and service management officers by increasing their professional knowledge (e.g., the behavior change approach introduced in this paper). As mentioned above, currently one can qualify with practical experience and training only, but it is worrying that an incorrect rule of thumb only with practical experience is being applied.

Therefore, it will be necessary not only to extend the training time but also to impose some national exam, like an elderly care manager. Further, methods must be considered to test whether the content of the training was truly understood or not.

In future work, I will propose more concrete means of achieving these goals.

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Conflicts of Interest

There are no conflicts of interest to declare.

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