The “Act on Decisions on Life-Sustaining Treatment” in Korea and Measures to Support Decision-making of Persons with Developmental Disabilities*

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Abstract

The “Act on Hospice and Palliative and Decisions on Life-Sustaining Treatment for Patients at the End of Life” in Korea was enacted on February 3, 2016. This study examined characteristics of the Act and the methods used to identify patients’ wishes regarding termination of life-sustaining treatment. This study also notes the gap in protection that may arise by not acknowledging the wish presumption or surrogate decision-making of third parties aside from patients’ family members. In particular, persons with developmental disabilities (PDD) are vulnerable to abuse, negligence, or economic and physical exploitation because of their limited cognitive ability, communication difficulties, or lack of family members to represent their wishes. To resolve this issue, this study reviews Korea’s public guardianship service for PDD and physicians in charge of the health of persons with disabilities. This study highlights methods of supported decision-making to guarantee patients’ right to self-determination based on their wish and remaining capacity of PDD in case of decisions on life-sustaining treatment.

Keyword: persons with developmental disabilities, right to self-determination, adult guardianship system, Act on Decisions on Life-Sustaining Treatment for Patients in Hospice and Palliative Care or at the End of Life, supported decision-making.

I. Introduction

The “Act on Hospice and Palliative Care and Decisions on Life-Sustaining Treatment

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for Patients at the End of Life” (hereinafter referred to as “The Act”) was enacted in Korea on February 3, 2016. “The Act” is an outcome of social consensus over the need for legislation to resolve the issue of decisions on life-sustaining treatment, which was sparked after the Korean Supreme Court’s decision regarding “old Mrs. Kim’s case.” In 2008, Mrs. Kim fell into a persistent vegetative state during an examination at the hospital. As she was receiving treatment, such as antibiotics, artificial nutrition, and an infusion solution, while wearing a respirator in the intensive care unit, her family filed a suit against the hospital to remove the respirator. The Supreme Court decided through a written judgment that if a patient in a state of irreversible death exerts the right to self-determination, termination of life-sustaining treatment is permitted: “Forcing meaningless life-sustaining treatment to patients that have reached the state of irreversible death rather damages human dignity and value. Therefore, termination of life-sustaining treatment may be permitted if the patient exerts the right to self-determination based on human dignity and value as well as the right to pursue happiness in an exception.”

In 2012, the National Bioethics Committee, which is a presidential committee, organized the “Special Committee for Discussion on Systemizing the Termination of Meaningless Life-sustaining Treatment” (hereinafter referred to as the “Special Committee”). Experts and authorities recommended by all spheres of social activities, such as medical, religious, ethical, and legal circles, as well as representatives of patient groups under the National Bioethics Committee, were employed to resolve the issues regarding termination of meaningless life-sustaining treatment. They discussed key issues regarding life-sustaining treatment in five meetings, and they held a public hearing to announce the Special Committee’s recommendations and to collect opinions. Consequently, the Special Committee submitted the final recommendation to the National Bioethics Committee on June 18, 2013. In this process, efforts were made to include various perspectives to respect patients’ right to self-determination while guaranteeing their best interests.


However, despite these efforts, there was insufficient participation of organizations or associations to represent the voices of persons with disabilities until the enactment of “The Act.” In July, the Korean Society for Disability Studies (2015) issued the following statement: “Due to the absence of a structure for persons with disabilities to participate and a forum for debate throughout the entire process of legislation, “The Act” completely lacks the perspective of the disabled.” As claimed by the statement, organizations representing the disabled has constantly raised the concern that persons with disabilities may not receive the treatment they prefer, or in a timely manner, just because they have disabilities.

This study examines the characteristic of “The Act” in Korea and methods of identifying patients’ wishes regarding termination of life-sustaining treatment, and notes the gap in protection that may arise by not acknowledging surrogate decision-making of a third party aside from patients’ family members. This may be more dangerous for persons with developmental disabilities (PDD) who have limited cognitive ability or communication difficulties. Therefore, to resolve this issue, this study reviewed the adult guardianship system of Korea as part of public guardianship service for PDD and physician in charge of health of persons with disabilities. In addition, this study seeks methods of supported decision-making to guarantee the right to self-determination based on their wish and remaining capacity of PDD in case of decisions on life-sustaining treatment.

II. Main contents and issues of “The Act” in Korea

The purpose of “The Act” is “to prescribe matters necessary for life-sustaining treatment and determination to terminate life-sustaining treatment for patients in a hospice, receiving palliative care, and at the end of life, and the implementation thereof, and thereby to protect the dignity and value of human beings by assuring the best interests of the patients and by respecting their self-determination” (Article 1). To

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achieve this purpose, “The Act” presents patients’ right to self-determination and medical persons’ duty to explain them as the basic principles.

Regarding patients’ right to self-determination, “every patient has the right to receive the best treatment and clearly know about the status and prognosis of the injury or disease he/she suffers and the subsequent medical services, and to make decisions for himself/herself thereon” (Article 3 (2)).5 Here, every patient includes both persons with disabilities and persons without disabilities, indicating that patients with disabilities also have the right to make decisions for themselves. Moreover, regarding medical persons’ duty to explain, “each medical person shall provide patients with the best treatment, explain hospice, palliative care, and determination to terminate life-sustaining treatment, accurately and in detail, and shall respect patients’ decision made based thereon” (Article 3 (3)).6 Accordingly, medical professionals have the duty to explain information about decisions on life-sustaining treatment so that the patients can understand, and to respect the decisions made by the patients after listening to the medical explanation, which fulfills the purpose of the enactment of this Act to protect patients’ dignity and value as humans.

1. Characteristics of “The Act”

“The Act” limits the point of determination to terminate life-sustaining treatment to patients at the end of their life (Article 15).7 The end-of-life process is defined by this Act as “a state of imminent death, in which there is no possibility of revitalization or recovery despite treatment, and symptoms worsen rapidly” (Article 2 (1)).8 As such, regarding whether the patient is in the end-of-life process, “a doctor-in-charge shall diagnose, in cooperation with one medical specialist, whether his/her patient is in

5 Ibid
6 Ibid.
7 Ibid.
8 Ibid.
end-of-life process” (Article 16). Therefore, according to “The Act,” persons with disabilities who are not in the end-of-life process are definitely not “persons subject to implementation of determination to terminate life-sustaining treatment” defined by this Act just because they have a disability.

Furthermore, “The Act” limits life-sustaining treatment to the four following medical interventions: “Life-sustaining treatment means medical treatment by cardiopulmonary resuscitation, hemodialysis, administering anticancer drugs, and mechanical ventilation to a patient at the end of life, which merely extend the duration of the end-of-life process without curative effect” (subparagraph 4 of Article 2). Cardiopulmonary resuscitation, hemodialysis, administering anticancer drugs, and mechanical ventilation that have a curative effect for general patients instead of those in the end-of-life process, shall not be avoided or terminated according to this definition. Moreover, since life-sustaining treatment is limited to four medical interventions, in implementing a determination to terminate life-sustaining treatment, “the medical care for relieving pains and simple provision of nutrients, water, and oxygen, shall be provided without ceasing” (Article 19 (2)). In this sense, “The Act” acknowledges the right to refuse treatment in determining whether to implement or terminate the four limited medical interventions that merely extend the duration of the end-of-life process without curative effect on a patient who has received a medical prognosis that he/she is in a state of imminent death. Here, methods to identify patients’ wishes regarding termination of life-sustaining treatment are critical.

2. Methods to verify patients’ wishes

“The Act” classifies the methods to verify patients’ wishes about termination of life-sustaining treatment into “when it is possible to verify patients’ wishes” and “when it is impossible to verify patients’ wishes” based on the basic principles (Article 17 (1)). The following shows the methods to verify the patient’s wish (Figure 1).

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9 Ibid.
10 Ibid.
11 Ibid.
12 Ibid.
When it is possible to verify patients’ wishes

1. When it is possible to express their wishes

2. When it is impossible to express their wishes (family members’ wish presumption)

When it is impossible to verify patients’ wishes

3. When it is impossible to express their wishes (family members’ surrogate decision making)

**Figure 1. Methods to verify patients’ wishes**

Patients’ wishes can be verified by each method; when it is possible to express their wish, the two following methods are adopted to express patients’ explicit wishes: 1) life-sustaining treatment plan written with the doctor at the end of life, and 2) advance statement on life-sustaining treatment written in advance by an adult at least 19 years old when he/she was healthy. The patient shall receive sufficient explanation for both documents before preparing them, regarding matters concerning the methods of providing life-sustaining treatment and matters concerning determination to terminate life-sustaining treatment; matters concerning selecting and using hospice care; concerning preparing, registering, keeping, and notifying each document; and matters concerning amending and withdrawing each document, and subsequent measures (Article 10 (1), Article 11 (1)). It is necessary to verify whether the patient properly understood the content and have him/her prepare the document without coercion or compulsion, thereby obtaining informed consent about determination to terminate life-sustaining treatment.

Furthermore, when it is impossible to express their wish, even though a patient’s wishes can be verified, the two following methods are adopted to presume a patient’s wishes: 1) when it is impossible to express the wish even though a patient’s wishes can be verified from the advance statement on life-sustaining treatment written by the patient when he/she was healthy, it is regarded as the person’s wish: a) if the doctor-in-charge and one medical specialist in the relevant field verify the medical

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13 Ibid.
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judgment that the patient lacks mental capacity to verify details of the advance statement on life-sustaining treatment, and b) if it is verified that the person actually wrote and prepared the advance statement on life-sustaining treatment (provisory clause of Article 17 (1) 2)\(^{14}\); 2) if there are two or more identical statements from the members of a patient’s family regarding his/her wishes to determine when to terminate life-sustaining treatment that is consistently expressed for a period sufficient to construe it as the patient’s intention to determine to terminate life-sustaining treatment, such statements shall be construed as the patient’s wishes following verification by the doctor-in-charge and one medical specialist in the relevant field (Article 17 (1))\(^ {15}\). A patient’s family here refers only to someone at least 19 years old who is either the spouse or is related by blood, such as a lineal descendant or lineal ascendant. According to this clause, the presumption of the patient’s wishes to terminate life-sustaining treatment can be made only by his/her family members.

Next, where it is impossible to verify a patient’s wishes and he/she is in a medical condition that prevents him/her from expressing his/her wish, determination to terminate life-sustaining treatment is made on behalf of the relevant patient in only one of the two following cases (Article 18 (1)\(^ {16}\); 1) a legal representative (limited to a person of parental authority) of a patient who is a minor has expressed an intention to determine to terminate life-sustaining treatment and the doctor-in-charge and one medical specialist in the relevant field have verified such intention; and 2) where all members of the patient’s family have unanimously expressed an intention to determine to terminate life-sustaining treatment and the doctor-in-charge and one medical specialist in the relevant field have verified such intention.\(^ {17}\) Such surrogate decision-making must be

\(^{14}\) Ibid.

\(^{15}\) Ibid.

\(^{16}\) Ibid.

\(^{17}\) In the latter option, there may be questions about the extent of “all members of a patient’s family.” Instead of prescribing the extent thereof, those excluded are presented as follows. A person in whose case at least three years have passed since his/her disappearance was reported to a police office, a person judicially declared missing, or a person whose medical condition has been diagnosed and confirmed by at least one specialist, as a person whose medical condition prevents him/her from expressing his/her own intention due to unconsciousness or similar reasons” (Article 9 (1) of the Enforcement Decree of the Act). Ministry for Health, Welfare and Family Affairs, Enforcement Decree of the Act on Hospice and Palliative Care and Decisions on Life-Sustaining Treatment for Patients at the End of Life (2018). https://elaw.klri.re.kr/kor_
done with unanimous consent of all members of a patient’s family, and dissent of even one member prohibits determination to terminate life-sustaining treatment, which is more strictly regulated than is the presumption of a wish.

Accordingly, determination to terminate life-sustaining treatment shall be implemented immediately if this is the patient’s wish and it is not against the wishes of the patient at the end of their life. Moreover, the head of a medical institution shall notify the head of the National Agency for Management of Life-Sustaining Treatment of the result of implementation. The entire flow of the implementation of determination to terminate life-sustaining treatment is shown in Figure 2.

As examined above, “The Act” does not permit wish presumption or surrogate decision-making of a third party aside from the patient’s family. This is due to the familial culture of Korea, which assumes that the patient’s family best understands his/her beliefs or values and thus will make the right decision for him/her. According to a survey on the perception of 500 Korean adults regarding medical decision making in 2015, several respondents (41.2%) claimed that the patient, caregiver, and doctor shall make the decision together. According to a survey on the perception of life-sustaining treatment, most elderly patients who responded to the survey chose their spouse (53.3%) and child (36.7%) as their most suitable representative. Furthermore, 56.7% of them also responded that the most important requirement in designating a representative is “understanding their usual words and actions.” As such, most Koreans want their caregivers to participate in the medical decision-making process, and they believe that the person who best understands the patient’s values through his/her usual words and actions is a family member.

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1. Whether the patient is in the end-of-life process

2. When it is possible to verify the patient’s wishes
   - When it is possible to express the wish
     1) When there is a life-sustaining treatment plan written at a medical institution
     2) When the doctor-in-charge confirmed the details of an advance statement concerning life-sustaining treatment from the patient
   - When it is impossible to express the wish
     1) When there is medical judgment that the patient lacks the mental capacity to express his/her wishes and when the person wrote and prepared an advance statement concerning life-sustaining treatment
     2) When there are two or more identical statements of the members of the patient’s family

2-1. When it is impossible to verify the patient’s wishes
   - When it is impossible to express the wish
     1) When it is verified by a legal representative (person of parental authority) of a patient who is a minor
     2) When all members of the patient’s family unanimously agree

3. Immediate implementation of the determination to terminate life-sustaining treatment

4. The head of a medical institution shall notify the head of the National Agency for Management of Life-Sustaining Treatment of the result of implementation

**Figure 2.** Flow chart of the implementation of determination to terminate life-sustaining treatment
In that sense, “The Act” reflects consideration of Korea’s familial culture. Even so, if only the patient’s family is permitted to presume the patient’s wishes or make surrogate decision-making, there may be an issue with patients who have no family to represent their wishes, and thus their right to self-determination about decisions on life-sustaining treatment may not be guaranteed or rather be violated.\(^\text{20}\) In particular, PDD face difficulty in exerting their right to self-determination or being respected because of limited cognitive ability or communication, and in many cases, they have no family to represent their wishes, leaving them vulnerable to this issue. The following section examines why they are vulnerable to this issue by focusing on the current state of PDD in Korea.

### III. Current state of PDD in Korea

According to 2011 World Health Organization (WHO) data, over a billion people (or about 15% of the world’s population) are estimated to be living with disability.\(^\text{21}\) There were 2.54 million persons with disabilities registered in Korea as of the end of December 2017, accounting for 4.9% of the total population).\(^\text{22}\) In Korea, PDD includes persons with an intellectual disability and persons with autistic disorder (Article 2 of the Act on Guarantee of Rights of and Support for Persons with Developmental Disabilities).\(^\text{23}\) By type of disability registered, physical disability is the most common type (49.3%), followed by visual impairment (9.9%), hearing impairment (11.8%), brain lesions (9.9%), intellectual disabilities (7.9%), and autistic disorder (1%), with PDD comprising about 9% of all registered persons with disabilities.\(^\text{24}\) As such, it seems


there are only a few PDD according to the ratio by type of disabilities registered; however, according to the disability grading classified by the severity of disability, persons with intellectual disabilities account for 25.3% (50,428 persons) of all persons with Grade 1 disabilities (199,186 persons), and 20.6% (70,226 persons) of all persons with Grade 2 disabilities (340,202 persons), showing that there are more persons with severe disabilities compared to other types.25

Furthermore, all disability grades of persons with intellectual disabilities and Grades 1 and 2 of autistic disorder have a lower intelligence quotient than 70, thereby limiting their cognitive ability and communication. As for the communication ability of persons with intellectual disabilities, many (34.4%) “can communicate briefly by themselves,” followed by “can communicate mostly by themselves” (26%), and “can communicate briefly with help” (25.5%); however, there were also those who “cannot communicate at all” (10.3%).26 This survey shows that very few of the respondents can communicate mostly by themselves, while most persons with intellectual disabilities can only briefly communicate by themselves or with help, and even cannot communicate at all in some cases. This difficulty in communication can be found in the following question, “Do you have experience of failing to go to a clinic or hospital when you wanted to in the past year?” Specifically, 15.2% of persons with intellectual disabilities and 8.9% of persons with autistic disorder said yes. The reason was, according to 27.4% of persons with intellectual disabilities have “difficulty in communication”27. For this reason, PDD are vulnerable to suspicion about their communication ability itself, and often become the target of abuse, negligence, or economic and physical exploitation.28


25 Ibid.


27 Ibid.

Moreover, regarding the current residential state of persons with disabilities, 30,980 persons are living in 1,505 residential facilities\(^{29}\) for the disabled as of December 2016. Furthermore, the ratio of persons with intellectual (autistic) disabilities was highest (39%, 12,112 persons).\(^{30}\) As such, most PDD living in these residential facilities either have no family or do not have contact or interaction with their family. In this situation, it is likely that the family cannot properly represent the wishes of PDD regarding determination to terminate life-sustaining treatment. There may also be a risk of making the decision to terminate life-sustaining treatment against the wishes of the patient because of financial burden.\(^{31}\) However, under “The Act,” there is no specific law or system in favor of supportive medical decisions of vulnerable groups lacking decision-making ability, such as PDD. To overcome the limitations of “The Act,” it is necessary to utilize the adult guardianship system of the civil law that was institutionalized to allow for a guardian to be appointed for making family court decisions or in a guardianship contract, in order to provide a wide range of protection and support for property management and daily life of an adult who needs help to handle office work due to disability, illness, and old age, etc., and a system for a physician in charge of the health of persons with disabilities to facilitate the healthcare management according to the chronic disease or disorder of the person with severe disability. Based on this, comprehensively considering cognitive restraints, difficulties in communication, and the residential status of PDD, it is necessary to multilaterally seek required measures and supported decision-making methods to exert their right to self-determination in decision making on life-sustaining treatment of PDD.

\[^{29}\text{Residential facilities for the disabled refer to facilities in which persons with disabilities recuperate for a long time due to disabilities or preparations for return to normal social life, receiving services such as counseling, treatment and training required for rehabilitation for a required period of time. In Korea, such facilities accommodate people with the same or similar disabilities and provide residential and rehabilitation services such as healthcare, education, psychotherapy and social life that are suitable for the type of disability.}\]


IV. Supported decision-making methods in cases of decisions regarding life-sustaining treatment of PDD

Many patients in the end-of-life process face difficulties, either physically or mentally, at the point of making the decision to terminate life-sustaining treatment. In particular, PDD face many difficulties in expressing and conveying their wishes during daily medical decisions. However, despite these difficulties, the right to self-determination of PDD must not be ignored or denied. Instead, it is necessary to provide sufficient information and services required for decision making so that they can exert their right to self-determination. However, “The Act” only mentions patients’ right to self-determination as a basic principle, while lacking consideration of measures related to supported decision-making that are required for them to exercise their right to self-determination. Therefore, to solve this problem, this study made active use of the existing system in the Korean context to seek supported decision-making methods for PDD in cases of decisions on life-sustaining treatment.

1. Providing opportunities for advance care planning

In “The Act,” the most essential element of seeking methods to support decision-making of PDD is to approach them differently as per the degree and level of their decision-making ability and the specialty of medical decision-making at the end of life. In other words, under the basic principle of patients’ right to self-determination, PDD can equally use their wishes and remaining capacity, like persons without


33 This can be found in the UN Convention on the Rights of Persons with Disabilities. Article 12 Equal Recognition before the law (2) prescribes that “States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.” Based on this, (3) prescribes that “States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.” United Nations (UN), *Convention on the Rights of Persons with Disabilities*, 2006, [https://www.humanrights.gov.au/our-work/disability-rights/international/united-nations-convention-rights-persons-disabilities](https://www.humanrights.gov.au/our-work/disability-rights/international/united-nations-convention-rights-persons-disabilities).

34 Yoo Su Jung & Park So-You. “Respect for Self-Determination and Supported Decision-Making in Life-Sustaining Treatment Decision-Making for Patients with Disabilities.”
disabilities, to make their own decisions on life-sustaining treatment. This indicates that one shall not assume that PDD lack the ability to make decisions without sufficient information and supported decision-making required to establish advance care planning. For instance, in the UK, the General Medical Council assesses the patient’s decision-making ability using the “Flowchart for decision-making when patients may lack capacity.”35 Thus, it is necessary to make an effort to create tools and guidelines that medical professionals can use to evaluate patients’ decision-making ability in clinical situations.

Also, if a PDD wants to prepare a life-sustaining treatment plan with a medical professional, information required for making decisions on life-sustaining treatment shall be provided using easily recognizable texts, images, and videos considering the cognitive ability, literacy, and information processing characteristics of the PDD.36 According to the current Act on Guarantee of Rights of and Support for Persons with Developmental Disabilities, “the State and local governments shall prepare and distribute information about statutes that substantially affect the rights and duties of PDD and important policies on various welfare assistance programs in a form that PDD can readily understand” (Article 10 (1)).37 For example, source books are made and distributed for PDD to easily learn about laws and policies related to their disabilities.38 According to this clause, “The Act” can also be considered a law that has a significant impact on the rights and duties of PDD. Therefore, various education and effort is needed to introduce information related to decisions on life-sustaining treatment in a form that is easily comprehensible for PDD, and to provide them with options regarding life-sustaining treatment. These supported decision-making services or programs

will contribute greatly to smooth communication between medical professionals and PDD, and the establishment of advance care planning.

2. Public support system for PDD: connecting “The Act” with the public guardianship service

Nonetheless, if reasonable grounds exist to decide that PDD lack the ability to make a decision independently, his/her family may assist him/her in making a decision. Regardless of whether there is a disability or not, patients’ medical decision-making process is interdependent. To make a certain medical decision, patients want to receive help or support from trusted family or friends or their doctor. If a person has considerable grounds to assume that he/she does not have sufficient ability to make decisions for himself/herself, he/she tends to desire decision-making support from someone they trust even more. However, in the absence of family members who can adequately represent the rights of PDD, serious focus is needed on the issue of who can make decisions for PDD on behalf of his/her family. The adult guardianship system is a system that provides extensive protection and support for property management and daily life through a guardian for adults in need of help in dealing with affairs.

In cases involving PDD, who may have difficulty in appointing a guardian for themselves even though they need to, the Ministry for Health in Korea has implemented a support project (e.g., financial support is provided to cover the costs of a request for a guardianship trial and public guardian activities) to claim guardianship judgment since September 1, 2013 (as part of the promotion of the adult guardianship system; Article 9 (1) 1, 2, 3 of the Act on Guarantee of Rights of and Support for Rights of People with Disabilities). 39

39 The National Assembly of Korea ratified the Convention on the Rights of Persons with Disabilities in 2008, which took effect on January 10, 2009. Accordingly, the Korean government amended the civil law in 2011 and newly adopted the adult guardianship system. The adult guardianship system in Korea is to provide extensive protection and support for property management and daily life through a guardian appointed by the decision of the Family Court or guardianship contract for adults in need of help in dealing with affairs due to disability, disease or old age. This system is divided into legal guardianship and voluntary guardianship, and legal guardianship is then divided into adult guardianship, limited guardianship and specific guardianship. As such, the guardianship system has multiple types of guardianship and adopts a pluralist method to decide on a suitable guardianship type in the judgment process flexibly. Ministry of Justice. Civil Act (2017) https://elaw.klri.re.kr/kor_service/ lawView.do?hseq=45912&lang=ENG.
PDD).\textsuperscript{40} This is referred to as the public guardianship service. The public guardianship system aims to provide public guardianship services to PDD having a limited ability to make decisions, and ultimately to support their independent living. In terms of the qualification of a public guardian, a person who (a) is or will be trained in the cultivation education of public guardian candidates, (b) works in a public guardianship corporation designated by the Ministry for Health, Welfare and Family Affairs, or (c) is eligible for the consideration of the relationship with the ward and the suitability of the public guardian activity, or recommended by the director of the Center for PDD, may be a public guardian (Article 2 of the Enforcement Rule of the Act on Guarantee of Rights of and Support for PDD).\textsuperscript{41} In the case of PDD living in residential facilities, those who are likely to have conflicts of interest with PDD, are excluded from the candidates for guardianship. In addition, the supervision of the public guardian is carried out by submitting the guardian’s activity report to the guardianship corporation every month and/or checking with the support center for the people with disabilities when necessary.\textsuperscript{42} Through this, the public guardianship service for PDD is provided to guarantee and support the rights of PDD in case of PDD without a family to represent his/her rights properly, and/or if it is highly likely that the rights of the PDD will be violated if no particular measure is taken.

Currently, the number of PDD using the public guardianship service is gradually increasing. The current state of using the public guardianship service shows that there were 560 requests for a trial in the public guardianship service from September 2013 to June 30, 2016. Furthermore, 214 public guardians have been appointed by the court as of June 2016, and 263 PDD were using the guardianship service.\textsuperscript{43} Moreover, efforts have been made at the national level for more PDD to use this service through

\textsuperscript{40} Ministry for Health, Welfare and Family Affairs, http://www.bokjiro.go.kr/welInfo/retrieveWellnfoDetail.do?welInfSno=36

\textsuperscript{41} Ibid.

\textsuperscript{42} Ministry for Health, Welfare and Family Affairs, Public guardianship support project for the developmentally disabled, http://www.mohw.go.kr/react/policy/index.jsp?PAR_MENU_ID=06&MENU_ID=06370401&PAGE=1&topTitle=

aggressive publicity and education. In this sense, if the decision of PDD can be confirmed, but if he/she cannot express himself/herself and has no family and if this service is linked to “The Act,” PDD can exercise their right to self-determination and be respected when they make decisions on life-sustaining treatment with the support of a public guardian even if they do not have family to properly represent their rights.44

However, since most staff in residential facilities for the disabled or public guardians do not receive formal medical education, they might have difficulty handling PDD’s medical crises.45 According to third-year inspection symposium data for the public guardian support project for PDD, Public guardians were “complaining of difficulty in handling fields they have never experienced, and in making decisions for legal issues or other issues related to property or medical treatment.”46 In that sense, if a PDD has a physician in charge of health, that physician will consistently meet with him/her and build a close trusting relationship, thereby best representing his/her medical preferences.

3. Countermeasure for the public guardian system: a system for a physician in charge of health of persons with Disabilities

According to a 2014 survey conducted in Korea, 75.8% of all persons with

44 For example, Je and Choi (2016) conducted a survey on public guardians nationwide currently providing guardianship services to examine the problems and improvement plans of the background, job details, and job satisfaction of public guardians. After analyzing 152 out of 200 copies of the questionnaire, it was discovered that over 90% of guardians had finished undergraduate studies (55.3%) or graduate school (34.9%). An analysis of multiple responses regarding the guardianship activities of guardians showed that 35.9% were property management, 53.9% were welfare protection services, and 10.2% covered both the fields of property management and welfare protection. Je, Cheolung & Choi Yun-Young, Yoo Hea-In. “Analysis of the Workload and Performance of Public Guardians and Its Implications.” Journal of Comparative Private Law 23 no. 2 (May 2016): 651–686. http://www.riss.kr/search/detail/DetailView.do?p_mat_type=1a0202e37d52c72d&control_no=462728893263f3476aae8a972f9116f8#redirect.


disabilities suffer from such chronic diseases as hypertension and diabetes, and their mortality rate is more than four times that of the total population.\(^{47}\) As such, there are increasing demands for use of medical service by persons with disabilities. Reflecting their voices, Korea established the Act on Guarantee of Right to Health and Access to Medical Services for Persons with Disabilities on December 29, 2015, which took effect on December 30, 2017.\(^{48}\)

This Act prescribes the implementation of a system for a physician in charge of health of persons with disabilities to provide healthcare for chronic diseases or disabilities of persons with severe disabilities (Article 16 (1) of the Act on Guarantee of Right to Health and Access to Medical Services for Persons with Disabilities).\(^{49}\) Persons with severe disabilities eligible for a system for a physician in charge of the health of persons with disabilities, according to this Act, are those rated as Grade 1 through Grade 3 disability, with a chronic disease or disability (Article 5 (1) of the Enforcement Decree of the Act on Guarantee of Right to Health and Access to Medical Services for Persons with Disabilities).\(^{50}\) Moreover, from the system for a physician in charge of the health of persons with disabilities, they can receive services such as management of the main disability in accordance with its characteristics, management of chronic disease considering the characteristics of the disability, prevention and management of ordinary disease, linking to health and medical institutions for treatment and healthcare, and information about healthcare programs for persons with disabilities (Article 5 (2) of the Enforcement Decree of the Act on Guarantee of Right to Health and Access to Medical Services for Persons with Disabilities).\(^{51}\)

As shown in the current state of PDD, they are all included in Grades 1 through


\(^{49}\) Ibid.

\(^{50}\) Ibid.

\(^{51}\) Ibid.
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3; therefore, if the relevant PDD wants to use the system for a physician in charge of health of persons with disabilities then it is possible. The procedures for using a system for a physician in charge of health of persons with disabilities are as follows. First, a doctor who intends to provide the service shall complete the physician education program conducted by the Ministry for Health, Welfare and Family Affairs (Article 7 (1) of the Enforcement Decree of the Act on Guarantee of Right to Health and Access to Medical Services for Persons with Disabilities), and be registered as a physician-in-charge to the National Health Insurance Service (Article 6 (1) of the Enforcement Decree of the Act on Guarantee of Right to Health and Access to Medical Services for Persons with Disabilities). Furthermore, persons with severe disabilities who intend to receive treatment or healthcare from such physicians shall apply for treatment or healthcare with the physician (Article 8 (1) of the Enforcement Decree of the Act on Guarantee of Right to Health and Access to Medical Services for Persons with Disabilities), and the physician who received application to use the service shall notify the National Health Insurance Service of this decision (Article 8 (2) of the Enforcement Decree of the Act on Guarantee of Right to Health and Access to Medical Services for Persons with Disabilities). As such, the system for a physician in charge of the health of persons with disabilities is registered and managed by a national institute.52 If a PDD uses this system to consistently interact with the doctor registered as his/her physician, and builds a close relationship based on trust, then this physician may be the person who can best represent this person’s medical preferences, and the physician’s opinion may support the reliability of the guardian’s statement. Therefore, to devise advance care planning that respects the wishes and preferences of PDD, a shared decision-making model is proposed. In this model, the family or a public guardian who grasps the PDD’s daily preferences, values, religious beliefs, or general attitude toward life, participate in supported decision-making, or, in which a physician in charge of health who can support the PDD’s medical needs or preferences participates in decisions on life-sustaining treatment (Figure 3).

The shared decision-making model above enables PDD to receive information about their options related to decisions on life-sustaining treatment, as well as the opportunity for them to explore their preferences on their own, and this must be conducted in the decision-making process that helps PDD make decisions according to their own will. With this shared decision-making model, public guardians and physicians-in-charge are anticipated to bridge the gap in protection for PDD without a family in “The Act.”

V. Conclusion

While it is vital to guarantee patients’ right to self-determination in discussing legislation of a system related to decisions on life-sustaining treatment, the Korean government has made efforts to build a social infrastructure to prevent side effects, such as abuse that may arise in the enforcement of this law. These efforts include establishing a system and facilities for hospice and palliative care, activating the hospital ethics committee, improving education and perception of medical persons, improving the public’s perception about death, and providing financial support for patients in the end-of-life process. These policies and education will form the social and cultural foundation for making the right decisions about life-sustaining treatment.

Despite these efforts, “The Act” has limitations in that it lacks the cognitive perspective of disabilities. The persons with disabilities population is expected to increase steadily owing to population aging, increased incidence of chronic diseases,
various accidents, and disasters. Among various disability types, PDD are likely to face difficulty in communicating with doctors about their wishes, preferences, and value system when making decisions on life-sustaining treatment because of limited cognitive ability and communication difficulties. Consequently, if PDD can express themselves, it is necessary to endeavor at the national level to develop communication support services or programs, such as providing information related to decisions on life-sustaining treatment using terms and images suitable to the needs of PDD.

However, without sufficient ability to make decisions on their own, they may require help from family or a guardian to support and represent their will and preferences. A guardian shall not represent the decisions of a PDD because he/she has low cognitive ability or difficulty in communication and thus is considered someone who has no ability to make decisions. Instead, the guardian shall support the PDD’s decision making to guarantee and respect his/her rights, will, and preferences.

As examined above, unlike the advance directives of the US that embrace the living will and durable power of attorney, Korea does not allow designating a representative to make decisions on behalf of the patient when the patient cannot express his/her wishes. Therefore, there is a gap in protection that may arise if the patient does not have family, as the wish presumption and surrogate decision-making by a third party aside from the patient’s family members is not acknowledged. Therefore, if the wishes of a PDD can be verified by an appointed guardian and physician in charge of the health of persons with disabilities, it is necessary to have the laws reviewed so that these wishes can be granted after verification from the doctor-in-charge and one medical specialist in the relevant field.

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