



# How Must We Prepare in the Next Decades When Caring for Those With Developmental Disabilities: “Grown Up” (2018)

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The Guarantee of Rights and Support for Persons with Developmental Disabilities Act was enacted and revised in 2014. However, national measures for persons with developmental disabilities remain insufficient. In the film, “Grown Up,” director Hyeyoung Jang filmed the daily life of her sister, who has developmental disabilities. She raised not only the issue of institutionalization in people with developmental disabilities in Korea but also the issue of a lack of policies that would be essential to them and their family members. In the future, I hope that as experts, child and adolescent psychiatrists in Korea will pay more attention to the lives of people with developmental disabilities outside the clinic and propose policies to help them and their family members.

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The Guarantee of Rights and Support for Persons with Developmental Disabilities Act [1] has been enacted and revised in 2014 in Korea. According to this act, people with a developmental disability include people with intellectual disabilities, people with autistic disorders, and people who are specified by a Presidential Decree as those who have considerable impediments in their daily lives or social lives because of a lack or significant retardation of ordinary development. In fact, as there have been no provisions in the Presidential Decree regarding a person with a developmental disability at present, developmental disability has included only intellectual disability and autism spectrum disorder in Korea. Article 3 of the Act states that every person with a developmental disability has the right to receive assistance as necessary for understanding matters that have legal and factual effects on them, express their opinions freely, and express their views and opinions in the process of formulating policies related to them. The number of people with developmental disabilities in Korea was 247910 in 2020, accounting for 9.4% of the total number of registered people with disabilities [2].

Grown Up, a 2018 documentary film directed by Hyeyoung Jang, dealt with the daily life of her sister, who had a developmental disability, after deinstitutionalization, which was un-

familiar to most child and adolescent psychiatrists. Hyejeong, the director’s sister and protagonist who was institutionalized for 18 years, from 12 to 30 years of age, had a national disability card because of her intellectual disability, and showed some autistic features throughout the film. She seemed to have a poor ability to perform her activities of daily living. For example, she was unable to calculate well when she visited a convenience store. She could read letter by letter. She would make the room untidy, which might be explained by her poor organizational skills. Sometimes, she showed some socially disinhibited behaviors (e.g., singing and dancing in public without noticing the reaction of others) that required social skills training, which was recommended by a child-adolescent psychiatrist, Professor Keun-Ah Cheon. Such deficits due to her intellectual disability, autistic features, and lack of experience in developing skills while she was in the institution seemed to make it difficult for her to manage daily life without her sister or personal care assistant.

However, she could only get 94 service hours per month of public personal care support after a telephone interview. Moreover, her sister could not find a personal care assistant even after all public personal care assistant agencies were contacted. Therefore, her sister had to look after her all day without public support, which should have been provided according to the Guarantee of Rights of and Support for Persons with Developmental Disabilities Act. Through this manifesto

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film, the director raised not only the issue of institutionalization in people with developmental disabilities in Korea without the chance to choose where they would live only because they had a disability, but also the issue of lack of policies that would be essential to them and their family members. She also insisted that there was no humane life for all, without humane life for those with developmental disabilities.

Although President Jae-In Moon promised the responsibility of the state for the care of people with developmental disabilities during the presidential election campaign of 2017, the national budget for the same has been decreased after the election. The national budgets were 9.1 billion Korean Won in 2016 and 8.5 billion Korean Won in 2018 [2]. In 2018, in collaboration with the Ministry of Health and Welfare, Ministry of Education, and Ministry of Employment and Labor, the Korean government announced Comprehensive Plans for the lifetime care of persons with developmental disabilities [3]. In the plans, the 10 major tasks included the enhancement of early diagnosis, care or education, and early intervention in infancy; the support for individually customized education and job training from childhood to adolescence; the activation of community participation via daytime activity support plans and job support in early and middle adulthood; and the enhancement of community care and health services as well as the establishment of guaranteed income in late adulthood and old age. In addition, the enhancement of medical accessibility (e.g., rehabilitation services, central regional hospitals for the developmentally disabled, centers for problematic behaviors), protection of the rights of people with developmental disabilities, and emotional support for their families were proposed across all ages. Following the detailing of the plans in 2018, 10 central regional hospitals for developmentally disabled people and related centers for problematic behaviors have been founded.

However, follow-up measures for individuals with developmental disabilities remain insufficient. Moreover, the responsibility of the state for the care of people with developmental disabilities has not yet begun. Although the director herself was elected as a proportional representative of the Republic of Korea National Assembly in 2020 and proposed acts for the disabled [4], many of the remaining problems have not been solved. For example, only 9000 people with developmental disabilities in adulthood could receive the daytime activity support plan in 2020, covering only approximately 4% of all people with developmental disabilities. In

addition, they had no choice but to give up part of the public personal care assistant service during the daytime activity support plan [2]. To date, there have been no national plans for research on developmental disabilities, especially the development of confirmatory diagnostic instruments and basic behavioral intervention programs for people with developmental disabilities, measures on the increased numbers of educated and trained teachers for special education or related professionals, and strategies for nationwide coverage of hospitals for rehabilitation, central regional hospitals for the developmentally disabled, and centers for problematic behaviors.

During the recent twentieth presidential election in Korea, some candidates agreed to a national responsibility system for those with developmental disabilities [5,6]. In future, as experts in the field, I hope that child and adolescent psychiatrists in Korea will pay more attention to the lives of people with developmental disabilities outside of the clinic and propose policies to help them and their family members.

#### Conflicts of Interest

The author has no potential conflicts of interest to disclose.

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#### REFERENCES

- 1) **Korea Legislation Research Institute.** Act on guarantee of rights of and support for persons with developmental disabilities [Internet]. Sejong: Korea Legislation Research Institute; 2020 [cited 2022 March 7]. Available from: [https://elaw.klri.re.kr/kor\\_service/lawView.do?hseq=53998&lang=ENG&searchTxt=developmental%2520disability&searchTxt2=&searchType2=engWordView](https://elaw.klri.re.kr/kor_service/lawView.do?hseq=53998&lang=ENG&searchTxt=developmental%2520disability&searchTxt2=&searchType2=engWordView).
- 2) **Oh JH.** The state is responsible for implementing consumer-centered welfare [Internet]. Seoul: Hankookilbo; 2021 [cited 2022 March 7]. Available from: <https://www.hankookilbo.com/News/Read/A2021051615030002622>.
- 3) **Ministry of Culture, Sports and Tourism.** Comprehensive measures for lifelong care for the developmentally disabled [Internet]. Sejong: Ministry of Culture, Sports and Tourism; 2018 [cited 2022 March 7]. Available from: <https://www.korea.kr/news/visualNewsView.do?newsId=148853925>.
- 4) **Bill Information.** Act on the 24-hour guarantee for disabled people's activities [Internet]. Seoul: Bill Information; 2020 [cited 2022 March 7]. Available from: [http://likms.assembly.go.kr/bill/billDetail.do?billId=PRC\\_C2E0T0J6K1P5T1T7H1W0H3P8R5W3V3](http://likms.assembly.go.kr/bill/billDetail.do?billId=PRC_C2E0T0J6K1P5T1T7H1W0H3P8R5W3V3).
- 5) **Democratic Party of Korea.** Candidate Jae-myung Lee's 'promise for the disabled!' [Internet]. Seoul: Democratic Party of Korea; 2022 [cited 2022 March 7]. Available from: <https://theminjoo.kr/board/view/online/753858>.
- 6) **Justice Party.** Policy promises. Seoul: Ellelit Publishing; 2022.