A Narrative Inquiry into the Life of a Mother for a Child with Developmental Disabilities

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Abstract
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Keywords
adults with developmental disabilities, mother raising a child with developmental disabilities, narrative inquiry

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This study explores the life story of Jane, who has an adult child with developmental disabilities and who serves as the director of a community welfare center for people with developmental disabilities in South Korea. To this end, this study used narrative inquiry methodology. The experience of a parent was described in terms of the following themes: (i) Narrative experience as a parent in a family: The irony of life—living in a place where guilt and desire coexist, Sub theme: Building up a broader window of communication; (ii) Narrative Experience as the head of an institution: Learning betrayal and making considerations, Sub theme: Breaking free from obsession and finding genuine happiness. In South Korea, there is growing societal interest in adults with developmental disabilities and their families. In this social context, the authors of this study hope that the story of a participant like Jane will help adults with developmental disabilities, parents of children with other types of disabilities, and heads of institutions that provide care for them reflect on and have a deeper understanding of their lives, and present future visions for themselves.

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Introduction

Although the general public awareness of disability has been improved with the continued efforts of individuals from all social standings, including but not limited to government workers, people with disabilities, and parents, being a parent raising an adult child with developmental disabilities in modern society still involves various challenges, such as psychological and physical burnout (Burke et al., 2017; Cetinbakis et al., 2020; Gebeeyehu et al., 2019). A developmental disability is a type of disability that is related to an individual’s development, such as an intellectual disability or autism (Pineda, 2021). Parents who have a child with developmental disability can better raise their child when social support is provided than when they have to rear the child by themselves (Robinson & Weiss, 2020). As a result, the responsibility of a parent to take care of an adult child with a developmental disability during his/her entire life becomes fairly challenging, particularly if the parent does not receive any help or support from society (Ardic, 2020; Cantwell et al., 2014).

Meanwhile, specialists working at institutions whose work involves persons with developmental disabilities are carefully listening to the diverse opinions of parents who take care of adult children with developmental disabilities (Butrimaviciute et al., 2016; Jurewicz, 2020; Pegg, 2014).

This study reviewed the life of Jane, who has raised an adult child with a developmental disability in South Korea and who serves as the director of a community welfare center for people with developmental disabilities.
In other words, this study examines the life story of Jane who has primarily lived within two different places—the parent and the institution—while bringing up her adult child with a developmental disability and simultaneously working as the director of a community welfare center for people with disabilities. Above all, this narrative inquiry is related to the ego identity (meaning that having a strong sense of self which is manifested by a confident awareness of one’s enduring characteristics) of Jane who has lived in two different places as a parent of an adult with a developmental disability and as the head of an institution, respectively. This ego identity of Jane was something that the researcher obtained from the process of learning the meaning of her life experience. This personal life experience became a driving force in Jane’s life as she reflected on her life changes and experiences.

Further, focusing on how Jane’s life can have a positive impact on other parents of children with disabilities, this paper wishes to offer a message of hope to parents with adult children with developmental disabilities in South Korea and the West.

The narrative inquiry methodology is one of the qualitative research methods that can be used to understand a certain individual’s experience (Artiles, 2019; Aydin & Avincan, 2020; Haydon & van der Riet, 2017). This research aims to help parents of children with disabilities by examining the life and experiences of Jane who has raised an adult child with developmental disabilities while working as a director of a community welfare center for people with developmental disabilities. This can be said to be different from other studies that deal with stories in one space.

In South Korea, there is prejudice against people with developmental disabilities and their parents (Kim et al., 2022). Compared to countries in the West, social integration of persons with developmental disabilities is difficult in South Korea. Moreover, although children in South Korea with developmental disabilities receive school education while they are school age, when they age out of the education system, their parents are responsible for their daily life and education. In South Korea, a community welfare center for people with developmental disabilities is a leading institution that provides education for adults with developmental disabilities. To access services offered by the center, individuals often need to wait for a long time. Sometimes they are rejected, depending on their level of disability.

Research in South Korea has shown that parents of adult children with developmental disabilities carry a significant psychological burden. By contrast, parents of children with developmental disabilities in the United States have been shown to receive a lot of psychological support (Wang, & Singer, 2016). The results of the current study solidify the importance of family support in the lives of families of children with developmental disabilities.

**Methodology**

I am working as a teacher at a special school for developmental disabilities in South Korea. This is why we were interested in this topic in particular. The present study used a narrative inquiry method based on an in-depth interview with a woman named Jane. This study was approved by the IRB (IRB number 20223) as a human research activity.

**Narrative inquiry**

People use narratives to understand their own experiences and present them to others. Thus, a narrative inquirer aims to understand a participant’s life experience through the lens of that participant’s narratives, and the inquirer is given an opportunity to examine the cultural and social meanings that are the basis of such experiences when a story is understood and analyzed through such narratives (Hamilton et al., 2017; Ropo, 2019).
Studying a research participant’s experience necessarily involves examining the participant’s life itself (Mehrotra et al., 2014; Stuart, 2012).

The following reasons are given to secure the justification for using the narrative inquiry methodology in this research. The primary purpose of this research is to examine the meaning of experience by investigating the life story of Jane, a parent of an adult child with a developmental disability and the director of a community welfare center for people with developmental disabilities. A narrative inquiry can more effectively reveal the life, story, and meaning of an individual that this study focuses on to achieve its purpose (Şen, 2021).

Jake is Jane’s son, and he has developmental problems. In this study, Jane’s support system includes Jane, Jake, Jane’s husband, daughter, and the researcher. They have all built a close relationship with each other over many years. Even before Jane consented to participate in the present research, the researcher, as a homeroom teacher, often met with Jane, as Jake’s parent, thus helping them both open their hearts to each other. This cordial relationship ultimately contributed to enhancing the confidence of this research, thus helping clarify the support system in this study.

Narratives are considered to be one of the most useful research methodologies since they require a close relationship between the researcher and participant, and since they can be used to collect meanings in the participant’s life and experiences (McAlpine, 2016; Mendieta, 2013). The research process was conducted based on the narrative inquiry procedures suggested by Clandinin and Connelly (2000). In this study, details recorded in the research text were based on the on-site text (O’Kane & Pamphilion, 2016; Wang & Geale, 2015). Following the research method used by Clandinin and Connelly (2000), this study was conducted by repeating the process of data collection – data analysis – final text preparation.

Research participant

The researcher first met Jane in 2013 through the relation between a parent (Jane) and a teacher (the researcher) while Jane was working at a special school. Jane requested several consultations about her son with the researcher, who was then the homeroom teacher of Jane’s child in the third grade of high school. Such meetings became a basis for the relationship between these two.

Jane, who is the participant of this study, has worked as the director of a community welfare center for people with disabilities in South Korea, for 15 years. She is 52 years old as of this writing. She has a husband, one son, and one daughter in her family. Her son, aged 26 as of this writing, has a developmental disability and expresses his feelings through meaningless utterances (e.g., Ah!), facial expressions, laughing, and crying. Despite his disability, he can recognize simple receptive language in daily life and act in response to directive sentences (e.g., Please bring me an eraser.). In terms of his 1498 ehaveiory development, Jake tends to scream at or attack people who he feels are offensive to him. In these cases, Jane and her family members need to closely look at Jake’s non-verbal expressions (e.g., facial expression, voice tone, laughing, crying, etc.) to communicate with him. In this process, they can understand what Jake wants and how he is feeling. Jake’s favorite statement is “I love you.” Saying this in the above-stated situation is likely to help him recover his mental stability.

Bringing up Jake with this condition, Jane has always been eager to learn more about her son’s disability. Before working as the director of the present community welfare center, she majored in Social Welfare and minored in Infant Education. She also worked as a teacher at a daycare center for children with developmental disabilities before working in her current position.
Data collection from the field

For this narrative inquiry, the researcher created a research context where the participant could freely and frankly talk about her stories. The narrative inquiry was conducted based on the procedures of narrative inquiry suggested by Clandinin and Connelly (2000). Data collection occurred between August 1, 2020, and December 31, 2021. Interviews were used for data collection. These interviews, which were crucial to understanding Jane’s experience (Johnson & Thacker, 2023), were conducted as follows:

During the research period, the researcher visited the community welfare center for interviews with Jane 15 times. Data were collected from a total of 60 sessions (42 rounds comprising 3,650 minutes in total).

The researchers collected the interview content on their mobile phones and repeatedly received synchronized content. We also attempted to make the most of on-site events. After the COVID-19 outbreak, interview data were collected via a contact-free method such as ZOOM.

Beyond in-depth interviews as well as conversations during the interviews, we collected indirect data comprising hand-written letters by family, plans for work performance, performance reports, and reports on the statuses of running programs, which we used for the analysis of the interviews.

Informed consent

Before conducting the main research, the researcher explained that the participant was free to reject revealing certain information or answering sensitive questions and that she could withdraw any answers after the interview. The researcher also explained that when statements were recorded with the participant’s consent, an assumed name would be used and substantial efforts would be made to thoroughly maintain confidentiality. The participant reviewed the contents of the agreement and signed the consent form. The locations and times for the interviews were decided in consideration of the participant’s preferences. Further, the transcripts and recordings were kept in a laptop computer or in a USB stick in an encrypted state. The narrative inquiry sought to comprehensively understand the general meaning of the participant’s experience in the life story rather than examining a certain experience related to the given theme. Accordingly, an assumed name was used instead of the participant’s real name in order to protect her privacy. By the end of the interview, she was asked her feelings about this experience and interview, and her answers were added to the recording to aptly finalize her experience. Written, informed consent was obtained from the [individual(s) AND/OR minor(s)’ legal guardian/next of kin] for the publication of any potentially identifiable images or data included in this article.

Focusing on participant’s perspectives and stories

In this study, the researcher put consistent effort into self-examination, self-knowledge, and self-reflection regarding the proper attitude toward the research while preparing the journal for the purposes of research and introspection.

The researcher carefully listened to the life story of Jane and tried to find meaning in it through the interview environment (i.e., atmosphere) and Jane’s facial expression, voice tone, and behavior during the interviews. The researcher made notes of these observations. Karami and Seraji (2020) argued that this process can enhance the quality of a research paper based on narrative inquiry.
While preparing the journal, the researcher repeatedly listened to the interviews recorded for the transcript on the day of interviewing. The atmosphere and thoughts of the researcher during the interview were summarized and reflected in the journal.

Narrative inquiries had to be conducted in consideration of a three-dimensional narrative inquiry space for the analysis and interpretation of data (Estefan et al., 2016; Jack-Malik & Kuhnke, 2020; Zhong & Craig, 2020). The three points of temporality, sociality, and space were included. First, temporality means the temporal continuity connecting the past, the present, and the future. Sociality implies the perspective that experience is formed by a complex interaction of personal, internal, social, and external conditions. Finally, the concept of “place” indicates a series of places or certain physical spaces where inquiries or events occur (Farman, 2015; Kaljevic, 2018). In this process, the four directions for experience inquiries are presented (Stavrou & Murphy, 2019).

**Understanding experiences through life of participant**

Accordingly, the participant’s life stories and how she was affected by them were examined by the researcher to understand the meaning of such experiences.

**Three-dimensional narrative inquiry space**

In terms of sociality, this study examines interactions among various factors related to the formation of the participant’s experience including personal and social conditions, internal conditions, and external environments. In terms of temporality, this study examines how the participant’s temporal elements in the past, the present, and the future affected the formation of each experience. Lastly, in terms of space, this study explored the participant’s experiences as a parent at home and as the director for a community welfare center for people with disabilities. To this end, the researcher conducted the thorough process of data analysis and interpretation in applying the narrative inquiry methodology.

**Data analysis**

To maintain the flexible and open characteristics of narrative inquiry, the researcher sought to understand the meaning of the participant’s experience by newly reorganizing various collected stories in writing rather than strictly following a pre-determined methodology or coding, so as to avoid the deconstruction of stories (Venuleo, et al, 2020; Wang & Geale, 2015). In particular, the general structure of the participant’s stories was examined with a focus on changes in the flow or theme of the general story depending on the place or context. To avoid considering only a part of the participant’s story, personal, relational, and business areas were all encompassed. In this process, the researcher’s feelings and reflections were utilized as analysis data. After the in-depth interview, the researcher wrote down the emotions felt through the conversation with the research participants. To this end, emotions in the tone of the conversation during the interview with the participant were analyzed. Interpretation of narrative inquiry materials is a critical step in this type of procedure. It aids in communication between research participants and researchers. Therefore, in the following paragraphs, we will explain the influence that the interpretation of such narrative inquiry data has on communication between researchers and research participants.

The researcher—who majored in special education, worked in the field, and deliberated on the issue of education for adults with developmental disability—considered the social context of the participant based on personal experience, and they sought to understand the
implications representing the major feelings that were not explicitly revealed in her story but that were evidently mirrored in it.

To analyze the participant’s experiences, the field texts were converted into research texts. This process was divided into the following steps: In the first step, the researcher read the participant’s narratives repeatedly, collected various narrative elements, and reorganized them into one story; the data collected in this step were analyzed thoroughly. To this end, narratives contained in the participant’s stories were clustered by theme. Narrative inquiry involves deriving a topic by listening to the life stories of research participants and presenting subareas of this topic. This is the sub-topic, and such sub-topics can be said to have been created from the stories of the research participants. Narrative inquiry themes and subtopics can be considered to be key phrases representing the research results. Communication between the researcher, participant, and special education experts continued during this process.

By strictly sticking to the collected data, the researcher sought to gain authenticity for this research. In the second step, the researcher and participant read the texts together and discussed whether any of them needed to be revised or supplemented. At the same time, the researcher asked the participant whether the narratives corresponded to her actual experiences. It was also checked whether the researcher correctly understood the participant’s narratives. Throughout the research process, there were constant conversations and feedbacks regarding the narrative inquiry between co-researchers. This process is a highly critical step in enhancing the confidence and quality of a narrative inquiry (White, 2021). In this manner, the researcher sought to secure a high level of accuracy of data analysis in the process of conducting the narrative inquiry. According to Yeong-suk Hong (2019), the ethical validity of narrative research can be examined from the perspective of relational ethics. In addition, Jane’s stories were received as they are. Further, the focus was on securing authenticity for this research. Likewise, the researcher tried to find a unique form of narrative while preparing research texts, seeking to express the theme with metaphors. Throughout this process, the meanings of the participant’s experiences were sought. In the following paragraphs, the results are presented based on the themes derived from the research participants’ life stories. Interpretation of the narrative from the interview with Jane was provided in the results section.

Results

Presenting the narrative experience of Jane raising an adult child with a developmental disability

Narrative experience as a parent in the family: The irony of life – living in a place where guilt and desire coexist.

Jane nursed her sick mother-in-law so arduously while she herself was pregnant that she gave birth to her son Jake only 8 months into her pregnancy due to toxemia. For decades, she has felt guilty about her son Jake not being healthy. She told the following stories about her son:

I felt guilty about my son’s condition as if I left an indelible stain on him. I felt like it was all my fault. My husband also said that he felt like the sky was falling when Jake was first diagnosed with a “developmental disability.” He and I together have probably said sorry to Jake hundreds of times. Since then, my husband and I have been losing our identities in our lives. We have tried to make up for our son. We have never bought luxuries like expensive clothes that we
I wish that I can be proud of myself and that my love for my son could be recognized by my son. Other mothers of children with developmental disability would think “Why did this thing happen to me?”. They would think too much about what kind of person they have to be. It is the same for me. I have lived my life just to be a mother who is unashamed of her son. As I talk about my story like this, I feel truly relieved. (Interview with Jane, August 16, 2020)

The position of a parent is presented as one that involves challenges—going beyond boundaries set by destiny and becoming more mature.

Meanwhile, she had acted somewhat differently from what she said. She was worried that there was nothing else she could do except to feed him and make his bed for him. Jane talked about these difficulties below:

I am a director of an institution, but at home, I am just an ordinary mother and wife. After working hard and coming back home, I feel comfortable. However, a sigh drops from my lips when I see my son. What should I do for him? Rather than staying home, I come home late on purpose several times a week and make excuses like, “It's for overtime work.” My children and husband might have noticed it. (Interview with Jane, October 23, 2020).

Jane said that she loves her son Jake, but her heart is full of worries about his future. She exhibits “avoidance of situations.” Regarding her life pattern at home, Jane said:

My son Jake keeps following me, my every step, wherever I go, in the kitchen, or to the porch to hang clothes washed. It seems that it is his way of saying “I missed you” since we did not see each other for a while during the day. When he sees me on the sofa, my son comes to me right away, hugs me, and rubs his cheek against mine, expressing his affection. I know that it is an expression of love, but when the same act is repeated several times, then I end up turning my back on him. Looking at me while this happens, my husband and daughter say that I lack the ability to face an uneasy situation. (Interview with Jane, October 30, 2020)

Jane sometimes felt lost while living as Jake’s mother. She described herself as a zero-score mother. When the researcher asked why, she told the following story:

I sometimes feel annoyed by my son and sometimes I even hate him. As I am the head of the organization, I am self-conscious before other parents and hesitate to express feelings, but at home, I feel free to let my feelings show.
Noticing this, my family comfort me, telling me to accept the destiny of a family with a disabled child. I view myself as an immature parent barely coping with this big assignment. (Interview with Jane, November 07, 2020)

Humans show different behavioral patterns depending on the particular situations and contexts. From the family perspective, Jane is going through inner conflicts as a parent and as an organization head, which few people might have experience with. This is a type of scenario from the perspective of narratives. As a parent, Jane is at a loss about her son’s future, specifically when looking at him after coming back from work. As an organization head, she always has to find a solution for her institution users and their parents. This is probably why she has to be absorbed in her job and other affairs: to escape from reality. This is the cover story or secret story reflected in Jane’s narratives.

Sub theme: Building up a broader window of communication

Jane believes that it would be wrong to expect the institution or the government to sympathize with parents’ challenges and take care of everything even if they do not talk about it. She hopes that parents having an adult child with developmental disability would also be recognized as ordinary parents. Jane admitted that the awareness of adults with developmental disabilities has improved significantly. However, there are still problems. She talked about the following problems:

As a matter of fact, it is not easy for adults with developmental disability to live in South Korea. I have seen many around me emigrate to another country. In general, adults with developmental disability are viewed in our society merely as people who need help or who are pitiful. I think that such views can hinder social growth of adults with developmental disability and their parents. I wonder why people, particularly those who are well-aware of people’s need for social independence, do not fully understand disability. (Interview with Jane, November 11, 2020)

From the cultural perspective, although there have been significant improvements, Koreans have more negative perceptions of persons with disabilities than people in the West. Specifically, according to a news report, prejudice on persons with developmental disabilities and their parents was revealed as a motivation behind an objection to the establishment of a special education school for people with disabilities. Some parents of children with developmental disabilities have had their heads shaved, calling for increased numbers of lifelong education institutions for people with developmental disabilities and a state responsibility for persons with developmental disabilities. This demonstrates a poor awareness of persons with disabilities in the Korean society.

To Jane, the biggest challenge in her life was facing views other people have on disability. That challenge made her worry about things that she did not have to be ashamed of or care about. These things made Jane shrink. In the face of depression, she had to find a defensive mechanism for her own life. When asked why she lived her life like this at that time, Jane frankly shared:

Among parents having an adult with developmental disability, is there anyone who says constantly, “I am a mother of an adult with developmental disability”? I thought that even though I felt sick at heart so badly, pretending to be strong was the right response. That seemed to be the right way to cope with the wrong
and biased views of people in the world. (Interview with Jane, November 13, 2020)

Just to survive, Jane has intended to find ways not to be hurt rather than trying to change minds of parents without children with developmental disabilities. In the meantime, she joined a parent association and met parents of adults with disabilities more serious than Jake’s, which was a turning point for her.

Taking suggestion by my mother, I attended an association for parents having an adult with developmental disability. At first, I was half-hearted about joining. I doubted that parents in a similar situation could give me comfort because I myself was not confident about comforting others. However, I learned a highly valuable and fundamental lesson from that gathering. That is, no one can live alone. People should share and communicate. Realizing this, I made up my mind to pioneer a new life on my own. (Interview with Jane, November 15, 2020)

Jane’s life is not merely a life as a parent of an adult with developmental disability. Jane’s mother felt pity for her as Jane declared that she was separating herself from the world and rejected compromise. The following is the story of how Jane finally started to form an SNS (social network service) with the parent’s association and sought to broaden their channel of communication.

Communication is important for us as parents having an adult child with developmental disability, even more so than others. How, then, can we communicate smoothly? Above all, we have to begin with trying to understand one another. Whatever relationship we might have with someone, it begins as a relationship between persons after all. In this regard, parents also need to be well aware of the actual situations of the local community or public institution concerned. Of course, relevant institutions should also understand the reason or the origin of parents’ requests. When communication is successful, both parents and institutions can have a win-win situation. That is the right objective for our children as well. (Interview with Jane, November 17, 2020)

Jane believes that communication represents the most beautiful connection between humans. Although its beginning might seem insignificant and develop slowly, we should constantly put forth efforts, and the path will be broadened gradually. Further, the difference between environments can be overcome in the end. She emphasized the need for parents including herself to take such initiative so that the day everyone looks forward to could come earlier.

Narrative Experience as the head of an institution: Learning betrayal and making considerations

When first appointed as the head of an institution, Jane felt sorry for adults with a developmental disability like her son Jake who had graduated from a special school but did not know where to go from there. This was the reason why she decided to study further in relevant areas. Before taking up her present position, she worked as a minor social welfare worker at a community welfare center. She was firmly determined and believed that there would be nothing that she could not do once she made up her mind. However, things were not as easy as she
thought. Rather than giving in, she spared no effort to fulfill her original intention. When asked about why she tried so hard, Jane made the following point:

If I had only stayed in my family as a parent, I would have wished for everything to be done, even things that parents did not typically ask for. I might have given an area due consideration, taken it for granted, or felt hurt when it had not been given. I learned, however, that it was important to understand who was asking, what was asked for, and in what situation it was asked. Even if it was the same request, prioritization was essential. (Interview with Jane, November 28, 2020)

Jane stated in the interview mentioned above that living as a parent in her family was different from living as the head of an institution.

Sub theme: Breaking free from obsession and finding genuine happiness

Jane called herself an “iron man,” but her acquaintances said that she was far from it. She devoted herself to the service at the institution because she wanted so much to be recognized by everyone, including her parents, as a person capable of operating the institution and maintaining good relationships with others. However, some said that she was obsessed with work because of her son Jake; in response to this, she tried to change her way of thinking. She did not understand why people would say such a thing while there were many other institution heads who had no child with disability and worked hard. Jane spent many sleepless nights agonizing over that thoughtless comment. She was even swayed by misgivings, repeatedly asking herself if she had lived her life in the wrong way. However, she changed her mind, realizing that blaming herself could be an obstacle to her performance as an institution head and her own self-development. Making up her mind not to listen to such comments from others, she took it easier for a while and focused on her interpersonal relationships. As a result, she broke free from the mentality of “I have to do it better than others” and retrieved some peace of mind. People often learn that, in life, when one relieves one’s mind, their anxieties and worries disappear. Jane likewise started to see people around her and realized what was really precious to her. She made it clear that she would no longer work hard merely for Jake and that she did not want to be recognized highly as the head of the institution who had a child with disability either. When asked about whether she wanted to continue living that way, Jane shared:

I admit that I have lived relentlessly. As the head of my institution, heads of other institutions criticized that what I wanted was to achieve tangible results. After years had passed, however, I realized that there was something more important than merely working hard. I was obsessed with the idea that I had to be special because I had an adult child with developmental disability. Realizing this, I had tried to live a totally different life. Lately, I tried to consider not myself only, but us in life. (Interview with Jane, January 02, 2021)

While living dual roles as a parent in her family and as the head of an institution, Jane expected that she could transfer what she learned by experience to other parents and sympathize with their anguish. As a result, she often felt happier as the head of the institution. This was because she admitted the barrier of “reality.” While living as a parent in her family, Jane felt burdened. She tried hard to make a better future with her own efforts, but she seemed to make little progress, so she felt as if her son Jake had an uncertain future. This anxiety made her feel confused about her ego identity and made her lose her way. However, while serving as the head
of her institution, Jane was absorbed in operating it. She could see tangible results which motivated her to work harder. However, she finally regained genuine happiness by realizing that such obsession could be an obstacle not only to herself, but also to her relationship with her family and other acquaintances. Going through this process, she learned that the most important things were not to do things better than others, but to pursue “happiness” for herself and all people around her. She hoped that others who were trying to live a double life in two different spaces like her could finally realize this as well.

Jane was confused between the inner value and the contrasting criticism from outside in her life as the head of an institution. However, the key to solving this confusion was not far from her. It was “changing her point of view in life” and “letting things go.”

Sub theme: Love for All Exists Behind Distinctness

While her philosophies of administration were supported by other parents, they often said that one thing might need to be changed. However, that was something that Jane could never give up. She believed that trainees should never think that adults with developmental disability could choose to follow or not follow social rules. When the researcher asked why she had this conviction, Jane gave this answer:

Adults with developmental disability are also persons, are they not? From the moment of birth, persons learn right and wrong, don’t they? Likewise, we have to teach our children that the routine of life has a fixed code. Otherwise, they will face difficulties when they start their social life in the future. So, I tell parents that our institution will teach them such rules and codes correctly. Of course, gaining more knowledge is important. However, getting along well with others is more important, is it not? If so, they also should follow such rules at least to some extent. Having a serious disability should not always become an absolute excuse for indulgence. (Interview with Jane, December 19, 2021)

To complete a task, one’s reasoning and sensitivity need to be in harmony with each other. The story of Jane as the head of an institution touched other parents’ hearts. This achievement was possible since trainees were viewed not merely as “adults with developmental disability”, but as ordinary community members just like people without any disabilities. For this reason, Jane gained trust from parents and accelerated her pace in running the institution. Understanding her motives, other parents were grateful for her efforts. Jane smiled at them, saying that she herself was more grateful.

Jane is called the “teacher mom” among trainees. She would give unstinted praise towards trainees when they did something well. However, when they did something wrong, she would point that out and wait until they corrected their behaviors. This was the reason why she was given the nickname “mom” and she likes it. Jane has had many different names as the head of an organization, thereby living a unique life.

Jane always tries to help parents understand that teaching kids to distinguish right from wrong correctly and that waiting until they could practice it is a good way of teaching a lesson to adults with developmental disability. Other institution heads criticized that her way of teaching was excessive, although they understood her intentions. Nevertheless, she felt happy and joyful while working as the head of the institution. When the researcher asked her what was most rewarding in her life, she provided this response:

I am sometimes confused whether I am a parent or the head of an institution. Oftentimes, I am puzzled about which I should be in my life. After all, I can say
that I am happy to contribute to trainees’ growth as an individual. Now they can sleep and wake up all by themselves without needing assistance from others. I believe that hard training in their daily routine works. In any case, whatever others might say, I feel really rewarded while seeing them get better day after day. While teaching my trainees daily, I learn better ways to teach my own child. (Interview with Jane, December 31, 2021)

Jane believes that for adults with developmental disability in Korea to live independently, their parents need to view them as capable individuals first. She says that the first point to be considered in this regard is “to set achievable goals.” On this basis, she emphasizes that parents could better understand their children’s disability and focus on their potential. She also believes that this can help children view their disability positively and face reality. Jane’s stories as the head of an institution (stories to live by) caused conflicts with other parents due to their different perspectives regarding developmental disability. The world neither permits everything to those with developmental disability nor keeps a strict stance to those without developmental disability. Both Jane and other parents admit these facts in their mind. However, there are differences depending on situations and contexts of each individual. Moreover, these differences caused Jane confusion regarding her identity as an institution head and as a parent. In this identify confusion, Jane was enjoying happiness in her life while trying to understand her ego in each space and attempting to handle the given obligations in each case.

**Discussion**

This study aimed to explore Jane’s accomplishments by examining her past and present life. Jane has an adult child with a developmental disability and serves as the director of a community welfare center for people with disabilities. The research conveys a message about how her life can make a positive impact on other parents with children with disabilities.

Jane’s life is highly representative of the lives of Korean parents with children with developmental disabilities. Specifically, she has expressed often feeling sorry and guilty along with love for her child as a parent. She also equally applied her obsession that she has in bringing up her child well to her workplace, as a new space. Parents who rear children with disabilities tend to neglect their own lives, as they tend to have a “superman syndrome” that causes them to believe that they have to be strong mentally as well as able to do everything flawlessly. However, when Jane broke out of this obsession over time, she was eventually able to reflect on her inner self. This is a milestone that ultimately needs to be noted by other parents who have children with disabilities; this is the core of this study. Based on the research results, further discussions are listed in the following.

First, Jane felt guilty as a parent in her family about the fact that her son Jake had to live as an adult with a developmental disability for his entire life. She blamed herself about her son’s developmental disability and felt extremely sorry about it to the point that her own appetite suffered. She wanted her son to understand that she loved him more than anyone else and would continue to love him even more. This gave Jane meaning in her life. This corresponds to finding happiness through the narrative identity stated by Bauer et al. (2008). Bauer et al. (2008) stated that narrative identity should play a key role in the consequential interpretation of an individual’s happiness (Adler et al., 2015; Habermas & Reese, 2015; Shin, 2015). Jane experienced psychological burnout while raising her son with a developmental disability, but she found herself to be a happy person while realizing her narrative identity through this research.

Second, Jane did not merely try to avoid the difficulties as a parent in her family, but she tried to develop into a mature parent. While living as a parent to her son Jake, whose
developmental disability would last during his entire life, she felt pity for him, but she also sometimes wished to get out of that situation as she always found him in the same condition after coming back from work. For this reason, she often came home late from work. Looking at her life, Jane’s husband and daughter accepted that it was the destiny of a parent of a child with disability; they supported her journey as one such parent. With this type of encouragement from her family, Jane also admitted that there was much to do to become a more mature parent. She was motivated to put forth efforts to grow further in that regard. This underscores the need for family support for parents with children with developmental disabilities. Hsu et al. (2021) and Sahni and Hasan (2020) stressed that it is important for family members to support parents with children with developmental disabilities.

Third, Jane felt skeptical about being a good mother and about Jake, fearing he would not get better despite all their family’s efforts. Nonetheless, she pretended to be strong before others, living a sort of double life. She felt that she had to do something to change, so she joined a parent club, as her mother suggested. In that club, she realized the need to communicate while talking with other parents with painful experiences. That opportunity helped her understand that sympathizing with others’ environments would be essential in improving communication between the parents and the institution. She believed that admitting and addressing this fact would be beneficial for everyone.

Fourth, Jane felt happy when she finally broke free from the idea that she should run her institution better than other institution heads. The fact that she had an adult child with a developmental disability imposed a substantial burden upon her. For this reason, she was obsessed with the desire to perform better than other institution heads and even forced her employees to do the same. However, others’ sharp questioning with implicit bitterness on why she was living that way because of her son Jake made her look back on her own life. This caused her to lay down the burden from her mind, live her own life, and let go of her tensions as the head of an institution. James (2018) argued that parents rearing children with disabilities tend to be obsessed with their roles; however, this study found that one needs to reflect on his or her own inner self to establish self-identify and live a truly happy life. To this end, Jane has tried to enjoy her life without trying to find her identity. She not only has regained true happiness that she has been seeking, but also has been able to better fulfill her role within her circumstances and contexts. Therefore, this study can reflect the typical situation faced by parents of adults with developmental disabilities in South Korea.

In conclusion, as a parent of an adult with a developmental disability and as the director of a community welfare center for people with disabilities, Jane inhabited her own unique persona in different environments and contexts, in her home family and in the institution. By examining these narratives, this research was able to examine her life involving her son, her husband, her daughter, and her mother.

As for her life story in the institution, she had to make judgments objectively and practice what would be authentic approaches for trainees and their parents, in the process forcing herself to forget that she herself was a parent of a person with a disability. These two different environments and persons constituted the life stories of Jane. It was not important whether she was living with her family or in the institution. In either case, she constantly experienced frustration and conflict while bringing up her son Jake, but such dilemmas in life motivated her not to give up in growing as a human. All these environments are part of Jane’s personal life, and as they are considered important, her narratives could only become more enriched.
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