


ORIGINAL ARTICLE

Between “devoted mothers” and “disability advocates”: When Korean mothers of developmentally disabled adults become committed to social change

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Abstract

This study explores how mothers of children who are young adults with developmental disabilities in South Korea experience identity strain and tension when they engage in advocacy on behalf of their children. Based on in-depth interviews with 20 mothers in Korea who are members of parents' advocacy groups, this article found that women experienced feelings of tension that arose when they deviated from normative understandings of what it means to be “devoted mothers.” Furthermore, they created two alternative versions of maternal roles—professional “I” mothers and professional “WE” mothers—that supported their identities as “disability advocates” in order to alleviate their emotional experiences. Such differences led them to practice different styles of advocacy in their interactions with disability welfare services. Based on these findings, this article discusses identity strain that emerges during the mothers' political engagement on behalf of their disabled children. In doing so, it contributes to expanding current attention to parental advocacy activities in order to more deeply understand women's agential power to force social change and to act against existing state policies and power.

KEYWORDS

advocacy, developmental disability, gender, identity strain, maternal empowerment, South Korea

INTRODUCTION

To live independently from their families while being integrated with communities as adult members of society, adults with severe DDs (Developmental disabilities)¹ need a wide range of assistance for their intellectual abilities and social skills in everyday lives, such as daily living assistance for household activities, mobile transportation, economic, and vocational activities as well as protection and advocacy for their rights as citizens. However, the laws and policies that support and provide assistance for them in South Korea are still in the inchoate stage, and the broad legal definitions of DDs are insufficient to meet individualized needs. Therefore, many assistive services are not yet established firmly enough for them to pursue independent lives without getting support from families. Due to such insufficiency, 40% of adults with DDs living in Seoul, Korea are isolated at home during the daytime without having social engagement, and 92% live with their family. Only 20% use personal assistant services (PAS)², meaning that the rest rely on their families' care (Yoon & Moon, 2018).

Korean welfare laws and policies continue to reproduce cultural expectations that families are legally responsible for finding solutions to problems experienced by family members. For example, the National Basic Livelihood Security Act (*pu-yang-ni-mu*) requires economic support obligations from immediate family members (i.e., between married couples and their adult child) for those who face economic hardship. In addition, Korean society's disability stigma centers around viewing disability as a curable condition; under this viewpoint, the disabled themselves as well as their family members are compelled to focus their efforts on "curing" disabilities as a means to practice their civic duties (Kim, 2017). Due to legal and moral obligations, Korean families with disabled members face a strong stigma while trying to "care" for and "cure" their loved ones.

In the family unit, such "caring" and "curing" responsibilities for disabled children predominantly fall to the mothers because of the gendered division of caring work at home. In Korean society, married women have been expected to follow gendered scripts assigning them to be primary caregivers for the family members (Chang & Song, 2010; Kim, 1994); they are socially expected to be the "wise mother and good wife" who is a devoted and docile informal caregiver at home in order to guarantee the well-being of their family (Choi, 2009; Seo et al., 2020). This moral imperative has reinforced not only women's legal responsibilities for their disabled children but also their moral obligations to care for them, leading them to feel culpable if they fail to "cure" their disabled children.

Accordingly, living as mothers of people with DDs in Korea means living at the intersection between disability stigma and gendered caregiving roles. Mothers of adults with severe DDs must ponder what will become of their lives after their children graduate from the mandatory education course, which takes 12 years of education from age six. Under the strongly institutionalized family/gender ideology and disability stigma, mothers of people with DDs mainly accept their endless caring responsibilities as primary caregivers. Some even feel guilty about being "separate" from their disabled children even after those children grow up and become adults.

Mothers in this study testified that they were not able to imagine new possibilities of maternal roles at home and "separate" their lives from their disabled children; their lives got mired in despair, and they lost a sense of self as they practiced ascribed maternal responsibilities. They cannot avoid thinking of the insecure future after their children's graduation, which increases their care burdens and emotional stress (Choi, 2010; Lim et al., 2017). Studies have argued that mothers with disabled children redefine the meaning of disabilities from the dominant perspective of disabilities as they engage with embodied experiences of impairment through their children (Landsman, 2008). Rapp and Ginsburg (2011) argue that families of disabled children rearrange their kinship to raise their "atypical" children, and in this reframing process, these families influence society to make it respond to differences that their children have. However, the strong family/motherhood ideology and disability stigma in Korean culture has made it difficult for most mothers of adults with DDs to imagine new kinship relationships in society.

Despite the hardships of imagining new kinship, mothers in this study eventually new possibilities through parental advocacy. In advocacy activities, they worked to make society respond to their children's

differences. In this process, they began to advocate for the “independence” of their adult children with DDs. When asked what they thought about the “independence” of their children, they enthusiastically described various possibilities for their future lives. Some imagined their children living in independent households like group homes or single homes under the management of social workers. Others envisioned their children working during the daytime and sharing stories about their day at the dinner table. No matter what they dreamed, these women’s imagination of independence meant creating distance between their disabled children and themselves and preserving respect for their respective lives with support from the state. Such hope and aspiration shown in their voices when imagining independence were different from the uncontrollable weeping that characterized their descriptions of their past life experiences when they were unable to conceive of separation from their children because of the unquestioned assumptions and norms. However, through their parental advocacy activities, they began to engage in public actions where they could raise their voices by showing up at schools, district offices, and in the streets. By doing so, they transgressed scripted maternal norms in Korean society and challenged the state to take actions that could reshape their futures.

This study explores how mothers of young adults with severe DDs in Korea experience the tension between the socioculturally prescribed maternal roles and their emergent identities as disability advocates, coming to stand up against the strongly institutionalized family/gender ideology and disability stigma in Korean society through their advocacy activities. My research contributes to multidisciplinary literature by drawing on two findings. First, this study discovered that women in this study experienced identity strain as they engaged in parental advocacy due to their stigmatized identities and their efforts trying to live up to expectations of normative maternal roles. Second, all mothers in this study shared the same goals for advocacy as well as living in similar social positions (e.g., socioeconomic status, educational background, living area, etc.). However, in their efforts to resolve the tension, they created two different alternative identities as disability advocates either as the professional “I” mothers or the professional “WE” mothers. Based on how they represent themselves when explaining their advocacy activities as well as how they define the nature of the disabilities and the ideal type of care, mothers undertake different types of advocacy activities, and furthermore, they develop distinct understandings of the “state” as they make efforts for social change. Accordingly, this article argues that mothers resolve the tension in various ways. Some of them appear to conform to the hegemonic maternal role scripts; however, even when this is the case, there are still differences in that they have transformed understandings of their care work and strive to change society, suggesting the intersubjective processes of transformation of women’s identities for social change should receive more academic attention in the study of the intersection of disability and gender inequality.

PARENTAL ADVOCACY AND EMPOWERED MATERNAL IDENTITY

This article follows the theoretical debates on the social construction of the gendered self accomplished by everyday interactions and practices (West & Zimmerman, 1987) as well as the play of power in the construction of the gendered identity (Butler, 1990). Women transform their identities as mothers in their processes of becoming mothers, and they develop their maternal identities in their relationships as mothers (Laney et al., 2015). To mothers of disabled children, parental advocacy affects their identity changes by opening new relationships. For example, Traustadottir (1991) argues that women in the US feel they are making professional careers while being involved with advocacy for disability in general. Also, McLaughlin and the author’s colleagues (2008) claim that parents of disabled children in the UK develop their identities in a broader sense of “carers” who fight for disability justice based on acquired societal resources and knowledge in their experiences. Studies have shown that mothers themselves contribute to parental advocacy by considering it as maternal duty (Naschen, 1999; Wang et al., 2004). While doing their special maternal duty, these women undertake a process of identity changes as disability advocates.

The process through which these women’s unique experiences of becoming disability advocates is an interesting research site when considering the relationship between women’s identity and motherhood ideology. Feminist scholars have long discussed that motherhood ideology in culture shapes how women

practice as mothers (Hays, 1996; McMahon, 1995) or how they think as mothers (Ruddick, 1980). The cultural schemes in idealized motherhood are strong enough that these schemes work as motivational forces of self-understandings as good wives in successful marriages (Quinn, 1992) or make women feel inadequate and like failures when they find discrepancies between the culturally idealized images of good mothers and their actual maternal practices (Choi et al., 2005). Likewise, mothers of disabled children in parental advocacy, particularly in a society like Korea where family/gender ideology is deeply institutionalized through legal and moral norms, can experience identity strain. For example, their new maternal identities can conflict with family/motherhood ideology embedded in disability welfare services, such as the family-centered service distribution system or the emphasis on family functioning and family resilience, if these services implicitly ask them to be affectionate informal caregivers to receive the services, (e.g., Heller et al., 1999; Muir & Strnadová, 2014).

Despite such potential identity strain for mothers of disabled children, most studies of mothers of disabled children have focused on the psychological and sociocultural perspectives that can be created between the private and the public sphere (Knight, 2013); for example, how they deal with disability stigma or care burden coming from the gendered division of care labor (Green, 2003; Raina et al., 2005). In addition, characterized by a binary of the “private (caring) sphere” and the “public (working) sphere,” the sociopsychological stresses that mothers of disabled children have experienced in work-family conflicts (Porterfield, 2002; Scott, 2010) have been illustrated mainly. There are significant studies that explore how mothers of infants and children with disabilities resist and redefine the cultural understandings of motherhood in the “abled” and “mother-blame” society (Blum, 2007; Landsman, 2008). Still, there has been relatively little scholarly attention to these women’s subjective and psychological experiences when they attempt to blur the binary of the “private (caring) sphere” and the “public (caring) sphere.”

Many feminist scholars have delineated maternal empowerment and mothers’ extended care for communities against socially structured injustice (Abrahams, 1996; Naples, 1998) or against state violence based on the reconstruction of the past memories of dictatorship and their children’s disappearance (Bosco, 2004; Burchianti, 2004). Compared to the significant coverage by scholars given to women’s community actions for human and social rights, minimal attention has been given to the topic of empowerment of mothers of disabled people and the process of transforming identities while resisting culturally ascribed norms and assumptions in the state’s policies as well as society. Many studies have reported that mothers of disabled children in various countries actively educate themselves to advocate for their children’s inclusiveness, acceptance, and equality in the education and welfare system (Bacon & Causton-Theoharis, 2013; Krueger et al., 2019; Wright & Taylor, 2014). Nevertheless, discussion of these women’s development of competence to make social changes has been largely absent in disability studies and the broader literature because the mothers themselves most often have nondisabled bodies and have been interpreted as constraining disabled children’s opportunities and aspirations (McLaughlin et al., 2008; Ryan & Runswick-Cole, 2008). Therefore, this article navigates very personal and yet very public struggles in social roles and self-understandings for mothers of people with DDs. In so doing, it aims to explain how these women adjust their maternal identities when becoming disability advocates and how this identity adjustment shapes their journeys to work toward their imagination for new kinship in society.

METHOD

This is part of a larger project exploring the hermeneutic struggles of Korean activist mothers for alternative care arrangements in the disability rights movement. I conducted 15 months of fieldwork between August 2018 and March 2021. During this period, I participated in meetings and events held by a local chapter and the national chapter of the Korean Parents’ Network of People with Disabilities³. For this article, 20 mothers who had young adult children with severe DDs⁴ as well as members of parents’ advocacy groups were recruited. Mothers interviewed for this study were all aware of PAS and social services for family caregivers of persons with severe DDs, which were initiated under *the Act on Guarantee of Rights of*

and *Support for Persons with Developmental Disabilities* in 2017 to offer education, counseling, and respite care for parents of people with severe DDs.

Interviewees were mothers of 11 female and 11 male children with severe DDs; two raised more than two disabled children. The children's ages were between 12 and 36. Four of their children had Autism Spectrum Syndrome (ASD), 10 were with intellectual disabilities (ID), and seven of them had disabilities accompanying severe DDs. Their ages ranged from the forties through the sixties. All interviewees were from two-parent nuclear families, married biological fathers of their disabled children with one or two children. They were all middle-class women most with university education and experience working in careers in the past, and they all lived in a large urban area.

Interviews were one-on-one in-depth interviews and semi-structured. First, I opened up an interview by asking about an interviewee's demographic information and asking her how she came to terms with her child's disability. I shared my personal stories when listening to her story, and it worked well to build rapport. Then, I asked about what an interviewee had practiced as a mother at home after her child's diagnosis, how she felt in her ongoing informal caring experiences, and what changed after she engaged with parental advocacy. While we talked about her experiences in parental advocacy, we shared more thoughts on her standpoint on current Korean disability support and services and her experiences in them. Interviews usually lasted for about one hour or a little longer and were held in a paid rental space to keep privacy. Later, in the process of the transcriptions, I did one or two follow-up calls with the interviewees through a phone to clarify the unclear statements.

This study analyzed data with Interpretative Phenomenological Analysis methodology (Smith & Shinebourne, 2012) as this study aims to explore how mothers of DDs perceive and interpret their personal lives as well as subjective and psychological experiences in Korean society. After transcribing all the interviews verbatim, I repeatedly read the transcriptions. I marked “explanatory noting,” leaving comments on the responses showing the respondent's understanding and sorting similarities and differences among these comments based on the assumption that they may have taken similar trajectories of care and parental advocacy in Korean society. While sorting out themes, I found that mothers represented themselves in two different ways; when they discussed their advocacy activities, they referred to themselves as either “I” or “We.” Furthermore, I discovered that how they talked about their advocacy indicated how they thought about their identities as mothers and their goals as advocates. Accordingly, I use these categories to map the common themes from their interviews.

For the rigor of this study, I used reflexivity (Salzman, 2002) throughout the analysis process. I have an older sister with severe disabilities in Korea, and my personal background has taught me much about the language and sentiments pervasive in the Korean disability field, enabling me to comprehend both explicit references and the less noticeable or even hidden sentiments that are present in specific contexts. However, I also recognized that my personal experiences can affect my interpretations, so I have discussed my findings with several other researchers, some of whom have cultural knowledge of Korea and some who do not.

WHEN TENSION SURFACES

I let go of everything. [...] I...really... tried everything I could do for my disabled boy, so I would not be blamed. I really did my best (Mother F).

As in Mother F's statement, during the interviews, I frequently encountered the phrase: “I let go of everything (*nae-hyō-nob-ta*).” In Korean, “*nae-hyō-nob-ta*” originally means the act of putting an object down on the ground. The mothers in this study used this phrase to figuratively describe that they “released something” that they had held fast, and when I asked them to be specific, these mothers could not clearly explain what object they released. Instead, their statements often came along the lines of, “It was personal greed (*yok-sim*) that made me hesitate to let go of everything.” They said they could “let go of everything

in their lives” by no longer holding onto their *yok-sim*, and in the context of their stories, they meant they “let go” of *yok-sim* to achieve being a “good mother.” For example, Mother F said that she struggled to “cure” his son’s intellectual abilities for three years; she harshly punished her son if he failed to follow her instructions. She believed she should do so, but she later realized it was her *yok-sim* to try to make her child “normal.”

You and McGraw (2011) found that mothers of children with ASD in Korea were aware of disability stigma and resisted it, but they still followed the dominant maternal role scripts of “being good mothers,” which equates good mothering with the success of their children thus pursuing their disabled children’s success in society. Like mothers in You and McGraw’s study, mothers in this study also spent their lives doing their best to be “good mothers.” Particularly when their children were young, with the expectation that their children could receive “successful” treatments these mothers sought any resources within their reach, from medical facilities across the country to even Korean shamans (*Mudang*). These expenses strained their family budgets, and these efforts were exhausting for the mothers. Each mother had a personal reason that justified their guilty feeling, the feeling that reinforced an obsession with seeking a cure as a good mother should. Mother E had blamed herself for her child’s disability by believing that her child’s ID was a direct consequence of her decision to stop breastfeeding in order to go back to work. Mother H thought that she contributed to her son’s ASD by not taking its early signs seriously. With such feelings, these women implicitly accepted the disability stigma in Korean society:

When my child made weird sounds in class, a homeroom teacher called me and said that my kid ruined the class climate and interfered with his classmates’ ability to study. In that situation, I just answered sorry, sorry, and sorry without any excuses. To the teacher, I said that I would educate my kid not to do it and that the issue would not recur. I always had heavy guilty feelings [for every conflict that he created outside at home] (Mother A).

While attributing their children’s disabilities to their own failures as mothers with guilty feelings, mothers’ identities became stigmatized resulting in what Goffman labels “spoiled identities (Goffman, 1963).” Concretely, in their effort to respond to disability stigma, self-stigma occurred when they concluded that they had been doing something wrong for their disabled children from the onset of their children’s diagnosis. This led them to internalize stigma and develop stigmatized identities in their inner selves, pushing them to practice endless devotion to being “good mothers” as “bad mothers” having disabled children.

When they devoted themselves to their children’s treatments, they used internet websites and books as primary sources to collect information; however, interviewees said that the most helpful information came from other mothers they met in preschools or waiting rooms of their children’s treatment or rehabilitation sessions. There, these women had opportunities to meet other mothers who also raised disabled children of similar ages. They shared their concerns as well as encouragement with one another. As these women found support and understanding from other mothers of disabled children, they became less hesitant to join local chapters of the parents’ advocacy group when introduced to those groups.

Interviewees said that they initially decided to join the group simply because they wanted to collect more information. However, after joining the advocacy group, their minds changed. These women interacted with other mothers through various activities offered by the groups, such as self-help groups and parents’ education, participating as often as possible because the lessons they learned were “sensational and striking (Mother G).” In these activities, they learned that disability is not a mother’s fault but an individual characteristic; they also learned that the Korean government as the welfare state is meant to assist its citizens by distributing services and resources. Such lessons led them to problematize their maternal roles, eventually leading them to decide to “*nae-hyō-nob-ta* (let go).” While demanding caring responsibilities from the state for their children, these women came to realize that they were not only intervening to change the current insufficient public interventions and callous social attitudes but were also working against the dominant image of “being good mothers,” an idea deeply embedded in their own identities as women, wives, and mothers.

Interestingly, the women in this study did not immediately resist or redefine the dominant motherhood ideology. When faced with their first realization of the dominant image of motherhood inside themselves, they found themselves criticizing their own past childrearing experiences from the hegemonic perspectives as Mother F self-evaluated her past efforts to “cure” her child. This was common to other women in the study as well. They interpreted their pursuit of being “good mothers” as their unwarranted desire for something they did not deserve, their *“greed (yok-sim),”* and they came to think that they had been pursuing something that had always been out of their reach. This unique interpretation shows how mothers lived with their stigmatized identities. In an ongoing inner struggle with self-stigma, they belittled their past efforts even at the moment when they realized that it was the dominant image of motherhood that made them live as “bad mothers” with guilty feelings.

In an inner dynamic of multiple personal identities, it was not easy for these women to immediately detach themselves from their stigmatized identities to make it possible for them to act in accordance with their new perspective on their role in society. Even after they were able to problematize them, the deeply rooted family/gender ideologies embedded in their personal identities unconsciously affected their thoughts and feelings. Therefore, mothers of DDs in this study experienced extended periods of holding two contradictory identities simultaneously. Here, the tension surfaced. On the one hand, they recovered their self-esteem and were able to detach themselves from any feelings of guilt. On the other hand, stigmatized identities still lingered within themselves, obstructing the changes that were being made. These women experienced complex emotional and psychological experiences as they struggled to navigate the distance between the prescribed maternal roles and their newly emerging maternal roles.

However, the tension did not last long; these women attempted to untangle the tension by creating alternative maternal roles. With their newly defined maternal identities, these women not only detached themselves from the stigmatized identities but also performed alternative maternal practices, practices that eventually enabled them to challenge the dominant family/gender ideology. For example, Mother A recalled that after participating in various advocacy activities, she realized that she was changed; she explained to a teacher why her boy made noises and what types of assistive tools were available for him in class. Her transformed maternal standpoint led her to raise her voice for her child instead of remaining silent at home with feelings of guilt.

TWO DIFFERENT TYPES OF SELF-UNDERSTANDING AS COMMITTED DISABILITY ADVOCATES

Mothers in this study came to think of their own maternal identities as disability advocates in two different ways: professional “I” mothers and professional “WE” mothers⁵. Based on how they defined the nature of disabilities and the ideal type of care, they practiced two different advocacy styles to challenge the gendered roles of family caregivers and the family-centered nature of care practices in Korean disability social services.

“I” mothers tended to believe that they had the personalized expertise to discern the appropriate services and treatment for their own disabled children. This belief led them to think that they were the most reliable care providers who were skilled in maintaining subtle and reliable care for their children’s lives. They viewed disability as a status that needed timely treatment and opportune assistance with the support of the state. Their standpoint as reliable care providers led them to continue their maternal care duties even after their children became adults; they pursued a certain distance from their disabled children by sending their children to day activity programs or training for social skills, but they still took their care work significantly. If they were silent and obedient mothers in the past, these women began to actively correct the unjust treatment of their children and of themselves which was a typical occurrence in everyday communications with teachers, personal care attendants (PCAs), and social workers.

The “I” mothers expanded their advocacy activities at the community level by addressing the present issues related to the material conditions of their children’s living situations and familial care work. For the immediate response, “I” mothers tended to rely on a close-knit group of other mothers or act individually.

For example, Mother A educated teachers about the special characteristics of children's DDs or how to assist their children. Mother G continuously wrote petitions on e-People, a website where citizens could file petitions to the government, and visited the district office to ask for services to be available for mothers like her. Mother M acted with another mother of a child with cerebral palsy whom she met in her child's elementary school—they went to the principal's office together when they knew their children were in trouble. She relied on the other mother even after her child graduated; they organized a self-help group with several other mothers and volunteered for senior citizens to change the disability prejudice of neighbors. In these ways, they challenged the agents of the "state" they met in their everyday lives, such as social workers and state officials, to improve their children's living conditions in communities.

The "WE" mothers described themselves as "representatives" who do care work for their adult children on behalf of society. They viewed disability as a characteristic of someone who is a member of Korean society and believed that the laws of the state must protect disabled citizens in the same way that the state must guarantee equal treatment for citizens of different class positions or genders. They took care of their disabled children for granted when their children were young. However, as Mother O articulated, her son deserved to "live his independent life" once he becomes an adult since "my son is not my possession," and if "he cannot make money by himself, the government needs to assist him to live independently and to sustain his life." Therefore, the "WE" mothers tended to expand the focus of their advocacy with the intent to create changes for the future of their disabled children. Rather than focusing on the immediate issues in their everyday lives, they sought institutional changes in welfare laws and disability policies at the national level by fighting for a wider meaning of support from the "state."

Given this broader targeting of advocacy, the "WE" mothers underwent additional preparations to be able to effectively communicate their needs and additionally learned the professional languages required to build compelling advocacy strategies. Some mothers connected their caring expertise to paid occupations, such as obtaining PCA/social worker certificates or attending online colleges. Their targeted audience also became wide and diverse. Several mothers worked as disability rights instructors, giving lectures to people with the aim of enhancing disability sensitivity. Mother D launched a series of weekly podcasts about the lives of people with DDs and their families, with the aim of spreading her thoughts on the need for policy changes. In these podcasts, she invited other advocate mothers to her show to openly discuss the concerns and issues surrounding people with DDs and their families.

The "WE" mothers exerted organizational power by participating in national-level protests; for example, they occupied the Seoul City Hall for 42 days in 2016 to demand a better policy for adults with DDs. They met with politicians and the officials of the Office of Education and the Ministry of Health and Welfare to remind them of the urgent need for the improvement of social policies and disability welfare programs. With the ultimate aim of building Korean society as a cooperative care network by establishing right-based disability laws and policies, they performed public strikes on the streets; in 2018, approximately 200 parents shaved their heads in the *Gwanghwamoon* square to display their grievance and desperation to society. They acknowledged that the consequences of their efforts would not immediately be obvious as systemic changes take time; however, they firmly believed that mothers would finally reap changes if they united and acted together as an organization.

The "I" mothers and the "WE" mothers shared common goals for advocacy—disability justice for people with DDs and their families who care for them. However, their advocacy styles were clearly different. The "I" mothers believed that they were the most reliable care providers as they had care expertise for their children's disabilities. Accordingly, they had an interest in responding to immediate daily issues through negotiation with agents of the state they encountered in their everyday lives. In contrast, the "WE" mothers believed that they were representatives who assisted their disabled children on behalf of the state. Therefore, they advocated for long-term institutional and systemic changes that would support their adult children's social, material, and physical independence from their families. This advocacy interest led them to engage in demonstrations and protests against the state at the national level. Such differences between the "I" and "WE" mothers were clearly shown in the ways they interacted with PCAs and social services for family caregivers of people with DDs.

Professional “I” mothers: The most reliable caregiver

“I” cannot be replaced with “unqualified” personal care attendants

The “I” mothers believed that the current 40-hour certificate training program for PCAs is not rigorous enough to produce qualified caregivers when compared to the mothers’ lifelong efforts in caring for their children. As Mother L said, they believed that they had more sophisticated knowledge of care than PCAs because mothers were always with their children:

There is prejudice against personal care attendants... [What kind of prejudice?] ...they are not like mothers... But you know, it is true. They are not mothers in fact. They do not know every detail of my child. I can feel that my child knows it as well, so she refuses to accept them... She is looking for me at every single moment... and her mom is the most comfortable person to her... one that is the best caregiver to her.

According to the “I” mothers, the difficulty of behavioral controls and communication caused PCAs to resign within a relatively short period. For example, Mother N attempted to use PAS when her child was seven, but PCAs resigned after only a few days because her child was too “picky.” She also observed many PCAs for people with severe DDs left after just one day because of the heavy workload. After numerous refusals from PCAs, Mother N decided not to use PAS during her child’s school years. However, she began considering using PAS again when her child graduated high school because she wanted her child to enjoy his own independent and separate social life without her interventions.

“I” do not want to spend money on loveless care

Disabled people in Korea have to copay to receive PAS⁶. However, many “I” mothers explained that, like Mother M, they chose not to use PAS because they found it to be too expensive. Moreover, they were not willing to pay for unsatisfactory care services offered by the state; for example, mothers said that PCAs frequently missed delivering briefings given by physicians, social workers, or teachers. Although the briefing sessions were short, mostly less than 10 min, these sessions were crucial sources for comprehending their children’s current health and living status. These mothers believed that most PCAs do not take the daily briefings seriously because they do not care for the children with love like mothers do. Mother N also made a similar point:

When coming to assist an individual who spends her day lying on the bed due to her cerebral palsy, some PCAs just stare the whole day at her lying on the bed. PCAs can read a book to her and chat with her. I also saw some cases in which PCAs did not care for disabled children when in the disability rehabilitation centers. Some PCAs just let the children play with cell phones while they watch series on their own cell phones. Then, they were 10~15 minutes late for their treatment programs, but PCAs did not appear to care about it.

Accordingly, although they had access to outsourced care, the mothers chose not to copay for these state-supported services. This decision is one way in which “I” mothers resist the current policy. Mother M explained that if they chose not to use this service, it would result in a lower statistical number for the service usage and ultimately demonstrate the failure of the state’s policy and the misallocation of resources in the national budget for disability welfare. Mother G continuously filed a petition on the online government site to allow families to work as PCAs for their members with severe DDs to lower the financial burden of hiring an outside PCA.

“I” can be socially recognized by public support for family care

The “I” mothers’ belief that “mothers” have the competence to appropriately allocate caring resources led them to insist that mothers need diverse aspects of the state support for their special care work.

Regarding a human capacity... well... I don’t believe we can capture an individual capacity as one picture. It is not fixed. The capacity only exists in the form of consecutive practices, a person can cultivate and raise it... Even though we stay at home as housewives, it does not mean that we have limited capacity to be developed. We are just disregarded... All we want is living in a socially acknowledged place where we can get enough [material or psychological] support for caring for our children... or at least some sort of favorable environment... they will cheer me up thus I believe I can live my life better even though I still continue with my care as usual. (Mother Q)

When asked about the potential monetary compensation from the state for their care labor, several “I” mothers were positive. They claimed it would improve their self-esteem because they sometimes felt a “void in their hearts” when their time-consuming and skillful care work was simply dubbed as mothers’ work by kin members and friends. The “I” mothers emphasized that cash payment will create a climate to recognize their care expertise as “hardworking and skilled paid caregivers” in society.

[Do you think monetary compensation from the government can change your life as a caregiver?] Um... well... from my perspective... I have low self-esteem... I am trying to recover it, but I sometimes wish I would have some paid work as I did before marriage. ... As a housewife, nobody recognizes my work and my contribution. Rather, some people look at me with a hostile glare when walking on the street with my child. They look at me as if I am doing something wrong or bad. If my kid makes a small mistake, I always need to apologize to all the people around us. As such humiliating experiences have happened over and over, eventually, I lost all my self-esteem. Ma’am... you can understand this way. I am on a course of losing myself... This is why I feel something popping in my head and become annoyed when somebody provokes me with trivial stuff. It is like poking me with a tiny needle... But if I can imagine that I can get rewards for my care, it would be great, and I think I would feel more empowered. (Mother B)

Several “I” mothers added that the mothers would not care how much they would be compensated because “I will use all the cash support for my disabled child” (Mother Q). As Mother M explained, they “feel pressured when spending the family budget for expensive treatments.” The “I” mothers believed special treatment for their children is requisite; however, the treatment is mostly expensive, and mothers had no availability to work for paying jobs as they focused on fulfilling their children’s care needs. To these mothers, the cash payment was symbolic. It symbolized social recognition for their skilled care work, and moreover, for their knowledge of how best to manage services for people with DDs. It was a means for them to feel that they contribute to fulfilling society’s care needs as citizens with their competence.

In sum, the “I” mothers’ belief that mothers are the most reliable care providers who can provide quality assistance for their disabled children with expertise was bolstered by their past negative experiences with the “unqualified” PCAs. Also, past unsatisfactory interactions with PCAs motivated them to undertake the role of managing everyday care instead of paying expensive copayments. However, their changed maternal roles prompted the “I” mothers to exert agential power when using the related services; if they were silent in the past, they started to act against everyday encounters with unjust treatment. Accordingly, their efforts to change services were not visible at the national level; however, they continuously negotiated with service providers and attempted to destabilize disability prejudice at the community level through their activities. Moreover, the “I” mothers came to recognize the social value of their care work and their care expertise.

They were overall positive about the state’s direct care payments but not because they needed money. It was symbolic to get recognition for their care work and knowledge from society so that they could raise their self-esteem and confirm their status as citizens who contribute to the state.

Professional “WE” mothers: Representatives for adults with developmental disabilities

“We” have a role in educating “unprofessional” personal care attendants

If “I” mothers expected other caregivers to be assistive to the primary caregivers—mothers, the “WE” mothers prioritized their roles as representatives for disabled people. Therefore, when it came to everyday care, “WE” mothers complained about “unprofessional” PCAs, those who did not have a solid work ethic as state care service providers. For example, some “WE” mothers described some PCAs, particularly those who were older than them, as “unprofessional” by treating mothers as “pitiful and incompetent people on welfare,” trying to teach them. These mothers described feelings of stress when those PCAs behaved like “know-it-alls” simply because they were older than the mothers. Mother P once was lectured by her child’s PCA about why she “treated the poor little kid so harshly” after asking PCA to manage her child’s diet when outside because his brain did not control his appetite well.

Additionally, the “WE” mothers argued that many PCAs interpreted their own jobs as auxiliary and voluntary work based on the dominant social beliefs that care is a familial duty or voluntary work. Therefore, those PCAs did not devote themselves to their labor; for example, mothers experienced difficulties in being matched with PCAs because the PCAs tended to avoid the physically and mentally intensive care of severely disabled service users. The “WE” mothers argued that PCAs could maintain their unprofessional attitudes because the current state care service system institutionally failed to supervise PCAs. Mother R said that that is the reason why mothers must fight for changes in the system of state care services; they believed that the institutional changes would improve PCAs’ sense of occupational duty.

“We” do not want a temporary short break

The “WE” mothers criticized the current services for family caregivers for their inconsistency. For example, psychological counseling sessions for parents of disabled children are limited as they are available only a few times a year; respite care is offered in the form of urgent care services when the parents must run unexpected errands; domestic family trip services are offered occasionally in an event-like manner rather than through a consistent schedule. Mother H explained that the inconsistency of the service provision made her think that she needed to remain in the family. I asked Mother D what she thought about Mother H’s statement, and she responded:

Um... the government thinks parents should take caring responsibilities for children with DDs and take it for granted just because we are their parents. Like, “it is ‘you’ who gives birth to your child, so you must take responsibility for your child.” Every time, I feel it is difficult to demand any kind of support from the government for our children and for us. The government only responds when the mothers collectively move together and ask for something loudly... If we ask for this amount of support, the government only fulfills a little of our demands. This is not just about the problem of recognition... our society, including the government, just takes it for granted that disability is the family’s responsibility. (Mother D)

When I asked the other mothers in this study whether they agreed with her expression, some deeply agreed while others did not. Even those who disagreed understood the point she wanted to convey since

they had somewhat similar emotional experiences even in different situations; they all understood the same “tone” embedded in the state policy that needed to be changed.

“We” want social changes as compensation for our care labor

The “WE” mothers admitted that caring for their disabled children is far more demanding and time-consuming than raising nondisabled children. However, they also acknowledged that mothers’ informal care work would not be easily compensated unless welfare distribution systems were reformed. In this light, the mothers disagreed with financial payments as public support for family caregivers because they viewed them as obstacles to demanding their needs and interests from the state. Several “WE” mothers answered that mothers do not need the care payment from the state as they give love to their children as their mothers did to them; however, their objection appeared to have an ulterior motive. Mother K explained: “I do not want to describe our care labor as something special because this way of public valorization can socially naturalize mothers’ intensive care.” Similarly, the mothers appeared to have concerns about the possibility that financial support could minimize other care professionals’ duties.

After I had participated in many different training sessions and seminars for parents of children with DDs, I suddenly realized that disability was not my duty, and it was not my fault. Beforehand, I thought that I had to take all caring responsibilities for my son. However, my son didn’t want to be disabled, and I didn’t want to give birth to him as disabled. Why then, do I have to take all the responsibility? ... There is an old story that it takes a village to raise a child, which is true for my son. The only difference from other kids is that he has a disability, but that cannot be an excuse. Our village also needs to raise him together. (Mother F)

Mother F added that, instead of improving the material conditions of the mothers’ care work, the state should develop the living conditions of people with DDs. The “WE” mothers believed that building better social infrastructures, such as welfare laws, disability policies, and welfare distribution systems, for their disabled children to live independently from their families after they became mature and adults would be the only way to “compensate” mothers’ full-time labor, freeing them from endless care duties “without agony.”

We do not know how our children will be treated after our death. Our children do not have a good ability to make the right decisions... We do not know how such a lack of abilities will be treated after we are gone... I believe it [having good living conditions for people with DDs] is our right to peacefully pass away, to prepare for our old age with serenity and dignity. (Mother F)

In sum, the “WE” mothers emphasized the state’s responsibility to preserve the social rights of disabled people as fellow citizens by building society as cooperative caring networks. These “WE” situated themselves as representatives of their disabled children rather than full-time caregivers, advocating for changes in a wider context of society. Therefore, these “WE” mothers rejected being full-time caregivers at home; instead, they wanted the state to fulfill their children’s care needs. With the goal of changing the current PAS system to solve the PCA’s unprofessional attitudes, they suggested solutions that were systematic and institutional. They also were not satisfied with the current family support services as well as the potential cash payments to family caregivers due to the possibility that these services would prevent them from raising their voices against the state.

CONCLUSION

This article explores how Korean mothers of young adults with severe DDs navigate the tension between the sociocultural maternal role scripts and their emergent roles as disability advocates, constructing alternative maternal identities through advocacy activities. In their process of becoming mothers, women adjust their maternal identities to the cultural motherhood scripts, and in this sense, mothers of disabled children are no different. However, academic attention on mothers of disabled children has mostly focused on the sociopsychological strains created in-between “the private (caring) sphere” and “the public (working) sphere.” Therefore, studies have explored how mothers experience the burdens coming from the gendered division of caregiving (Green, 2003; Raina et al., 2005) and work-family management (Porterfield, 2002; Scott, 2010). Moreover, compared to a wider literature on mothers’ activism against the state for social justice (Abrahams, 1996; Naples, 1998) and human rights (Bosco, 2004; Burchianti, 2004), mothers of disabled people have drawn little academic attention as its subjects.

This article found that mothers of disabled children experienced identity strains and tension during the process of becoming disability advocates. When they began to reframe their maternal roles at the intersection of family/gender and disability ideologies, they felt complex emotions that toggled between their emerging identities and the past stigmatized identities. This psychological and emotional experience implies that mothers of disabled children can experience identity strain and feelings of tension as their own actions eventually challenge hegemonic gender norms. To put it differently, mothers of disabled children can feel tension not only in the dichotomy of “the private (caring) sphere” and the “public (working) sphere” but also in their processes of expanding their caring sphere from the private home settings to the public social settings. This suggests that the sociopsychological experiences of mothers of disabled children coming from their ways of overcoming both gender ideology and disability stigma should be explored in a wider sociocultural context instead of confining them to the traditional dichotomy between the private and public spheres.

Mothers resolved the tension by developing emergent maternal identities as disability advocates. They shared the same experiences of raising disabled children in similar social locations (e.g., Socioeconomic status, educational backgrounds, etc.) in Korean society, and they all were striving to change society. Despite such homogeneity, my finding shows that Korean mothers developed two distinctive identities: Professional “I” and professional “WE.” Their advocacy styles varied based on how they represented themselves as disability advocates, and moreover, how they defined the nature of disabilities and the ideal type of care. Moreover, the “I” mothers and the “WE” mothers had different interpretations of the “state” in advocacy activities. In most studies of political motherhood, the state is deemed as an institution that rules over its citizens by laws and policies thus maternal activism against the state has been focused on women’s national-level movements for social justice and human rights. However, this article found that the “state” can be represented as a service provider and as a professional to mothers in their everyday interactions. The state permeated everyday lives through the form of social services as well as practitioners who conveyed these services, and the “I” mothers struggled with this particular form of the state while recognizing the social value of their care labor and their accumulated care expertise.

This distinction demonstrates that identities held by advocates matter in part because they represent different ways to imagine new kinship; moreover, their different ways of reshaping a citizen’s relationship to the state. Their imaginations of the new arrangement of society are critical in determining the nature of the agency exercised when promoting social changes. Thereby, this study suggests the necessity of a nuanced approach to the process of empowerment and transformation of social identities that women have undergone as they come to engage in political actions. This nuanced and detailed approach will allow us to understand women’s diverse processes of transformation of social identities as well as different understandings of the “state” and citizenships in the process of political actions.

Lastly, the “I” mothers’ ways of performing advocacy appear to align with the hegemonic maternal role scripts in Korean society as they still prioritized their roles as informal caregivers. However, they exerted their agential power as advocate mothers by educating service providers and questioning the

current disability services instead of compromising to meet the dominant gendered role expectation as devoted mothers expected to be silent at home for their families' well-being. This finding indicates that women's transformed identities are not always drastically different from their past identities, still, they can create a noticeable accomplishment of social change. Accordingly, to better understand women's diverse forms of empowerment for social change, efforts need to be made to discover the voices of mothers like the "I" mothers, those whose actions may be unearthed as they appear to conform to the hegemonic role scripts.

These findings suggest two focal points for future research. First, most research interests in advocacy have been placed on women's broad advocacy, such as the roles the "WE" mothers partook in forms of community action; therefore, advocates like the "I" mothers have not been widely discussed. Therefore, this article suggests future research to explore the personal understanding of the "state" and the diverse forms of everyday negotiation in practices of welfare state policies that empowered mothers can take when they have not entirely escaped the realm of the family but have come to speak out and resist disability stigma and gendered role scripts that silence them and make invisible their expertise.

Second, both "I" and "WE" mothers engaged in long-term care through parental advocacy, even after their children became adults, and they experienced another dimension of the tension between informal caregivers and other social identities that were distinctly different from the individual tension created by the intensive care burdens and work-family conflicts. Such unique lived experiences will provide resources for us to understand their lives and practices, particularly in the sociopolitical sphere where they encounter the "state." For example, considering the divergent roles played by family ideology across different sociocultural contexts, future studies can compare how gender norms embedded in disability policies in different countries constrain the ability of mothers to become disability advocates and how mothers manage to overcome these limitations to enter the sociopolitical sphere to advocate for social change.

This article highlights a new focus on women's identity strain and political resistance at the intersection of family/gender ideology and disability stigma by introducing the Korean case. This new focus on women's experience with identity strain in acts of political resistance allows us to better understand the agential power of mothers who commit their lives to disability justice.

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ENDNOTES

¹ This study followed the Korean legal definition of people with Developmental Disabilities because it aims to examine mothers' interactions with the Korean state welfare services. According to the Act on Guarantee of Rights of and Support for Persons with Developmental Disabilities in Korea, a person with DD is defined as one who needs assistance to sustain personal and social lives due to incomplete development or disorder of bodily, intellectual, and/or cognitive abilities. In this vein, this Act includes persons with (1) Autism Spectrum Disorder (ASD), (2) Intellectual Disability (ID), (3) "significant retardation of ordinary development" specified by Presidential Decree. For (3) generally persons having genetic conditions (e.g., Down syndrome, Prader-Willi syndrome, Williams syndrome, cerebral palsy) are considered. Therefore, in this study, ASD, ID, and other types of related disorders were considered as DDs. In terms of severe DDs, the Korean Ministry of Health and Welfare considers various indexes, such as Intelligence Quotient (IQ), DD-GAS (Global Assessment Scale), and the Vineland Social Maturity Scale. According to the Korean Ministry of Health and Welfare, people with severe IDs are those with IQ scores lower than 50, and people with ASD are those with IQ scores lower than 70 and GAS scales lower than 40.

- ²Personal Assistance Services (PAS) are social services offered to people with severe physical and/or mental disabilities that provide assistance for daily lives and social activities. These services vary depending on the recipients' needs but are confined to the assistance of physical activities, household activities, and mobility assistance, based on the Act on Activity Assistant Services for People with Disabilities. PAS was initiated in Korea in 2007.
- ³Korean Parents' Network of People with Disabilities (KPNPD) is one of the largest national-level parents' advocacy groups for people with DDs in Korea. This network was established in 2009 by parents who previously fought for education rights of children with DDs. KPNPD has approximately 160 local chapters across the country with the aim of fighting for human and social rights of people with DDs and their families in all aspects of their social lives, including housing, employment, labor, welfare, education, etc.
- ⁴This article confined its research subjects to mothers of young adults with severe DDs. By doing so, this article traced the identity transformation of mothers who perform childcare that is beyond the expectation of normal caregiving. In addition, this article focused on this particular group of mothers because they faced the unique challenge of life after their children's graduation and the limited state assistance accompanied with it. Lastly, this article considered this particular group of the subjects with the assumption that these women would have longer period of parental advocacy activities, allowing them more time to transform their self-definitions when compared to younger mothers.
- ⁵The article uses the word “professional” based on Traustadottir's (1991) finding that some mothers feel as though they are undertaking professional careers when advocating for their disabled children. Using the word “professional,” does not necessarily mean that mothers should be called “experts.” Rather, this article attempts to highlight that these mothers feel and interpret their maternal roles differently from the dominant definitions, and they recognize the public values of care labor outside the family. With this respect, the article uses the word “professional” to emphasize mothers' empowered standpoints and self-awareness of these women on their expertise on care and advocacy, which do not necessarily correspond to the socially gendered maternal role scripts.
- ⁶The amount of copayments depends on household income and the severity of a recipient's disability. It is typically 20,000 Korean Won (approximately 16 dollars) for the lower income family, but many of people with severe disabilities must pay 164,900 won (approximately 130 dollars) if their family members have stable income (for more detailed information on copayments, see: https://www.mohw.go.kr/react/policy/index.jsp?PAR_MENU_ID=06&MENU_ID=06370408&PAGE=8&topTitle=)

REFERENCES

- Abraham, Naomi. 1996. “Negotiating Power, Identity, Family, and Community: Women's Community Participation.” *Gender & Society* 10(6): 768–96.
- Bacon, Jessica K., and Julie Causton-Theoharis. 2013. “‘It Should Be Teamwork’: A Critical Investigation of School Practices and Parent Advocacy in Special Education.” *International Journal of Inclusive Education* 17(7): 682–99.
- Blum, Linda M. 2007. “Mother-Blame in the Prozac Nation: Raising Kids with Invisible Disabilities.” *Gender & Society* 21(2): 202–26.
- Bosco, Fernando J. 2004. “Human Rights Politics and Scaled Performances of Memory: Conflicts among the Madres de Plaza de Mayo in Argentina.” *Social & Cultural Geography* 5(3): 381–402.
- Burchianti, Margaret E. 2004. “Building Bridges of Memory: The Mothers of the Plaza de Mayo and the Cultural Politics of Maternal Memories.” *History and Anthropology* 15(2): 133–50.
- Butler, Judith. 1990. *Gender Trouble*. New York: Routledge.
- Chang, Kyung-Sup, and Min-Young Song. 2010. “The Stranded Individualizer under Compressed Modernity: South Korean Women in Individualization without Individualism.” *The British Journal of Sociology* 61(3): 539–64.
- Choi, Hae-Kyung. 2010. “Sōng-in pal-tal-chang-ae-in-ül tol-po-nūn pu-mo-ūi po-ho-pu-tam-kwa sa-hoe-chōk chi-chi-ka u-ul-e mi-ch'i-nūn yōng-hyang” [The Effect of Caregiving Burden and Social Support on the Depression Level of Parents Caring For Adult Children with Developmental Disability]. *Journal of Social Science* 21(2): 243–63.
- Choi, Hyaewol. 2009. “‘Wise mother, Good Wife’: A Transcultural Discursive Construct in Modern Korean.” *Journal of Korean Studies* 14(1): 1–33.
- Choi, Precilla, Carole Henshaw, Sarah Baker, and Joanne Tree. 2005. “Supermum, Superwife, Supereverything: Performing Femininity in the Transition to Motherhood.” *Journal of Reproductive and Infant Psychology* 23(2): 167–80.
- Green, Sara E. 2003. “‘What Do You Mean ‘What’s Wrong with Her?’”: Stigma and the Lives of Families of Children with Disabilities.” *Social Science & Medicine* 57(8): 1361–74.
- Goffman, Erving. 1963. *Stigma: Notes on the Management of Spoiled Identity*. New York: Simon & Schuster, Inc.
- Hays, Sharon. 1996. *The Cultural Contradictions of Motherhood*. New Haven: Yale University Press.
- Heller, Tamar, Alison B. Miller, and Kelly Hsieh. 1999. “Impact of a Consumer-Directed Family Support Program on Adults with Developmental Disabilities and Their Family Caregivers.” *Family Relations* 48(4): 419–27.
- Kim, Eunjung. 2017. *Curative Violence: Rehabilitating Disability, Gender, and Sexuality in Modern Korea*. NC: Duke University Press.
- Kim, Rosa. 1994. “The Legacy of Institutionalized Gender Inequality in South Korea: The Family Law.” *Boston College Third World Law Journal* 14(1): 145–62.
- Knight, Kathryn. 2013. “The Changing Face of the ‘Good Mother’: Trends in Research into Families with a Child with Intellectual Disability, and Some Concerns.” *Disability & Society* 28(5): 660–73.
- Krueger, Kristen, Jessica D. Cless, Meghan Dyster, Mollie Reves, Robert Steele, and Briana S. Nelson Goff. 2019. “Understanding the Systems, Contexts, Behaviors, and Strategies of Parents Advocating for Their Children with Down Syndrome.” *Intellectual and Developmental Disabilities* 57(2): 146–57.
- Landsman, Gail. 2008. *Reconstructing Motherhood and Disability in the Age of Perfect Babies*. New York: Routledge.

- Laney, Elizabeth K., M. Elizabeth Lewis Hall, Tamara L. Anderson, and Michele M. Willingham. 2015. "Becoming a Mother: The Influence of Motherhood on Women's Identity Development." *An International Journal of Theory and Research* 15(2): 126–45.
- Lim, Hye Gyeong, Jae Kuk Park, and Yeon Jae Lee. 2017. "Pal-tal-chang-ae cha-nyŏ-ŭi sŏng-in-ki salm-ŭl chun-pi-ha-nŭn ō-mŏ-ni-ŭi kyŏn-hae-e tae-han kŭn-kŏ-i-lon-chŏk chŏp-kŭn [A Grounded Theory Approach to Mother's Opinion Preparing Adulthood Life of Young People with Developmental Disabilities]." *Journal of Special Education: Theory and Practice* 18(4): 289–326.
- McLaughlin, Janice, Dan Goodley, Emma Clavering, and Pamela Fisher. 2008. *Families Raising Disabled Children: Enabling Care and Social Justice*. New York: Palgrave Macmillan.
- McMahon, Martha. 1995. *Engendering Motherhood: Identity and Self-transformation in Women's Lives*. New York: The Guilford Press.
- Muir, Kristy, and Iva Strnadová. 2014. "Whose Responsibility? Resilience in Families of Children with Developmental Disabilities." *Disability & Society* 29(6): 922–37.
- Nachshen, Jennifer Sara. 1999. "Advocacy, Stress, and Quality of life in Parents of Children with Developmental Disabilities." PhD diss., Lakehead University.
- Naples, Nancy A. 1998. *Grassroots Warriors: Activist Mothering, Community Work, and the War on Poverty*. New York: Routledge.
- Porterfield, Shirley L. 2002. "Work Choices of Mothers in Families with Children with Disabilities." *Journal of Marriage and Family* 64(4): 972–81.
- Quinn, Naomi. 1992. "The Motivational Force of Self-understanding: Evidence from Wives' Inner Conflicts." In *Human Motives and Cultural Models*, edited by Roy G. D'Andrade and Claudia Strauss, 90–126. New York: Cambridge University Press.
- Raina, Parminder, Maureen O'Donnell, Peter Rosenbaum, Jamie Brehaut, Stephen D. Walter, Dianne Russell, Marilyn Swinton, Bin Zhu, and Ellen Wood. 2005. "The Health and Well-Being of Caregivers of Children with Cerebral Palsy." *Pediatrics* 115(6): e626–36.
- Rapp, Rayna, and Faye Ginsburg. 2011. "Reverberations: Disability and the New Kinship Imaginary." *Anthropological Quarterly* 84(2): 379–410.
- Ruddick, Sara. 1980. "Maternal Thinking." *Feminist Studies* 6(2): 342–67.
- Ryan, Sara, and Katherine Runswick-Cole. 2008. "Repositioning Mothers: Mothers, Disabled Children and Disability Studies." *Disability & Society* 23(3): 199–210. <https://doi.org/10.1080/09687590801953937>
- Salzman, Philip Car. 2002. "On Reflexivity." *American Anthropologist* 104(3): 805–11.
- Scott, Ellen K. 2010. "I Feel as If I Am the One Who Is Disabled": The Emotional Impact of Changed Employment Trajectories of Mothers Caring for Children with Disabilities." *Gender & Society* 24(5): 672–96.
- Seo, You Jung, Charissa SL Cheah, and Hyun Su Cho. 2020. "The Gender Ideology of 'Wise Mother and Good Wife' and Korean Immigrant Women's Adjustment in the United States." *Nursing Inquiry* 27(4): 1–13.
- Smith, Jonathan A., and Prina Shinebourne. 2012. "Interpretative Phenomenological Analysis." In *APA Handbook of Research Methods in Psychology, Vol 2: Research Designs: Quantitative, Qualitative, Neuropsychological, and Biological*, 73–82. MA: American Psychological Association.
- Traustadottir, Rannveig. 1991. "Mothers Who Care: Gender, Disability, and Family Life." *Journal of Family Issues* 12(2): 211–28.
- Wang, Mian, Hasheem Mannan, Denise Poston, Ann P. Turnbull, and Jean Ann Summers. 2004. "Parents' Perceptions of Advocacy Activities and Their Impact on Family Quality of Life." *Research and Practice for Persons with Severe Disabilities* 29(2): 144–55.
- West, Candace, and Don H. Zimmerman. 1987. "Doing Gender." *Gender & Society* 1(2): 125–51.
- Wright, Amy Conley, and Sarah Taylor. 2014. "Advocacy by Parents of Young Children With Special Needs: Activities, Processes, and Perceived Effectiveness." *Journal of Social Service Research* 40(5): 591–605.
- You, Hyun-Kyung, and Lori A. McGraw. 2011. "The Intersection of Motherhood and Disability: Being a 'Good' Korean Mother to an 'Imperfect' Child." *Journal of Comparative Family Studies* 42(4): 579–98.
- Yoon, Min-Suk, and Moon, Jin-Young. 2018. *Sŏng-in-pal-tal-chang-ae-in in-saeng-chŏn-hwan-ki-e tae-ŭng-hae sŏ-ul-si, chi-yŏk-sa-hoe tol-pom-ch'e-kye ku-ch'uk p'il-yo* [The Needs of Caring System for Adult with Developmental Disabilities in Seoul]. Seoul Institute.

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