

## **From Housewives to Activists: Lived Experiences of Mothers for Disability Rights in Taiwan**

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### **Abstract**

When a family has a disabled child, the mother usually takes on the caretaker role and also carries the social stigma associated with disability. Based on participant observation and in-depth interviews with members of the Parents Association for Persons with Intellectual Disabilities (PAPID), this article explores the meanings of activism for parents who participate in the disability rights movement. First, it shows the impact of disability stigma on family members, especially the mothers of disabled persons. Second, the study shows that the participants of this movement, mainly the mothers of intellectually disabled children, not only promote the welfare of their children but they also learn to confront social stigma and renegotiate their gender roles. Parents' associations have become an important public space for these mothers to escape home confinement and enjoy civic life. In contrast, the fathers who were interviewed saw activism as an obligation and were less likely to show emotional attachment to the civic organizations.

### **Keywords**

Disability rights; social movement; civic organization; gender; stigma; motherhood

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## Introduction

For mothers, having disabled children usually implies the physical burden of care and stigma associated with disabilities. The interplay of gender and disability further places mothers of disabled children in a marginal position. Ryan and Runswick-Cole point out a contradiction in disability studies and the disabled people's movement. On the one hand, the literature on mothers of disabled people demonstrates the lives of women who speak up for their children and develop the skill to negotiate with the stigma associated with disabled children or cope with the material and social burden. On the other hand, the disabled people's movement questions the lack of understanding regarding the perspectives of disabled people. Thus, the experiences of mothers with disabled children on gender and disability deserve more attention (see Ryan and Runswick-Cole, 2008 for a complete review).

This paper shows that when mothers undertake advocacy on behalf of their children, they usually need to involve themselves in a process of negotiating their gender identity. Women who participate in parents' associations for disability rights transform their identities from housewives to activists for disability rights. The first part of the paper describes the stigma associated with parents who have intellectually disabled children in Taiwan. Based on their life experiences, I suggest that this stigma is gendered within a patriarchal culture focused on filial piety and the women are confined at home. They face tremendous pressure not only from society but also from their in-laws as a result of the patriarchal family structure.

The second part of this paper looks at how participation in parents' organizations empowers parents, especially mothers, to establish a community and transform their identity. I seek to show that in advocacy groups they learn to identify themselves as activists for disability rights. Mothers who volunteer in the advocacy groups begin to consider it their work, which becomes an important part of their identities. Their experience in participating in the disability

rights movement empowers them to also renegotiate gender relations in the domestic sphere. By participating in advocacy associations, mothers of intellectually disabled children not only construct a new identity but also increase their social status and gain greater respect at home. Finally, I argue that in a gendered society where mothers are primarily assigned to do housework, participating in civic organizations enables them to enter civic life and provides them with a way to escape confinement at home.

### **A Theoretical Overview: Gender and Social Movement**

Identity politics and identity transformation have been widely addressed in contemporary social movement literature. Scholars focus on the framing process of the movement, the formation of identity in the process of the movement and the construction of collective identity as its outcome (Hunt, Benford & Snow, 1994; Swidler, 1995; Polletta & Jasper, 2001; Bernstein, 2005). New social movement theorists argue that in post-industrialized societies, social movements become identity-based and value driven (Offe, 1985; Cohen, 1985; Buechler, 1995; Melucci, 1996). Framing theorists focus on the linguistic tactics of the movement (Hunt et al., 1994). Other scholars analyze the construction of identities in the process of collective action (Lichterman, 1996; Yang, 2000; Dugan & Roger, 2006) and how collective identity facilitates the continuity of the movement (Taylor, 1989; Whittier, 1997; Haenfler, 2004).

Since McAdam (1989) showed that there are biographical consequences for social movement participants, some recent studies pay attention to the consequences of identity politics for activists. Taylor and Raeburn (1995) demonstrate the negative impact of the practice of identity politics in activists' careers. Others argue that the experience of participation in social movements and identity transformation empowers activists. Koo (2001), for example, describes how Korean workers formulated a new class identity and contested the stigma of

being working class by participating in social protests and strikes. In particular, because women are usually excluded from politics and the public sphere, they attract significant attention in social movements. Scholars demonstrate that civic engagement brings about identity transformation and empowerment for women (Herda-Rapp, 2000; Shriver et al., 2003; Narushima, 2004). Traustadottir (1991) suggests that caring experiences of mothers of children with disabilities enable them to reconsider broader societal issues. This paper focuses on Taiwanese mothers who developed their gender consciousness by engaging in disability rights' groups and movements for their children.

### **Parents' Organizations and the Disability Rights Movement in Taiwan**

Taiwan and other newly industrialized countries (NICs) in East Asia are known for rapid industrialization in the post-World War II era. The disability rights movement, which demands that disabled citizens have equal rights to vote, to be educated, to work, to access public facilities, to be included in the community and to enjoy a certain quality of life is fairly new.<sup>1</sup> The Taiwanese disability rights movement emerged in the 1980s, in tandem with the transition to democracy. As was the case in many recently industrialized countries, parents played a leading role in bringing disability rights issues into the public sphere in the early 1980s. In 1982, a group of parents of persons with intellectual disability voiced demands for their children's rights to education and for community living in Taipei.<sup>2</sup> From 1982 to 1986, various parents' groups worked closely with charity organizations such as "Association for Mental Retardation" (Qi-zhi xie-hui, AMR) and related professionals to provide training for children with intellectual disabilities, since public services for persons with intellectual disabilities were very limited.

Since the end of martial law in 1987, the disability rights movement has become a visible force in civil society, which initiated and

participated in many social movement protests. The League of Welfare Organizations for the Disabled (Can-jhang-lian-meng) was officially founded in 1990 by disability-related NGOs (non-governmental organizations) and became the major disability rights social movement organization in Taiwan. The Parents' Association for Persons with Intellectual Disabilities (PAPID or Jhong-hua-min-guo Jhieh-jhang-jhe-Jia-Jhang Sie-huei) was officially founded in 1992 as a national organization by parents' organizations from different parts of Taiwan. PAPID aimed at engaging in public policy, advocating for the rights of persons with intellectual disability and worked closely with the League of Welfare Organizations for the Disabled. In other words, in the process of democratic transition, PAPID was built on the basis of self-help civic organizations and became a social movement organization.

Since 1997, PAPID has become one of the most well organized civic organizations, with 37 local parents' associations and 12 associated foundations that provide direct services and are run by parents. Unlike other social movement organizations that lost their members or were turned into elite, lobby-oriented interest groups during the transition to democracy in Taiwan, PAPID membership kept growing. As of 2003, it boasted over 10 thousand members from all over the nation. It played an important role in shaping disability policy in Taiwan such as the de-institutionalization, independent living and self-advocacy for persons with developmental disabilities (Chang, 2007). Through the cooperation of disability advocates (parents, persons with disabilities, related professionals) disability rights legislation and public services for people with disabilities were gradually established. Disability has gradually become a public issue in Taiwan over the past twenty years and the social stigma associated with it has also gained public attention.

## Methods and Data

In this study, I focus on one of the most influential disability rights social movement organizations in Taiwan, PAPID. The main sources of data used in this are in-depth interviews conducted in 2003. I interviewed 38 disability rights activists (22 mothers of children with intellectual disabilities, nine fathers, three siblings, four professional staff in the associations) selected through snowball sampling.<sup>3</sup> All of them were the main organizers and active participants in the parents' organizations for disability rights from different regions. All had engaged in activities for the parents' organization for at least five years, and some had even participated in the local parents' association before the founding of PAPID. I also collected data from secondary sources that included autobiographies of disability rights activists, newsletters from NGOs and documentaries on parents with intellectually disabled children.

PAPID is a national organization located in Taipei; 19 interviews were conducted in Taipei, three in the local chapters in Kaohsiung and fifteen in the local chapters in other counties (see Table for background information at a glance). Most of the mothers interviewed (except one, who was a high school teacher) in these studies did not have full-time jobs before the family started to receive social support from the parents' organization. Some of them became professional staff in the non-profit organizations. All the fathers interviewed in this study had full-time jobs. Most of the families in this study were from nuclear families, except one, whose husband was a medical doctor and passed away a few years ago. There were no cases of divorced mothers with disabled children in this study.

### **“Misfortunate Women”: Gendered Stigma and Confinement**

Goffman (1963:30) points out that people closely related to stigmatized individuals, for instance, the loyal spouse of a mental patient,

the daughter of the ex-con, the parent of the cripple, or the friend of the blind, will acquire a “courtesy stigma” from society. That is, social stigma is transferred to them by association. Family members of disabled people certainly carry the courtesy stigma associated with disability (Green, 2003; Green et al., 2005). For example, they experience labeling, stereotyping, separation, status loss and discrimination in the United States (Green et al., 2005). Few studies have examined how people burdened by courtesy stigma perceive, negotiate and confront such a label in different socio-cultural contexts. In my study sample, for example, a father described his first encounter with disability-based stigmatization:

When my wife gave birth to my kid [with Down syndrome], I immediately recognized that he looked different; there must be something wrong. But the doctor avoided seeing us and did not return our phone calls. It was the nurse who pulled me aside and whispered to me, “According to my experience, it must be Down syndrome. Doctors do not want to talk about it. It’s all in the genes, there’s not much modern medical technology can do.” At that moment, I felt like it was a death penalty (Interview #17).

By avoiding telling parents the bad news, medical professionals in Taiwan informed them that the disability was stigmatized. Instead of receiving emotional and professional support in the hospital, the father felt that the birth of his child was like a “death penalty.”

The stigma associated with disability can be explained in part by the traditional belief in filial piety. Chou and Palley (1998) explain that having well-educated, high-achieving children to honor ancestors and continue the family lineage is emphasized in Taiwan.<sup>4</sup> They argue that “the meaning of having ‘a good child’ is for not only the family but also their ancestors. Having a child with developmental disabilities not only involves losing face but is also viewed as a family disgrace” (Chou and Palley, 1998: 42). As a result, family members of developmentally-delayed children usually confine themselves to the private family sphere and are unwilling to seek public support.

The traditional focus on filial piety does not fully account for the extra burden placed on mothers, however. At the end of the documentary about the experiences of Taiwanese parents with intellectually disabled children, Lin, President of the Wen-shan special school, pointed out:

It is usually the mother who can accept the developmentally delayed child. I don't know why. My guess is that probably [it is because] mothers give birth to children, which creates a natural connection that traditionally fathers do not have (Yang, 2005).

Mothers tend to take on not only all the care-giving work but also the moral responsibility of having given birth to a disabled child. They are usually more isolated from society than fathers, in part because of their shame regarding the stigma of having a disabled child. One mother wrote about isolating herself and her disabled daughter:

I built a wall in my heart, a wall not allowing strangers to visit; my little daughter built a wall in school, a wall not allowing friends to visit home; my mom also built a wall of grief. My elder daughter, a girl with intellectual disability, was at the center of the wall. I, her mother, was the one who incarcerated her inside the wall. . . . I never talked about her in front of new friends. All the friends who know about her were the friends I had before I gave birth to her. It is me who started to build the wall. The rest of the walls were built by my mom, my daughters, and other relatives. They saw me avoiding my daughter, so they decided to not recognize the existence of my daughter (Liu, 2002: 21).<sup>5</sup>

A mother I interviewed recognized that the stigma came not only from the public but also from her own family members. She used “information control” and “passing,” terms suggested by Goffman (1963) to negotiate the stigma in her familial relationships:

In the early days it was really hard for me. I had to hide my child's delayed development. I had to swallow all the tears and sweat. I

could not even tell my siblings. I just told them that it is hard to take care of and educate a kid. They might know that it is difficult to raise my kid, but they don't really know what's going on. I never told them. I have to face all the problems myself. Sometimes I would suddenly wake up at night and think, "Who can take care of my child in the future?" (Interview #21).

In this case, the mother hid the disability from her siblings, telling them only that "it is hard to take care of and educate a kid."

In general, besides the social stigma in public, mothers of children with intellectual disabilities experience tremendous pressure from their in-laws. One mother remembered, "When they found out that my child has intellectual disabilities, my mother-in-law did not even want to look at us at home. We [she and her disabled child] are invisible in the family" (Interview #13). One of the parents from Chou and Palley's study similarly reported: "My mother-in-law told me that I should not go out with my [disabled] child, in order to avoid people's attention, since people think that to have given birth to a mentally retarded child is caused by our ancestors lacking virtue" (Chou and Palley, 1998: 43). Mothers are often blamed for giving birth to an intellectually disabled child. One mother I interviewed said: "My in-laws suggest that since I gave birth to the intellectually disabled kid, we should get a divorce and find someone who can deliver a healthy baby" (Interview #25). Another mother simply said, "I don't want to talk about them [her in-laws] and their ignorance" in blaming her for giving birth to a disabled child (Interview #11). Isolation and discrimination comes from the extended family as well. One mother "gradually realized that we [she and her intellectually disabled child] were not welcome at main family events like weddings. It was not only inconvenient [for them], but they thought that I was a misfortunate woman who would bring bad luck to the newly wedded" (Interview #38).

Mothers with intellectually disabled children thus not only carry the courtesy stigma associated with their children, but also a gendered stigma that does not affect their husbands.<sup>6</sup> Fathers frequently

mentioned that it was their destiny, a patriarchal obligation, to take care of their disabled children, but expressed less concern about social pressure and stigma. One father said that although “it is inconvenient to take him to family gatherings or out in public, I do not feel embarrassed or anything” (Interview #16).

The difference between mothers’ and fathers’ experiences suggests that under the paternalist family ideology of Taiwan, mothers take the moral blame for having given birth to intellectually disabled children. They take the responsibility because the social function of the female body is reproduction and thereby manifest the moral lapse of their husbands’ ancestors. When mothers do not produce “good” children, the patriarchal family blames them and sometimes excludes them and their children from the family; they become an invisible burden on the family. Since fathers are not considered the cause of the disability, they are merely pitied for having the obligation to care for their misfortunate wives and children. In this way, the courtesy stigma associated with intellectually disabled children is gendered. The supposed family-orientation of Asian societies does not therefore extend to supporting disabled children and their mothers.

### **Parents for Disability Rights: Identity Transformation and Empowerment**

Before the lifting of martial law in 1987, the conservative political environment did not allow parents direct confrontation with the state. The language of rights may have been used in the media, but in social contexts it provided little support for intellectually disabled children. The Taiwanese mothers interviewed sought any possible information and assistance that was available.<sup>7</sup> They attended relevant talks at hospitals or college campuses. Some even went back to school and got degrees in related fields such as special education or social work. They organized after-school programs whereby they could share their experiences and educate their children (Chang, 2007).

Since the political opening in 1987, parents have started to organize parents' associations to advocate for disability rights. The engagement in civic organizations also brought new meanings to their identity. Parents established a collective identity and were empowered by participating in these organizations. First, they established bonds with other parents. Their organizations became a new home for them. They also learned a new language that helped them redefine their stigmatized status. Second, many of them found greater meaning through volunteerism, which became the "real" work of their lives.

### *Sharing Grief and Advocating for Rights*

After martial law was eliminated in 1987, many parents with intellectually disabled children founded organizations. By participating in such associations, parents adopted new concepts for negotiating and reconstructing their identities. For example, in Hsin-Lu and PAPID publications, medical definitions of disabilities were introduced to reframe issues and encourage parents to face their children's disabilities as a medical issue. Statistics were used to show that disability was neither a private problem nor an individual anomaly. This framing tactic was reflected in how parents interpreted disabilities in our interviews. One mother said:

It is just by chance. Two percent of the population will have intellectual disabilities. It is not my fault, nor does it have anything to do with my previous life. I will not be bothered by their [her in-laws'] ignorance (Interview #17).

Thus, parents borrowed Western discourse, statistical reports and scientific evidence to redefine disability and contest traditional beliefs.

More importantly, such associations provided a civic space<sup>8</sup> into which parents could escape the confinement of home and find a community. One mother said:

In the beginning, I just wanted to escape from home, since we lived

together [with my in-laws]. By the end, I started to enjoy sharing experiences with others and helping others. I realized that my status in the family changed after they knew that I was helping others as well (Interview #24).

Another mother stated:

What affected me the most in the parents' association was that I could hear echoes [of my own experience]. It was not only that I no longer felt alone, but I felt that I was not the only one who went through this. Many people had the same experiences and they all went through it. What I gained the most was their experiences. I learned a lot from other parents' experiences (Interview #23).

Parents' associations were more than mere places where friends with similar experiences got together; they became idealized, "supportive families" for parents with disabled children. As one of the mothers put it: "We are like brothers and sisters, I feel closer to them than to my real siblings. Our grief, sufferings, and worries can only be shared with those who have similar experiences" (Interview #14).

Meeting other parents also enabled members of these associations to change their attitudes toward their own children. A mother remembered:

I felt uncomfortable and was unwilling to take my child out with me. It was a matter of face. After participating in the parents' association and getting to know other parents, I gradually opened up my mind. I felt that, just like me, they have kids like this, too. There is nothing to be ashamed of. In addition, if we did not start by changing ourselves, if we looked down on our kids and were not willing to take them out in public, who would accept them? After a while, I started to take him out with me. [...] Actually, I started it. I took him with me to the annual meeting every year. Others started to follow. Now, many parents have done that. All of us have gotten used to it. If I did not have these sisters [in the parents' association], I do not think that I could bring my child out in public (Interview #21).

As Goffman (1963) recognized, stigmatized people find a new sense of self when they participate in groups made up of others like themselves. These parents were empowered when they confronted social stigma and refused to be limited by it. One father mentioned how sharing his experience with others resulted in a sense of pride in how his child had touched the heart of others:

I took my kid everywhere, even when we [the parents' organization] visited other countries. The parents in Macau and Hong Kong all treated him well. I was impressed. When we visited Guangzhou, you could really feel touched. He was very active there. The parents from China were in tears [because it had been unthinkable that an intellectually disabled child could travel with his father and have a meaningful social life] (Interview #33).

Gaining a new pride in parenthood thus played a key role in consolidating a collective identity among participants in these associations. Many early participants expressed the desire of Zong Jing-yi, the pioneer of the parents' movement, who said during a national tour, "All I wish is that I can live one day longer than my daughter" (quoted in Liang, 2000: 33). Ironically, outliving one's disabled child is seen as a form of filial piety on the part of the child. A seventy-three-year-old mother whose disabled child had passed away said:

You know, my boy is really a filial child. He passed away peacefully a few years ago. He knew that I was getting old and could no longer take care of him. He knew that I would go peacefully with no more worries if he passed away before me (Interview #14).

Another mother from a parents' association echoed her sentiments. She wrote:

When I heard her child had passed away all of a sudden, while sleeping, it might be unforgivable to say it, but I felt that it was a happy ending. What's unbelievable is that almost ninety-nine percent of the mothers felt the same way. Some even sighed and

said, “The boy was a filial child. He knew that his mom was old and could no longer take care of him, so he went first. A child used death to show his filial heart.” This is an unbearable pain and it is also so real. Most parents might feel pain when they lose their children. But the parents with disabled children have this abnormal reaction. This kind of pain cannot be understood by others (Su, 2000: 56).

Sharing such “abnormal” grief allows parents to establish strong solidarity and a collective identity within the civic space of parents’ associations.

In public, association members present themselves as concerned and worried parents who are speaking for their children’s rights. The slogan of PAPID is “Parents love, never give up: parents’ voices for persons with intellectual disabilities.” The slogan suggests that parents will never abandon their children because they love them. Belonging to the association and sharing their experiences with others enables them to “never give up”:

What keeps this organization strong is that we are all parents with intellectually disabled children. Because we are all concerned about the rights and welfare of our children, we can work across gender, class, and ethnic lines and overcome our differences. We do not have any selfish thoughts. It is all for our children (Interview #7).

This discourse of obligation and concern, coupled with the concept of citizens’ rights, became the language of parents’ associations. One mother explained:

We were not troublemakers. We did not beg for charity. We just wanted to have what our children deserved. Why can other kids go to school, but ours cannot? The constitution did say that everyone has the right to be educated (Interview #35).

In this discourse, it is a parental obligation to speak for their disabled children because parents cannot take care of their disabled

children forever. The disability rights movement thus frames parental obligation as demanding social protection and public support for their children. The idea of individual civil rights plays an important role in justifying their actions and confronting the moral responsibility of mothering. The rights and obligations between citizens and state are contested as parents demand that practical support comes from the state.

Citizens' rights language was also evident in parents arguing for group homes for disabled people. When a group home was being established in the Jian-Jun Apartment Complex in 2003, community residents argued against it by saying, "Take your children home. It is your responsibility to take care of the children." Parents from PAPID and the Parents Association in Taipei replied, "It is our children's right to be part of the community." The idea of citizens' rights enables parents to confront a hostile social environment that presumes that the entire obligation to care for intellectually disabled people should rest on their mothers.

In sum, parental concerns about educating and caring for their intellectually disabled children initiated the parents' movement for disability rights. The tacit rights and obligations between citizens and the state were renegotiated in the process of mobilizing the social movement. Specifically, parental obligation was redefined. Instead of caring for their children in the private sphere, it came to mean guarding their children's rights in the public sphere. In this process, the identities of these parents changed. They went from being parents of disabled children to parents for disability rights.

### *Finding Meaning in Volunteerism and Civic Engagement*

Many mothers with intellectually disabled children quit their jobs in order to take care of and educate their children at a time when the support system in Taiwan was very limited (Chou, 1997). As social service programs for the disabled developed along with the disability rights movement, the activism and volunteerism began to have an

impact on their lives and identities. While some mothers who participated in parents' associations retained their status as housewives, others found new careers for themselves as volunteers. A career in activism/volunteerism is here defined as either working for a non-profit organization as a full-time employee or volunteering in an unpaid position that requires a hefty time commitment, such as serving as the president of a committee. In this section, I examine how parents, especially mothers, perceived their work in these parents' associations and what volunteerism means to them.

The commitment to volunteer work provided mothers with a social space different from that of being housewives at home with disabled children. A president of a local parents' association expressed her excitement over her new social status:

If I had not participated in the organization, I might not have ever had the chance to visit Taipei. When my work got recognized by the media, my husband actually started to help me take care of my daughter and even helped with the work in the parents' association. In addition, my in-laws and relatives actually looked at me differently (Interview #13).

Many mothers began to consider volunteering at PAPID as their real work. In interviews, they often commented, "This is my work" or "I have to get my work done." One mother said: "I come to work at 8:00 a.m. and go home at 5:00 p.m. I also work overtime a lot. I am working here; I just do not get paid. But I love my job. It is my career" (Interview #8). In other words, volunteer work in parents' associations thus became an important part of the mothers' life experiences and identities. They also sought to redefine the meaning of work, from paid work to volunteer work in the NGO, which became part of their new-found identities.

Activism in NGOs did not allow mothers to give up their housework, of course. Many of them commented that it was a constant battle to find the extra time they needed to do volunteer work in a parents' association. One mother noted:

Of course, I had to finish my [house] work before I went to the association to help out. Sometimes my husband complained. I tried my best to keep a balance between maintaining the house and working for PAPID at the same time (Interview #36).

Another mother explained:

It was not that easy. My husband spent more time with my child [than I did]. In the beginning, my family was not used to it. But they gradually accepted it and got used to it. [...] I had to make arrangements. People thought that I spent a lot of time at the association and did not do housework. They were wrong. My husband did not go into the kitchen; he did not even know how to wash dishes. I had to do everything: cooking, washing dishes, doing the laundry, and cleaning the house. When he realized that my work was important, gradually he could accept it and take our child to eat in a nearby diner (Interview #8).

In other words, the autonomy of these mothers was still restricted within the family-gendered division of labor. They might have found a way to negotiate with the share of work in the domestic sphere, but still considered housework and care-work as mothers' work. As this study shows, the participation of the parents' organization enabled them to negotiate more time and space for themselves or search for support outside the family domain. The gendered division of labor in the family was challenged, negotiated and reshaped, but was not totally changed.

Most of the mothers interviewed had to quit their fulltime jobs when they had to take care of the disabled children. Not surprisingly, when they had a chance to participate in the parents' association and receive social support, those who had previous work experience were more likely to take up positions, paid or unpaid, in the parents' associations. Mothers who had been housewives before they had the intellectually disabled children might have been willing to participate in the associations, but were less likely to take leading roles or paid jobs. In other words, previous working experience may

have influenced their commitment to the NGOs.<sup>9</sup>

There was only one respondent in this study who had continued her regular job as a high school teacher and at the same time took a key position in the parents' association. She pointed out that as a high school teacher with tenure, she had a flexible schedule, so she could devote time to the parents' organization. Eventually, it became too burdensome and she had to make a choice. "I cannot put any more time into the association any more," she decided; "I am willing to do more after I retire" (Interview #11). In other words, volunteering in the civic organizations was still considered secondary to paid work.

Fathers had very different experiences in parents' associations compared to mothers. First of all, most households were registered in the associations under the father's name, even though mothers were the more active participants in the organizations.<sup>10</sup> Second, fathers viewed their involvement as part of their obligation to their children. They may have agreed that they gained a lot from being involved in the movement, but they generally did not see their participation in the movement as "work." It was more in the way of a surplus or addition to their career, or an extracurricular activity to find new meaning in life. One father said:

Of course, I sacrificed some of my career in order to get involved in the advocacy work and parents' association. However, I realized that it was more meaningful than my regular job. I certainly found the joy of helping others (Interview #16).

Mothers and fathers also had a different experience in that many mothers were discouraged by their husbands from engaging in the public sphere. One mother remembered that "the president of our organization had to talk to my husband and ask him to let me work in the organization" (Interview #20). Some husbands thought they would lose face if their wives appeared in public. Another mother recalled her husband cursing and saying, "You are so proud of having a mentally retarded kid, right? You feel really good about show-

ing up on television!” (Interview #15).

Mothers developed different strategies to negotiate with their husbands' expectations that they should remain in the domestic sphere as housewives and caretakers. One mother told her husband, “I do the volunteer work for our children who carry your family name, not for myself” (Interview #24). Another mother said: “What I have done will benefit our family as well” (Interview #36). The idea that involvement in the parents' associations contributed to the family was a regular theme in these negotiations. When their work was recognized as important and brought benefit to the family, such as free health insurance for the disabled children, some mothers found that their status at home improved. One mother commented: “Somehow, I felt like I was a more valuable person. My status at home actually improved. My in-laws started to give me more respect” (Interview #13). To some extent, by advocating for their intellectually disabled children's rights, mothers also advocated for their own rights. They used the language learned in the movement to frame their own positions. One mother said: “Just like my kid, I need my own space and my own social life. I am not a slave to my husband” (Interview #38). A better public support system and the civic space provided by the volunteer associations freed them from confinement at home.

Most parents mentioned that they considered their work in parents' associations to be social, not political. They described it as “social business” that was “good for the society.” Their advocacy work, including street protests and lobbying, certainly engaged the political sphere, but in their understanding, however, “social business” referred to something that was good for the general society, especially marginalized groups, while “Politics,” was what the government and parliament do. In every interview, parents expressed their frustration with and disappointment in politicians and bureaucrats. Interviewees regularly commented: “Government officials are very unprofessional and bureaucratic” or “Politicians only care about their own interests.” Thus, while parents did not describe their involvement in the movement as a form of civic engagement or civil society, they did have

a strong sense that their “social commitment” was separate from the state and political society.

## Conclusion

In the past twenty years, disability rights have gradually become a public issue in Taiwan. The social and cultural meanings associated with disability remain uncontested. This paper shows that living with the ideology of patriarchy and filial piety, mothers carry all the moral responsibility and public shame associated with disability because they have not produced “good children” to sustain the family line. As a result, they experience stigmatization not only in public, but also in the family.

Although having intellectually disabled children entails tremendous care work and social stigma, advocating for their children’s rights opens another door for the mothers. Participating in volunteer associations enables parents with intellectually disabled children to transform their identities. They establish a strong support community and learn to consider themselves activists for disability rights. In addition, they learn new techniques for negotiating social stigma. Furthermore, mothers become empowered through volunteerism. NGOs create a civic space for women who have intellectually disabled children. They consider their involvement in the parents’ associations their “work” and use their involvement to negotiate their roles as housewives and caretakers in the domestic sphere. In some cases, their social status improved by committing to such parents’ organizations. Volunteering in advocacy organizations enables women to enter civic or public life; in advocating for their children’s rights, thereby, mothers of intellectually disabled children find new identities and gain a sense of autonomy.

**TABLE 1. SUMMARY OF PARTICIPANT INFORMATION**

<b>Background</b>	<b>Categories</b>	<b>N</b>
Gender	Male	11
	Female	26
Age	60 and above	7
	50–59	19
	40–49	5
	39 and below	3
	N/A	3
Education	Graduate School	8
	College	12
	Junior college	8
	High school	5
	Elementary school	2
	N/A	2
Occupation (current)	Housewives	6
	Work in NGOs (paid)	13
	Work in NGOs (unpaid)	5
	Other occupation	12
	Government official	1
Relation to people with disabilities	Mother	22
	Father	9
	Sibling	3
	None (Professional staff)	4
Residence	Taipei City	19
	Kaohsiung City	3
	Other regions	15
Ethnicity	Hoklo (minnan)	23
	Hakka	2
	Mainlander	5
	Other & N/A	7
Total Numbers of Participants		37

### Notes

1. The disability rights movement also waged a struggle in defining identity and challenging the stigma associated with disabilities. The

disability rights movement was part of the new social movements of the time because it: (1) was located at the periphery of traditional political systems; (2) offered a critical evaluation of society; (3) was concerned with issues relating to post-materialist values; and (4) focused on issues that crossed national boundaries (Oliver, 1990: 118–123).

2. The disabled people's movement of the UK and the independent living movement in the US both emphasize the self-advocacy and self-determination of disabled people. The Taiwanese disability rights movement, however, had a different issue in the 1980s regarding the context in which support for disabled people was considered to be a family issue. The independent living movement in Taiwan emerged in 2003. The self-advocacy activities for persons with intellectual disabilities were initiated by PAPID in 2003. One can even argue that there was no "disability rights movement" in Taiwan before 2003. However, since parents in the 1980s started to use the language of rights, Chang (2007) suggests that the early 1980s should be seen as the starting point of the disability rights movement in Taiwan.

3. The main purpose of this paper is the gendered experiences of parents who have disabled children and participate in advocacy NGOs, thus, the perspectives of their children with disabilities were not included.

4. There are three forms of filial piety: (1) continuing one's lineage by getting married, having a family and rearing children; (2) adding to the value of one's parents' and ancestors' lives by having well-educated children; and (3) fulfilling one's parents' and ancestors' ambitions and expectations by making up for their lack of achievement (Young, 1988). The third may warrant great self-sacrifice (Shu, 1988) (cited in Chou and Palley, 1998: 38–39).

5. Such isolation is not limited to Taiwanese mothers. A mother of a disabled child in the United States reported that, "When you're in a difficult situation like that, it's very hard to reach out to somebody. You tend to isolate yourself. You don't want to be social . . . You don't want to look good. You don't want to have friends over for dinner" (quoted in Green, 2001: 808).

6. The stigma attached to infertility is similarly gendered. In some cases when the husband is infertile, the wife not only shares the stigma, but tries to cover up for her husband in order to protect his masculinity

(Wu, 2002). Under patriarchal social structure, men and women have different experiences of stigmatization.

7. Even when disabled children are entitled by law to social welfare, Read (2000) shows that mothers of disabled children in Britain have to constantly voice their children's needs for adequate services.

8. I use the term "civic space" to refer to the sphere which is situated between public and private and not totally open to the general public. In other words, it is similar to "Alternative publics" in Nancy Fraser's words (1997).

9. As the cases in this study were limited, I will not make a strong general argument on these lines here.

10. Since caretaking is such demanding work, it is unlikely that both parents can get actively involved in the associations, since someone always has to be at home to care for the child. Consequently, with the exception of two couples, I interviewed either mothers or fathers from any given household, not both. Only in one case both parents were actively involved, but the husband was employed by the association

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