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ORIGINAL ARTICLE

Working but not employed: Mothers of adults with intellectual disability as hidden workers[†]

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Abstract

Background Earlier research shows that nonemployed mothers of children with intellectual disability (ID) have lower wellbeing than employed mothers. This study explored why and to what extent these mothers did not participate in the labour market.

Method An in-depth interview was employed, and 18 working-age and nonemployed mothers in Taiwan who had an adult child with ID were interviewed in their homes between July 2009 and May 2010.

Results The mothers left the labour market at different stages of the family life cycle due to a lack of formal/informal support for the care needs of their young children, and the continuing intensive care needs of their child with ID. Mothers were officially nonemployed; however, to meet their family's financial needs, they were hidden workers in practice.

Conclusions Policies are required that support these hidden female workers, who are also lifelong carers, by offering financial support and affordable social services.

Keywords: *mother, hidden worker, care, employment, intellectual disability, Taiwan*

Introduction

The conflict between paid work and family responsibilities and the effects of this conflict on women's lives have become a great concern over the last three decades. Difficulties encountered by women who try to balance paid work and childcare have been addressed in many Western studies (Beaujot & Liu, 2005; Biernat & Wortman, 1991; Crouter, 1984) and Asian studies (Aryee, Luk, Leung, & Lo, 1999; Lu, Gilmour, Kao, & Huang, 2006). The findings of these studies have consistently indicated that, compared with men, women continue to have a larger share of household and unpaid childcare responsibilities, even when employed (Aryee et al., 1999; Bird & Fremont, 1991; Emslie & Hunt, 2009; Ross, 1987). Motherhood is a social construct and the expectations of a "good mother" or "intensive mothering" are shaped by both culture and

history (Gerhard, 2005; Hays, 1996). However, these studies have usually focused only on working women and on care for young children without disability.

In comparison with other mothers, mothers of children with disability are less likely to be gainfully employed or involved in full-time work (Freedman, Litchfield, & Warfield, 1995; Lewis, Kagan, & Heaton, 2000); these mothers have considerable difficulties associated with employment due to the care demands of their child with disability and inadequate childcare support (Brandon, 2007; Porterfield, 2002; Shearn & Todd, 2000). According to intellectual disability (ID) studies, mothers of children with ID are more affected than fathers concerning their wellbeing and participation in paid work (Olsson & Hwang, 2006). In addition, wellbeing is lower among nonemployed mothers of children with ID than among

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employed mothers (Bourke-Taylor, Howie, & Law, 2011; Chou, Pu, Kröger, & Fu, 2010; Eisenhower & Blacher, 2006). The present study focuses on the conditions of Taiwanese nonemployed mothers who have an adult child with ID who was over 20 years old.

Employment patterns of married women

Sørensen (1983) categorised the employment patterns of women after marriage as conventional, interrupted, double track, and unstable based on whether women leave and/or return to the labour force after marriage or giving birth to a child.¹ A Taiwanese study applied Sørensen's patterns to women aged 40–49 and synthesised four patterns of women's employment from their findings: conventional, interrupted, continued (work until retirement), and others (quit due to health or market reasons; Li & Yang, 2004). Government statistics show that marriage and childbirth markedly impact employment for Taiwanese women during the family life cycle; for example, 26% and 16% of women left the labour force after marriage or childbirth, respectively, and roughly 50% returned to the workforce (Directorate-General of Budget, Accounting and Statistics, Executive Yuan, Taiwan, 2013). After becoming a mother, and in order to meet their care responsibilities and their family's financial needs, some Taiwanese women become involved in informal work such as being a babysitter, a market peddler, or working at home in outsourcing. Such employment is paid, but is not recognised by the government and is not covered by labour and employment insurance (Chang, 2011). However, all these studies or statistical data usually refer to mothers whose children are without disability.

Work and care among mothers of children with disability in Taiwan

In Taiwan, care for family members (e.g., children, older adults, and persons with disability) has been a family responsibility, because most of those in need of care live with their families. For example, 93% of people with ID in Taiwan live with their family (Department of Statistics, Ministry of Interior, Taiwan, 2009). Moreover, informal and unpaid family caregivers who provide regular care or help for family members with ID are typically female, and generally mothers (Chou, Lin, Chang, & Schallock, 2007). Additionally, the primary family caregiver must not only provide long-term care but also needs to cope with the social difficulties that result from people's prejudices, together with a feeling of

being devalued by society (Chou & Palley, 1998; Chou, Pu, Lee, Lin, & Kröger, 2009). A previous survey study (Chou, Chiao, & Fu, 2011) found that these family caregivers of adult children with ID who provided highly demanding care were more likely to have a lower level of health status and a lower quality of life than their counterparts whose adult family members had less severe disability.

In Chinese society, traditional Confucian values often still prescribe a sharp gender division of labour in which men are primarily concerned with breadwinning and women, even when in paid employment, are concerned with homemaker and childcare roles (Aryee et al., 1999; Lu et al., 2006). In Taiwan, which is a highly urbanised country, the employment rate among married women (15–64 years) in the labour market is still less than that in many Western countries, even though this rate has increased over the last two decades from 46.9% in 1990 to 54.5% in 2010 (Directorate-General of Budget, Accounting and Statistics, Executive Yuan, Taiwan, 2013). However, Taiwanese government policies supporting reconciliation of paid work and care among the mothers of adult children with disability are not institutionalised or recognised. For example, only since 2009 has paid parental leave, paid at a rate of 60% of one's salary for 6 months for both the father and mother, been available to parents whose child is aged ≤ 3 . However, flexible working hours and part-time work by informal caregivers are not covered by Taiwanese public policy. Formal support is only provided to people with disability or to older adults in low-income families. When using social services, such as homecare, day care, respite, or residential care, the family must pay or co-pay for services.

This qualitative study explored the experiences of nonemployed mothers caring full time for their adult children with ID. The research questions of this study were: (1) What were the reasons for these mothers to leave the labour market and when did it happen? (2) Why had these mothers not returned to the formal labour market? (3) What were the employment patterns of these mothers in comparison with the mothers in previous studies (Sørensen, 1983; Li & Yang, 2004)? This study is the first to examine the issues associated with working-age mothers of adults with ID who have intensive care needs, and it focuses on their perceptions of their care responsibilities and of their reasons to leave the labour market. This information can be used to identify the needs of mothers who are nonemployed and also life-long carers, especially those needs that are not being met by their social networks.

Methods

To investigate a participant's experience of a particular phenomenon, this study used in-depth interviews and an interview guide for data collection.

Participants

According to Taiwan's Central Government (Directorate-General of Budget, Accounting and Statistics, Executive Yuan, Taiwan, 2011), an individual is not in the labour force when that individual has no job or is not looking for a job because of school, household responsibilities, is too old, or has a disability. In order to focus on the nonemployed mothers who are of working age and have had intensive caregiving responsibilities for their children already for years, the enrolment criteria for this study were as follows: (1) full-time mother-carers, aged < 65, of an adult with ID who self-reported that they were non-employed; and (2) mothers caring for an adult child who had significant care needs, had been diagnosed with severe or profound ID,² aged ≥ 18, and lived with his or her family.

Participants were first recruited via an ID survey of health and social care issues conducted in Hsinchu City, Taiwan, during 2007–2008. All 33 non-employed mothers were called by telephone and invited to take part in this study. Twelve agreed and completed the interviews. Six nonemployed mothers were referred through a parental organisation and three day-care service centres located in other cities and counties in Taiwan. In total, 18 non-employed mothers who had an adult child with severe or profound ID completed the semistructured interviews at their homes between July 2009 and May 2010.

The 18 mothers were aged 38–64; 13 were married, two were divorced, and three were widows. Ten had completed primary school; three and four had completed junior and senior high school, respectively; one had completed college. The age range of the adult children with ID was 19–44 years; 11 of the 18 children were male (see Table 1).

Ethical considerations

Interviewees were first contacted by telephone. Only participants who accepted the telephone invitation were enrolled into the study. Before each interview, both written and verbal informed consent was obtained from each participant. Each consent form was signed by the principal researcher, the participant, and an interviewer as a witness. All participants

were informed that they could withdraw from participation at any time and that confidentiality was assured. Ethical approval for this study was obtained from the Institutional Review Board of the National Yang-Ming University, Taipei, Taiwan (code number: 990008).

Interview schedule

All interviews were conducted at the participants' homes by one of the researchers from the research team. Interviews lasted between 50 and 120 minutes. All interviews were recorded and later transcribed.

The interview guide,³ with 25 open-ended questions, was developed by the first author. Questions were derived from the international Working Carers – Caring Workers (WoCaWo) project but were adapted to the conditions of Taiwan. The guide covered seven areas related to the participants' care and work responsibilities: care work (e.g., "Are you the primary carer of your child with disability?"), previous experiences of employment (e.g., "Can you describe the characteristics of your previous paid work?"), the reasons for and timing of leaving the labour force (e.g., "Can you describe the reasons and when you quit your previous paid work?"), whether the participant's care responsibilities and paid work were in conflict (e.g., "Did your previous paid work influence your caring for your child with disability?"), care/work identity (e.g., "What do you think about the role of taking care of your child with disability?"), social culture (e.g., "What do you think about our society and culture, supporting women to carry on the role of working women?"), and formal service use (e.g., "Has your child with disability used any formal services or welfare benefits from the government?"). Characteristic data of mothers and their adult child were also collected: (1) adult child's age, degree of disability as documented by the government, activities of daily living (ADL), instrumental activities of daily living (IADL), and service usage; and (2) mother's age, education level, marital status, family income, and number of family members living in the same household (as shown in Table 1).

Data analysis

Transcripts were analysed via interpretative phenomenological analysis (Smith, Flowers, & Larkin, 2009). First, the principal researcher conducted an unfocused overview of the interview texts to identify significant words, phrases, or paragraphs related to issues explored in this study. The principal researcher

Table 1. Characteristics of the 18 nonemployed mothers and their adult children with ID

Name ^a	Mother				Adult child with ID		
	Age range	Marital status	Education	Paid work history after marriage	Age/gender	Diagnosed level of ID ^b	Formal service use
Sue	60–64	Widow	Primary	Was an outsourced home worker	44/M	Severe	Had used day care but not anymore
Lu	50–55	Married	Junior high	Was an outsourced home worker, helped mother-in-law at a market, & is involved in casual work	32/M	Profound	Respite
Lin	46–50	Divorced	Primary	Was an outsourced home worker & ran a cafeteria or restaurant	20/M	Severe	Respite
Ting	46–50	Married	Primary	Was an outsourced home worker	27/F	Severe	Not used
Dai	56–60	Married	Primary	Was an outsourced home worker; is a nanny to grandchildren	32/M	Profound (with Down syndrome)	Respite
Yin	50–55	Married	Primary	Was an outsourced home worker; is a nanny	30/F	Severe	Not used
Wu	56–60	Married	Primary	Was an outsourced home worker; is a nanny for others and her grandchildren	35/M	Severe	Not used
Ku	50–55	Married	Senior high	Works casually in a department store	27/M	Profound	Not used
Shei	60–65	Married	Primary	Was an outsourced home worker & helped husband paint walls	33/F	Profound	Not used
Fun	40–45	Married	Senior high	Had tried to work but did not last long	20/F	Severe	Not used
Jin	36–40	Married	Junior high	Had worked in a factory	21/M	Severe	Not used
Chen	50–55	Married	Primary	Had worked in a restaurant in the evening; is a nanny for her grandchildren	28/F	Severe (nonverbal, hearing disability)	Had used day care but not anymore
Yuen	50–55	Married	College	Had worked at a grocery store	19/M	Profound (with epilepsy)	Day care
Zou	46–50	Divorced	Primary	Worked casually; helps son (with ID and a cleaner) do cleaning work	21/M	Severe (with hearing & verbal disability)	Not used
Shi	56–60	Widow	Primary	Was an outsourced home worker	32/F	Profound (with epilepsy)	Day care
Jen	60–65	Widow	Senior high	Was an outsourced home worker	30/F	Severe (with Down syndrome)	Day care & respite
Shao	46–50	Married	Senior high	Helps the family business	27/M	Severe (with Down syndrome)	Day care
Ju	50–55	Married	Junior high	Was self-employed	32/M	Severe (with Down syndrome)	Had used day care but not anymore

^aPseudonyms^bThe recipients of welfare disability benefits in Taiwan must go through official registration based on their medical diagnosis, which is assessed by doctors based on the individual's IQ score and neurological examination results, mental health conditions, self-care ability, communication skills, and maladaptive behaviour.

then reviewed the texts to identify an initial set of themes. Successive readings continued and themes identified in successive transcripts were retained. Once all three research team members had completed an initial independent analysis, findings were combined for comparison and analysis. Themes were retained only when the research team achieved consensus. This process resulted in a condensed list of themes. These themes were then grouped into

closely related wider themes under appropriate headings.

Results

From the analysis of the data, four main themes emerged: moving from the formal to informal labour market, employment patterns, hidden paid work, and why mothers did not return to the labour market.

Moving from the formal to the informal labour market

Similar to the study by Li and Yang (2004), almost all mothers were employed before marriage. Some (33.3%) mothers left the labour force after getting married or giving birth to their first child. Only these six mothers can be defined as having the conventional employment pattern based on Sørensen's (1983) definition. Seven mothers (38.9%) left when their child with ID had intensive and long-term care needs. Furthermore, based on the work by Sørensen (1983) and Li and Yang (2004), the remaining five (27.8%) mothers were classified as showing the unstable pattern (e.g., Fun and Jin; Sørensen, 1983), continued pattern (i.e., quit until retired; e.g., Ju; Li & Yang, 2004) or other patterns (i.e., quit due to health or market reasons; e.g., Lin and Yuen). Most mothers (83.3%) had been involved in the informal labour market after leaving the formal labour market. That is, they were not employed outside the home and became undocumented workers.

Becoming an outsourced home worker. Ten mothers were outsourced home workers; that is, they worked at home after they quit their outside job. The 1972 "Xiao-Kang Plan" (help poor families in Taiwan) and the *living-room-is-the-factory* policy during the 1970s and 1980s increased family income to meet family financial needs. Working at home became a way for housewives to join in the labour market (Shieh, 1992). As a mother said, "I could work at home. I was able to take care of my family and kids" (Sue). And another said, "When he [son with ID] was sick, I was working at home all day and I needed to take care of my kids. I worked [i.e., outsourced home work] as much as I could" (Lin). Housework, caregiving work, and outsourced home work were combined for these mothers.

Becoming a child-minder at home or having casual work. Some mothers worked as nannies for neighbours (e.g., Yin and Wu) or had casual work near their homes (e.g., cooking for wedding banquets, working as substitute clerks at department stores, or delivering flyers; e.g., Lu, Ku, Zou, and Shi). In addition to looking after a child with ID, some mothers were also nannies for their grandchildren at home (e.g., Dai, Wu, and Chen), helping their daughters-in-law, who were gainfully employed.

Helping the family's business without pay. Some mothers helped their husband, son, mother-in-law, or husband's family (e.g., by painting walls, cleaning, selling vegetables at markets, or cooking for workers). A mother who prepared meals for workers in the family's business mentioned that she quit work

when she became engaged, as her mother-in-law had requested (Shao). Her husband's family was an extended family (more than 20 family members living together) who were running a business: "I was very busy cooking, buying food, and doing laundry by hand from morning to evening."

Employment patterns: when and why mothers quit outside employment

According to the interview results, mothers left the formal labour market or outside employment at different life stages—when married, when pregnant, when giving birth to a first child, when giving birth to a child with ID, when having a grandchild to care for, when a company shut down, or when having health problems.

Mothers quitting employment after the first child was born. Most mothers quit their employment when they gave birth to their first child (with or without a disability); the key reason was lack of childcare support. As discussed previously, paid parental leave has been available only since 2009 and take-up rates for leave have been extremely low (e.g., 5.9% in 2011 and 7.7% in 2012; Council of Labor Affairs, Executive Yuan, Taiwan, 2011).

During my second year of marriage, I gave a birth to my eldest child, and I quit my job. My daughter with ID was my fourth child. I did not have a mother-in-law to help, and childcare was too expensive... I didn't want to use my salary to pay for childcare, so I quit work to care for my child. (Shei)

Demanding care needs. Some mothers left outside employment when they had a child with ID (e.g., Ting and Wu) or because caring for a child with ID was extremely difficult (e.g., Ku, Fun, Jin, and Jen):

He [son with ID] was very difficult to care for. ... Both my mother and mother-in-law were unable to care for him. ... I am the mother, and I know what he needs ... My husband needed to sleep and work, so I quit work. (Ku)

Initially, my mother helped me care for her [daughter with ID]. I was working and I needed to check on her during my lunch hour every day. ... At that time, my mother was not so well. ... It was difficult to find a child-minder, so I quit my job. (Jen)

Expensive day care without an end. Most mothers stated that (co-)payment for day care for their child with ID was a significant financial burden; thus, some did not use this service due to its high cost (e.g., Sue, Ting, Yin, Ku, Shei, Fun, and Chen). The co-payment policy is based on family income.

One mother, Shei, mentioned that day care for her son with ID was more expensive than sending a child to university. Another mother, Ku, indicated that her child with ID had been using day care for more than 20 years, thus the family had been required to pay a user fee for 20 years and this financial burden would continue. Low service use means that the state does not share care responsibilities with families. In these circumstances, informal social networks become necessary for working mothers. The findings suggested that daughters-in-law, and probably daughters as well, expect that the older generation will help them care for their children, not the state.

No husband and/or no family support. As institutions are shaped by norms and values at national and local levels, so are interpersonal relations between men and women, and within families and households (Crompton, Lewis, & Lyonett, 2007). Some mothers mentioned that they wanted to work outside the home, but their husband did not support this idea (e.g., Sue and Jin) or their husband was unable to care for their child with ID (e.g., Yin and Ku). For example, one mother stated, “My husband says bathing a child is women’s work” (Jin). Another stated that “My husband says taking good care of my son with ID comes first and work comes second” (Yuen). Some mothers mentioned that their original family and husband’s family did not agree to a woman working instead of caring for family/children (Ku and Chen).

Quit work to care for grandchildren. “I quit work at the restaurant two years ago to take care of my grandchild because my son wants me to help so his wife can work” (Chen). This mother had worked evenings at a restaurant (7.00 pm to 3.00 am), as her family (e.g., husband and siblings of the child with ID) helped care for her daughter with ID. She was taking care of her grandchildren when interviewed.

Hidden paid work

Most mothers in this study moved from the formal labour market to the informal labour market and had many types of work to help meet their financial obligations, such as rent payments, purchases of nappies and milk, day-care fees for their children with ID. Regardless of whether the mothers had paid work at home (e.g., as a child-minder or outsourced home worker) or unpaid family work (e.g., self-employed work), they did not identify themselves as employed or as one of the family earners. Compared with studies by Aryee et al. (1999) and Lu et al. (2006), which determined that employed Chinese/Taiwanese women were concerned with

their childcare roles, most mothers in this study were not formally employed; they were working to help their family financially, or worked at home without pay. All were caregivers and most of them became hidden paid or unpaid workers.

Why mothers did not return to the labour market

These mothers did not return to the labour force for multiple reasons, including individual perceptions (e.g., motherhood identity, no support from their husbands, having no parents or parents-in-law to help) and social factors (e.g., childcare too expensive, special care needs of their child with ID, expensive long-term day care for their child with ID, day-care timetable did not fit work hours, labour market favoured young people and people with high levels of education).

Taking care of the child(ren) with ID was all these mothers’ first priority. Some mothers (e.g., Lu, Jin, Shi, and Jen) believed that children who are cared for by their mothers have better quality of care. The mothers did not complain about this long-term care work; they believed that caring for children was not difficult (Sue, Lin, Dai, and Yuen), that it was their responsibility (e.g., Lu, Ting, Yin, and Chen), and, as a biological parent to the child with ID, it was their fate (e.g., Lin, Dai, and Jin). Some mothers also perceived they were the main pillar of the family and their children and family counted on them:

He [son with ID] is the first priority in my life. ... I have no position to be pessimistic, because my family needs me. I am the only person of the family carrying on this care work. You all [husband and other children without a disability] can choose to leave the care work to me. Because I am the mother, I can do this care work better. (Ku)

I am just like an iron chain to have my family tied together. ... it is my responsibility to take care of my children and to maintain intimacy between all the family members. (Lu)

The majority of mothers in our study had completed only primary school education and their husbands were working as drivers, carpenters, machine operators, clerks, or were veterans. The mothers’ previous jobs included working in a cinema, as a waitress, factory work, as a typist, or as a salesperson. They had left the labour market decades ago due to caregiving for their adult child with ID and were now middle aged. The women were not as physically robust as they once were (e.g., Chen and Yuen), and searching for a job was not as easy for them as it might be for young people (e.g., Lu, Dai, Chen,

and Yuen), particularly if these mothers did not have a professional qualification and work experience (e.g., Ting):

Society does not support a person like me, not young anymore, to be employed. (Yuen)

Currently, labour market is getting worse and worse, and now many people are unemployed, ... for me it is even more difficult. (Ting)

Furthermore, some mothers mentioned that they would return to the workplace if they could take their child with ID to work. For example, two mothers planned to purchase a small restaurant and sell breakfast foods and other simple foods. Their children with ID would be able to work and have social contact with people. Thus, these mothers would combine work and care in the same location.

Moreover, similar to the study by Hays (1996), the women in this study were mostly working class, and the only reason they were working was to ensure the economic survival of their family. The findings obtained by this study echoed findings from Kahu and Morgan's study (2007) and a Taiwanese survey (Chou et al., 2010) that mothers of children with disability with a low education level receive little informal support. Unlike the Western and Taiwanese women in previous studies, who did not have a child with a disability (Li & Yang, 2004; Sørensen, 1983), the mothers in this study had little chance of returning to the formal labour market as they lacked the money to pay for long-term childcare.

Discussion

The results indicated that having a child with ID had a marked impact on the employment patterns of mothers throughout the family life cycle, and that these patterns were more complex than those of mothers not having a child with a disability (Li & Yang, 2004; Sørensen, 1983). First, these mothers had a high likelihood of being stuck in a conventional pattern once they left the labour market. For example, some mothers left the labour market and did not return because of the traditional roles and expectations of their families and society, as shown in the findings of DeVault (1991), Hays (1996), and Traustadottir (1991). Additionally, many had a child requiring long-term care and lacked support from informal and formal networks (Bourke-Taylor et al., 2011; Chou et al., 2010; Shearn & Todd, 2000).

Second, these mothers stated that they were non-employed, but most had acquired or still had unreported paid or unpaid employment. Thus, these

women were juggling both work and home, and combined paid/unpaid work with unpaid care/housework. Rather than reconciling the two roles of care and work in two locations (home or outside the home), these mothers were caring for their children and family as well as being one of the family earners. Furthermore, these married women had moved from the formal labour market to the informal labour market, and when they worked and what they contributed was part of Taiwan's underground economy and not reported as formal employment. However, their pay was not recognised by the government, so they were not covered by labour and employment insurance. This study found that instead of using social services most of the adult children with ID stayed at home and were cared for by the mothers. Thus, these mothers and their children with ID were not protected from social isolation and poverty, and were more vulnerable than employed mothers in the formal labour market (Bourke-Taylor et al., 2011; Chou et al., 2010; Eisenhower & Blacher, 2006).

Additionally, mothers in this study were the primary caregivers of their children with ID, and this caregiving and unreported work would continue. No employment pattern, or an unstable employment pattern, best describes the experience of the mothers in this study. Some of their employment experience might be classified as conventional by Sørensen (1983) and Li and Yang (2004) because the mothers left the labour force when they married or had their first child. However, beyond these descriptions, another employment pattern of these mothers should be recognised. This additional pattern included a move from the formal to the informal labour market or a move from the public workplace to the private sphere. Moreover, these mothers found it hard to return to the labour market once their child with disability was born because they lacked informal and formal support to meet the long-term care needs of their child. This suggests that the interrupted pattern and double-track pattern for mothers of children without a disability does not apply to mothers of children with disability.

Furthermore, these mothers had a high likelihood of leaving the labour market, not only at childbirth, but also at other life-cycle stages. For example, in addition to being married and giving birth to their first child, the intensive and continuing care needs of their child with disability increased the possibility of these mothers moving out of the labour force. Having a child with ID was an indirect reason why mothers left the labour market; other reasons were the lifelong special care needs of their child with disability, and unaffordable long-term day-care services.

It was notable that the employment patterns of these mothers differed from those of mothers of children without disability, as childcare is only intensive before a child goes to school.

In Taiwan as in many societies, women's status as carers is often important to them because caring for one's children or one's older parents is often identified to be a duty (Lewis & Campbell, 2007). The findings of our study show that the mothers did not recognise their "hidden work" (i.e., their undocumented paid work) as employment, and they only identified themselves as a house woman rather than a breadwinner of the family. In contrast to Hughes's (2002) argument, these mothers were not struggling for gender equality or striving to pursue personal careers in paid employment; instead, they were employed, and became nonemployed or hidden paid workers all for family reasons. Further, the mothers used their personal beliefs (e.g., fate, identity) as the coping strategy to maintain the traditional female roles they pursued. They were not only the cultural carers (DeVault, 1991; Hays, 1996), but were also the hidden breadwinners of the family.

In Taiwan, the welfare policies (including disability and childcare policies) and labour market do not help women to combine work and family care. Childcare for mothers with a child with ID lasts for decades; thus, both welfare and labour policies are needed that support these mother-caregivers, such that work and care responsibilities are compatible. First, these mothers need affordable day care. Second, seamless community-based services are crucial to meet the considerable support needs of children with ID. Moreover, intervention programs that help these mothers remain in employment or return to the labour market must meet the needs of the mothers and their child with ID. For example, whether mothers can combine both care and work in the same location is important to help mothers re-enter the labour market. For mothers working in the informal labour market, interventions should focus on how to help them avoid social isolation and how to be included in social insurance schemes.

In conclusion, 18 nonemployed mothers of 18 adult children with ID were interviewed to determine why they chose to leave the labour market. In contrast to the mothers of children without a disability (Li & Yang, 2004; Sørensen, 1983), these mothers still took on the role of the family breadwinner, and just moved from the formal labour market to the informal one and became hidden paid or unpaid workers. To support the mothers of children with disability, and to reconcile the conflict between care and work, formal care resources must be made available, not

only for employed mothers but also (and in particular) for those mothers who report that they are not employed.

Despite its contributions, this study has certain limitations. First, the results were based on single interviews and a cross-sectional sample of participants. To understand the care and work patterns of these mothers in different life-cycle phases, and the interactions between mothers and the social contexts in which they live, life history narrative research is needed. Second, the study results are limited to mothers with a working class background, who had a child with severe or profound ID, and who were recruited voluntarily to the study. However, this study is the first to focus on the experiences related to caregiving and the work of mothers who have left the formal labour market. From the perspective of ID research, this study broadens the discussion of work/family reconciliation and patterns/reasons for leaving formal employment among mothers who have cared for children with ID for over two decades.

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Conflicts of interest

No conflicts of interest have been declared.

Notes

1. *Conventional*: Women who had left the labour force upon marriage or the birth of their first child and who had not returned to the labour force. *Interrupted*: Women who had left the labour force upon marriage or the birth of their first child and who had returned after the last child was born. *Double track*: women who returned to the labour force before the last child had been born. *Unstable*: women who had left and entered the labour force several times (Sørensen, 1983, p. 313).

2. In Taiwan, disability welfare benefits are only available to those who are diagnosed with a disability, have the approval of the local government, and have been provided with a disability certificate or handbook. The level of disability is categorised into four levels, namely, mild, moderate, severe, and profound, which are based on the individual's medical diagnosis. The diagnosis of ID is based on the individual's IQ score and her or his neurological examination results, mental health situation, self-care ability, communication skills, and maladaptive behaviour.
3. The interview guide is available upon request from the corresponding author.

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