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Lost in translation: implementing personal assistance in an East Asian context

Yueh-Ching Chou, Bowei Chen & Teppo Kröger

Abstract

Since 2012, Taiwanese citizens with disabilities have been entitled to personal assistance from local authorities. To explore current features of personal assistance and barriers to its implementation, and distinguish it from homecare services, 33 disabled people and 12 staff members representing 10 local authorities in Taiwan were interviewed. Findings indicate that disabled people prefer personal assistance to homecare and perceive that relationships with their families have improved since the availability of personal assistance. However, many users' needs are unmet due to insufficient hours of service and costly co-payments. Results also show that development of personal assistance has been hindered not only by limited resource allocations but also by a lack of awareness of the concepts of independent living and personal assistance among staff. In the context of East Asian culture, independent living is misinterpreted as self-reliance, leading to the resurrection of the medical model of disability.

Keywords: independent living; personal assistance; home care; medical model; East Asia; Taiwan

Introduction

Personal assistance (PA) is seen as a primary achievement of the independent living movement, which originated in the US in the 1960s and continues to thrive globally (Gibson et al. 2009; White et al. 2010), including the East Asian countries, China, Japan, Korea and Taiwan (Chou et al. 2019; Fisher and Li 2008; Hayashi and Okuhira 2001; Kim 2008).

With PA, disabled people employ their own assistants instead of receiving established institutional and homecare services (Christensen and Pilling 2014). In many Western countries, PA has become the mainstream of home and community-based support services for disabled people (Askheim et al. 2013; Glasby and Littlechild 2009), and is included in Article 19 of the Convention on the Rights of Persons with Disabilities (CRPD) (United Nations 2006), and recently it has been extended to people with intellectual disabilities and older people (Glasby and Littlechild 2009; Ungerson and Yeandle 2007). Unlike professionally managed, often medicalised social services, a main principle of PA is enhancement of disabled people's self-determination (Brennan et al., 2016; Christensen and Pilling 2014). Thus the most common model for PA is direct payment to users (Askheim 2005; Christensen 2012; Graham 2015) so they can choose where, when, how, and by whom assistance is provided (Ratzka 1996).

Overall, the independent living movement has challenged professional notions of disability as a dependent status (Berg 2005; Shakespeare 2006) and emphasised disabled people's entitlement to PA so they can participate fully in society and manage their lives (Morris 2004; Ratzka 2015; White

et al. 2010). These views were launched in Japan in the late 1980s (Hayashi and Okuhira 2001), in Korea in the early 2000s (Kim 2008) and in Taiwan in the early 2010s (Chou et al. 2019). In China, disability services are provided for in the Protection of Disabled Persons Law issued in 1990 (Fisher and Li 2008), but most disabled people are supported by the family, so the law, which covers institutional care, is in effect a safety net for those who have no family or place to live, and PA has no the priority in current Chinese disability policy (Fisher and Li 2008). In general, the independent living movement has met resistance in Asia due to narrow understanding of independence and disempowering cultural attitudes toward disability (Hayashi and Okuhira 2008; Yang 2014). This study is an exploration of PA in Taiwan, the East Asian in which it was most recently implemented, including how independent living and PA have been understood and implemented in policy and practice, and how they impact disabled people.

Independent living movement in Taiwan

In Taiwan the concept of independent living was extended to people with intellectual disabilities as an alternative to institutional care in 2001 (Chou et al. 2001; Chou et al. 2002), and in 2004 a new policy allowed up to six persons with intellectual disabilities to be supported to live together (Chou and Schalock 2007; Chou et al. 2011). In 2007, the Taiwan Community Living Consortium was established by a group of academics and professionals to support this policy and organise residential facilities and services. However, because the board members of the Taiwan Community Living

Consortium were managers or employees of NGOs working specifically with people with intellectual disabilities, the initiative did not necessarily extend to other disabled people's organisations (DPOs).

In 2007, the New Vitality Independent Living Association of Taipei (aka New Vitality), created mostly by wheelchair users, became the first established independent living centre in Taiwan. In 2009, New Vitality launched Asia Try, the disabled people's movement in Taiwan, the first independent living campaign initiated by a DPO, that is, by disabled persons themselves rather than by professionals or guardians (for details of Taiwan's disability rights movement, see Chang 2015; 2017).

Although non-governmental organisations (NGOs) have been legal in Taiwan since the abolishment of martial law in 1987, and many self-help organisations had been launched by various disability (e.g. vision, hearing and spinal cord impairments; Chou et al. 2016; for details, see the League for Persons with Disabilities, Taiwan 2020), the concept of independent living did not emerge until New Vitality was founded. To date, six independent living Associations/Centres (including New Vitality) have been established in six local authorities. As a result of a New Vitality campaign, in 2018, the Taiwan Disabled League of Independent Living Centres was organised to bring the centres under one umbrella.

New Vitality's (2010) definition of independent living as 'self-choice, self-determination and self-responsibility' is used extensively by disabled people in contact with New Vitality, including

users of PA (Chou et al. 2019). However, the term 'self-responsibility,' which is not used by European disability activists (e.g. Morris 2004) and DPOs (e.g. European Network on Independent Living 2015), has proved to be problematic. While it is intended to emphasise disabled people's right to choose, it might also imply that to avoid institutionalization and family control, disabled people should be fully accountable for their lives.

The launch of personal assistance in Taiwan

A year after its establishment, New Vitality implemented the first PA for disabled people as a three-year pilot project (2008-2010), concurrently with the independent living movement by people using wheelchairs (i.e. Asia Try in 2009). According to New Vitality (2010), the services provided by personal assistants should function as the disabled person's 'eyes, ears, hands and/or legs,' that is, facilitate what the users expect to do, both indoors and outdoors.

Chun-Chieh Lin, a wheelchair user and a pioneer of Taiwan's independent living movement, helped found New Vitality after she returned in 2006 from training in independent living in Japan, hosted by Japanese disabled activists (Duskin Leadership Training in Japan, 2021) (for details of this training programme, see Hayashi and Okuhira 2001, 2008). She was also the first to employ a personal assistant in the pilot project. Thus Lin's training in Japan was the impetus for and therefore the origin of Taiwan's PA model, which was established by New Vitality (Lin 2012).

Since the beginning of the pilot project in 2008, the term ‘personal assistant services’ rather than PA was used in Taiwan, and that term was superseded by ‘Independent Living Support Services’ in a 2011 amendment to the Taiwan Disability Act. In 2012 the Taipei City Government outsourced Independent Living Support Services to the New Vitality in its area. Thus, disabled people in Taipei City were the first users of government-sponsored personal assistant services.

Based on amended Article 50 of the Taiwan Disability Act, Independent Living Support Services are included in the Regulation of Personal Care Services for disabled people, which requires a person applying for personal assistant services to have peer support from another disabled person (‘peer support service’) and an Independent Living Plan, proposed by and signed under the supervision of the disabled peer. Based on Article 71 of the Regulation of Personal Care Services, the personal assistant should support the disabled person’s participation in social activities, rather than provide assistance in daily living.

The amount of government support for personal assistant services is based on family income, ranging from full subsidisation for individuals in low-income families to 70% subsidisation for those in middle-income families. The number of personal assistant services hours offered is based on the users’ level of disability according to the needs assessment of the Activities of Daily Living (ADL) and the Instrumental Activities of Daily Living (IADL), following the International Classification of Functioning, Disability and Health (ICF). The maximum number of personal assistant services hours per month is from 60 to 80 hours, depending on the local authority. Instead

of the users, only the providers (NPOs or DPOs) can recruit personal assistants, most of whom are funded by the central government (Chou et al. 2015).

Disabled people's choices of personal assistance, homecare and live-in migrant care worker

Since June 2017, all disabled people, including older people, have been included in the current '10 Year Long-term Care Plan 2.0.' In June 2019, individuals aged 65 and over constituted 14.9% of the population of Taiwan (DGBAS 2019) which is expected to rise to 20.4% by 2026 and to 41.2% by 2065 (National Development Council, Taiwan 2018), making long-term care policies and services priorities of the current government. Along with daycare and family foster care, homecare is one of three primary home/community-based services funded by the long-term care scheme. In addition, since 1992 families with a member needing regular assistance are eligible to hire a live-in migrant care worker at their own expense through an application and needs assessment process (for details, see Chou et al. 2015). However, regulations stipulate that live-in migrant care workers cannot be employed as personal assistants, meaning that having a live-in migrant care worker disqualifies disabled people for personal assistant services. Thus in effect there are three home-based assistance alternatives to institutional care for disabled people: homecare, personal assistant services, and a live-in migrant care worker.

Initially, homecare was, considered the main service of the long-term care scheme (Wang 2004), which was developed to help older people avoid institutional care. Conventionally such services include assistance with bathing, eating, dressing, moving about, cleaning, and management of medicines, etc. Applicants for homecare must undergo a needs assessment focusing on ADLs and IADLs. Research has shown, however, that homecare is accessed mainly by those with minor care needs as these services are limited and there is a co-payment for middle-income families (Chen and Wu 2008; Huang et al. 2006; Lin and Chiou 2004), making it cheaper to hire a live-in migrant worker. In 2013, the cities of Taipei and New Taipei funded a pilot program in which four non-profit organisations (NPOs) hired migrant care workers to provide home-based care, but it was terminated in 2019 due to a lack of users, as it was still less expensive for families to hire a live-in migrant care worker themselves (Huang 2016; Yeh 2019). Additionally, live-in migrant care workers often do most of the housework although it is illegal for them to provide any services not related to disabled people's care needs (Workforce Development Agency, Ministry of Labour, Taiwan 2019). In short, families pay more for home-based care and receive fewer services from it, making this program an unpopular option compared to institutional care or hiring a live-in migrant care worker, which is one of the main challenges for the development of long-term care policy in Taiwan (Chou et al. 2015).

Personal assistant services not included in Taiwan's long-term care scheme nor under consideration by its decision-makers, practitioners, and potential users and their families. On the

one hand, in 2019 Premier Su announced a 2020 budget for long-term care that was eight times the budget in 2016 (Su 2019). On the other hand, since 2012, the lack of public funding for personal assistant services has been the key barrier to their use, followed by a shortage of personal assistants. As a result, disabled and older people continue to use homecare (Chou et al. 2019).

Disability seen from the charity perspective

Wang (2007) has described Taiwanese disabled people as compelled to 'beg for help' (p. 84) due to lack of services, which forces them to depend on family, friends and colleagues. According to Chang and Wang's (2016) analysis of Taiwanese newspapers published between 1953 and 2014, 'helpless and needy' was the most frequent image of disabled people shown in the news, a charity perspective that has persisted in the mass media even after 2000. When assistance is received from outside the family, whether from public or private agencies, it is viewed as benevolent charity work deserving of gratitude from the recipient (Chang and Su 2009). Moreover, as in Korea (You and Hwang 2018), professionals and policy makers generally view disability services from their own medical and rehabilitation perspectives, ignoring disabled people's voices. Recipients of disability benefits must also undergo needs assessment, which since 2012 is based on the ICF. However, the application of the ICF in Taiwan has been criticized for adhering to the medical model and professional management of services (Chou and Kröger 2017).

Methods

To address the above-mentioned issues, this study is an exploration of both the experiences of disabled people with personal assistant services and the perspectives of local authority staff responsible for implementing Independent Living Support Services in Taiwan. Primary data consist of open-ended interviews conducted between September 2015 and June 2017 with 33 disabled people and 12 staff members from 10 local authorities.

The following research questions guided this study: (1) What are disabled persons' experiences as users of personal assistant services and homecare? (2) How do local authority staff members working for Independent Living Support Services understand independent living for disabled people?

Participants

The 33 disabled participants in this study, 19 women and 14 men, were mostly recruited through New Vitality and included participants in the nationwide disability/ independent living movement. All but one, who difficulty with balance, were wheelchair-users due to cerebral palsy, osteogenesis imperfecta, muscular dystrophy, scoliosis, polio, congenital malformation, spinal cord injury, rheumatoid arthritis, and motor and language nerve necrosis. They were interviewed individually for 100 and 180 minutes and responded independently, though four who had cerebral palsy used an IPAD as assistive equipment and/or received assistance from personal assistants or friends who

were familiar with their body/oral language. Eleven were 23-30, 11 were 31 to 40, and 11 were 41-56. Thirteen were employed (mostly by disability DPOs) or self-employed, seven were doing casual work (such as vending small merchandise), four were students, four were volunteers, and five could not undertake employment due to their impairments. Eight were not using any services at the time they were interviewed, four were using personal assistant services only, four were using both personal assistant services and homecare, two were using homecare only, and five received assistance from a migrant care worker. Sixteen were living with family, six were living with friends, one was living with a migrant care worker, and ten were living alone. Nearly a third (10) had previously lived in an institution.

The 20 local authorities in Taiwan comprise six metropolitan areas, three cities, and eleven counties. In this study, 12 staff members responsible for personal assistant services in 10 representative local authorities (50% of the total), were interviewed: three males and nine females, of whom nine were married and three never married. Five had master's degree and seven bachelor's degrees. Five were heads of disability services, two were frontline managers of PA, and five were frontline social workers/supervisors.

Data collection

We conducted face-to-face interviews with 27 disabled people and three staff members and Skype interviews with the rest, according to their convenience, helped by the research assistant, a graduate student in social work. The interviews took place in the participants' accommodations, service

centres for disabled people, or workplaces. The disabled people were interviewed by the principal investigator of this study, members of New Vitality, and/or the research assistant. The staff were interviewed by the principal investigator or the research assistant. Interview protocols for the disabled people and staff members were developed by the research team, led by disabled people from New Vitality. For disabled people, the semi-structured questions focused especially on their own experiences with independent living and independent living support that they had received, including homecare and support from a personal assistant or migrant care worker. For the staff members, the open-ended questions elicited their perceptions of independent living and personal assistant services and comparisons between homecare and personal assistant services as practiced in their local authorities.

Before participants were interviewed, we provided assurances that their confidentiality would be respected and their identities not revealed. We also obtained their written consent to have their interviews audio-recorded. We mailed each his/her interview transcript to check for accuracy. Three of the participants with disabilities were not able to read, so the research assistant of this study read them their transcripts and obtained their confirmations or revisions. The confirmed or revised transcripts were used in the data analyses. All names used in this paper are pseudonyms. The study was approved by the Research Ethics Board of the National Yang-Ming University (approval number: YM103098F).

Analysis

Data analysis proceeded as follows. First, the transcripts were read three times by the principal investigator, after which the full transcripts were edited by cutting out text that was unrelated to the research questions of this study. Second, members of the research team independently reviewed the transcripts to identify an initial set of themes. As new themes emerged, the set of themes was re-evaluated. Themes that continued to be supported in successive readings of the transcripts were retained, and those without broad support in successive readings of the transcripts were removed. Once this initial independent analysis was concluded, the reviewers discussed their findings for comparison and additional analysis. The team again evaluated the remaining themes to determine whether there was sufficient evidence to warrant their inclusion and were retained only if there was consensus on their validity.

Findings from disabled persons

Three themes were synthesised based on the extent to which disabled people had used personal assistant services and their experiences with using both personal assistant services and homecare: (1) preference for personal assistant services over homecare; (2) experiences using personal assistant services such as feeling greater autonomy and improved family and social relationships; and (3) experience of 'semi-independence' rather than full independence.

Preference for personal assistant services over homecare

All 14 participants who had used both personal assistant services and homecare preferred personal assistant services for the following reasons: homecare was available only during work-day hours; homecare assistance was specified and allocated by the provider, not in accordance with users' needs; and homecare assistance was confined to the user's home. As one participant stated,

> I have been qualified for 90 hours of homecare per month, because I work days, and homecare is not available evenings and Sundays or outside the home, I can use only 20 to 30 hours a month. Homecare is insufficient to meet my needs. (Shin, M, age 25)

Wun (F, age 50, needing support in getting up, toileting etc.) had been assessed to receive homecare 72 hours per month, but no home carer was coming to her. She described the differences between homecare and personal assistant services as follows:

> A home carer treats the person receiving support as a care target who only has needs such as toileting, eating, dressing for maintaining basic living. …Unlike a home carer a personal assistant sometimes accompanies me for shopping or for recreation.

Experience of greater autonomy and improved relationships with family and friends

The use of personal assistant services raised the participants' hopes for their future and improved their family relationships:

> Before, I had planned to work hard in order to have enough savings to afford to live in a nursing home when I am old. … Now that I know about independent living, I realize I could have my own life if I have a PA to help. … I can hope for a better future. (Lin, F, age 30+)

After using homecare four hours a week for four years, Yu (F, age 56, living alone) had recently started to use personal assistant services 30 hours per month. While the home carer helped her by cleaning and doing laundry, the personal assistant did things with her in and outside her home that the homecare was not authorized to do. She shared:

> Earlier when I did not have a personal assistant, I needed to ask my friends' for help. … and then I needed to treat them in return, such as buying them a meal. Now that I have the personal assistant for such help, I do not feel I owe somebody for giving me a favour. … Previously my sister, who has already passed away… felt that I would become her burden. If I had had a personal assistant at that time, my relations with my sister might have been better.

Pei (F, age 25+; she and her sister both have muscular dystrophy) explained how personal assistant services resolved her feelings of guilt about her mother:

> Since I've had a personal assistant coming to help me for bathing, my autonomy has increased. … I like to use soap more than shower gel. Before, when my mother helped me bathe, I felt shy to tell her what I wanted because I felt I already owed her too much. … Earlier, if we went out to a restaurant, my mother spent two hours helping me and my sister bathe, and once we were ready to go out, she

> was exhausted and we felt guilty. So the meal time was just totally destroyed. Now, when we go out together, our personal assistants come to help us bathe, and my mother can have time to dress herself up. When she came to ask me how her dress looked while the personal assistant was helping me bathe, I could not help but cry, because that was the first time in 27 years when I saw my mother having her own time to dress up. ... Then we really did enjoy our meal time together at the restaurant. …Our relationship is just like a normal one between a mother and a daughter.

Thus, the use of personal assistant services not only gave disabled people greater autonomy but also helped to improve their relations with family members who were relieved of some care responsibilities.

Experiencing not independence but 'semi- independence'

As discussed above, disabled people have been empowered with the use of personal assistant services. However, there remain two key barriers to autonomy in the present PA system: insufficient PA hours and unaffordable co-payments.

Limited PA hours. Almost all the disabled participants who had used personal assistant services reported that their needs could not be fully met because of the limited PA hours they were allocated. Some had to continue living with family and/or hire a live-in migrant care worker.

Kong (M, age 40+, using an IPAD and translators during the interview) said that his PA quota was only 60 hours per month, but he needed an additional 25 hours, for which he had to pay fully.

To make up for the extra cost, he was changing nappies only twice a day, once in the morning, assisted by the homecare provider, and the other in the evening with the help of the personal assistant. He also worried constantly that no personal assistant or home carer would come to assist him, especially during the holidays. He said that to live with dignity, he would need to have 24 hours of PA support per day.

Chong (M, age 35+) needed 10 hours of support per day for bathing, toileting, eating, and shopping; but currently he was allocated only two homecare hours in the morning and four PA hours in the evening. He considered his quality of life to be only half as good as that of people without disabilities because of the insufficient hours of assistance provided.

Ming (M, age 50+), who used a special wheelchair that required ample space for manoeuvring, was living alone in a rented flat and using both PA and homecare. He shared:

> I do not feel I am treated equally. … You can take a shower or a bath every day, but I cannot. … I cannot have a home carer coming to help me for bathing on Sunday. ... I am allotted 60 hours of personal assistant services per month, which is two hours a day, so I cannot use the PA for bathing or I will exceed my time.

Chen (F, 25+) had a paid job, lived with family, and received PA and homecare services. She, too, shared that she felt only semi-independent due to the shortage of support services: *'…the limited*

resources cannot meet my needs. Therefore I still count on people like my mother and my colleagues to help me. ...It makes me feel I have lost my life autonomy.'

Huei (F, 25+), who had used only PA, felt that her life was controlled by her limited hours of personal assistant services. For example, she could not socialize with her friends in the evening without paying the full cost of PA overtime. Some disabled people would have preferred to live independently with the support of a personal assistant rather to stay with family, but they did not have that option due to their limited quota of personal assistant services. As Zei (M. 20+) shared, '*I cannot move out to live alone. I don't have enough PA hours to meet my needs*.'

Some participants, whether they lived alone or with their family, were depending on a migrant care worker rather than personal assistant services. Han (M, age 30+) shared that his family had to hire a live-in migrant care worker for him as he needed 24-hour support. The current systems of homecare and PA could not meet his needs for independent living.

Unaffordability of PA co-payment. Hiring a migrant care worker, counting on family carers, or moving to institutional care were the only options for some because of unaffordable PA co-payments and/or insufficient service hours. Chong (M, 35+) was using both personal assistant services and homecare, each with a co-pay of 30%, costing him 160 Euros (minimum wage: 570 Euros) per month. Kong (M, 40+), who was granted 90 hours a week of homecare, the maximum

hours for users assessed with profound disability, was required pay 30% of the cost in addition to paying for additional PA when needed.

Wun (F, 50+) could not get homecare assistance due to the shortage of homecare workers and was receiving 180 hours of personal assistant services a month although she needed 270 hours to maintain a good quality of life. She had to pay for 30% of 60 hours and 100% of the remaining 120 hours and sometimes for even more hours in the event of unexpected or urgent needs. At the time of the interview, her PA support was costing her almost 1,200 US dollars a month.

Consequently, disabled people with intensive support needs like Kong and Wun who cannot afford such high costs for minimal support services have only two choices: to move to an institution with lower costs, or to hire a live-in migrant care worker at minimum wage, which would cost less than the personal assistant services they were using. After our interview, Wun, similar to other participants in this study (Yen, Mei, Chun, Lee, Han), chose the migrant care worker option because of the insufficient PA hours and costly co-payments.

Findings from representatives of local authorities

Three themes were identified: (1) myths about and misunderstandings of independent living and PA; (2) mixed uses of PA and homecare; and (3) shortages of both funding and personal assistants.

Myths about and misunderstandings of independent living and PA

No clear idea about the concepts of independent living and PA. We found that all participating staff members had vague notions about or outright misconceptions of the principles and purposes of independent living and PA, which are integral to Independent Living Support Services, as the following examples illustrate:

> I am not so sure my idea about Independent Living Support Services is correct. … (G5)
>
> We do not know much about the spirit and implications of independent living. … (G6-2)
>
> PA looks like a kind of out-door homecare. …I wonder if other people in my position have the same understanding. … (G9)

Some participants shared that not only some service providers but also the general public do not understand the meaning of independent living. This conceptual confusion hinders efforts to put Independent Living Support Services into practice.

> Independent living is a new concept for Taiwanese people. …Traditionally disabled people stay at home because they have difficulty going out. …It is a good movement, but the public and NGOs still retain the traditional idea. This presents a barrier for us in practice. (G4)

'Disqualified' PA users? Some comments made by staff interviewees illustrate Taiwan's cultural disconnect as an East Asian country from Western values of autonomy and independence, resulting in confused notions of independent living, peer support, and PA even at the level of

government policy. This confusion is illustrated in the following attempt by a staff member to sort out the services of different programs:

> A disabled person with a profound impairment needs to have her/his nappy changed at her/his workplace at noon time. ...A home carer cannot go to help (due to regulations which prohibit provision of homecare services outside users' home). Care needed at the place of employment meets with the conception of independent living, so s/he is fine to use personal assistant services. … If a disabled person needs a companion to go out to meet with her/his friends or for school, s/he is also eligible to use personal assistant services. In contrast, if a disabled person who has been a stroke victim for years applies for a personal assistant to accompany her/him to regular physical rehabilitation, I do not think such a need fits the notion of independent living because this is a long-term medical care need. …So s/he should apply for homecare instead of PA. (G9)

This explanation implies that, following incoherent Regulation of Personal Care Services directives, the local authority staff understood the use of PA to be restricted to supporting self-reliance in employment and social participation while excluding support for medically prescribed routines and perhaps other daily activities.

Another staff member commented that a client's *' Independent Living Plan is not progressive enough, not so much different from his previous life. ...we cannot see he is planning to*

something new' (G4), suggesting that the investment in independent living should yield something more than enhance quality of life.

Another criticised any use of PA to meet a person's needs, in this case helping with a parental responsibility, that was not restricted to personal care of the disabled person:

> One disabled user had asked the personal assistant to take her child to see the doctor. …The personal assistant services are for disabled people, not for their family members. (G8-1)

Eligibility for using personal assistant services was often confusing for the staff participants as is evident in the following statements:

> You would find that the definitions of Independent Living Support Services differ among the different local authorities. ... such as whether only people with severe impairment are eligible for PA or whether only those who have received peer support services and have an Independent Living Plan are eligible to use PA. (G6-1)

> The peer supporter goes to see whether the applicant for PA has an idea about independent living first and then personal assistant services would be provided later. …It means that, in order to use personal assistant services, you need to have peer support first, but to use peer support, you don't need to have PA. (G5)

Our findings show that rather than the disabled person, it is the local authority and/or the provider of PA who defines the acceptability of the use of PA and an 'independent enough'

Independent Living Plan. The application of PA in Taiwan has thus disregarded the original emphasis on user-control of the disabled activists who initiated it (for details, see Ratzka 1996) and as it has been implemented in European countries (Christensen and Pilling 2014).

Mixed uses of PA and homecare

PA cannot be used at home. Further illustrating their unclear notions of independent living and PA, which are now included in the Independent Living Support Services, some representatives of local authorities asserted that PA should not be used for domestic services, which was the domain of homecare. For example, one staff member explained,

> If the applicant's Independent Living Plan is only for domestic services, which should be provided by a home carer, this does not match with the spirit of Independent Living Support Services, which emphasises using PA for participation in society. ...(G8-2)

Conflating/confusing PA with homecare. As discussed above, because both PA and homecare are included as personal care services and regulated by the law, some staff members had difficulty distinguishing them. Additionally, because homecare can be used only in the home and is not available during evenings and Sundays. PA was often perceived a supplement to or an outdoor version of homecare; or the two services were viewed as mutually exclusive alternatives. Expressing this confusion, staff members stated,

The differences between PA and homecare are not sufficiently clarified by the laws [Disability Act and Regulation of Personal Care Services]'. (G1),

The assessment tool for both personal assistant services and homecare is the same, ADL, so these two become confused. (G2)

It's difficult to distinguish personal assistant services and homecare. …, the personal assistant accompanies the disabled person for social activities, [but] the personal assistant also needs to provide physical help, like toileting, which is also provided by the home carer. (G8-2)

PA is like homecare and serves as a supplement for the limited hours of homecare. …There is serious overlapping between PA and homecare. … PA becomes the outdoor form of homecare. (G9)

Some staff members came up with their own distinctions between PA and homecare when disabled people apply for services:

A home carer would cook for the user in her own way; but a personal assistant would cook for the user in the user's way. … (G10)

Nowadays, the personal assistant provides those services that a home carer would not provide. … We have defined domestic assistance to be delivered by a home carer, and the personal assistant provides support out of the home. … Personal assistant has been defined as the disabled person's hands and

legs. If the user wants the toilet cleaned, the personal assistant would do so, though such cleaning work is part of homecare. (G6-1)

While the above accounts might be close to disability activists' notion of PA, they also suggest that PA in Taiwan is not perceived as an innovative alternative to homecare but as a supplemental to it. Additionally, in Taiwan the shortage and high turnover rate of home carers remain a major issue (Chou et al. 2011; Chou et al. 2019). Thus staff members regard PA, not as a new approach to enhancing disabled persons' self-determination, but as a way to fill the gap in homecare when users need extra assistance in or outside of the home.

Shortage of both funding and personal assistants

In addition to staff members' inconsistent notions of homecare and PA, the relationship between them, and confusions/conflations of services to be provided by each, inadequate funding for PA and difficulties recruiting personal assistants are primary barriers to the development of PA in Taiwan.

Recruitment difficulties and high turnover rate among personal assistants. Similar to PA in the US (Matsuda et al. 2005), almost all staff members interviewed mentioned the difficulty of recruiting personal assistants and their high turnover rate. One cause of this shortage is unequal status between personal assistants and home carers. Despite the CRPD's claim that the disabled people are themselves the employers and supervisors of their own personal assistants, in Taiwan, a personal assistant, like a home carer, is viewed as a para-professional care worker who according to

law must be trained by the service providers (i.e. NGOs which contract with a local authority). However, home carers receive many more hours of pre-service training than personal assistants (90 vs 25 hours), so they are considered more professional and receive higher pay.

> Because of the discrepancy in amount of pre-service training, a home carer can be hired as a personal assistant, but not vice versa. (G8)

> A personal assistant only receives 25 hours training, so if you wanted to increase her/his hourly pay, her/his training would not qualify for the raise. (G1)

> A personal assistant is not required to have as many hours of training as a home carer, which means that a personal assistant's services are regarded as less professional. … This also results in low pay for personal assistants. (G3)

The staff members also argued that the professional pre-service training for personal assistants was insufficient.

Unlike the spirit of PA emphasizing the agency of the disabled person embodied in the disabled activists' campaigns (e.g. Ratzka 1996, 2003; ENIL 2015), they do not have free choice of personal assistants but can hire only those who have completed certain training courses and become licensed care workers (e.g. home-based, day-care or institutional care workers) or certified personal assistants as regulated by the Regulation of Personal Care Services.

Limited funding to support PA for disabled people. As discussed above, the primary source of difficulty for implementation of the PA system in Taiwan is the government's limited allocation of funds to the program. Independent living and PA have not been formally acknowledged by the government or incorporated in the recent long-term care scheme, resulting in strict limitations on the number of users of PA and the hours they receive:

> The funding from the central government is very limited, which imposes strict limitation on hours that can be allocated to users of PA. (G5)

> The primary problem is the sparseness of the budget. …We have to discuss with disabled PA users the need to stop the use. (G10)

> There are only 30 disabled persons [in this local authority] who are now using PA. … Because of the shortage of funds, as long as the current users continue to use PA, we cannot have new users. (G9)

Discussion

PA in Taiwan, modelled on the Japanese program, is in the beginning stage. Like the Japanese system, as well as the Korean (Kim 2008) and the US (Hagglund et al. 2004) systems, PA in Taiwan is not a replacement for homecare, and it does not make direct payment to users but channels services through providers (e.g. NGOs) that are contracted by the local authority, which is different from practices in

many European countries (Askheim 2005; Christensen 2012). Therefore, the users rarely choose the personal assistants who work for them and do not have control over the services provided as recommended by the United Nations.

Based on the findings here, from the disabled people's perspective, PA is preferable to homecare, and the use of PA has had positive effects on the users' personal relationships. However, the limited PA hours available disallow disabled people to achieve their goal of living independently in the community. We also found that the independent living movement faced further cultural challenges in an East Asian society, which thwart the activists' aim of empowering disabled people as self-determining members of the community (Barnes 2003; Morris 1993; Oliver 1990). In Taiwan, it is the local authorities rather than the disabled people that determine what PA and independent living mean.

These findings are consistent with those of Wang's (2007) study showing that Taiwan citizens with visual impairment who used personal assistant services at work had little control over the services, reflecting professionals' lack of full understanding of the core principles of independent living and PA. In Taiwan as well as China, Japan, and Korea, disability still carries the stigma of being a 'personal tragedy' or an 'individual's problem,' and 'independence' is considered synonymous with 'self-reliance,' so disabled people are expected to deal unobtrusively with their own issues instead of demanding the necessary services to live with autonomy and dignity (Yamaki

and Yamasaki 2004; Kohrman 2008; Chang and Su 2009; Yang 2014; You and Hwang 2018; Qu 2020).

Under the influence of Confucianism and its emphasis on five cardinal relationships (*wu-lun*, for details see Feng 2009), people in Taiwan are culturally accustomed to the idea that the social hierarchy assures societal stability, making it easier to obey than to challenge authority. Thus, unequal power relationships, commonly observed in daily contexts such as parent-child or teacher-student relationships, tend to go unquestioned, the relationship between the local authorities and service users in our research being no exception. Rather than the disabled people, it is the government officials who determine who can receive personal assistant services, under what circumstances, and to what extent. While in principle a public system should be accountable and some gatekeeping is needed, in practice the government officials are not compliant with the spirit of independent living and PA.

Before the 1980s, like other social benefits, support for disabled people in Taiwan was extended as charity, in particular by religious organizations, e.g. the Catholic church (Chou and Schalock 2007). Later Taiwan has been recognised as a weak welfare state (Ku 1997), in which eligibility for government disability benefits is based on means-testing of family income and level of disability (Chou et al. 2008). This practice implies that supporting disabled people living in the community vs. moving them to an institution is more the disabled person's family issue than the responsibility of the state (Goodman and Peng 1996). Moreover, Taiwan, like other East Asian

countries, has also been described as a ‘productivist’ welfare state, as policies concerning economic development have been prioritised over those concerning the people’s social rights (Holliday 2000). Under such circumstances, although both PA and CRPD have been officially endorsed, PA is still implemented based on an ideology of selectivism and family responsibility. For example, we found that some participants in this study were supported by a live-in migrant care worker instead of a personal assistant due to unaffordable co-payments for personal assistance services, limited PA hours, and/or unavailability of a personal assistant who could meet the participant’s intensive or unique needs. It’s worth noting that not only are live-in migrant care workers for disabled people in Taiwan fully paid by their families, but also hiring them precludes eligibility for government social services (for details see Chou et al. 2008; Chou et al. 2015). Some disabled people in this study who used both PA and homecare instead of a migrant worker still needed the help of others to remain living in the community instead of an institution.

Global influences like the independent living movement in Western and Japanese societies have had widespread impact, and the establishment of New Vitality has been a landmark of the independent living movement and PA in Taiwan. Unlike previous disability movements, which were managed by parents or professionals, New Vitality is identified as a DPO, and its programs are organized and managed by disabled people. However, PA development in Taiwan is greatly affected by political and cultural issues. Unlike older people within the general population, disabled people remain largely under the radar of politicians and mass media. This study suggests that the

meagre funding and the lack of a qualified and sufficient labour force for PA result from such neglect. Culturally, the ideology of the charity paradigm still shapes public understanding of care for disabled people in Taiwan (Chang and Wang 2016). Yet the well-being and dignity of disabled people should not rely only on non-disabled individuals' good deeds. Failure to recognize the rights of disabled people to equal citizenship as a societal rather than familial or personal responsibility, making their welfare largely dependent on charitable acts, largely excuses the authorities from assuming responsibility for the welfare of this segment of the population (Mor 2006).

So far, PA in Taiwan is only an innovation with limited reach that has brought about no real change, such as a policy mandating the movement of money from institutional to community/home-based services. Thus it must be acknowledged that deinstitutionalization has not been incorporated in Taiwanese disability policy, and institutional care is still preferred by the government, professionals and parents (Chou and Schalock 2007; Chou 2017). Unlike PA policies in many Western societies that prioritise the autonomy of disabled people, Taiwan still favours a top-down care model in which PA users are recipients of a dole of personal assistant services with no control over what, when, how and how much support may be provided. Moreover, applicants for PA are required to go through a complex eligibility process that includes a needs assessment based on ADL and IADL criteria, disabled peers' evaluation of the applicant's need, and an Independent Living Plan by the applicant, which makes applying for PA more difficult than applying for homecare. Thus, although PA should be grounded on a social model, its practice in Taiwan is based primarily

on a medical model under the authority of professionals.

Conclusions and implications

Since 2012 in Taiwan, as in several Western societies (Leece and Peace 2010), disabled people are entitled to use PA, which this study found they prefer to homecare as it is more flexible in terms of time and tasks and so can be tailored to the actual needs of individual disabled people. However, the PA model in Taiwan is based not on disabled people's but on the government's and providers' control and is often misunderstood by the staff working in the local authorities, who also generally subscribe to an interpretation of independent living as self-reliance. Thus, PA is not administered as an alternative to homecare but rather as supplemental to or an out-door version of homecare. Meanwhile, the lack of public funding and policies that fail to support the core principle of independent living are the main barriers to effect implementation of PA in Taiwan.

By situating the cultural significance of PA in an East Asian context, the present study extends scholarly understanding of independent living outside a Western setting. While PA is understood as an effective measure for overcoming social barriers and achieving independent living in Western societies, it is lost in translation in East Asian settings such as Taiwan in which independent living is culturally misinterpreted as self-reliance and PA is not considered as a social right but as another charitable provision of a welfare system designed for administrative efficiency rather than disabled people's quality of life. Our research has demonstrated that the empowering

potential of a social model of disability can be fully realized only when cultural barriers and reductive societal values are acknowledged and tackled. Further research on independent living as a social movement can benefit from focusing on various political-geographical locations and sociocultural beliefs in order to reshape the cultural landscape of PA at a time of rapid global change.

Based on the findings of this study, we suggest, first, that in order to meet disabled people's needs in Taiwan and promote the spirit of independent living, as indicated in Article 19 of CRPD, authority and funding should be transferred from institutional care to community/home-based services. Second, the disabled people in this study preferred PA to homecare, suggesting that expansion of PA in its own right rather than as an addition to homecare is necessary to meet disabled people's needs. For example, the user should determine where, when and how PA is provided. Third, PA and homecare could be integrated into a single program offering disabled people the opportunity to plan their own service programs choosing among the offerings of both. Fourth, cross-national comparisons of the implementation of PA and how independent living is recognised in different societies, both within and outside East Asia, are warranted.

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Yueh-Ching Chou designed the study, collected and analyzed the data and wrote the paper; Bowei Chen and Teppo Kröger assisted in discussion and revising the paper.

Disclosure statement

No potential conflict of interest was reported by the authors.

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