Personal assistance (PA) as an innovation in Taiwan: features, barriers and service user participation

Abstract

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Background: In Taiwan personal assistance (PA) was launched by a three-year (2008-2010) pilot program run by a disabled people's organization, New Vitality Independent Living Association, Taipei (NVILAT). NVILAT had been established in 2007 following the independent living (IL) movement, being the first IL organization of disabled people in Taiwan. The pilot resulted in a law and, since 2012, disabled people have been entitled to receive PA from their local authority. Taipei city was the first local authority to provide PA, making an outsourcing contract with the NVILAT in 2012. However, up to date, PA has not yet been widely used by disabled people. Neither central nor local authorities recognize PA as an alternative to home help (HH) services. This study aims to explore current features of the PA system and barriers for using PA and also to compare HH service and PA from the user participation perspective and the local authority.

Method: Except secondary data from related documents, an in-depth interview was employed: 32 disabled people and 12 governmental officials representing 10 local authorities participated in our interviews between September 2015 and June 2017.

Results: Like in Western societies, we found that disabled people in Taiwan prefer PA to HH services. Relationships with family have also been promoted after the use of PA. The barriers to use PA include: 1) needs cannot be met due to limits hour and high co-payments; 2) PA being not seen as an alternative to HH services, resulting in a lack awareness of the notion of IL and PA and in limited resources allocated to PA by the authorities; 3) the entitlement to use PA being based on the 'level of disability' instead of needs. Those disabled people who could not use PA therefore hire live-in migrant care workers instead.

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Conclusions: In comparison with HH, PA has not been recognised as an alternative to support disabled people living independently. PA in Taiwan is still based on professional domination and 'care model' instead of IL thinking or the social model of disability.

Keywords: independent living, personal assistance, home help, Taiwan

Introduction

Personal assistance (PA) has been seen as the achievement of independent living (IL) movement in the 1960s originated in the US and continuing globally (Gibson et al., 2009). Following, PA is stated as a community-based service to support disabled people's independent living and inclusion in the society on equal terms, ensuing the Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD). Different from the traditional social services that are more likely to be medicalised and professionally dominated, the main principle of PA is to enhance disabled people's self-determination (Brennan et al., 2016; Christensen & Pilling, 2014). Direct payments have become the most common managed model (Askheim, 2005; Christensen, 2009; Graham, 2015).

In Taiwan, personal assistance (PA) for disabled people was launched for the first time as a three-year pilot project (2008-2010) by a disabled people organization (DPO), New Vitality Independent Living Association Taipei (NVILAT), in which the organisers and members are mostly with mobility impairment. The NVILAT is the first established independent living centre (ILC) for disabled people. Taipei City Government was the first local authority to purchase such services in Taiwan and it made an outsourcing contract with the NVILAT in 2012 after Independent Living Supportive Services (ILSS) was included in the Amended Disability Act in 2011. It needs to be noted that, unlike in Western societies, the PA project comes with other supportive services (e.g., Peer Support Service) and is therefore included in the package of the ILSS. Instead of using the term PA, the ILSS package is funded mostly by the central government by lottery funds, which are since 2012 distributed to social welfare projects for disabled people and implemented by local authorities. The establishment of the NVILAT has been a landmark of IL movement in Taiwan; unlike previous disability movements, this organization and movement were organized and managed by disabled people as a DPO, instead of being run by parents or professionals as a non-profit/non-governmental organization/NGO. However, with regard to ILSS, currently there are not so many disabled people who use PA because of the limited and unstable budget of ILSS. Generally, such ILSS are not well known by disabled people; additionally, ILSS are not recognised by the government or by the majority of NGOs in Taiwan. It is a result from deinstitutionalization not having been incorporated in Taiwanese disability policy and from institutional care still being preferred by the government, professionals and the parents (Chou & Schalock, 2007).

This study aims to explore the experiences of those disabled people, who are involved in the independent living movement (some of them having used PA) and the local authorities that are responsible for the ILSS project. The research team of this study includes disabled people from the NVILAT, the researchers and a research assistant. Except secondary data from related documents, open-ended interview guides were developed by the research team to collect primary data from 32 disabled people and 12 staff from 10 local authorities between September 2015 and June 2017.

Independent living movement in Taiwan

Influenced by the independent living movement in Western societies, the independent living (IL) movement, opposing institutional care, was launched in 2001 to advocate for people with intellectual disability (ID) to have rights to choose where to live and whom to live with (Chou, 2002; Chou et al., 2001). The result of the movement has caused a new policy, named as ‘community living’, in which living with less than seven housemates/flatmates could since 2004 be sponsored by the central government in Taiwan (Chou & Schalock, 2007; Chou et al., 2011). The project was named as Community living and living independently (IL). However, the IL movement for people with ID was initiated by professionals and researchers instead of disabled people. For example, in 2007 Taiwan Community Living Consortium was initiated for supporting people with disability living in the community in order to initiate residential services that would be an alternative to the institutional model. Different from NVILAT, the majority of board members are professionals who are organisers or employees of other NGOs.

In Taiwan some organisations are also organized by disabled people (11 NGOs working for disabled people where >51% of Board members are PWD) but IL had not been recognized or used by these orgnisations until NVILAT was established in 2007. NVILAT not only adopts the term IL as its name and commitment, but also insists that its management and membership have to be determined by disabled people across different types of disabilities. For instance, over 51% of all board members including the staff of NVILAT are disabled people. Up to date, there are nine IL Associations/Centers, like NVILAT, that have been established in nine local authorities (i.e. metropolitans/cities/counties; there are 20 local authorities in total in Taiwan) because of the effort of NVILAT. In general, all the initiators of IL Association/Centres in local authorities are disabled people who have support needs for their daily life. Since PA service was first initiated by NVILAT in Taipei City in 2008, PA service together with peer support service has by 2016 been made available and funded by all 20 local authorities. In total, however, in 2016, PA services had only 285 users in Taiwan, which makes only 0.025% of the whole population with a disability (Ping-An Social Welfare Foundation, 2016).

Personal assistance established in Taiwan

Taiwan has a population of 23 million people and around 1,157,000 persons have been diagnosed to have a disability (5% of the population). The recipients of welfare disability benefits in Taiwan must go through official registration based on a needs assessment, which is based on the ICF since 2012 (before 2012, the assessment was based on a medical diagnosis of the individual’s physical or mental impairment, given by a physician; Chou & Kröger, 2017).

Instead of ‘personal assistance’, the term ‘personal assistant’ has been used since the beginning of the pilot project that was implemented by NVILAT in 2008. As described above, following the PA pilot project, the ILSS was in 2011 added in the article 50 of the Disability Act. According to the Regulation of Personal Care Services for People with Disabilities, a person applying for the PA service needs to come with the peer disabled person’s support, namely ‘peer support service’, and an Independent Living Plan (ILP), which is proposed under the supervision of the peer disabled person. Migrant care workers cannot be recruited as personal assistants, based on the above regulation. Furthermore, the user cannot use more than one PA at the same time.

According to NVILAT, the innovator of PA project in Taiwan, the definition of PA services means that the services provided by the PA need to be arranged by the association that makes the contract with the local authority and that is in charge as a broker between the users and the PA. Only those who have completed certain training courses and obtained a license of being a care worker (e.g., home-based, daycare or institutional care worker) or a personal assistant can become PAs. The recruitment interview and pre-service training for PA are provided by the association that has made the outsourcing contract with the local authority.

Not only DPOs can be providers in charge of ILSS. Instead, all organisations working with disabled people or older people are eligible to be providers of ILSS, according to the Regulation of Personal Care Services (RPCS). Currently, the ILSS have been mostly funded by central government and outsourced to local NGOs by the local authorities. So far, only one of 23 providers of the ILSS in the local authorities is a DPO (i.e., NVILAT). Mostly the users of PA are those with mobility impairment and a considerable number are with mental difficulty, learning difficulty, vision and hearing impairment, rare disease, multiple disabilities or autism (Ping-An Social Welfare Foundation, 2016).

Based on NVILAT (2010), the services provided by the PA are to be viewed as the disabled person's 'hands and legs', meaning that the services provided by the PA are to be based on what the users expect to do, both indoors and outdoors (NVILAT, 2010). The payment for PA is based on family income: free of charge for individuals coming from a low-income family, subsidized by 90% and 70% by the government for individuals from near low-income families and ordinary families respectively.

In particular, Chun-Chieh Lin[5] is the pioneer of the Taiwan IL movement and one of the main founders of NVILAT after she came back from IL training in Japan in 2006. She was also the first person to employ a PA in the pilot project before the ILSS was endorsed in the Disability Act. It can be said that the PA model in Taiwan, established by NVILAT, has been adopted from Japan because of the impact of Lin's journey to Japan (Lin, 2012).

However, there is a lack of studies that focus on both users and local authorities of PA service in Asian countries, including Taiwan.

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[5] Lin is with osteogenesis imperfect (OI) and uses wheelchair (for her information, see http://www.normanet.ne.jp/~duskin/english/alumni-news/no06/person5/index.html)

Contest or compromise between personal assistance, home help and hiring a migrant care worker

In Taiwan, the percentage of individuals aged 65 and over is expected to rise to 20.4 per cent by 2026 and 37.0 per cent by 2051 (National Development Council, Taiwan 2012). Long-term care (LTC) policies and services have become one of the priorities of the current government to meet the increasing need for LTC. All disabled people are included in the current '10 Year Long-term Care Plan 2.0' since June of 2017. Home help (HH) is one of three primary care services (including daycare and family foster care) funded by the LTC scheme. On the other hand, families with a relative needing regular assistance are since 1992 eligible to hire a live-in migrant care worker through an application and assessment from the public sector. However, hiring a live-in migrant care worker is market-driven, despite its state regulation, as the families pay the full cost. And receipt of the qualification to hire a migrant carer nullifies eligibility for all formal care services (for details, see Chou et al., 2015).

Traditionally Taiwanese authorities provide institutional care services and most of the disability welfare budget is used for institutional care instead of community or home-based services. For example, deinstitutionalization has not been taken into account by the current disability welfare policy (Chou & Schalock, 2007).

Home and community based services for supporting disabled people living in the community include HH and daycare services. HH services are used (only) at home, providing assistance for example for bathing, eating, dressing, moving, cleaning and use of medicine. Originally these services were developed for frail older people to avoid using institutional care and they are considered as a main part of long-term care services in the current Taiwan long-term care scheme. The applicants of HH services also need to go through the needs assessment where Activities of Daily Living (ADL) and Instrumental Activities of Daily Life (IADL) are used as tools of the assessment. Additionally, several studies claim that HH services are available only for those with relatively minor care needs, as the intensity and flexibility of these services are limited and the family needs to co-pay for the services (Lin & Chiou, 2004; Huang et al., 2006; Chen & Wu, 2008). For example, people with profound/severe disability are only subsidized for 90 hours of HH services a month and those users who are not from a low-income family still need to co-pay. The users need to self pay 100% for those HH hours that go beyond 90 hours a month. There are two consequences from such LTC policies: 1) hiring a live-in migrant worker is cheaper than the use of institutional care and HH; 2) living in an institution that are free of charge is the only option for those users who are from a poor family.

Research questions

The research questions of this study are: (1) What are disabled persons' experiences of the use of PA and HH services? (2) Why do disabled people hire a migrant care worker instead of using PA or HH services? (3) How do the staff working for Independent Living Support Services (ILSS) in the local authority explain Independent Living for disabled people? (4) How is PA applied in the local authority?

Methods

In order to explore the current features and practices of the PA project and barriers for its use, we interviewed disabled people and those governmental officials who are working for the PA project in the local authority. In addition, we collected and analyzed the documents, laws and regulations and statistical data which are in relation to independent living or the personal assistance project from both governmental and non-governmental sectors including from the NVILAT.

Participants

As mentioned as above, NVILAT has played a very important role in the innovation of the PA service and also in the IL movement in Taiwan. Disabled people for the study were mostly recruited through the NVILAT, including people who have taken part in disability/IL movement around Taiwan. In total, 32 disabled people were invited and completed our interviews between September, 2015 and May, 2017. All of these disabled people had a mobility impairment because of: cerebral palsy/CP; Osteogenesis Imperfecta/OI; muscular dystrophy/MD/肌肉萎縮; Scoliosis/肌椎側彎; poliomyelitis/polio; congenital malformation/先天畸形, spinal core injury, rheumatoid arthritis(類風溼性關節炎) and difficulty for balance. All of them were interviewed personally and responded by their own; during the interview four of them (with CP) had used IPAD as assistive equipment and/or received assistance from their personal assistants or their friends who understood their language. The interviews lasted between 100 and 180 minutes. The age of the participants ranged from 23 to 56 years; 19 of the participants were women and 13 were men. Among these participants, 13 were employed (mostly working at disability NGOs) or self-employed, 7 were doing casual work (selling chewing gum and selling in vending), 4 could not be employed because of disability (see Table 1). Eight of them did not use any services during the time they were interviewed, four were using PA only, 13 were using both PA and HH services, two were using HCS only, five received assistance from a migrant care worker. Sixteen were living with family, five were living with friends with disability and one was living with a migrant care worker, eight were living alone. Nine out of all participants (28%) had previously lived in an institution (see Table 1).

There are 20 local authorities in Taiwan: 6 metropolitan cities, 3 cities and 11 counties. In this study, 12 governmental officials who are responsible for the PA project and representative 10 local authorities were involved in our interview. Three of them are male and nine are female; five are the heads of the disability section of the LA, two are line managers of the PA project and another five are front line social workers/supervisors. They were interviewed between November, 2015 and June, 2017 and each interview lasted for one to two hours.

Data collection

We conducted face-to-face interviews with 27 disabled people and 3 staff working in the local authorities; the rest of the participants were interviewed by skype to the participants' convenience. The interviews took place in the participants' accommodation or service centers for disabled people and at the work place for the staff. The disabled people were interviewed by the interview team that was organized by the principal investigator (PI) of this study, a member of NVILAT and the part-time research assistant. The staff were interviewed by the PI or the part-time research assistant. Interview guides for the disabled people and local authorities were developed respectively by the research team of this study, led by disabled people from the NVILAT. For the disabled people, the semi-structured questions focused especially on their own experiences of IL and the assistance that they have received for IL including HH and assistance from personal assistant or migrant care worker. For the staff representing local authorities, the open-ended questions included their indications of IL and PA and the comparison between HH and PA in practice in their local authority. All the participants' brief background data (e.g. age, sex, marital status, education, and etc.) were also collected, as shown in Table 1 and Table 2.

Before each interview began, participants were told that confidentiality would be respected and that identities would not be revealed. An informed consent form was signed by all participants and they also gave their permission to have the interviews audiotaped. Each participant was also told that the interview would be transcribed and that the transcript would be mailed to her/him for checking whether it was in accordance with what s/he had said in the interview. Three of the participants with disabilities were not able to read, so the research assistant of this study read their transcripts to her/him word by word to have her/his confirmation or revision. The transcripts that were used in data analyses were the revised versions, which the participants had confirmed and revised. In this paper, names have been changed into pseudo names and the type of impairment is not indicated individually in order to protect the participants' anonymity. The current study has been approved by the Research Ethical Board of the National Yang-Ming University (approval number: YM103098F).

Analysis

The analysis of this study consists of two parts. Among the disabled people, the analytic strategy in this study was to examine each transcript in relation to the extent of personal assistance that they have used and experienced. The analysis for the staff from local authorities focused on (a) how the local authority responds to the supportive service needs of disabled people to live independently; (b) how the local authority identifies the meaning of PA and HH services; and (c) how the PA project is managed and delivered by the local authority.

The analysis process for this study was as follows. First, the transcripts were read three times, after which the original transcripts were edited by cutting out conversations or words not related to research questions of this study. Second, the transcripts were reviewed at length 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. Themes that did not have broad support in successive readings of the transcripts were removed. Once this initial independent analysis was concluded, the findings were brought together for comparison and additional analysis. The remaining suggested themes were evaluated again to determine whether there was sufficient evidence to warrant their inclusion. Themes were retained only if they were able to commit consensus to the validity.

Findings from disabled persons

Prefer PA to HH

Thirteen participants have used both PA and HH and they all prefer PA to HH. One of the key reasons is that HH are not available in the evening time, on Sundays and during holidays. Furthermore, the home helper only does what she/he has been instructed to do by the provider in advance. As well, assistance from HH is limited to the user's home.

> *"I have been assessed to use 90 hours of HH a month, but I only use 20 to 30 hours a month. I am working during daytime; you cannot use HH out of home, evening time and during weekend. ...HH is difficult to meet my needs."* (FS, A1, M, 25, W/MD)

In addition to the above-mentioned limitations, the shortage of home helpers is another problem. For example, YW (P15, F, 50, having support needs in getting up, toileting etc.) has been assessed to receive HH 72 hours a month, but there is no home helper coming to her.

YW (P15, F, 50, w/MD) has shared the differences between HH and PA: *"Home helper treats the person receiving support as a care target who only has needs such as toileting, eating, dressing for maintaining basic living. ...Except these basic living needs, I want to be with my friends, go for conference, and etc. Different from PA, home helper does not provide such support. ...For example, PA sometimes accompanies me going out for shopping or for recreation. ...My first time taking the MRT was when I was escorted by PA."*

YY (A9, M, 30, w/MD, a doctoral student, stayed at the dormitory at the campus, living with family during weekend) uses both PA and HH. The home helper comes to his accommodation in the campus to help him for bathing, cleaning and doing physical exercise for two hours three days a week. He uses PA when he goes out or when his father is not home for job duty in order to reduce his mother's caregiving work. He shared that PA is more flexible in this regard.

YL (A10, F, 33, w/MD, counselor for the students at the university) uses PA in the workplace to perform those tasks which she cannot do herself, such as hanging something and managing the venue of activities.

All in all, from the users' perspective, HH cannot meet their needs; in contrast, PA is more flexible in timing arrangements and service tasks, which makes it more likely that the needs of the users are encountered.

Using PA gives me future hope and promotes my relationship with my family

The users of PA in this study were mostly introduced from NVILAT and they have been involved in the independent living movement or activities through the contact with NVILAT. Such contact and the use of PA has caused the participants to raise hope in future life and even to promote their relationship with family.

YL (A10, F, 30+, w/MD) shared: *"Before, I had planned that I would work hard in order to have enough savings that I could afford to live in a nursing home when I am old. ... Now I know about IL, I just notice that I could have my own life if I have a PA to help. ... Now I have hope in the future."*

WL (A11, F, 56, living alone) has used HH for four years, four hours a week, and has just currently started to use PA, 30 hours a month. The home helper helps her for cleaning, laundry and the PA goes out with her for swimming or doing something at home that the HH is not allowed to support. She shared: *"Earlier when I do not have a PA, I need to ask for my friends' help for those tasks that now the PA supports for me. ... When my friends gave me a hand, then I needed to treat them back, such as buying them a meal. Now when I get the PA for such help, I do not feel I owe somebody for giving me a favor. ...Earlier my sister, who already passed away, did not like me because she felt that I would be her caring burden. If I could have had a PA at that time, my relations with my sister might have been better."*

LY (A8, M, 35+, w/ CP; a PA and colleagues from NVILAT helped for oral translation during the interview) shared with us: *"Now I live in a rented flat; I use HH and PA services. ... I can arrange my life and I make a living myself. ... I do not need to count on my family; my mother and my siblings are therefore more independent too."*

CC (P7, F, 25+; she and her sister with MD) gave an impressive conversation with us:

> *"Since I have a PA coming to help me for bathing, my autonomy has been promoted and the relation between me and my mother has been improved too. …Taking a bath, I like to use soap more than gel. Before, when my mother helped me for bathing, I felt shy to tell her what I want because I felt I already owe her too much… In the past years she used the ways she likes instead of the ways I like… Now when we have a PA to help us (also her sister), my mother finally has some time for herself. Earlier, if we went out for a restaurant, my mother needed to help me and my sister for bathing for two hours and, once we were ready for going out, she was extremely tired and we also felt guilty. The meal time was just totally destroyed. Now, when we go out together, our PAs come to help us for bathing, and my mother can have time for herself for dressing up. She came to ask me how her dress looked like while the PA was helping me to have a bath. I could not help but cry, because that was the first time in 27 years when I saw my mother to have the time for herself to dress up… Then we really did enjoy our meal time together. So now our relationship is just like a normal one between a mother and a daughter."* (CC, P7, F, 25+, w/MD)

CC continued sharing with us: *"... Previously when I went to a bookstore, I needed to have my friend going with me to help me get the book. I always felt shy to bother my friends who may be busy or may not be interested in reading. Now I go with the PA and I feel more relaxed. ...The PA can help in many things, such as in going out for meal, having cash from the ATM, or paying bills with credit card. For family relationships, you do not want your family to know how much money you have in the account. ..."* (CC, P7, F, 29, w/MD)

My needs cannot be met due to the hour limit and high co-payment of PA

Limited PA hours. Almost all disabled people who have used PA and who were interviewed replied that their needs could not be met because of the limited hours of using PA. The participants in this study did not feel that they live with dignity or that they could live independently.

CL/P11 (CL, P11, M, 40+, w/ CP, using IPAD and translators during the interview) said that he always worries that there is no PA or HH coming for assistance, in particular during the holidays. Additionally, because of the hour limit of PA and HH services, he always needs to ask for favors from friends. For 80% of his daily life, he needs to count on other people: his PA, HH and friends whether they are happy to give him a hand. For CL/P11(M, 40+, w/CP), the limit of PA is 60 hours a month, but he needs at least 85 hours a month. Thus he needs to pay fully those 25 hours of overuse. In order to save the cost for PA, CL/P11 only changes a nappy twice a day, one in the morning by the HH and another in the evening by the PA. He said that if he wanted to live with dignity, he would need to have 24 hours support services from PA.

LY (A8, M, 35+, w/CP, with assistance for conversation) needs to have support for 10 hours a day for bathing, toileting and eating, shopping; but now he is allowed to have only 4 hours for PA and 2 hours for HH per day. The home helper comes to help him to get up from bed and for cleaning in the morning; and the PA comes for assistance in the evening. He is not allowed to have more PA hours for going shopping. He replied that his life quality is only half of people in general in the society because of the shortage of such supportive services.

LC (P10, M, 50+, w/polio) uses a special wheelchair that needs to have more space for moving. Now he lives in a rented flat by himself and uses both PA and HH. Previously, due to the difficulty for renting a flat, he had to live in an institution where he stayed for 5 years after his parents passed away. He could not find a job in the labor market thus he counts on social assistance, which pays for his rent and daily life costs. He does not need to pay for the cost for the use of PA and HH due to his low income position. However, the support services from the PA and HH could not meet his needs to have a good quality of life due to the hour limit for PA service and the inflexibility of HH. He shared:

> *"I do not feel I am treated equally. For example, you can take a shower or a bath everyday, but I cannot. Because I do not have a home helper coming to help me for bathing on Sunday. The home helper helps me for bathing, cleaning and doing laundry from Monday to Saturday, one hour or two hours a day. In total I use HH for 44 hours a month. ...Now I use 60 hours of PA, it means one day two hours; I cannot use PA for bathing otherwise I will overuse. If I overuse*

> *PA, I need to pay the full cost. To meet my needs, I need to have at least 80 hours of PA a month."* (LC, P10, M, 50+, w/polio)

SYC (P19, M, 30+, w/CP) moved to a rented flat from an institution where he had stayed for 20 years. He evaluated to be living only half-independently because he could not get help from HH for bathing everyday, like CC/P7's experience.

CS (P6, F, 25+, w/MD) has a paid job, lives with family and receives support from both PA and HH. She, too, shared that she feels her life is only half-independent due to the shortage of support services: *"... The limited resources cannot meet my needs, therefore my life still counts on people like my mother and my colleagues. ...They have no duty to do so and I also feel I owe them giving me a favor. ...It makes me feel I lose my life autonomy."*

Some disabled people would like to live independently with the assistance from a PA rather to stay with family, but they could not have such a choice due to the hour limitation of PA. LZ (P3, M. 20+, w/CP) shared: *"I cannot move out to live alone. I worry the hours of PA would not be supportive enough to meet my needs."* (LZ, P3, M. 20+, w/CP)

Some participants of this study were not using PA when they were interviewed; instead, they receive assistance from a live-in migrant care worker. CR (P13, F, 31, w/MD) had received assistance from PA earlier and her family had just hired a live-in migrant care worker for her. She shared that support from PA is her first preference but the hour limit of PA cannot meet her needs. YW (P15, F, 50, w/MD) had used PA in the past years and now she needs many more hours for support in her daily life. Owing to the high cost of having over hours PA support, just currently she has hired a migrant care worker. For the same reason, the hour limit of PA, CCH (P14, M, 33, with SMA), who knows about the spirit of PA system and also the IL movement in both Western society and Taiwan very well, shared that his family had to hire a live-in migrant care worker for him as he needs to have support for 24 hours.

> *"I need to have special care that is only possible for a person who has known me for a while. ...My mother had quitted her job in order to take care for me full-timely for the past years including my university life. Now she is getting old. ...I do not think HH and PA services could be an alternative. ..."* (CCH, P14, M, 30+, w/MD)

CCH (P16, F, 25+, w/Rheumatoid arthritis) only used PA and she shared that the limited hours of PA makes her life controlled. For example, she could not have recreation time with her friends in the evening because the PA cannot work late. She also hopes that she could have an hour extra help in the evening when she is in menstrual period.

CC (P7, F, 25+, w/MD) currently receives the maximum hours of PA assistance, 60 hours a month (i.e., 2 hours a day). She shared that having a PA's help for going out is very important for her. But now when the PA helps her for bathing, toileting and eating, there are no hours left so that the PA could help her for going out.

Many disabled people who use support services shared that they always need to worry whether the HH or PA will actually come as cancellations are usual due to the shortage of both HH and PA. For example, CFK (P20, M, 30+, w/CP) shared: *"The hour limit of support from HH and PA is one thing, for me, but what I worry most is whether the home helper and PA will come as expected. …One time the home helper went travelling for five days, and neither the provider of HH nor PA could not find substitutes. Then my life was totally disordered."*

PA Unaffordable co-payment. Like in HH, also the users of PA who are not from a low-income family need to co-pay 30% of the cost or, for the overhours, 100%. Such regular and monthly cost for using PA, in addition to HH, increases the regular cost for the users; therefore, such cost becomes a major financial worry for the users. For example, LY (A8, M, 35+, w/CP) uses both PA and HH and needs to co-pay 30% for both support services, costing him 160 Euros per month. CL (P11, M, 40+, w/CP) uses 90 hours of HH, the maximum hours for users who are assessed with profound disability. He needs to pay 30% of the cost and he also needs to pay the cost for PA including the overhours use. In total, he needs to pay around 200 Euros every month, which is one third of the minimum income of people in Taiwan. YW (P15, F, 50+, w/MD) could not get assistance from HH due to the shortage of HH workers; and she received assistance from PA only for 180 hours a month even when she would need to have 270 hours to maintain a good quality of life. It means that she had paid for 30% of the 60 hours and 100% of the extra 120 hours, sometimes even more hours for urgent needs. The support from PA for her daily life cost her almost 1000 Euros a month when she was interviewed.

Consequently, disabled people like CL/P11 and YW/P15 who cannot afford such high cost for having support services have only two choices: move to an institution where you do not need to pay so much, or hire a live-in migrant care worker who costs you less than the cost for PA service. CL/P11 moved out from the institution three years ago to the flat where he pays rent. He said that his current life quality is not good but the quality of life in the institution was even worse. YW/P15, as discussed above, hired a migrant care worker after the interview in this study.

As well, some other participants (YC/A2, CM/A12, LK/P2, CR/P13, CCH/P14) of this study now hire a migrant care worker because of the hour limit and the high co-payment of PA support.

Findings from local authorities

We interviewed 12 staff working for the ILSS project representative 10 local authorities and found that the thought and explanations of IL and PA, which are embedded in the ILSS as an innovative service, have not been fully understood. In particular, they are mixed with the HH service.

No clear idea about the notion of IL and PA

In this study we found that all the staff who were interviewed had no clear understanding of the meaning and definition of ILSS. The concept of PA was generally confused with the meaning of HH.

> *"For ILSS, we are working for it but we have no idea what ILSS are about. ...We get it confused with home help. ...We do not know much about the spirit and implications of IL. ...If we ask disabled persons to have their ILP before they have PA service; and the disabled persons are against such request or their family refuse to do so. ....It is difficult for disabled people and the family to follow why they need to have ILP."* (G6-2).

> *"I am not so sure my idea about ILSS is correct. ...We need to have more discussion and experiences."* (G5).

> *"I do not know much about the concept of ILSS. ...It looks like a kind of out-door home help. ...I wonder different person in my position would have the same explanation. ...Central government has no idea either and they have not*

> *given a clear definition of it. ...It was established by the disabled group and then we are required to do so. ...Many people working at the local authorities have misused it (ILSS).”* (G9).

> *“ILSS came very suddenly, the central government gave an order and then we need to follow. ...The biggest difficulty is that we have no idea what is the level of ILSS that would meet disabled people’s needs.”* (G8-1).

Lack of awareness of IL. The staff (G1, G4 and G5) shared that the public, the provider and also disabled people do not understand the meaning of IL and that this condition becomes a barrier for ILSS in practice.

> *“For Taiwanese people, IL is a new concept. ...Traditionally disabled people stay at home because they have difficulty to go out. ...But the concept of IL breaks through such old thinking of disability, instead, it is based on citizenship rights. ...Disabled people as general people can participate in activities in the community. ...It is a good movement, but the public, even disabled people, still have such a traditional idea. This becomes the barrier for us in practice.”* (G4)

Based on the law, social services are funded by the public sector and the local authority is in charge of responsibility to offer such services. However, providers of social services are almost fully non-governmental organisations, which make a contract with the local authority; ILSS, like HH, is not exception from this rule.

Myth and misuse of PA

The following conversations were quoted from the staff who were interviewed in this study. The information shows how the notions of IL, PA, peer support and ILP have been used in practice by the government in Taiwan. It suggests that Taiwan is an example for how IL and PA have been operated in East Asian societies.

> *“...One disabled person with a profound impairment needs to have his nappy changed at his workplace at noon time. ...A home helper cannot go to help (due to the regulation). Such kind of employment need meets with the conception of IL; thus this person is fine to use PA service. ... If the disabled person needs a companion in order to go out for meeting with her/his friends or for school,*

she/he is also eligible to use PA. In contrast, a disabled person who has got a stroke for years; if he applies for PA to be his companion for physical rehabilitation three to five times a week. I do not think such need meets the notion of IL. This is for long-term medical care need instead of acute need; instead he should apply for home help." (G9)

"His ILP is not progressive enough and not so much different from his previous life, …we cannot see he is planning to learn something new." (G4).

"If you (disabled person) want to apply for PA, you need to have peer support service first. If you want to have peer support services, it is not necessary to have PA first. …We have a budget shortage, thus we need to discuss with the disabled persons who use PA to end the use and who can try to be independent by themselves." (G10).

"It seems that only those disabled people who are already independent and mean that who does not use PA any more could be the peer supporter." (G9).

"I do not think that is a good idea in our culture, which is not so honest in general, that the user chooses her/his own PA,. …It would be like the case that the same home helper has been providing services for the same user for years and the user and the home helper become good friends. They might cheat. For example, today the home helper only came to provide assistance for one hour, but the user might sign that the home helper came for three hours." (G9)

"There is an argument case whether the PA is allowed to take care of the disabled person's family. For example, she asked the PA who took her kid to see the medical doctor. ...It sounds a bit strange. ...Our services are for disabled people and all our in-service trainings are related to the extent what the disabled persons need. ...But the disabled user said that she applied for PA service to help her to deal with life difficulties, e.g., her kid is sick and needs to visit the doctor." (G8-1)

> *"If the PA also provides domestic services, then it does not meet the spirit of the IL project."* (G8-2).

Who are eligible to use ILSS? The misuse of IL and PA is related to the eligibility for PA.

> *"... when we go for the nation-wide symposium for the local authorities, you would find that the definitions of the ILSS are different between different local authorities. ...For example, whether the ILSS are only eligible for people with severe impairment, whether only those who have received peer support services and had a ILP are eligible to use PA."* (G6-1)

> *"The central government regulates the eligibility for the use of ILSS, which is only available for those disabled people with severe impairment. Therefore, for us, the candidates of the users of PA are only those who have a disability certificate and they also need to apply for the use of home help."* (G10)

Assessment tool cannot meet the disabled people's needs. The staff interviewed also responded that the current tools of assessment, i.e., ADL and IADL, cannot meet the spirit of IL (e.g., G1). The staff also pointed out that the use of ADL as a tool for assessment would limit the users of PA to only those disabled people who have a physical/mobility impairment of a high level. People with vision impairment or mental difficulty would be excluded (e.g., G9, G10). In the majority of the local authorities, the users of PA are limited to people with mobility impairment (e.g., G2, G4, G5, G6, G8, G9, G10). However, when the central government now requests local authorities to use the ICF as the assessment tool, a local authority (e.g., G9) mentioned a problem, discussed in a previous study by Chou and Kröger (2017), that in the current Taiwanese ICF assessment, the applicant has to tick already before the assessment what services s/he needs and applies for.

Mixed use of PA and HH

Difficulty to deal with the differences of PA and HH. Because both PA and HH are named and included as personal care services and regulated by the law, it becomes difficult to get these two clarified. PA becomes a supplemental service for

HH, or viewed as an outdoor HH or another type of HH; or these two compete with each other.

> *"The differences of PA and HH are not clarified clearly by the act".* (G1)

> *"The assessment tool for both PA and HH is the same, ADL, these two become confusing."* (G2)

> *"Usually people apply for PA because of the hour limit of HH or because of the downsides of HH (e.g., HH only can be used at home). ... PA service becomes* ***the supplemental service*** *of HH. ...Currently for the applicant of PA, the peer supporter goes to see whether the applicant has an idea about IL first and then PA is provided later. ...It means that, in order to use PA, you need to have peer support first but, in order to use peer support, you don't need to have PA."* (G5)

> *"...We have confirmed with other authorities, all are doing the same, like HH, outdoor HH as a* ***supplement*** *of the limited hours of HH. ...The serious overlapping between PA and HH is that the PA becomes the regular assistance and thus the PA becomes the outdoor of HH."* (G9)

> *"ILSS is included in the Personal Care Services* (i.e., RPCS) *and the content of services is very broad and it seems that any kind of services are fine. ...There is no clear boundary to identify which one is better for the user, HH or PA. ...We have difficulty when we communicate with the applicants. ...We are still working for the clarifications between these two, we keep discussing with the NGOs who are the providers of ILSS."* (G1)

> *"We worry that PA becomes a* ***supplemental s****ervice of HH. So the peer supporter and social worker need to go with the user and her/his PA during the process including the development of ILP, which obtains clear direction and the goal of IL. ...Hope the ILSS would not become home help services."* (G4)

> *"Home help can be PA in many local authorities …then the home helper would provide her/his assistance based on the concept of HH instead of PA. …PA views the disabled person's wants as a center; it is different from the HH in which the user follows the helper who is the center. The concepts of these two are different."* (G1)

> *"It's difficult to distinguish PA and HH. For example, the PA accompanies the disabled person for social activities, the PA also needs to provide physical help, like toileting, which is provided by the home helper."* (G8-2)

More than one local authority (e.g., G1, G3, G9) argued that the professional pre-service training of the PA is not long enough. As the PAs only receive 25 hours of service training, their service quality has been doubted.

> *"We are now confused by both ILSS and HH. …Previously, if you use HH, then you cannot use ILSS. …But now it is fine for the user to have both due to the rights issue. … Now our problem is how to clarify the differences of these two. …Some people say that ILSS are higher level than HH. But the training for a PA and the payment is lower than a home helper."* (G3)

PA service cannot be used at home. Following the unclear notion of IL and PA, a local authority explains that PA, instead of HH, is not for use for domestic services.

> *"If the applicant's ILP is only for domestic servicers, provided by a home helper, this does not fit the spirit of ILSS, e.g., using PA for social participation. …If the need of domestic help is for social participation, it is fine. It means that the need of domestic help cannot be the primary one rather than the assistance for social participation."* (G8-2)

Contest between PA and HH

A couple of local authorities use their methods to make the differences between PA and HH while disabled people apply for use.

> *"A home helper would cook for the user in her own way; but a PA would cook for the user in the user's way. ...For example, a disabled person uses both PA and HH. A home helper helps the disabled person to clean the home and helps in medication in her own way. The PA would follow the disabled person's order for doing so. ...The ways of assistance between PA and HH are somehow a bit different."* (G10)

> *"Nowadays, the PA provides those services that a home helper would not provide. ... We have defined domestic assistance to be delivered by a home helper, and the PA to provide support out of home. ...However, PA has been defined as the disabled person's hands and legs. So if the user wants to clean the toilet, the PA would do so, though such clean work is part of the home help services. ...It would be better if these two could be integrated as one package of personal care services and a personal budget given to the user who could choose either PA or HH."* (G6-1)

Training issue determined the hierarchy between PA and HH. Under the regulations, formal carers, under a licensing system, need to receive training in relation to caregiving, while in PA the disabled person is the trainer of the PA. Currently, both the PA and the disabled person who is a peer support are required to receive training that is provided by the NGOs, which are the providers of PA services and which have made a contract with the local authority.

For example, G8-1 responded that: "*Both the payment and the qualification are based on how many hours the formal carer candidate has received. For example, a home helper and a PA currently has to receive 90 hours and 25 hours respectively. So, a person who has received the training for home help can be hired as a PA, but a person who only receives the training for being a PA cannot be hired as a home helper."* (G8-1)

> *"PA only received 25 hours training, you want to promote her/his hour payment, but her/his training is not qualified."* (G1)

> *"PA has not been required to have as many hours of training as a home helper, it means that the assistance from a PA becomes not so professional. ... This also causes the PA to receive low pay."* (G3).

Difficulty for recruitment and high turnover rate for PAs. Almost all the staff who were interviewed replied that the shortage of PA and the difficulty of recruitment of PAs, including a high turnover rate, are their largest difficulties. The hourly payment for a PA is lower than a home helper. A couple of local authorities (i.e., G2 and G10) also pointed out that compared with a home helper, a PA provides all kinds of assistance according to the users' need, and thus it is not fair that the payment to PAs is so low.

Limit of budget of ILSS provided to disabled people. All in all, the primary difficulty for the implementation of the PA system in Taiwan is due to the limits of budget from the government, as discussed above. Compared with HH, which is included in the Long-term care scheme as one of the primary concerns of the prevailing government policy, ILSS or PA are even not acknowledged by the government and also not planned to be incorporated in the long-term care scheme, which is currently receiving a growing budget. As a result, the hours and the number of users of PA are therefore limited on purpose by the government.

> *"The funding from the central government is very limited, ...that causes strict hours limitation for the use of PA."* (G5)

> *"The primary problem is the limit of the budget. ...We have to discuss with disabled PA users to stop the use."* (G10).

> *"There are only 30 disabled persons who are now using ILSS. ...If the current users of ILSS continue to use, then we cannot have new users as a result from the shortage of the budget."* (G9)

Discussion

(to be continued)

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Table 1. Background characteristics of the disabled participants (N=32)

	N (%)
Sex	
Male	13(40.6)
Female	19(59.4)
Age (years old) (range between 23-56)	
20–30	11(34.4)
31–40	11(34.4)
41–50	4(12.5)
>50	6(18.8)
Type of impairment	
Cerebral palsy	12(37.5)
Scoliosis (脊椎側彎)	1(3.1)
Muscular dystrophy/MD (肌肉萎縮)	10(31.3)
Osteogenesis Imperfecta/OI (先天成骨不全)	2(6.3)
Poliomyeliti/Polio	3(9.4)
congenital malformation/CM(先天畸形)	1(3.1)
Learning/Intellectual disability/ID	1(3.1)
Spinal Core Injury (脊髓損傷)	1(3.1)
Rheumatoid arthritis/RA(類風溼性關節炎)	1(3.1)
Wheelchair use	
Yes	31(96.9)
No	1(3.1)
Work	
student	4(12.5)
Non-employed	4(12.5)
Casual work (selling chewing gum; vending)	7(21.9)
Self-employed	1(3.1)
Part-time paid work	0(0.0)
Full-time paid work	12(37.5)
Volunteered	4(12.5)
Source of assistant service	
Personal assistant (PA) only	4(12.5)
Home help (HH) only	2(6.3)
Both PA and HH	13(40.6)
Migrant care (MC)	5(15.6)
None of three (PA, HH, MC)	8(25.0)

Currently who live with	
Live With family	16(50.0)
Live with migrant care worker	1(3.1)
Live with friends with disability	5(15.6)
Live with friends without disability (e.g. dormitory)	2(6.3)
Live alone	8(25.0)
Whether previously had lived in institution	
yes	9
no	23

Table 2
Characteristics of the staff representing local authorities (n=12)

	Number
Local authority	10
Metropolitan	6
City	2
County	2
Participants	12
Sex	
Male	3
Female	9
Married status	
Married	9
Never married	3
Education	
Master	5
University	7
Working position	
Head of the disability welfare section	5
Line manager of PA	2
Social worker /supervisor(front line)	5