Caring and ageing in place together? Care and housing transition plans of older parents and their ageing offspring with intellectual disability

(Draft version)

Yueh-Ching Chou & Teppo Kröger

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Abstract

Background: Little research has been conducted about ageing in place among old parents who cohabit with their ageing offspring with intellectual disability (ID). A mixed-methods approach and the "housing pathways" framework are employed to explore which older parents would choose ageing in place together with their ageing offspring with ID instead of moving and what factors are associated with such a choice.

Methods: All old parents (≥65) cohabiting with their aging offspring with ID (≥40) were invited from two local authorities in Taiwan; 237 families completed our census survey and 60 were involved in our in-depth interviews between May 2015 and July 2016.

Results: Qualitative findings present that ageing in the old place was more popular than moving. Survey study showed that 61.6% of the parents who were interviewed would choose ageing in place with their ageing offspring with ID and another 38.4% participants would stay in the old place without their disabled children or move to the other children's home/nursing home. Logistic regression analysis reveals that the parents who prefer ageing in place together with their offspring with ID were more likely to have house ownership and as well as have higher level of satisfaction with their life and current community, and these two variables were strongly related with each other and linked with their satisfaction with their housing and community identity.

Conclusions: In order to make ageing in place together for these families, housing and living support should be considered by current policies.

Keywords: intellectual disability, ageing, ageing in place, housing pathways, older parents, Taiwan

1. Introduction

The population of adults with intellectual disability (ID) experience health inequalities compared with the general population (Cooper et al. 2004). They have an earlier age of death, shorter life expectancy and raised standardized mortality rate (Landes, 2017; Patja 2000). Subgroups such as people with Down syndrome, cerebral palsy or multiple disabilities, are likely to experience premature ageing, effectively lowering the age at which individuals may require ageing-related services (Janicki & Dalton 2000). As such, various chronological figures including 45, 50, 60 have all been used in previous research to define when an individual may be considered ageing (Bigby, 2004). In a Taiwanese study (Shu, 2012) that analyzed data from 2011, the status of having reached the period of "ageing" among people with ID was defined as 12 (men with ID) and 10 (women with ID) years earlier than among the members of the general population. On the basis of definitions of late middle-life (≧55) and old age (≧65) in the general population in Taiwan (note: the general population aged 55 and over comprises 25% of the total population in Taiwan; Department of Statistics, Ministry of Interior, 2014), adults with ID aged ≧45 and ≧55 can be defined being in late middle-life and old age, respectively. When individuals with ID are aged ≧ 45, their parents are usually aged ≧65. Thus, older people with ID and their elderly parents become older two-generation families where both generations are in old age at the same time.

Clapham (2005) has developed the concept of "housing pathways" as a way to focus study on individual biographies, decision-making, and cultural and environmental issues in older people's housing. Four issues included in the concept of "housing pathways" are: personal control, identity and self-esteem, social support and inequality. Thus, these four aspects can be the four dimensions of the decision process regarding moving or not moving. According to Clapham (2010), personal control can be defined as "feeling in control of one's housing circumstances and the process of achieving one's goals" (p. 260), and it can involve

having the ability to make appropriate choices. The meaning of home for people is linked to their individual experiences of security, positive identity and self-esteem (Clapham, 2010). Positive identity and high self-esteem are associated with a sense of an ability to cope and a sense of ownership, both of which are essential for positive outcomes in housing transitions (Clapham, 2010). Identity comprises both self identity and social identity, which is linked to class, gender, ethnicity, sexuality and health and disability (Clapham, 2002). Social support can be provided by family and close friends but also by health and social care professionals. "Inequality" can be seen as social exclusion and lack of resources that have effect on the chances to be in control of one's life and self-esteem (Clapham, 2002, 2010).

Taiwanese as well as Western studies on health, care needs, and ageing rarely pay attention to these older two-generation families, ageing adults with ID and their older parents; in particular these families, have hardly received any concern as a whole. For example, research literature and policies on long-term care (LTC), ageing/gerontology and housing have almost fully focused on older people in general; and the same goes for care research and advocacy for caregivers. All in all, ageing and housing transitions among these older individuals/families are new issues for care research, disability and housing studies as well as for health and LTC policies in Taiwan. A new LTC insurance scheme is currently under development and is planned to be issued in the near future in Taiwan. However, the NGOs that represent people with disabilities and family caregivers are now boycotting this planned version of the LTC service scheme. They argue that users with ID and their family caregivers are excluded from the current scheme. Following the traditional organization of services for older people, the current plan for the LTC Insurance scheme divides services into three areas: home-based services (e.g., home care), community services (e.g., day care) and institutional services. According to the criticism of the NGOs, these services cannot meet the needs of people with disabilities and their family caregivers (Chou, Lee, & Wang, 2018). As well, the future of

residential care services for people with ID and their family caregivers is a significant policy issue in Taiwanese society (Cheng et al., 2004; Wang, 2011). The rate of institutionalization of people with ID has recently been on the increase (Chou et al., 2007), which is in contrast with results from empirical studies that have shown that subjective and objective quality of life of people with ID is better in small group homes than in institutions (Chou et al., 2008). Still, people with ID and their family caregivers are excluded from policy making when housing choices (where to live and with whom to live) are concerned.

In Taiwan, there is no empirical data covering ageing issues and living arrangements for both ageing adults ID and their older parents as entire families. However there have been regular surveys for people aged 55+ conducted by both the Ministry of Health (MOH) and the Ministry of Interior (MOI); and since 2015 such a national survey is integrated and managed by the Ministry of Health and Welfare.

There is a gap between the related studies, policies and the subjective perspectives of about moving in old age or ageing in place, concerning the needs of these older two-generation families. In order to meet the health and social care needs including residential needs related to ageing for both the older parents and their older sons/daughters with ID, moving in old age or ageing in place and choices are a rather important issue for this group of people and families.

This study employed mixed methods to explore how the views and decision-making of ageing in place are shaped by health, care needs/disability, social and culture factors and support network among the older parents who cohabit with their ageing sons/daughters with ID.

2. Methods

A mixed methods approach and the “housing pathways” framework are employed to explore which older parents would choose ageing in place together with their ageing

offspring with ID instead of moving and what factors are associated with such a choice. Sixty old parents cohabiting with their ageing offspring with ID were involved in our in-depth interviews from two local authorities; as well, 237 two old-generations families were invited to take part in our survey study between May 2015 and July 2016. The four dimensions of "housing pathways," namely personal control, identity and self-esteem, social support and inequality, orient the data collection and analysis of this study. Ethical approval for the study was obtained from the Research Ethics Board at the National Yang-Ming University (IRB: YM103016F).

2.1. Qualitative study

As discussed above, research is lacking on ageing in place together or moving in old age among these older parents cohabiting with their ageing offspring with ID. A qualitative research design was used to gain a better understanding of the dynamics and pathways of ageing in place together among older parents and their ageing offspring with ID.

Sixty aging individuals with ID aged ≥ 40 and their older parents/families were invited to participate in our in-depth interviews (Table 1). We define people with ID to include those classified with ID by the government and through a disability certificate issued by the local authority. The participants were invited from adults with ID aged ≥ 40 and their older parents/families living in H City (urbanized city) and W County (remote areas included). In order to include participants with diverse backgrounds, the recruitment varied based on age and living areas. The PI and co-PIs were the interviewers, and all the interviews were carried out at the participants' accommodation.

The semi-structured interview questions aim to explore the participants' subjective views of moving or not moving. The interviews were tape-recorded and then transcribed for further analysis. The data from the in-depth interviews were transcribed, coded and

analyzed by the research team. Coding is the first preliminary part of the analysis process. The transcripts were coded by using pre-existing codes and open coding following an inductive process. Pre-existing codes are from the interview topics under which data are grouped. Open coding allows potential new topics and themes to appear and to be included in the analysis. After the coding process, the data were analyzed using thematic analysis. The analysis process consists of grouping coded text fragments into larger units and forming more abstract categories (derived categories), and establishing relationships between these categories. In order to preserve the broader context of the categories, the transcribed interviews were read in their entirety and individual accounts were placed in the contexts of the participants' backgrounds. While the shared characteristics of the categories were grouped through comparative analysis, the derived categories were further saturated by maximizing variations and establishing relationships (Strauss & Corbin, 1998).

<Please insert Table 1 about here>

2.2. Survey study

2.2.1. Data collection and participants

The participants in this survey study were older parents and their aging offspring with ID who co-habit in the same household, namely old two-generation families, in two local authorities, H City and W County located in northwestern and northeastern part of Taiwan respectively. H City is in general a wealthy city with a relatively younger population and better welfare system than the rest of the island. In contrast, W County is in general a remote area and has higher proportion of ageing population than other cities and counties in Taiwan. We define ageing individuals with ID to be those adults assessed by the government to have ID, including those assessed with multiple disabilities in addition to ID, aged ≥ 40 who live with their older parents in the community. All of these ageing individuals with ID and their

older parents of the two local authorities (LAs) were invited to take part in our face-to-face interview survey.

In Taiwan, disability welfare benefits are only available to those who are assessed to be with disability, approved by the local government, and provided with a disability certificate. We were not provided with any information related to where and who our study population were or where they lived; we only knew that each individual with ID aged ≥ 40 did not use residential care service, which means they lived with family. This is because the local authority is only able to provide a list of people who are assessed to be with disability, including those with ID and those with multiple disabilities (including ID).

The above limitation to the available information meant that we needed to screen the listed citizens of two LAs with ID or multiple disabilities (MD) including ID (MD + ID) aged ≥ 40 to reach our study population. This was carried out by approaching the older parents of a son or daughter identified with ID or with MD + ID aged ≥ 40, cohabiting with one of his/her parents. The screening involved making individual telephone calls to the individual with ID aged ≥ 40 living with at least one of the parents who were/was assumed to be older than 60. If the families fitted the criteria, we invited them to join our study and asked whether they would allow us to interview them at home.

Based on the government list of H City, there were 589 individuals with ID (517 with ID and 72 with multiple disabilities in addition to ID) aged ≥40 and out of them,195 fit the criteria of our study: 10 had passed away, 205 had both parents passed away, 62 used residential service, 42 did not live with parents, and 75 could not reached. In the end 161 completed our study (response rate 82.6 %) as 34 declined to participate. In W County, 795 individuals were listed and 102 met the sampling criteria (4 had passed away, 121 used residential service, 441 had both parents passed away, 31 did not live with parents, 96 could not be reached). In total 76 completed our study (response rate 74.5%) as 26 declined. In

sum, 237 old two-generation families, having older parents cohabiting with their son/daughters aged ≥40, took part in this survey between June and December of 2015 (response rate 79.8%) (Figure 1).

First, we sent an invitation letter by post to the families with a member with ID (including MD + ID) aged 40 or older, sent by the principal researcher's university and the county government. This was followed by a telephone call, at which time informed consent for the interview was obtained from those families that met the criteria of our study: individuals with ID whose aged is 40 or older and who live with parents, at least one parent has not died. Structured interviews were then conducted at the participants' home by one of the trained interviewers (15 working in H City and 13 in W County), who read through the questionnaire and recorded the answer to each question. All of the interviewers had completed 6 hours of interviewer training prior to beginning this survey interview. During the data collection, three senior social workers working with people with ID were employed to supervise the interviewers, review the data, check for missed questions or answers, and make corrections to the questionnaires that the interviewers completed.

<Please insert Table 2 about here>

As presented in Table 2, among the interviewed, 58.6% were mothers, 21.9% were fathers and 19.4% were siblings or in-laws of the ageing adults with ID as the parents were too frail to be interviewed. The mean age of the individuals with ID was 48.6 years (*SD* = 6.5, range: 40-76); 62% were male. Mean age of the parents interviewed was 75.4 (SD=8.0, range: 59-99) and 84.4% of the participants had received no formal education or only primary school. Among the families, 73.8% lived in urban area and 11.4% hired a live-in migrant care worker, and 83.5% owned the house/flat where they lived. In terms of housing ownership among the parents, 30.4% of the parents still kept it and had not transferred it yet to their children. A very small proportion of the older parents (4.6%) and of their ageing offspring

with ID (14.8%) were using any social services (e.g., daycare, home care) while interviewed. Most (82.7%) of these older parents told that they did not have any formal and informal social support or that it was not helpful. Half of the older parents (50.2%) self-reported to have a bad or very bad health condition. Over three quarters (78.8%) of the families had a monthly income less than US$1,000. In an average the participants were satisfied with the living community but not with their life.

2.2.2. Dependent variable

"*Ageing in place together*" was measured by the question, "*What is your future living arrangement when you are disabled*?" (1 = *not moving*, 2 = *move* to a sibling (of the offspring with ID), 3 = *mov*e to more than one sibling, 4= move to a place close to the siblings, 5 = *move to residential setting*, and 6 = *never thought about it*). The participants who replied to 1 (not moving), were also asked the question, "*You have replied that you will not move when you are disabled. How about son/daughter with ID? Will she/he will continue to stay with you here when she/he is getting old*?" (1= yes, 2= no). If the parents replied "yes", it was coded as "*ageing in place together*" and the other answers were coded as "other" (i.e., not moving without offspring with ID, moving to live with a sibling of offspring with ID with/without offspring with ID, moving to more than one sibling of offspring with ID with/without offspring with ID, moving to the nearby place of the sibling of offspring with ID with/without offspring with ID, moving to residential setting with/without offspring with ID).

2.2.3. Explanatory variables

The explanatory variables include four domains of housing pathways based on Clapham (2010) as discussed above.

Personal control is defined by the item of the questionnaire: *"Does the house/apartment belong to your family?"* and was coded as *"yes"* and *"no"* (including i.e., It is rented; It belongs to parents/other relatives or to employer).

Positive self-identity was measured by the question: *"Are you satisfied with your current living community, e.g., the area and the image of it?"* and rated by five ordinal categories from *very dissatisfied (1)* to *very satisfied (5). Positive social identity* was defined as the question asked*: "Are you willing to tell people where you live?"* and rated by five ordinal categories *(1=very unwilling; 5=very willing)*.

The participants' *self-esteem* is defined as whether the participants had the *ownership of their home/housing* based on the question: *"who is the owner of the apartment/house?"*. If the parents replied her/himself, the answer was coded as "yes", and the other answers (spouse, parents, OO, the siblings and other relatives) were coded as "no".

Social support, including formal and informal support, *is* measured using a translated local version of the *Family Support Scale* (Dunst, Jenkins, & Trivette, 1984). A higher score indicates greater support ($\alpha = .71$ in this study).

Inequality was defined as the participants' demographic and socio-economic variables including *the level of disability of offspring with ID* (based on the assessment data shown in the disability certificate and categorised into four levels: mild, moderate, severe and profound), the participants' *age (coded as interval variable), gender, level of education, health* (asked by the question: "*How is your health in general*?") *and life satisfaction* (measured by the question: *"In general, are you satisfied with your current life?");* and *family income* and *housing geography (coded as urban and rural area).* The participants' *level of education, health and life satisfaction* were rated as ordinal categories, with a higher rank indicating higher education, better health and life satisfaction.

2.2.4. Data analysis

The individual participant was the unit of analysis. We analysed the results using the Statistical Package for Social Sciences (SPSS), Version 20.0. Descriptive analysis was used for the characteristic data and the quantitative variables were described in terms of means and standard deviations (Table 2). Cross-table analysis and F-test were used to compare if there were significant differences between the two groups: "Ageing in place together" and "Others" in terms of the participants' characteristics (Table 3). The Pearson's correlation coefficient was used to measure the associations between 13 independent variables (Table 4). Logistic regression analyses were used to identify the factors associated with ageing in place together with ageing offspring with ID (Table 5). The level of statistical significance was set at $p<0.05$.

3. Results

3.1. Findings of qualitative study

Majority of the families had moving experiences and owned their home. Housing in general was old, e.g., 30 to 80 years; such old housing were given by parents-in-law or ancestors and renovated. Majority of housing were with two or three levels without an elevator; however almost all participants replied that they were used to this and did not have any problem with the barriers in their home.

Families including older parents and ageing adults with ID rarely used formal services which are provided for people with disability and older people. The parents' care transition plan for ageing adults with ID and their own moving plan in old age were intersected, connecting parents' and siblings' individual, family and social contexts. Majority of them did not plan to move. The types of pathways of moving in old age and care transition among parents are related to individual parents' autonomy and home identity and to both parents' and siblings' cultural identity as well as to the family relationship and financial conditions.

The parents, who did not want to move, had at least one of the following three conditions: hoping that one of the siblings would become the carer, being satisfied with their current housing, or believing in traditional family values. Some siblings were also involved in the interviews with their older parents and shared their idea about future care and housing transition related to their older parents and their siblings with ID. Some of the siblings, whose parents were too ill to be interviewed, had therefore become the substitute of their parents to answer the questionnaires. Qualitative data also found that family relationship and financial conditions were correlated with the ageing-in-place choice of the older parents and their ageing offspring with ID.

Who would not want to move in old age

Hoping the siblings would become carers

For example, the parents hoped that the siblings would become carers.

"Lived one day to the next, I do not want to move. ...I have so many children (7 children), they will look after me." (S14, TW, mother, aged 77, did not receive formal edu., carer of husband, too, three generations [living together]; son with ID aged 57)

"I will not send her to the residential setting, his brother will be my successor as carer" (S16, SM, mother, aged 79, primary school, widow, two generations; daughter with ID aged 57)

"I am still able to take care of her, I do not need other people coming to help. ...I don't need any social services. When I am not able to do so, my other children will take up. ... When I am too frail to take care of myself, they (other children) will manage it." (S17, CH, mother, aged 83, no formal edu., carer of husband, three generations; daughter with ID aged 62)

Housing identity

"Earlier we moved too many times because those living places were rented. We bought this apartment (5th floor without elevator) from the government, ...Now it is our own apartment; we will not move again." (S26, HCS, mother, aged 33, widow, primary edu.; son with ID aged 50)

"This is our own house, our home, ...I like H City. I have never considered that I would move to an apartment. A person who is content will be happy." (S24, SCY, mother, aged 69, widow, primary school, three generations; daughter with ID aged 46)

Belief of traditional culture

Siblings living with older parents and the sibling with ID, three generations living together, replied that they would be carers of their older parents and of the sibling with ID as it is their responsibility. For example, they shared:

"*Taking care of her (sister with ID) is, for sure, it is my responsibility, ...we (siblings) will care for her until she goes. ...we will not send her (sister with ID)to an institution. ...We will not let my mother to live in a nursing home either even when my mother has been sick for years, ...".* (S20, SC, younger brother, aged 60, sister with ID aged 67, mother aged 95 and ill & unable to talk, hiring a migrant care worker, three generations)

"My father has no plan to move. Living here is very convenient and we are very satisfied with S City. Co-residing with my younger brother's family, three generations living together, we can care for one another." (S21, TD, younger brother, mother aged 80 with dementia, father aged 83, son with ID aged 60, three generations)

Some siblings thought that the meaning of family is that all family members should live together and that they would not let their older parents and siblings with ID move to a nursing home or residential center. For example:

"We all live together, we will not separate" (S13, KS, sister-in-law of brother with ID aged 55, mother aged 82, father died, three generations)

"All family members living together, care for one another. … If we sent her (with ID) to a residential care home, it means we do not have heart." (S10, ZW, sister of brother with ID aged 62, aged 49, mother aged 88, father died, three generations)

"No way, LZ (with ID) will not move to an institution. I will move to live with him when he needs to be cared." (S30, LZ, younger brother, mother sick & aged 80, father died, brother with ID & aged 49, two generations)

"She (with ID) will not be out-of-home, use residential care service, as long as she is still alive." (S23, MY, older brother, both father (aged 88) and mother (aged 80) sick, daughter with ID & aged 49, two generations)

Who would choose to move in old age

Having human capital and resources

In families where siblings living in other city, none of the parents, cohabiting with children with ID, plan to move to live with the siblings as the parents did not want to transfer their caring responsibility to their other children without disability. Among these parents, those who plan to move in old age are those who have human capital and resources conditions. They plan to move with sons/daughters with ID to a nursing home or to an apartment with an elevator. For example, one mother (received high education, middle class family), different from the parents who were more traditional, has planned to move to a nursing home and, if it is possible, her son with ID would move with her and her husband

together. Another mother (S18, HZ, aged 77, son with ID aged 55, husband aged 90) shared: *"We would not count on children. ...HZ's (name of son with ID) father is a veteran and we are elegible to live in the veteran nursing home. We three would move there together".*

AC (#S5, mother, aged 62, son with ID aged 43, husband disabled for years, hiring a live-in migrant care worker) shared: *"I would not ask for AC's (name of son with ID) sibling to take over such a care responsibility, ...When we are old, I and AC would move to a small apartment with an elevator nearby, and I would hire a migrant care worker to care for AC..."*

Hiring a migrant care worker as an alternative or rationalized sibling care

Becoming the alternative for sibling care

The parents who would not transfer care responsibility to the siblings would hire a live-in migrant care worker, as the mother (S5, AC, mother, aged 62, father disabled and aged 69 and cared by a live-in migrant care worker; son with ID aged 45) shared above. She said: *"Hiring a live-in care worker is the best choice as I and AC (son with ID) could live together and the sibling would not have care burden".*

Father of ST (#S12, ST, aged 87, mother died, living with son with ID aged 62 alone in an apartment) also replied that he would not ask for his son without disability to be the successor in caregiving and he would not let the son with ID to move to residential service as he could not trust the service. So he said *"If I could not continue to care for ST (son with ID), I would find a migrant care worker to do so."*

Another mother (S8, CD, aged 70, father died, three persons living together including stepfather; son with ID aged 47) also shared: *"My young son has promised to care for CD (son*

with ID), but I would hire a migrant care worker to help."

Sibling care rationalized

Self-reliance culture impact on those families who would not use social services but rather care for by themselves or hire a migrant care worker. For example, a father needed to care for both son with ID and spouse with disability but he did not use social services and he shared *"I seem to be used to"* (S21, TD, Father, aged 83, mother 80 with dementia; son with ID aged 21). Some siblings would hire a live-in migrant care worker to continue care work for the disabled sibling as they did not want to count on the government due to the impact of traditional culture which values self reliance instead of depending on others. For example brother of SC (with ID) shared: *"We are not poor and leave social services to other people to use."* The payment of migrant care workers is fully paid by family.

LCC's Family (S22, mother, aged 84, father 94, 5 siblings; son with ID aged 55) hired a live-in migrant care worker caring for LCC (son with ID) for over 10 years and the younger sister of LCC replied: *"We would not let LCC move out to live in an institution as we can have the capability to care for him"*. It means that the family could afford the cost of migrant care worker to care for LCC.

This implies, first, that, as many parents want to avoid burdening their children without disabilities with care responsibilities for their disabled sibling, hiring a migrant carer becomes an alternative for sibling care when financial conditions allow this. Second, when financial resources are available to hire a migrant carer, siblings feel that they carry on the caregiver role for their sibling with ID as well as for their parents by employing the migrant care worker.

3.2. Results from survey study

3.2.1. Comparison between two groups: "ageing in place together" vs "others"

As seen in Table 2, most (61.6%) older parents who were interviewed replied that they would not move when they were disabled and that their ageing sons/daughters with ID would continue to live with them as well "ageing in place together" (G1). The rest of the older parents, that is, those who were not planning to age in place together with their ageing offspring with ID, were named as "others" (G2).

Comparison between these two groups (G1 and G2) found that there were significant differences between the two groups in terms of housing geography ($p<.05$), parents' education ($p<.05$), house ownership ($p<.001$), parents' satisfaction on living community ($p<.05$) and life satisfaction ($p<.05$). The findings suggest that, when compared with G2, the parents from G1 were more likely to live in rural area, have lower level of education, have higher proportion of home ownership, have higher level of life satisfaction and satisfaction with the living community.

However, statistical comparison revealed no significant differences between the two groups concerning gender, age, level of disability, and social service use of the offspring with ID and in terms of the parents' age, gender, health, living with siblings, social support, and social service use as well as family income, concerning whether the family hired a live-in migrant care worker or not.

<Please insert Table 3 about here>

3.2.2. Correlations between indicators of four domains of housing pathway

Table 4 shows the correlations between 13 variables that were defined based on the housing pathway framework of this study. The findings show that parental personal control (housing ownership of family) and self-esteem (housing ownership of older parents) were

strongly correlated (p<.001). The two domains of housing personal identity (satisfaction with community) and housing social identity (willingness to tell people where one lives) strongly related with each other (p<.001). Housing personal identity/satisfaction with community was significantly associated with social support (p <.05), family income (p <.05) and life satisfaction (p <.01).

Parents' self-esteem/home ownership was negatively related to living in urban area, being mother, and family income (p<.05). Social support is positively related to life satisfaction (p <.05). In terms of social and demographic context, parents living in urban area were more likely to have higher level of education (p<.05) and less likely to be mothers. As well, mothers were less likely to be older and more likely to have lower level of education and health than fathers. Parents' age is negatively correlated to education (P<.05) and parents' education is related to health (p<.05). Family income is positively correlated to life satisfaction (p<.001). Level of disability of offspring with ID was not significantly correlated with other 12 variables.

<Please insert Table 4 about here>

3.2.3. Factors associated with ageing in place together with offspring with ID

Table 5 shows that logistic regression model on "ageing in place together" was statistically significant (p<0.01) based on Chi-square tests. The strongest positive factor associated with "ageing in place together" is the housing ownership of family (p<.01) which is defined as "personal control" based on the housing pathway framework, followed by satisfaction with the living community (defined as "positive housing self-identity") (p<.05) and social support, which is negatively related (p<.05). All the variables reflecting "inequality", such as the participants' demographic and socio-economic variables, which

mean resources what the participants obtain, are not significantly related to "ageing in place together" among the participants.

The results indicate that whether the older parents can control the housing and as well as their housing identity are important in the decision making of relocation or ageing in place together with their ageing offspring with ID. Surprisingly the findings show that those older parents who have a higher level of social support are less likely to be "ageing in place together". It implies that ageing in place together with their ageing offspring with ID is more likely for those parents who do not have strong social support, though the families own the house/flat and are satisfied with the living community.

<Please insert Table 5 about here>

4. Discussion

In general these older parents who participated in the current study had a low level of social support, health, family income, education and only a very small proportion used social services. However, many had a high level of personal control (family owned the house/flat), and strong personal and social housing identity. A previous study has found that older parents are more likely to have a lower level of social support and human capital (health, income, and education) than younger parents of children with ID (Chou, Lee, Lin, Kröger, & Chang, 2009). Compared with those who had other options, the older parents, who would choose not moving and keep being with their ageing offspring with ID, were more likely to have lower education and to live in rural area, and to own the housing/flat and have a higher level of satisfaction with the living community and life satisfaction (as shown in Table 2). This is consistent with the qualitative findings, which found that the parents living in their own house had rarely thought about moving and appreciated the environment where they lived (e.g., good air) and the neighborhood that they had known for years. In contrast, those very

few parents who were planning to move to live in a nursing home with their disabled children were more likely to have a higher level of human capital and resources, such as a higher level of education and income (including good pension or welfare support from being a teacher or a veteran, based on the findings of qualitative data).

The findings suggest that these older parents chose ageing in place with their ageing offspring with ID because they own the house/flat and they also like the community. They had been living with their offspring with ID for over 40 years, even those living in rural area were used to the situation. They did not want to move or change their life style and living place, which has been observed in general by Western studies on housing of older people (Carroll & Qualls, 2014; Litwak & Longino, 1987), particularly among those older parents who lack social support. This echoes the qualitative findings, which found that the majority of parents replied that they did not want to move, replying that after several years they have "got used to" the situation, including taking care of their offspring with ID. The qualitative findings found that some older parents had walking difficulty as their housing had barriers; but these older parents replied that it was fine and it was not necessary to fix such barriers even if the government would reimburse renovation costs. Previous Taiwanese studies (Chou et al., 2013; Chou & Kröger, 2014) have presented that families having a higher level of education and income are more likely to have also a higher level of formal and informal social support. The current study revealed that the older parents with a higher level of social status did not want the other children without disability to become their future family carers or their caregiving successors for the disabled siblings. Under current familistic and market-oriented care policy regime in Taiwan, these older parents would be more likely to be able to afford a nursing home with good quality. In terms of social support, this implies that the parents choose ageing in place together with their disabled children because they are lacking support and resources and also because they are more likely to follow the traditional values,

according to which caring for older parents and for disabled family members is a responsibility of the children and the siblings. For example, one family lived in a house where its land belonged to the government and the father (H2, CC, aged 76, son with ID aged 47) shared in the interview of qualitative study: *"Moving? No place to move, housing is so expensive. … We do not have money to pay for the nursing home."*

Some parents and some siblings replied in the interviews that they had already hired or would hire a migrant care worker to care for the disabled children/siblings and/or older parents in order to avoid their disabled offspring/siblings and older parents being placed in residential care. Therefore, in terms of the relationship between family and state, migrant care workers seem in Taiwan to strengthen and rationalize such family care responsibilities and the current model of marketisation of care. Regarding parents caring for their disabled children, siblings caring for their disabled siblings and children caring for their older parents, migrant care workers become the substitute and alternative for family care, meeting the traditional values, e.g., "family should live together" and the social expectation of filial piety (Lan, 2006). However, employing migrant care workers is connected to status and inequality in many ways: economic inequality between different countries (Global North vs Global South) (Ehrenreich & Hochschild, 2003; Lan, 2005; Williams, 2011; Yeates, 2009) and inequality between women (Lin, 2000) and it is also an issue of divisions between social classes and different groups of women inside the countries: only middle-class and upper-class families and women can afford to employ migrant care workers. Beyond caring for older people in the family (Chen & Wu, 2008; Chou, Kröger, & Pu, 2015), this study found that migrant care workers also substitute sibling care responsibility for disabled siblings in those families that can afford the cost of hiring a migrant care worker and that follow traditional family values. These two substitute models of migrant care workers, caring for disabled siblings and caring for older parents, warrant further studies to compare their features.

Concerning housing pathways (Clapham, 2002, 2010), based on the regression analyses of this study, we found that only the domains of personal control and self housing identity were positively significantly related to "ageing in place together", additionally social support was negatively related. None of the demographic and socio-economic variables (namely the "inequality domain", which was explained as care needs and resources of the participants) nor self-esteem (housing ownership of parents) was found to be among important factors in making the choice whether the older parents would age in place with their ageing children with ID. First, different from previous studies focusing in general on older people moving in old age due to care needs or service use (Bradley, 2011; Faulkner, 2007), this study found that the older parents' age, gender, education, living geography, family income, care needs of children with ID (e.g., level of disability) and their own health were not determining the parents' ageing in place together with their children with ID.

Moving to a nursing home still carries a stigma in the Taiwanese society. If parents move to a nursing home, they often feel that they are abandoned by their children (as the findings of current qualitative data). In addition, the family also needs to pay for the living costs in the nursing home, and having better quality is more expensive. Consequently, LTC policy needs to pay attention especially to those families who cannot afford the cost of a migrant care worker and who are now ageing in place together with their disabled children. For these families, ageing in place may not be the best choice but rather the only choice.

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Table 1: Participants of in-depth interviews (60 families)

		N （%）
Local Authority	H City	30(50.0)
	W County	30(50.0)
Recruitment	Related service centres	12(20.0)
	From survey	48(80.0)
Offspring with ID		
Age	40-44	13(21.7)
	45-50	23(38.3)
	51-55	10(16.7)
	56-60	8(13.3)
	>60	6(10.0)
Sex	Male	36(60.0)
	Female	24(40.0)
Disability	LD/ID	54(90.0)
	Multiple disabilities (+ID)	6(10.0)
Severity of impairment	mild	12(20)
	moderate	15(25)
	severe	18(30)
	profound	15(25)
Disability service use	Yes	13(21.7)
	No	47(78.3)
Hiring a migrant care worker	yes	6(10.0)
	no	54(90.0)
Older parents		
Interviewed	Both parents	7(11.7)
	Father	10(16.7)

	Mother	29(48.3)	
	Sibling involved(during interview)	10(16.7)	
	Only sibling (parents sick)	4(6.7)	
Education		father	mother
	No formal education	6(10.0)	18(30.0)
	Primary education	37(61.7)	35(58.3)
	Junior high education	7(11.7)	2(3.3)
	Senior high education	5(8.3)	2(3.3)
	College education	1(1.7)	0
	University education and beyond	4(6.7)	3(5.0)
Living arrangement	Parents + ID child (2 generations)	20(33.3)	
	Parents + ID child +sibling/s	20(33.3)	
	Three generations	20(33.3)	
Housing	2 or more floors housing without lift	47(71.7)	
	House with only one floor	9(15.0)	
	Apartment with lift	7(11.7)	

Table 2. Characteristics of older parents and of their ageing offspring (*N* = 237)

Variables	*M (SD)*; Range	*n*(%)
Future living arrangement plan		
Ageing in place together		146(61.6)
Other		91(38.4)
Gender of offspring with ID (male)		147(62.0)
Age of offspring with ID[a] （interval)	48.6 (6.5); 40-74	
Level of ID		
severe + profound		107(43.1)
mild + moderate		130(54.9)
Use social service （yes)		35(14.8)
Who was interviewed		
mother		139(58.6)
father		52(21.9)
other (siblings or other relatives)		46(19.4)
Geography		
urban		175(73.8)
rural		62(26.2)
Age of older parents who were interviewed[a] (interval)	75.4 (8.0); 59-99	
59-70		35(24.6)
71-80		65(45.8)
81-90		38(26.8)
91+		4(2.8)

Education of older parents interviewed[a]	2.0 (1.0); 1-7	
No formal education		72 (30.4)
Primary school		128(54.0)
Junior high school		17(7.2)
Senior high school and above		20 (8.4)
Health of older parents interviewed [a] (5 ordinal)	2.6 (1.0); 1-5	
Very good + good		56(23.6)
So and so		62(26.2)
Bad + very bad		119(50.2)
Family income (nine ordinal)[a]	2.7 (1.6); 1-9	
Below NT$10,000		51(21.5)
10001~20000		84(35.4)
20001~30000		52(21.9)
30001~40000		20(8.4)
400001 and beyond		30(12.7)
Hiring a live-in migrant care worker (yes)		27(11.4)
Family own the house/flat (yes) ***(no as ref.)***		198(83.5)
Social support[a]	12.1 (7.5) (0-43)	
Never ask for help/doesn't exist + not helpful		196(82.7)
A bit helpful		38(16.0)
Helpful and very helpful		3(1.3)
Life satisfaction (5 ordinal)[a]	2.8 (0.7); 1-5	
Very satisfied + satisfied		16(11.0)
So and so		103(70.5)

Very dissatisfied + dissatisfied		27(18.5)
Self identity **(satisfaction for current community) (5 ordinal)** [a]	3.7 (0.7); 1-5	
Very satisfied + satisfied		108(74.0)
So and so		36(24.7)
Very dissatisfied + dissatisfied		2(1.4)
Social identity **(willing to tell where one lives) (5 ordinal)**[a]	3.6 (0.7); 1-5	
Very willing to + willing to		105(71.9)
So and so		28(19.2)
Very unwilling to + unwilling to		13(8.9)
Home ownership by parents self		72(30.4)
others		165(69.6)
Parents' use of social services (yes) **(i.e., homecare or daycare)**		11 (4.6)

Note. [a]Ordinal/interval variables, a higher score indicates higher level of satisfaction, willingness, support, health, income and older age.

Table 3. Comparison between two groups (G1: Ageing in place together vs. G2: Others)

	G1: Ageing in place together N=146(61.6)	G2: Others N=91(38.4)	X^2	F test
Offspring with ID				
Gender (male) N(%)	92(63.0)	55(60.4)	0.16	
Age M(SD)	49.2 (7.0) Range: 40-74	47.7 (5.7) Range: 40-68		2.79(.10)
Level of ID (severe + profound) N(%)	67(45.9)	40(44.0)	0.08	
Health M(SD)	3.2 (1.0)	3.0 (0.9)		2.97
Geography (urban) N(%)	101(69.2)	74(81.3)	4.28*	
Social service use of (yes) N(%)	22(15.1)	13(14.3)	0.03	
Parents who were interviewed [a]				
Gender (mother) N(%)	111(76.0)	69(75.8)	0.001	
Age M(SD)	76.0 (8.1) Range:59-99	74.5 (7.8) Range:60-93		2.00
Education M(SD)	1.9 (0.8) Range:1-5	2.1(1.1) Range:1-6		4.29*
Health M(SD)	2.7 (1.0)	2.6 (1.0)		0.38
House ownership by family (yes) N(%)	130(89.0)	68(74.7)	8.36***	

Living with the siblings of offspring with ID (yes)N(%)	124(84.9)	80(87.9)	0.42	
Social support M(SD)	11.5 (6.8)	13.1 (8.5)		2.74
Life satisfaction M(SD)	2.9 (0.6)	2.7 (0.7)		5.60*
Satisfaction for current community M(SD)	3.8 (0.6)	3.6 (0.7)		7.73*
Satisfaction of current house M(SD)	3.7 (0.7)	3.5 (0.8)		3.27
Housing social identity M(SD)	3.6 (0.8)	3.6 (0.8)		.044
House ownership of parents (yes) N(%)	43(29.5)	29(31.9)	0.16	
Social service use of (yes) N(%)	7(4.8)	4(4.4)	0.02	
Family income M(SD)	2.8 (1.7)	2.6 (1.5)		0.57
Migrant care worker (yes) N(%)	15(10.3)	12(13.2)	0.47	

[a] The parents who participated in our interview.

$^{*}p < .05$; $^{**}p < .01$; $^{***}p < .001$.

Table 4. Pearson's correlations between the variables of four domains (13 independent variables)

	1.Personal control[a]	2.Housing self-identity[b]	3.Housing Social identity[c]	4.Self-esteem[d]	5.Social support	6.Geography (urban)	7.Level of ID	8.Parents gender/mother	9.Parents' age	10.Parents' edu.	11.Parents' health	12.Family income	13.Life satisfaction
1.Personal control	1												
2.Housing self-identity	.108	1											
3.Housing social identity	.052	.259**	1										
4.Self-esteem	.293***	.049	-.003	1									
5.Social support	.026	.128*	-.083	-.070	1								
6.Geography (urban)	-.109	-.080	-.025	-.129*	.008	1							
7.Level of ID	.037	.051	.063	.009	.029	-.019	1						

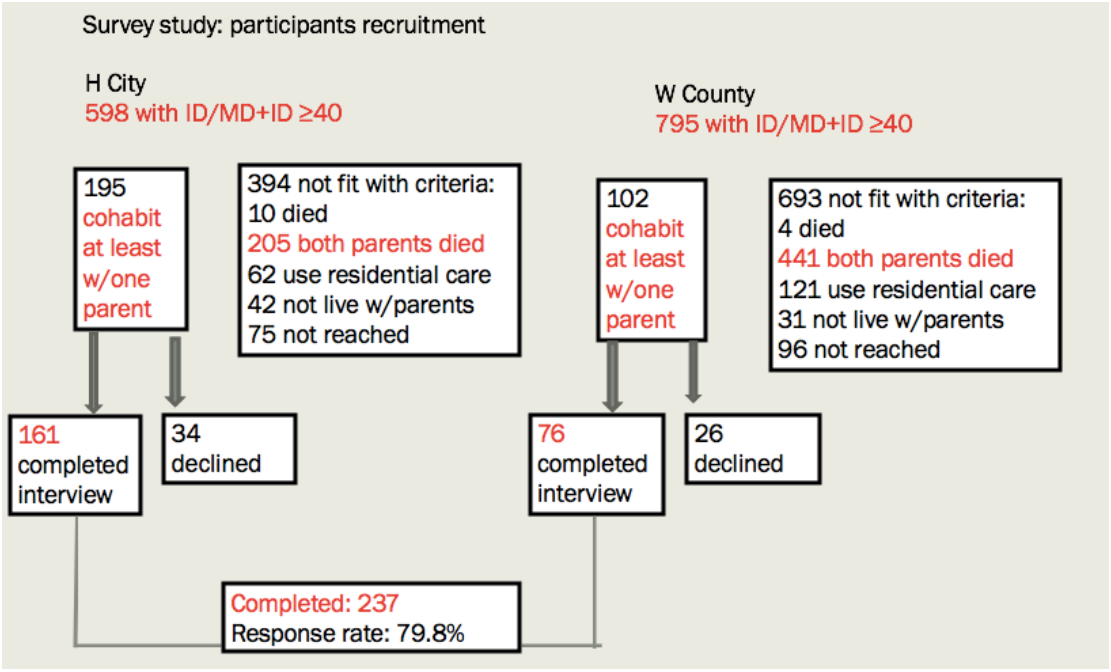
8.Parent's gender (mother)	-.037	.073	.087	-.143*	-.076	-.155*	.054	1					
9.Parent's age	.101	.030	-.088	.011	-.113	.013	.022	-.175**	1				
10.Parent's edu.	-.062	-.014	.008	.078	.108	.143*	-.025	-.329***	-.149*	1			
11.Parent's health	-.043	.080	-.012	-.004	-.056	.010	-.059	-.167*	-.086	.146*	1		
12.Family income	.043	.140*	.121	-.129*	.072	.118	.075	-.008	.110	.121	.100	1	
13.Life satisfaction	-.036	.204**	.034	-.125	.147*	-.018	.031	-.005	.031	.080	.196**	.251***	1

[a]Family housing ownership; [b] Satisfaction on living com; [c]Willing to tell where one lives; [d] Housing ownership of parents. *p<.05; ** p<.01; *** p<.001(two – tailed).

Table 5. Logistic Regression Analysis on Ageing in Place Together among Older Parents and Ageing Offspring with ID

Independent variables	Ageing in place together[a] (n = 237)					
	B	*P value*	*SE B*	Odds ratio	95%	
Personal control – housing ownership of family (nominal) (yes vs. no) (others/no as ref.)	1.114**	.007	.414	3.047	1.354	6.855
Positive self-identity – satisfaction with living community[b] (interval*5)	.578*	.015	.237	1.783	1.121	2.836
Positive social identity housing – willing to tell where one lives[b] (area and image) (interval*5)	-.185	.362	.203	.831	.558	1.237
Self-esteem – house/flat ownership of older parent (others as ref)	-.527	.126	.344	.590	.301	1.159
Social support [b/d]	-.046*	.029	.021	.955	.916	.995
Inequality – demographic and socio-economic resources						
Housing geography (rural as ref)	-.537	.128	.353	.585	.293	1.168
Level of impairment of offspring with ID (mild and moderate as ref)	.080	.786	.294	1.083	.609	1.926
Gender of parent interviewed (mother) (ref =father)	-.454	.247	.392	.635	.294	1.370
Age of older parent[c]	.005	.818	.020	1.005	.966	1.044
Education of older parent[b]	-.281	.101	.171	.755	.540	1.056
Health of older parent[b]	.026	.861	.151	1.027	.764	1.379
Family income[b]	.023	.811	.096	1.023	.847	1.236
Life satisfaction of older parent[b]	.467	.052	.240	1.595	.997	2.552
Model χ^2				32.47**		
Nagelkerke R^2				.177		

[a]13 independent variables. [b/c] Ordinal/interval variables. A higher score indicates a higher level of satisfaction, willingness, support, health, income and older age. [d] Social Support Scale (Dunst et al., 1984)
*$p < .05$. **$p < .01$.


Survey study: participants recruitment
H City
598 with ID/MD+ID ≥40
195 cohabit at least w/one parent
394 not fit with criteria:
10 died
205 both parents died
62 use residential care
42 not live w/parents
75 not reached
161 completed interview
34 declined
W County
795 with ID/MD+ID ≥40
102 cohabit at least w/one parent
693 not fit with criteria:
4 died
441 both parents died
121 use residential care
31 not live w/parents
96 not reached
76 completed interview
26 declined
Completed: 237
Response rate: 79.8%