

# How People with Intellectual Disabilities Experience getting old in Korea

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## **Abstract**

This study aims to explore how people with intellectual disabilities experience getting old in Korea. The data is composed with 28 middle-aged people with intellectual disabilities, families, personal assistants and group home workers of complementary interviewees for plentiful dates and to deeply understand this phenomenon. Using the data obtained for these interviews, interviewee's various perceptions and experiences of being old were analyzed and five meaning categories for experience getting old were identified: *Earlier aging occurred on body and mind/ Daily separation and stigma, who remain still lonely due to it/ Feeling of happiness at the moment and hoping/ Parents being old and family's aggravated burdensome/ As separation from family lives, considering to the disability institution.* The findings of this research can be used as foundational material in development of aging with disability policies and the improvement of social service, achieving respect, autonomy and inclusion in later life.

**Keywords:** people with intellectual disabilities, getting old, disability and aging, qualitative research

## **1. Background/ Objectives and Goals**

During several decades, the life expectancy increased dramatically throughout the world. While population aging has received considerable attention, the aging of the intellectual population has gone largely as well. This population has survived to later life compared with the 1960, 70s. For example, the life expectancy in England has grown from 20 ages in 1930 to 70-73 ages in 1990 year and in the United States, it has grown from 59 ages in 1980 to 67 ages in 2000 year (Emerson and Hatton, 2011). The National Association for Down syndrome reports that the average life expectancy of individuals with Down Syndrome is 55 ages, with many living into their sixties and seventies.

The Korea is not exception in ageing without mention. According to ageing transition of the

intellectual disabilities through research on the actual condition of the disability in Korea, proportion of over 40 ages is 18.3% in 2000, 27.7% in 2008 and 31.6% in 2014 year and in the case of over 50 ages, 6.30% in 2000 year, 11.2% in 2008 and 19.00% in 2014 year. The statistics show ageing trends radically.

That reasons are the beneficial results of deinstitutionalization, improved social services and better health care (Culham and Nind, 2003). Specially, as change of this paradigm, the larger member of people ageing with intellectual disabilities has lived with family in community (Walker and Walker, 1998; Bigby, 2002). But family-based support system may be less available and social service may be lack and improper suited to assist to live with ageing in place.

As a natural consequence of the normal aging process, people experience various changes due to biological and environmental factor. Biological changes are universal to humans, but people with intellectual disabilities tend to experience accelerated biological aging (Bigby, 2002; O'Brien and Rosenbloom, 2009). Moreover, the population is likely to experience emotional problems, relationship reduction and cognitive deficit (Bland et al., 2003). In other words, This population face greater challenge because they possess fewer external resources and more decline in their own capability at the same time, often at an accelerated pace in later life (Doka and Lavin, 2003; McCarron and Lawlor, 2003). Their systems of social support are likely to be less available. In particular, people older with intellectual face prejudice, discrimination and stigma because of their disability and ageing (Bland et al., 2003; O'Brien and Rosenbloom, 2009). Those things often leads to difficulty gaining access to needed healthcare and social service (Doka and Lavin, 2003). Also, the exclusion of opportunities of education, participation and relationships during whole life, etc more likely to face secondary conditions in later life as well aggravated ageing.

The population face multiple jeopardizes as to individual ageing like this. However, there are less prepared in later life in the respects to both of individual and government in Korea. On should design to serve the ways we make policies, practical invention and educate professional working in the fields of gerontology and intellectual disabilities (Walker and Walker, 1998). Until now, the research rated people aging with intellectual disability has less been studies in Korea. From this context, this study sets out to explore and deeply understand how people with intellectual disabilities experience getting old in Korea.

## **2. Method**

The purpose of this study is to understand the experience of intellectual disabilities being old through the eyes of people with disabilities. We carried out 28 middle-aged (40-50 age) people with intellectual disabilities in individual interview to uncover people's first-hand experience and knowledge about this subject. To deeply study the being old phenomenon, the

researchers invited participants to share and compare experiences for those. In beside, 7 their family members including the mothers and siblings, 3 personal assistants in individual interview and focus group interviews with 6 group home teachers were conducted for deeply understanding this phenomenon and considering date transferability. Interview question included, 'How person with intellectual disabilities are getting old?', 'What are your changeable experiences in physical, emotional, behavioral and relationships aspects as getting old?' etc. Between April 2016 and October 2017, we conducted individual and focus group interview.

### 3. Results

#### 1) Earlier aging occurred on body and mind

*(1) Senile diseases and mental problems;* There occurred to participants for senile diseases generally such as cataract, hypertension, etc with getting old. Also, most of participants already have several of chronic diseases with diabetes, heart diseases, the thyroid gland, tuberculosis, epilepsy, also become worse and developed complications. And Participants experience tinnitus, an auditory hallucination. They are muttering to themselves as getting old. Meanwhile, autism, anxiety disorder and depression, etc excepts previous mental problems have newly formed on them. They are suffering from so called secondary condition on body and mind.

*I have taken antidiabetic, antihypertensive drug.(participant 12). While going around in a mid-night, keep on saying(sister-in-law of participant 4). He go department of neuropsychiary and has pill. Without getting sleep, he makes those troubled..(sibling of participation 16). I am anxious, somewhere so(participant 8).*

*(2) Cognitive deficit about body's changes and communication limitation;* The majority of participants have cognitive deficit on odd symptom and changes of the body. Briefly, they ignore symptoms or even pains generally. It is regarded due to decrease of sensitive functioning and cognitive deficit. Besides, they have communication problems about which of body is suffered and how it is. Participant 4 case, nobody know a cataract at the early outbreak of her illness, the cataract has discovered by family after loss of one's eyesight.

*She went pussy, due to her toenail's gotten into skin. It's let her toenail cut off in a hospital. She never say it's sore and no shout how it's so.(sisters-in-law of participant 4). When I am pain, I stand on it and pray into the sky(participant 18). He not recognize which of the body is pain, I think that he seems to be sore and take him at the hospital.(mother of participant 1)*

(3) **Decreased physical functions and obesity;** Also, the physical function rapidly has declined as becoming old. Some of them have grown weak as much as unable to have a meal by oneself without help of family or personal assistant previously. Mother of participant 3 case has talked that her son has a difficulty in even working before about two or three years. Specially, most of them have teeth's serious impairment from unable to do toothbrushing by oneself, to get teeth medical treatment and further complication of diabetes. In the case of participant 11, an ulcerated gum caused to unable to swallow even saliva and foods.

## **2) Daily separation and stigma, who remains still lonely due to it: Why middle-aged people with intellectual disabilities still lonely in the community in Korea?**

(1) **Family's indifference and control;** Participants told that their families have't gotten any concerns toward them. Family members have the meal respectively and there is in less communication. Participant 19 says her families have gotten along with each one's a long time ago'. Like this, even though they have lived with parents and sibling, the relationships still be less intimacy.

*Family member have meals respectively, all go homes much later.(participant 19). Our family used to get along with each one's, there is no communication(participant 9).*

Meanwhile, their all daily life has been controlled by families. The choice and decision has been made where to live, what they have, where to go, etc but by families and other peoples. Also, participants' earning money on workplace has been managed by families. From this, even though they are adult, there is less get concept in money concepts and afraid in buying goods by oneself.

(2) **Ambivalence and isolation;** People show ambivalence between a kind of pity and a sense of distance toward older people with intellectual disabilities. According to experience of family and personal assistance, community people are seemingly kindly to them with a pity but get a sense of distance in real relationships. If the researcher asks them to get along with whom, most of them said ' I have been alone a long while'. If not participating in community center or sheltered workshop, they stay watching on TV and there be less contact except personal assistant all day long. Like this, daily space is limited such as only community center, shelter workshop, church and home, and they still are lonely in community.

*I'd like to belong to a frat with those, but people used to dislike me.(participant 27). If take them to community*

welfare center, People dislike them. So much (personal assistant of participant 1), community people regard him piteous and give something to eat for him.(teacher 1).

(3) **Relationship's experience deficit**; According to experience of group home's worker, participant like colleague and other people but not knowing how to make friends. They still are likely as children even though getting old, rather than to give concession and consideration toward others. Participants being middle-aged less have known how to have relationship and also, who get little concepts of relationship. There have been few opportunities to have relationship due to a kind of prejudice and stereotype toward intellectual disabilities.

### 3) Feeling of happiness at the moment and hoping:

(1) **Sharing others and daily happiness**; There have't been only to be negative and despair such as the kinds of multi- diseases, isolation, anxiety and disability worsened in their lives. There would be energy, positive and hope for living. Even though participants still lonely, they get daily energy and a kind of pleasant from interaction with the world. It's trivial to others but important life experiences for them such as going community welfare center, watching cinema and going to shop.

*Community welfare center let me serve up meals or something to eat for neighbors.(participant 18). I used to go to shelter workplace weekday, go bowling on Saturday and to church on Sunday. It's quite exciting.(participant 16). It's very pleasant to do some activity and go to cinema with colleague and teacher.(participant 20)*

(2) **Deep affections for one's job**; Participants going shelter workplace get attachment to their jobs. They said that it would be the most pleasant on work and also getting money. While they become immersed at the worktime, one's work is a sort of pride itself and resource of a sense of accomplishment.

*What it's very stuffy in staying home without working...(participant 6). It's good to work, but totally bored with not having any work to do..(participant 23).*

(3) **The expecting**; Participants respectively have the expecting and hoping in ageing life. The hopes are health, trip, money, do part-time work and knowing writing, etc reflected with physical, economical and relationship need. They said their expecting things through looking others' lives

### 4) Parents being old and family's aggravated burdensome

(1) **Hard caring and concerns**; The mother of participant 1 has talked to care child with

intellectual disabilities all the whole life by herself. However, now the mother has decreased and gotten pains due to ageing. They have devoted themselves in caring child during about 40-50 years standing against opposition of the father in law. A number of mothers have gotten suffering in rheumatism, degenerative arthritis, diabetes, hyperpiesia and physical mal-function. And further the parents have gotten much of concern how to do with the children after death's parents. The last wish of older parents in life is to be taken death of their children before their death.

*Only doing one's self is to have meals and unable to even do with defecation by oneself.(sister-in-law of participant 4). Caring is so hard, it's on beyond my capability now. I would like to have rest in send my wife to disability facilities.(husband of participant 13)*

**(2) Conflict of family member and entering group home;** The family members have struggled frequently due to problem of caring participants. Most cases of group home have entered as this cause. After living in group home, the relation of family get much better. That's why makes possible to do family independent life and decrease of caring burden.

## **5) As separation from family's lives, considering to the disability institution**

**(1) Parents' death and psychological trauma;** The mother is the absolute being for participants. The death of mother makes them shocked and felt much grief of losses. Moreover, it has made psychological condition negative and challenging behavior. Also, less saying, more radically depressed and negative unlikely before. They have occurred anxiety disorder, wandered from place to place in the mid-night and even done self-injury after parents' death.

*My mother's gone to the sky.(participant 2). It's worsen to mutter oneself and more depressed less saying, even they have done self-violence after mother's death.(teacher 1)*

**(2) less possible to living together in community;** Most of siblings have talked that it's unable to live together with them after parents' death. It's impossible to give care to them while giving up sibling lives. The siblings said that it's nearly impossible for people with intellectual to live any more in community because communication deficit, impulsive and offensive behaviors, etc make families and neighbors unable to cope with them. Like this, participants used to be regarded trouble maker or some burden and so siblings willing to avoid them. The families have no choice to take them into the disability institution after parents' death.

## 4. Conclusion

This brief results are like that

- The population has been experiencing earlier aging on physical, emotion, relationship also, challenge behavior.
- Changing family relationship after parents' death or ageing parents. having very few relationship with parents (living with family but daily have less contacts). less having relationship with siblings
- Even though this population has live in community during several decades, still lonely. Narrow relationships(due to daily separation and stereotype): only personal assistants, social workers, peer at workshop
- No support (no family based support, counselling on trauma) after parents' death/ have to move to another place (eg. hospital or disability institution, but quite lack of group homes and community facilities/ less prepared). No preparation to be adult and later life(no independence training, few social support, no choice of residence, etc)
- Few participation in only limited workshop, community welfare center. Most of them are at home in watching TV or get along with doing nothing all day long.

The population has faced significant challenges and considerable problems related ageing. Briefly speaking, person with intellectual disabilities multiple jeopardizes as they face these age-related transition(Bland et al., 2003). Even though multiple jeopardizes, it were something that would be positive daily energy, hoping, needs and unique meanings on their own life.

It's the citizenship for prepared later life. Healthy aging, active aging and ageing in community for the intellectual aging with disabilities should pursuit and make it happen from the perspectives of the citizenship and inclusion. The limitation of this study is as exploratory research. But the implication of this study results are for basic resource in understanding of the intellectuals aging, making social service and coping with age-related transition.

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