

RGC Ref. No.: UGC/FDS11/H06/15 _____ (please insert ref. above)
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**RESEARCH GRANTS COUNCIL  
COMPETITIVE RESEARCH FUNDING SCHEMES FOR  
THE LOCAL SELF-FINANCING DEGREE SECTOR**

**FACULTY DEVELOPMENT SCHEME (FDS)**

**Completion Report**  
*(for completed projects only)*

<p><b><u>Submission Deadlines:</u></b></p> <ol style="list-style-type: none"> <li>1. Auditor's report with unspent balance, if any: within <b>six</b> months of the approved project completion date.</li> <li>2. Completion report: within <b>12</b> months of the approved project completion date.</li> </ol>
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**Part A: The Project and Investigator(s)**

**1. Project Title**

Exploring family caregiving experiences and identifying the process of the ageing carers' planning for continuation of care for the community-dwelling person with intellectual disability

**2. Investigator(s) And Academic Department(s) / Unit(s) Involved**

Research Team	Name / Post	Unit / Department / Institution
Principal Investigator	Prof. Lisa Pau Le LOW Professor	School of Health Sciences Caritas Institute of Higher Education
Co-Investigator(s)	Dr. LAM Lai Wah Retired Former Professional Consultant	Nethersole School of Nursing Chinese University of Hong Kong
	Prof. CHIEN Wai Tong Vice-Director of Research / Professor	Nethersole School of Nursing Chinese University of Hong Kong
Others	Ms. WONG Ka Yin Research Assistant	Research Office Caritas Institute of Higher Education

**3. Project Duration**

	Original	Revised	Date of RGC / Institution Approval <i>(must be quoted)</i>
Project Start Date	1 Jan 2016	NA	NA
Project Completion Date	31 Dec 2017	NA	NA
Duration <i>(in month)</i>	24 months	NA	NA
Deadline for Submission of Completion Report	31 Dec 2018	NA	NA

## **Part B: The Final Report**

### **5. Project Objectives**

#### 5.1 Objectives as per original application

1. To explore how care is currently provided to the person with intellectual disability (ID) and how these caregiving experiences have evolved over the past year.
2. To explore family carers' perspectives of current caring needs and types of care needed by the person with ID.
3. To examine the extent to which the current level of support has met family carers' expectations and needs, and the caring needs of the person with ID.
4. To examine the plans family carers have for continuing the care of the person with ID as carers themselves are getting older.
5. To explore how family carers plan to achieve/ implement their plans for continuing care of the person with ID person from now until later life.
6. To develop a theoretical framework that captures the family carers experiences and processes of planning to meet the current and continuing care needs of community-dwelling persons with ID.

#### 5.2 Revised objectives

Date of approval from the RGC: NA

Reasons for the change: NA

#### 5.3 Realisation of the objectives

*(Maximum 1 page; please state how and to what extent the project objectives have been achieved; give reasons for under-achievements and outline attempts to overcome problems, if any)*

In achieving the six project objectives, an overview of the project progress and implementation of the data collection and analysis is presented below.

#### **Overall Project Progress & Implementation**

<b>Timetable of work</b>	<b>Period</b>
Prepared research documents and purchased equipment	2016, Jan-Mar
Obtained access and ethical approval from NGOs for study	2016, Mar-Apr
Site 1 data collection (1 <sup>st</sup> round)	2016, Apr-Aug
Site 2 data collection (1 <sup>st</sup> round)	2016, May-Dec
Site 2 data collection (2 <sup>nd</sup> round)	2017, Apr
Site 3 data collection	2017, Apr-Jun
Site 2 data collection (3 <sup>rd</sup> round)	2017, May-Jul
Site 1 data collection (2 <sup>nd</sup> round)	2017, Jun
Site 4 data collection	2017, Aug

#### **Data Collection**

- Good terms and relationships have been established with the staff at all the sites.
- *Site 1*: Some recruitment difficulties, data collection took 5 months (1<sup>st</sup> round) and 1 month (2<sup>nd</sup> round), final sample is 18.
- *Site 2*: Great recruitment difficulties, data collection took 8 months (1<sup>st</sup> round), 1 month (2<sup>nd</sup> round) and 3 months (3<sup>rd</sup> month), final sample is 19.
- *Site 3*: Some recruitment difficulties, data collection took 3 months, final sample is 15.

- *Site 4*: Approached another site to theoretically sample the emerging themes and to increase the chance of recruitment, data collection took 1 month, final sample is 8.
- Total sample size is 60 family carers participated in an individual interview that lasted 45-90 minutes from April 2016 to August 2017.

### Data Analysis

All interview recordings were transcribed verbatim, and field notes were kept to jot down issues that could not be audiotaped. Constant comparative analysis methods were used to analyze the data. Three major themes were identified: (1) Range of care provided to meet needs; (2) Current support received; and (3) Continuation of care towards the future.

### Extent the Themes Met the Project Objectives

<p><i>Theme 1: Range of care provided to meet needs</i></p> <p>This theme encapsulated objectives 1 and 2:</p> <ol style="list-style-type: none"> <li>1. To explore how care is currently provided to the person with intellectual disability (ID) and how these caregiving experiences have evolved over the past year.</li> <li>2. To explore family carers' perspectives of current caring needs and types of care needed by the person with ID.</li> </ol>
<p><i>Theme 2: Current support received</i></p> <p>This theme encapsulated objective 3:</p> <ol style="list-style-type: none"> <li>3. To examine the extent to which the current level of support has met family carers' expectations and needs, and the caring needs of the person with ID.</li> </ol>
<p><i>Theme 3: Continuation of care towards the future</i></p> <p>This theme encapsulated objective 4-6:</p> <ol style="list-style-type: none"> <li>4. To examine the plans family carers have for continuing the care of the person with ID as carers themselves are getting older.</li> <li>5. To explore how family carers plan to achieve/ implement their plans for continuing care of the person with ID person from now until later life.</li> <li>6. To develop a theoretical framework that captures the family carers experiences and processes of planning to meet the current and continuing care needs of community-dwelling persons with ID.</li> </ol>

### 5.4 Summary of objectives addressed to date

Objectives (as per 5.1/5.2 above)	Addressed (please tick)	Percentage Achieved (please estimate)
1. To explore how care is currently provided to the person with ID and how these caregiving experiences have evolved over the past year.	✓	100%
2. To explore family carers' perspectives of current caring needs and types of care needed by the person with ID.	✓	100%
3. To examine the extent to which the current level of support has met family carers' expectations and needs, and the caring needs of the person with ID.	✓	100%
4. To examine the plans family carers have for continuing the care of the person with ID as carers themselves are getting older.	✓	100%
5. To explore how family carers plan to achieve/ implement their plans for continuing care of the person with ID person from now until later life.	✓	100%
6. To develop a theoretical framework that captures the family carers experiences and processes of planning to meet the current and continuing care needs of community-dwelling persons with ID.	✓	100%

## 6. Research Outcome

### 6.1 Major findings and research outcome

*(Maximum 1 page; please make reference to Part C where necessary)*

#### **Health and medical profile of participants**

Of 60 family carers aged between 33-89 years, most of them had ageing health problems and depression. There were 35 mild, 24 moderate and 1 borderline ID members aged between 21-65 years. Six were single child, 51 had siblings without ID, and 3 had siblings with ID. They have used sheltered workshop from 3 months to 30 years. They had health, behavioral, emotional and psychological problems.

#### **Theme 1: Range of care provided to meet needs**

Mothers were the major carers who have provided long-term special care to their ID children with different caring needs that continued to linger into adulthood. They refocus on the way of caregiving and instill strategies to help ID members build greater independence to manage their later life, especially when both parties are ageing or soon-to-be old.

##### *(1) Self-care and living needs*

- Preparing meals, teaching, taking special care on eating and maintain healthy diets.
- Assisting with personal hygiene (i.e. body, hair, teeth and clothing).
- Repeated encouragement, reminders and assistance.
- Ensuring safety in daily activities (i.e. take transport, identify location and spend money).

##### *(2) Medical and psychological health needs*

- Visiting doctor or follow up regularly for health problems.
- Difficulties in visiting doctor and receiving treatment.
- Observing sickness, taking medicine, handling wounds and other health concerns.
- Attentive to puberty, relationships, criminal issue, emotional and behavioral problems.

#### **Theme 2: Current support received**

Sheltered workshop was the major source of service for family carers and ID members. Caregivers described the reliance on family and social support to release caring stress and emotions. Some faced difficulties alone owing to loss of spouses or poor family relationships. Personal strengths and positive coping strategies moved them on and delayed contemplating long-term care. Support received included (1) Support from sheltered workshops, (2) Family and social support, and (3) Personal strength and coping strategy.

#### **Theme 3: Continuation of care towards the future**

Both family carers and ID members were experiencing ageing health conditions. Some carers were ambivalence towards passing away. Staying hopeful was the way to release their worries. Hostel was the most important arrangement, with concerns on location, environment, quality of care and adaptability of their ID members. Some carers mentioned passing the responsibility and beginning to involve all family members to discuss long-term care. To embrace the situation of 'double ageing', hopes for supportive services were discussed as follows:

##### *(1) Medical and healthcare support*

- Regular health check for degeneration and mental concerns.
- Dental care and scaling services.
- Escort service for visiting doctor, medical home visit and medical allowance.

##### *(2) Accommodation, daily living and financial support*

- Temporary or short-term care hostel service.
- Living arrangement, employment, long-term financial allowance.
- Housework assistance and meal delivery service.

##### *(3) Educational and emotional support*

- Informational sharing and parents' support network.
- Living, job, communication skills, counseling and emotional control training.
- Life and death education.

## 6.2 Potential for further development of the research and the proposed course of action (Maximum half a page)

This project has provided its first comprehensive exploration of the caregiving experiences of Chinese family carers for ageing adults with mild and moderate intellectual disability (ID) residing at home. At this present stage, the study has outlined a theoretical framework to capture the experiences in the caring process over time to include the nature of caring needs, responses to address those needs, and trace the plans for the future care of ID sufferers in their later life. This practical theoretical framework hopes to provide knowledge about the caregiving processes and track the caregiving journey to guide the inputs of interventions to make changes to improve people's lives. .

The 'double-ageing' phenomenon is at the heart of this population group. Alongside ageing, medical and psychosocial health declines of these clienteles, caregiving can become a major challenge for both informal as well as formal caregivers. Timely recommendations and suggested supportive measures provided by this project will target at actual caring needs of caregivers of advancing age. Attention to support parent and sibling carers to proactively plan for the future and develop both in-home and out-of-home options before the ageing family carers reach a point where they can no longer provide care to their ID adult children. This project has led to the success in securing funds for an upcoming project (Project no: UGC/FDS11/M08/18). The endeavor of academic researchers and formal care providers will collaborate to unveil deeper caregiving experiences to directly impact and raise standards of care and practices for this needy population of ID sufferers.

## 7. Layman's Summary

*(Describe in layman's language the nature, significance and value of the research project, in no more than 200 words)*

Given that there is an imminent increase in longevity and number of ageing persons with intellectual disability (ID), there is a high uncertainty about future care options especially come a time when their ageing parents can no longer provide care for their ageing children with ID. The strains of caregiving on ageing carers coupled with age-related health and behavioral declines can make caregiving a highly difficult task. This project has provided in-depth coverage of caring needs and concerns faced by ageing carers of ageing ID adults. The data highlighted carers' obligations and how filial piety has influenced their caring expectation and lingering experiences. Carers realized the need to let go and instill strategies to build greater independence for ID members to manage their own lives, especially when both parties are ageing together. Current support and future needs to continue with their caring roles is highlighted. A theoretical framework has been outlined to trace the caregiving processes and track the caregiving journey to guide the inputs of interventions to make changes to improve people's lives. Listening to the caregivers has enabled timely and appropriate support measures to be identified to address actual needs to prepare them to deal with 'double ageing'.

**Part C: Research Output****8. Peer-Reviewed Journal Publication(s) Arising Directly From This Research Project**

(Please attach a copy of the publication and/or the letter of acceptance if not yet submitted in the previous progress report(s). All listed publications must acknowledge RGC's funding support by quoting the specific grant reference.)

The Latest Status of Publications				Author(s) (denote the corresponding author with an asterisk*)	Title and Journal / Book (with the volume, pages and other necessary publishing details specified)	Submitted to RGC (indicate the year ending of the relevant progress report)	Attached to this Report (Yes or No)	Acknowledged the Support of RGC (Yes or No)	Accessible from the institutional repository (Yes or No)
Year of Publication	Year of Acceptance (For paper accepted but not yet published)	Under Review	Under Preparation (optional)						
			✓		Case analyses of three mothers' experiences of raising multiple older adults with intellectual disabilities in the family		No	Yes	
			✓		Current support and anticipating future needs of ageing caregivers and their ageing adult children with intellectual disability.		No	Yes	
			✓		Ageing carers and their ageing family member with mild-moderate intellectual disability in Hong Kong: What needs and care do they have?		No	Yes	
2018				*Low LPL, Wong KKY, Lam LW, & Chien WT	Health, medical and psychological concerns of ageing family members and older adult children with intellectual disability. <i>Hong Kong Gerontology Nursing Newsletter</i> , Issue 29, p.2-4.	No	Yes Attachment 1	Yes	No
2017				*Low LPL, Chien WT, Lam LW, Wong KYK	A qualitative study protocol of ageing carers' caregiving experiences and their planning for continuation of care for their immediate family members with intellectual disability. <i>BMC Geriatrics</i> , 17, 81.	No	Yes Attachment 2	Yes	No

### 9. Recognized International Conference(s) In Which Paper(s) Related To This Research Project Was / Were Delivered

(Please attach a copy of each conference abstract)

Month / Year / Place	Title	Conference Name	Submitted to RGC (indicate the year ending of the relevant progress report)	Attached to this Report (Yes or No)	Acknowledged the Support of RGC (Yes or No)	Accessible from the institutional repository (Yes or No)
Aug 2018, Hong Kong	Case analyses of three mothers' experiences of raising multiple older adults with intellectual disabilities in the family	Community Health Conference 2018	No	Yes Attachment 3	Yes	No
June 2018, Japan	Current support and anticipating future needs of ageing caregivers and their ageing adult children with intellectual disability	The Asian Conference on Aging and Gerontology 2018	No	Yes Attachment 4	Yes	No
Sept 2017, Edinburgh	Ageing carers and their ageing family member with mild-moderate intellectual disability in Hong Kong: What needs and care do they have?	7th International Conference on Geriatrics Gerontology & Palliative Nursing	No	Yes Attachment 5	Yes	No
May 2017, Hong Kong	Elucidating understanding to strengthen ageing family carers capacity to continue caring for ID adults: Preliminary analysis from family interviews	40th Anniversary of Caritas Rehabilitation Service	No	No (Invited Symposium no abstract)	Yes	No
May 2016, Glasgow	Sampling issues using the grounded theory methodology: Applicability to family caregiving research of clients with dementia and intellectual disability	15th Qualitative Methods Conference 'Collaboration Considered Complexities and Possibilities across Communities and Cultures'	No	Yes Attachment 6	Yes	No

### 10. Whether Research Experience And New Knowledge Has Been Transferred / Has Contributed To Teaching And Learning

(Please elaborate)

This project has generated fruitful research experiences and new insights into the needs and concerns of ageing family carers' who continue to take care of and provide support for their ageing children with ID in their own homes. The data will be highly beneficial co-learning materials that can be shared among academic researchers to service providers and to carers who have ID persons in the family. Here, these teaching and learning initiatives need not be packaged to fit into the classrooms. Instead continual service development collaboration programmes and research-learning endeavor opportunities can arise from this project, where all parties teach and learn together. This project has led to the success in securing funds for an upcoming project (Project no: UGC/FDS11/M08/18) for researchers and front-line care providers to collaborate and learn about the formal caregiving experiences of persons with ID in order to directly impact and raise standards of care and practices for this needy population.

### 11. Student(s) Trained

(Please attach a copy of the title page of the thesis)

Name	Degree Registered for	Date of Registration	Date of Thesis Submission / Graduation
NA	NA	NA	NA

**12. Other Impact**

*(e.g. award of patents or prizes, collaboration with other research institutions, technology transfer, teaching enhancement, etc.)*

**Outstanding Poster Award**

**Low, L.P.L., & Wong, K.Y.K.** (2018). Case analyses of three mothers' experiences of raising multiple older adults with intellectual disabilities in the family. Poster presentation at the Community Health Conference 2018 (p.27), Open University of Hong Kong & Caritas Institute of Higher Education, Hong Kong, 30 Aug.

**Certificate of Recognition**

**Low, L.P.L., & Wong, K.K.Y.** (2017). Ageing carers and their ageing family member with mild-moderate intellectual disability in Hong Kong: What needs and care do they have? Oral presentation at the 7th International Conference on Geriatrics Gerontology & Palliative Nursing (p.59)., Edinburgh, 4-5 Sept.

**13. Public Access Of Completion Report**

*(Please specify the information, if any, that cannot be provided for public access and give the reasons.)*

<b>Information that Cannot Be Provided for Public Access</b>	<b>Reasons</b>
NA	



**RESEARCH GRANTS COUNCIL  
COMPETITIVE RESEARCH FUNDING SCHEMES FOR  
THE LOCAL SELF-FINANCING DEGREE SECTOR**

**FACULTY DEVELOPMENT SCHEME (FDS)**

**Completion Report - Attachment**  
*(for completed projects only)*

**RGC Ref. No.:** UGC/FDS11/H06/15

**Principal Investigator:** Prof. Lisa Pau Le LOW

**Project Title:** Exploring family caregiving experiences and identifying the process of the ageing carers' planning for continuation of care for the community-dwelling person with intellectual disability

**Statistics on Research Outputs**

	Peer-reviewed Journal Publications	Conference Papers	Scholarly Books, Monographs and Chapters	Patents Awarded	Other Research Outputs (Please specify)
No. of outputs arising directly from this research project [or conference]	1	5	0	0	1 Newsletter 1 Outstanding Poster Award 1 Certificate of Recognition