

LIVING WITH DISABILITY RESEARCH CENTRE



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13th August 2025

Outline

- Thesis title: Siblings' Involvement in Caregiving in the Chinese Context of Ageing with Intellectual Disabilities
- Structure of thesis
 - Introduction
 - More of the Same: A Document Analysis of the Government's Response to Ageing with Intellectual Disabilities in Hong Kong
 - Siblings of Adults with Intellectual Disabilities in Chinese societies: A Scoping Review
 - A Survey Study on Siblings' Involvement in Caregiving for Adults with Intellectual Disabilities in Hong Kong
 - Discussion and conclusion





Age Distribution of People with Intellectual Disabilities in Hong Kong

- The estimated number of people with intellectual disabilities is between 77,000 and 90,000, representing a prevalence rate of 1.0% to 1.2% (Census and Statistics Department, 2021)
- Only 41,400 people with intellectual disabilities are registered as holders of the Registration Card for People with Disabilities

	住院智障人士 Institutional residents with intellectual disability			居住在住戶內的智障人士 Persons with intellectual disability residing in households			整體人口 Total population
年齡組別/性別 Age group / Sex	人數 No. of persons	百分比 %	比率* Rate*	人數 No. of persons	百分比 %	比率* Rate*	百分比 %
年齡組別 Age group							
< 15	700	6.2	0.1	4 500	15.3	0.5	11.6
15 - 29	1 200	9.7	0.1	12 400	42.3	1.1	15.2
30 - 39	2 200	18.4	0.2	6 200	21.2	0.5	15.5
40 - 49	2 700	22.1	0.2	3 300	11.3	0.3	15.4
50 - 59	2 700	22.0	0.2	1 900	6.5	0.2	16.1
≥ 60	2 600	21.7	0.1	1 000	3.5	0.1	26.2
年齡中位數(歲) Median age (years)	Number in t	46 total: 1210 0)		Number i	n total: 293	45

- Among the population aged 15 and above, 14, 200 individuals (39.2%) are over the age of 40
- In residential services, 70% of service users are over the age of 40





In 1988, the Hong Kong Jockey Club Funded a Research Project on the Ageing of **People with Intellectual Disabilities**

1988-1995 Australian Scholar Lyn Gow



Australia and New Zealand Journal of Developmental Disabilities

ISSN: 0726-3864 (Print) (Online) Journal homepage: www.tandfonline.com/journals/cjid19

Survey of the needs of elderly people with mental handicap in Hong Kong

Lyn Gow & Rosalia Chow

To cite this article: Lyn Gow & Rosalia Chow (1989) Survey of the needs of elderly people with mental handicap in Hong Kong, Australia and New Zealand Journal of Developmental Disabilities, 15:3-4, 267-275, DOI: 10.1080/07263868900033731

To link to this article: https://doi.org/10.1080/07263868900033731



Published online: 10 Jul 2009.



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THE QUALITY OF LIFE OF AGEING PEOPLE WITH MENTAL HANDICAP IN HONG KONG: AN ACTION RESEARCH PROJECT

REPORT ON PHASE II

Prepared by:

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JUNE 1991

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OUALITY OF LIFE OF AGEING PEOPLE WITH MENTAL HANDICAP IN HONG KONG:

REPORT ON PHASE III

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Ouality of Life for Ageing People with Mental Handicap: Care Management in Hong Kong

by

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> Jockey Club Rehabilitation Engineering Centre The Hong Kong Polytechnic University

> > October 1995

Funded by The Hong Kong Jockey Club Charities Trust





Problems encountered in Gow's survey study (Gow & Balla, 1994)

Low response rate

- ☐ The estimated population is far larger than the number of individuals identified as holding a Disability Registration Card
 - > Estimated population (1986): 13,194 aged 40 and above
 - Identified: 631 individuals aged 45 and above with a Card
 - Eligible: 263 met the criteria

Main Difficulties

- ☐ Incorrect or changed addresses and phone numbers
- ☐ Death of individuals with intellectual disabilities
- ☐ Refusal to participate due to stigma
- ☐ Lack of IQ assessments hinders identification of older adults with suspected intellectual disabilities





Findings and Recommendations of Gow's Study

- Higher support needs (Gow, 1992)
 - People with intellectual disabilities aged over 65, compared to their younger peers aged 45–54
 - People who used residential services rather
 than those living with family
 Recommendations
- Support needs (Gow et al., 1992):
 - Less mobile, had fewer daily living skills, fewer social interactions, and more behavioural and health-related problems
- Those in the older age group who were living with families were supported by
 - Parents (30.0%)
 - Siblings (26.7%)
 - ☐ Nieces or nephews (23.3%) (Gow et al., 1991)

- People ageing with intellectual
 - disabilities (Gow et al., 1991; Wun et al., 1995):
 - Health care
 - Independent living skills training
 - Community participation support, including friendship development

Family caregivers (Gow et al., 1991):

- Enhance their understanding of intellectual disabilities
- Improve their caregiving skills
- Increase their motivation to seek help
- Policy and service model
 - Respite care
 - Caregiver allowance
 - Creating new homes for older people with intellectual disabilities and their parents





Research Question

How did the Hong Kong government understand ageing with intellectual disabilities and respond to this issue in light of the 1995 recommendations?



Method

Document analysis

□A systematic procedure for reviewing or evaluating a wide range of documents, including minutes of meetings, diaries and journals, letters and memoranda, newspapers, program proposals and organisational reports (Bowen, 2009), extracts meanings and develops knowledge (Corbin & Strauss, 2008)

Document text selection

- Inclusion criteria: i) Documents written by the Hong Kong government or any of its departments; ii) Documents that discussed the problem of ageing with intellectual disabilities or referred to actual or recommended policy measures related to ageing with intellectual disabilities.
- Search the websites of Social Welfare Department, Labour and Welfare Bureau, Legislative Council
- Phrases for searching: "ageing AND intellectual disabilit*" and "ageing AND disabilit*" (Chinse and English)
- Period: from 1995 to December 2024

Data analysis

Documents were imported into NVivo, open-coded, and inductively developed into themes





Identified Government Documents

A total of 53 documents

Category	No.
Funding and Service Agreements	3
Disability Policy Plan	6
Speech Manuscript	16
Government Report	10
Replied to Legislative Council	6
Financial Budget	8
Departmental Review	2
Service Information	2



Findings – What is the problem represented to be? (Part 1)

Sample quotation	Problem	Whose problem?
"Their [ageing] clients as people facing a 'deterioration in work abilities' and a		
'deterioration in health condition' (SWD, 2024a, 2024b)".		
"Rehabilitation training and/or physical exercises for sustaining the health and meeting the physical needs of service users (SWD, 2013)".	Physical decline	People ageing with intellectual disability
"2016 Report of Working Group on Ageing of People with Intellectual Disability (RAC, 2016) drew on findings from a Survey Study on Ageing Trend of People with Intellectual Disabilities (Pang, 2015) funded by LWB that asserted that "[A]dults with intellectual disabilities have a higher likelihood of having chronic illnesses compared to age-matched adults without disabilities, and this phenomenon is particularly pronounced in younger age groups" (RAC, 2016, p. 28).	Early onset of ageing	



Findings – What is the problem represented to be? (Part 2)

Sample quotation	Problem	Whose problem?
'Set up health education for parents and carers of people with intellectual		
disabilities and provide them with more health care training in respect of	Inadequate caregiving	
their children with intellectual disabilities and enhance their knowledge of	capacity	
disease prevention' (LWB & SWD, 2017).		Family caregivers
'Providing allowance for low-income carers of persons with		
disabilities' to 'ease the financial pressure on carers arising from the	Care burden	
need to take care of person with disabilities' (LWB & SWD, 2017).		
'They are in need of rather than intensive skill training' (RAC, 2007).		
'The Social Welfare Department earmarked approximately HK\$26 million	Inappropriate services	Service providers
in recurrent expenditure during 2019-20 to enhance speech therapy		
services to address speech and swallowing problems caused by ageing or		
severe disabilities among service users' (RAC, 2020).		



Findings – Government's responses to ageing with intellectual disability (Part 1)

- Extending the scope of adult services to address issues of ageing with intellectual disabilities
 - ☐ Add-on programs on existing day services since 2005, on residential service in 2023
 - Work Extension Program (WEP) on Sheltered Workshop
 - Extended Care Program (ECP) on Day Activity Centre
 - A pilot project funded residential hostels to provide 24-hour support.
 - Eligibility
 - WEP: Aged 60 or above, or aged 40 to 59 with an assessment of functional deterioration by a physiotherapist or occupational therapist
 - ECP: Aged 60 or above; aged 50 to 59, with an assessment mentioned above
 - ☐ The funds for add-on programs were primarily used to appoint support workers
 - > They need to share social workers, other allied health professionals and managers with day or residential services
 - Service nature of add-on programs
 - Medical and health care, therapy services (e.g., physiotherapy), casual work and social activities, self-care training and individual counselling
 - □ No add-on programs for services for adults with the highest functional abilities, such as Supported Employment





Findings – Government's responses to ageing with intellectual disability (Part 2)

Enhancing the capability of disability services

- Despite the government claim that the additional funding benefited people who were ageing and their family members, resources were allocated to enhance the overall capacity of disability services
- Enhancing the workforce of day and residential services
 - Senior social work management staff, medical and allied health staff, and support workers
 - □ Skill improvement, e.g. adopting the Ageing Checklist for Persons with Intellectual Disability to assess ageing
- > Enhancing the capacity of community services
 - Develop case management model in District Centres in 2014
 - ☐ The number of District Centres increased from 16 to 21 between 2020 to 2022
- Enhancing support for family caregivers
 - Services: Supporting parent self-help organisations, expanding the number of family resource centres, establishing a caregiver hotline, providing caregiver training, and enhancing respite services
 - ☐ Policies: Special Needs Trust and allowance for low-income caregivers





An Example

Initiative (year of implementation)	Purpose	Target Service Users	Programme / Service Component	Additional Resources
(4) Enhanced Physiotherapy Service and Health Care (EPSHC) (2010)	To strengthen support services for ageing residents living in HSMH and HMMH, additional resources for provision of physiotherapy service at HSMH and health care service (i.e. for employing Health Workers) at HMMH are provided.	HMMH residents.	 Physiotherapy service for residents of HSMH (including those services users of ECP). Provision of daily health care service to maintain or improve residents' general health conditions for residents of HMMH (including those services users of WEP). 	\$78,400 to \$198,000 from LF was granted for each HSMH in 2010 for purchase of F&E such as office furniture and training equipment.

Social Welfare Department. (2013). Report of the Task Group on Ageing of Users of Rehabilitation Services. Social Welfare Department.



Discussion and Conclusion (Part 1)

- With few exceptions, the government has not pursued specialist or independent programs targeted at ageing people or their families
- The few specific programs for ageing people were attached to services that primarily supported clients with higher support needs Sheltered Workshops or Day Centres
 - □ Such initiatives may have been informed by Pang's (2015) finding about the higher care needs of people with more severe disabilities
 - These initiatives may also have resulted from pressure by NGOs for funding to meet their increasing needs, as the block funding model only took into account the number of clients and severity of their disability
 - Adding programs to existing services avoided costs of additional facilities for new separate programs (SWD, 2013), given Hong Kong's high population density and limited land supply (Jim & Chen, 2010)
 - No specific ageing programs were developed to support people with lower support needs suggesting that the government may assume these clients would transition to high-support services if they experienced age-related physical or health decline
 - > Overlook the needs of support the retirement of clients working in integrated settings





Discussion and Conclusion (Part 2)

- The main government strategy during this period of enhancing the overall capacity of the adult disability service system
 - Served two purposes: **Meeting** the demand from younger clients for places in the system while also **addressing** the increased needs of ageing clients, particularly around health-related issues
 - Compared to day services, residential services received more additional resources, which aligns with Gow's (1992) and Pang's (2015) findings that clients who were using residential services were more likely to have higher health and care needs than those living at home with families
- The Hong Kong government did not respond to ageing issues until 2005, a decade after Lyn Gow's 1995 report.
 - Before 1995, there were low number of clients ageing with intellectual disabilities and high demand for services from younger adults
 - However, in the years following 1995, the average age of clients gradually increased, given the low dropout rate



Discussion and Conclusion (Part 3)

- Advantages and disadvantages of government's response to ageing with intellectual disabilities
 - Extending the scope of existing services to include older clients
 - Advantage: may benefit older clients by ensuring continuity of care and relationships
 - Disadvantage: may increase internal coordination costs and imposed a higher workload on management and administrative staff; may have stifled the development of innovative programs as funding was allocated to existing service providers
 - The expansion of family support measures (e.g. educational activities and allowances for caregivers)
 - Advantage: may reduce the burden of family care
 - Disadvantage: frame the challenges very narrowly, concentrating on parental capacity, and overlook the support from other family members, especially to siblings and the intergenerational transition of care
- Compared to Gow et al.'s recommendations (Gow et al., 1991, 1992)
 - Consistent: improving healthcare, offering respite care, and introducing a caregiver allowance
 - Explored but not progressed: shared aged care homes for older parents and their adult children with intellectual disabilities
 - ➤ Be not considered: promoting independent living, community participation, and developing diverse relationships beyond disability services



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