



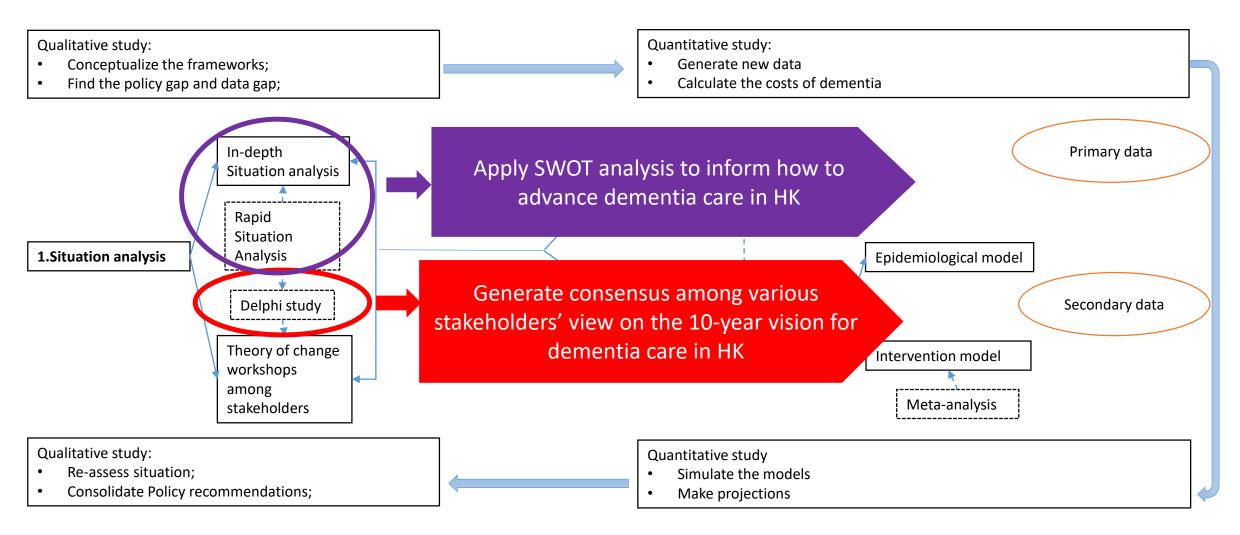
## Hong Kong's situation and stakeholders' views on dementia

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The University of Hong Kong



## **Research Design of TIP-CARD**

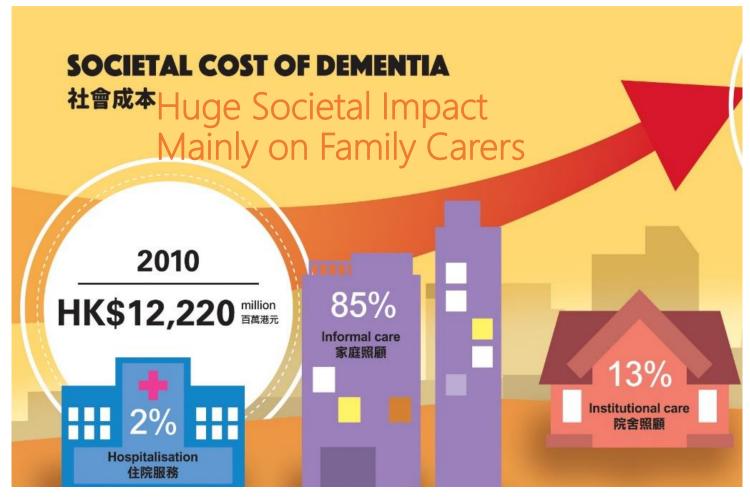


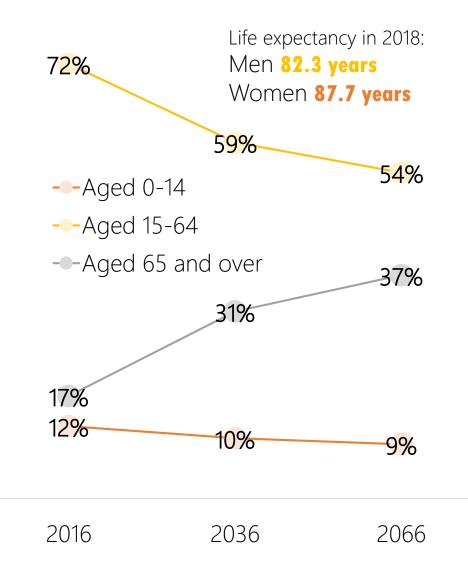


# Rapid Situation Analysis [Brief desk review & infographic design] Apr- Nov 2019







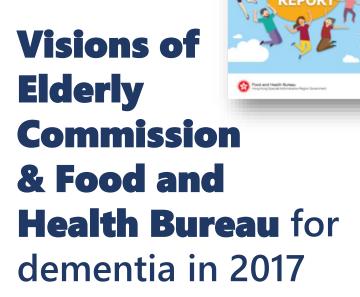


100,000 people living with dementia in 2009 -> 330,000 in 2039 Earlier study suggested 11% diagnostic rate; new study underway





"Services for elderly persons with dementia should be strengthened. The issue of dementia should be considered as an integral part in the whole spectrum of elderly services and a multidisciplinary approach should be adopted."



- Public education on awareness 加強教育公眾對認知障礙症的了解和認識
- 2 Territory-wide prevalence studies 進行全港認知障礙症患病率研究
- A common reference to support primary care 編制通用的參考資料為基層醫療工作提供支援
- 4 Enhancing the role of primary care 加強基層醫療的角色
- 5 Strengthening capacity of specialist services 加強專科服務能力

- 6 Increasing supply of healthcare manpower and strengthening training 增加醫療人力供應並加強其培訓
- 7 Strengthening social care infrastructure to allow persons remain in the community 加強社會護理基建,讓患者盡量留在社區
- **8** Enhancing medical-social collaboration to provide person-centered care 加強醫社合作以提供以人為本的照顧
- 9 Promoting end-of-life and palliative care 推廣在社區接受生命晚期照顧和紓緩治療
- 10 Enhancing support for carers 加強對照顧者的支援

### CARE SERVICE IN HONG KONG 香港的照顧服務

Social Care Service 社會服務

Healthcare Service 醫療服務





Food & Health Bureau



Social Welfare Department 社會福利康



**Elderly Branch** 安老服務



Community Care Service 社區照顧服務



**Residential Care** Service 院舍照顧服務

41 DECCs

41間長者地區中心 Community

60 IHCS

60隊綜合家居照顧服務

34 EHCCS

34隊改善家居及社區照顧服務

77 DEs/DCUs

77間長者日間護理中心/單位

**C&A Home** 護理安老院

**Nursing Home** 

Providing 27.567 subsidised places (including Enhanced **Bought Place Scheme**) 提供27.567資助宿位(包括改 善賈位計劃)



**Hospital Authority** 醫院管理局

43 Public Hospitals# 43間公立醫院

73 GOPC# 73間普通科門診診所

49 SOPC# 49間專科門診診所



**Department of Health** 衛生署

18 Elderly Health Centres 18間長者健康中心

18 Visiting Health Teams 18隊長者健康外展隊伍



#### DCSS

- For people with mild or moderate dementia & carers
- Centre-based with home visits
- Interdisciplinary care to reduce carer burden
- 5-9 months
- Serving 2,000 families/year
- What happen after service?

**Formal Care** in Hong Kong

### CARE SERVICE IN HONG KONG 香港的照顧服務

Social Care Service 社會服務

Healthcare Service 醫療服務



Labour & Welfare Bureau 勞工及福利局 Public services 公共服務



Food & Health Bureau 食物及衛生局



Medical-Social Collaboration 醫社合作

Dementia Community Support Scheme (DCSS): provided by all 41 DECCs and 7 hospital clusters



Self-finance / Private Services 自負盈虧/私營服務



At least 18 dementia-specific day care units 至少18間提供認知障礙症專門服務的日間護理中心



**47,789** non-subsidised residential care places 47,789個非資助院舍宿位



12 private hospitals# 12間私家醫院



2150 registered private clinics# 2150間註冊私家診所



#### DCSS

- For people with mild or moderate dementia & carers
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- 5-9 months
- Serving 2,000 families/year
- What happen after service?

Formal
Care in
Hong Kong

## **Formal Care** & **Public Awareness** in Hong Kong

## **Projects & New Initiatives**

- District Health Centre
- Care in Greater Bay Area
- Dementia Friends
- Numerous philanthropy funded projects & services operating by NGOs

## Sustainability & Synergy?

https://www.bayarea.gov.hk/en/opportunities/mainpointsmedical.html#opportunitiesPhoto-2

https://m.ehealth.gov.hk/en/publicity\_promotion/ehealth\_news\_18/m illionth registrant.html

https://www.dementiafriends.hk/en/









Tools to Inform Policy 華人社會認知障礙症策略工具

Promote integration of medical and elderly care services for creating an environment favourable for HK residents to retire in Guangdong

## **Informal (Unpaid) Care** in Hong Kong



People with dementia require daily 5.8 hours of care & support in activities of daily living.6

認知障礙症患者需要每天5.8小時 的照顧和支援來進行日常生活活動。



Note: Earlier US study found assumption on informal care cost (replacement vs opportunity cost) affects estimation by a factor of >2

> Hurd, M. D., et al. (2013). Monetary costs of dementia in the United States. New England Journal of Medicine, 368,1326-1334.









2018



HK\$0.9 billion



HK\$0.9 billion



HK\$1.8 billion

**Invisible Costs** Carers. Employers, & Society Bears

- Leave job / change from FT to PT mode
- Lost productivity
- 'Absenteesim'

2040







HK\$2.6 billion



HK\$5.3 billion

2060

Total Cost



HK\$4.3 billion



HK\$4.1 billion

Kong: The **Projected Societal** Cost of Eldercare in Hong Kong 2018 to 2060.





## **Informal (Paid) Care** in Hong Kong



Photo from HKSAR Government (2019). Retrieved from <a href="https://www.info.gov.hk/gia/general/201901/22/P2019012200399.htm">https://www.info.gov.hk/gia/general/201901/22/P2019012200399.htm</a>

Chan, C. K. L. (2012). Retrieved from <a href="https://theses.lib.polyu.edu.hk/handle/200/7623">https://theses.lib.polyu.edu.hk/handle/200/7623</a>; Chong, A. M., et al. (2014). J Gerontol B Psychol Sci Soc Sci, 69(6), 966-972. doi:10.1093/geronb/gbu034; Chong, A. M. L., et al (2017). Aging Ment Health, 21(10), 1023-1030. doi:10.1080/13607863.2016.1191059; Census and Statistics Department. (2019). <a href="https://www.statistics.gov.hk/pub/B11303032019AN19B0100.pdf">https://www.statistics.gov.hk/pub/B11303032019AN19B0100.pdf</a>; Yan, E., & Kwok, T. (2011). Int J Geriatr Psychiatry, 26(5), 527-535. doi:10.1002/gps.2561; Cheng, S. T., Lam, L. C. W., Kwok, T., Ng, N. S. S., & Fung, A. W. T. (2013b). Gerontologist, 53(6), 998-1008



### **Borrowed Strength**

- Currently 386,075 foreign domestic helpers (9.7% of labour force)
- Philippines (54%) & Indonesia (44%)
- In 9% households with an older person (13.2% if older persons only)
- 26-54% of families living with dementia
- Moderates the relationship between stressors (care needs) & carer distress
- Social Welfare Department Pilot Scheme on Training for Foreign Domestic Helpers in Elderly Care

## **Situation Analysis: Desk Review**



Sep 2019 – Jun 2020

Guided by the STRiDE project - In-depth Situational Analysis: Desk-Review Topic Guide

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Factors that have stimulated strong dementia care performance or factors that are considered an advantage for meeting

policy goal

dementia in Hong Kong S New initiatives & areas of growth available to the dementia care sector(s) / elements that could be harnessed to meet policy goal

Factors that have increased dementia care costs / reduced dementia care quality / would pose disadvantage for meeting policy goal

Factors that negatively affect dementia care performance or other elements that could cause trouble in meeting policy goal

Docrat, S., Lorenz K., Comas-Herrera, A. (2019) STRiDE situational analysis: guidance on developing SWOT analyses from the desk review. STRiDE research tool No.4 (version 1), CPEC, London School of Economics and Political Science, London.



public awareness

#### medical-social collaboration

Government & filial piety philanthropy funded service

Availability of domestic helpers



**policy vision** at Bureau level

public-private partnership
Greater
Bay remote service

district-based coordination

Dementia Friends

Tools to Inform Policy Chinese communities' Action in Response to Dementio

3x increase in PLwD in 2 decades

migration of younger population

economic & political stability

high prevalence of

risk factors

lacks
prioritisation or
long-term planning



service fragmentation

lacks primary care involvement great demand

sustainability

limited physical space

manpower



## **Delphi Study 10-year vision for dementia in Hong Kong**

- Policymaker/ government sector
- Philanthropy organization
- Academic/ researcher
- Social service providers
- Health service providers
- PwDs & families
- •General public

Define stakeholders

#### Generation Phase

- Solicit viewpoints from stakeholders about the 10-year vision on dementia care.
- Qualitative inquiry:
- Things to make happen for PwD & their families, and the most desirable support for them.

- Rate the level of agreement on the statements being generated in the previous phase.
- Check for the content adequacy.

Validation Phase

PwD & carer phone survey

Stakeholder Online survey

Delphi Study 2 [Apr – Jun 2020]

Delphi Study 1 [Nov 2019 – Jan 2020]



## **Delphi Study Demographic for Delphi Study 1 - Online Survey**

#### Total no. of participants

- Generation = 90
- Validation = 70 (Response rate = 78%)

#### Age

Average: 47±25 years

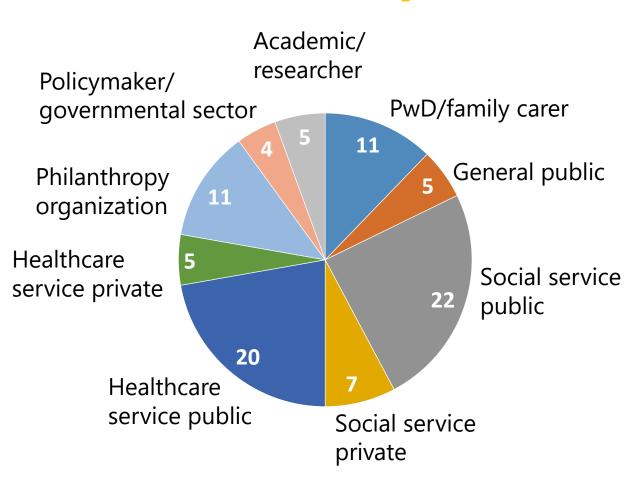
#### Gender

- Female: 56
- Male: 34

#### Education level

- Tertiary education or above: 85
- Secondary education: 5

#### **Stakeholders Categories**





## **Delphi Study Demographic for Delphi Study 2 - Phone Survey**

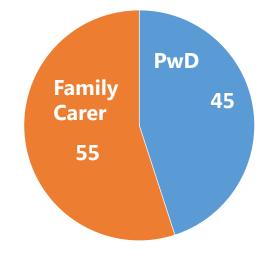
#### **Family Carer**

- Age
- Average: 60±26 years
- Gender
- Female: 43 | Male: 12
- Education level
  - No formal education: 1
  - Primary: 8
  - Secondary: 27
  - Tertiary or above: 19
- PwD dementia severity
  - MCI: 7
  - Mild: 22
  - Moderate: 16
  - Severe: 10
- Relationship with PwD
  - Spouse: 16
  - Adult child: 35
  - Sibling: 2
  - Daughter-in-law: 2

## Total no. of participants:

Generation = 100

Validation = 83 (Response rate = 83%)



#### Service utilization

- Specialist out-patient clinics: 100
- DECC/NEC: 83
- Day care centre: 33
- Home care service: 11
- RCHEs: 9
- Respite service: 9
- Others (e.g. Outreach service, Dementia Community Support Scheme, HKADA): 28

#### **PwD**

- Age
- Average: 79±19 years
- Gender
  - Female: 35 | Male: 10
- Education level
  - No formal education: 15
  - Primary: 21
  - Secondary: 5
  - Tertiary or above: 4
- Dementia severity
  - MCI: 16
  - Mild: 26
  - Moderate: 3



## **Results of Delphi Study 1: Six Key Themes**

- Preventive strategies & public education;
- Accessible & equitable screening & diagnostic service;
- 3. Effective referral with 'through train' service.
- ↑ medical-social, private-public, & wider seamless collaborative care;
- 2. ↑ Manpower capacity & dementiaspecific training across service sectors
- Dementia-specific policy & legal framework;
- Evidence-based care roadmap with stakeholder involvement, central coordination;
- 3. Shared burden by the society with equitable service.

Early prevention, screening & diagnosis

Care & intervention services

Capacity
building for
care providers
& service
integration

Family carer support

Dementia care planning & policy setting

Increase preparedness of society for dementia

- 1. One-stop service to address personcentered care needs along the disease course.
- 2. service accessibility, availability, affordability & specificity;
- 3. Optimized care for aging in place
- 4. Quality ACP & LTC service
  - 1.Skill, knowledge, online information system, hotline.
  - 2. Welfare, escort transportation
  - 3. Psychosocial, mutual carer and flexible respite care;
- Increase public knowledge & awareness
- 2. Dementia-friendly neighborhood & facilities
- 3. Novel research to enhance curative, E-based, and care Ix.



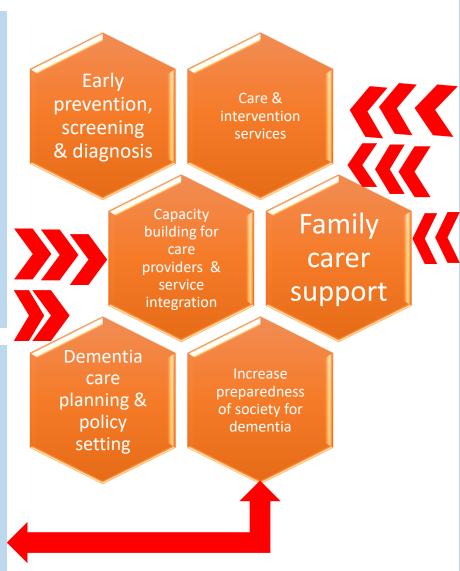


## Enhance service coordination & LTC planning

- Strengthen case management to enable continuity of care
- 2. Person-centered family-based LTC
- 3. research advancement (medication, gerontechnology, Ix)

## Age- & dementia friendly community

- Optimized normality for living with dementia
- 2. Suitable housing
- 3. Dementia-specific facilities& recreation;
- 4. Service of high equitability



#### Strengthen care service to PwD & carers:

1. Community care

Accessible dementia-specific training & more options on activities;

- 2. Health care service
- Comprehensive health assessment with specialist follow-up care;
- Person-centered consultation service; Informed care.
- 3. Home-based support
  Home assessment, facilitates, training for
  socially deprived/ frail cases
- 3. long-term care

  Dementia-specific day care service with

  more respite care.
- Quality residential care
- 4. Welfare support & subsidized care services
- 5. Carer support informational & emotional

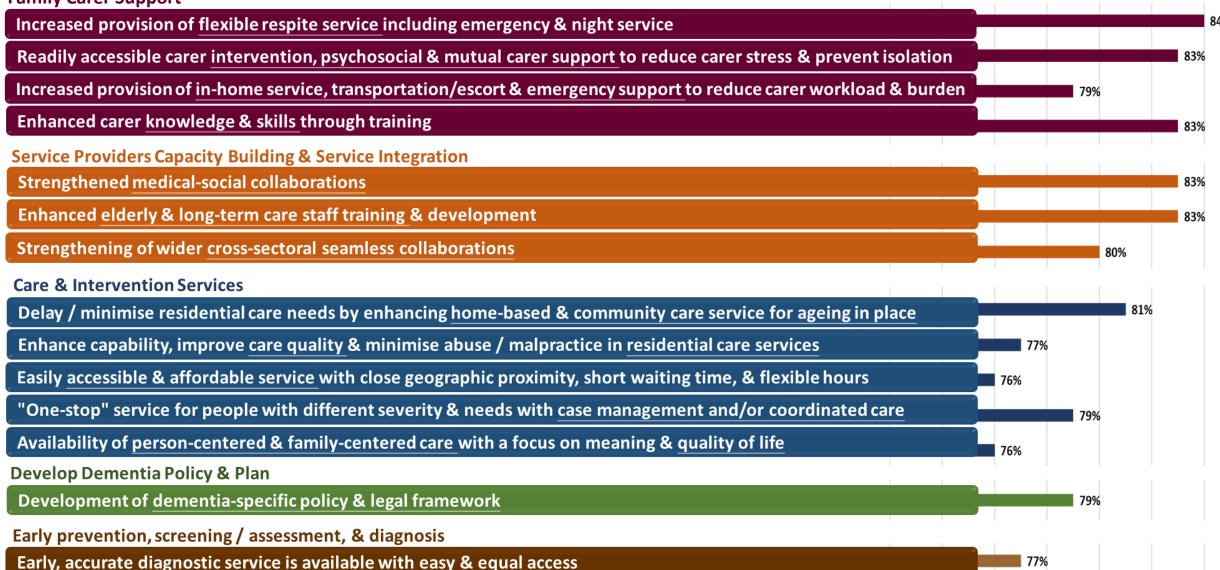
### **Delphi Study 1**

## Tools to Inform Policy Chinese communities' Action in Response to Dementic 華人社會認知障礙症策略工具

#### 14 Items with Very High to High Consensus

Median = 4.5 - 5; Interquartile range (IQR)  $\leq 1$ ; % of respondents rating 4 or  $5 \geq 75\%$ 

**Family Carer Support** 



## **Delphi Study 2**

## Tools to Inform Policy Chinese communities' Action in Response to Dementio 華人社會認知障礙症策略工具

#### 14 Items with Very High to High Consensus

Median = 4.5 - 5; Interquartile range (IQR)  $\leq 1$ ; % of respondents rating 4 or  $5 \geq 75\%$ 

Building an age- and dementia- friendly community

Building an age- and dementia- friendly community		
Enhance public awareness, attention and early recognition of dementia through education and publicity	93%	
Strengthening home-based care		
Provide more support for daily living, especially for elderly who are living alone, double aging or having health problems	93%	
Persons with dementia can live at home safely through home assessment and facility improvement	93%	
Provide more home training and treatment, especially for elderly with health problems who have difficulty to go out or lack of social interest	92%	
Strengthening community support to maintain social, physical and mental health of both persons with dementia and carers Community care services		
Provide more centralized and specific training through building more elderly centers (i.e., DECCs/NECs) and cognitive training centers in each district, with closer location to living place or shuttle bus services	94%	%
Long-term care services		
Provide more respite services and day care centers	92%	
Enhance <u>care quality</u> of day care centers	93%	
Health care services		
Provide more comprehensive heath examination to identify persons with dementia as early as possible and follow up with specialists regularly	92%	
Provide centralized or specialized health care centers, and escort services to facilitate the convenient use of health care services		95%
Improve health care quality by allowing persons with dementia and carers to understand the treatment process and having sufficient		
consultation time	92%	
Financial support	93%	
Provide more <u>free-of-charge or subsidized</u> training, social and health care services	3570	
Enhancing overall service coordination and long-term planning		050/
Review current service assessment mechanism, broaden application requirement and shorten waiting time		95%
Invest more resources and strengthen the manpower by training more professionals to meet the huge needs of dementia care services		95%
Strengthen case management by a dedicated social worker taking the initiative to follow up the situation on a regular basis	92%	



Building a dementia-friendly community
建設認知友善社區

Good **public awareness** of dementia

PwD & carers receive more respect & acceptance

There is a dementia-friendly environment

More community facilities & recreational activities

Early recognition of sign of dementia in the family level 2 P期診斷及醫療支援

Early detection of dementia

Effective **primary prevention** are in place

There is accurate, easily & equally accessible diagnostic service

There is accessible comprehensive & good quality healthcare service

There is **regular screening** for symptomatic & healthy population

Integrated healthcare service through building dementia-specific units

There is a clear triage system & care path for appropriate referral Number of PwD is **reduced** 

Review on existing advanced care directives

4 加強社區及長期照顧

More suitable **housing** for PwD

Living allowance & welfare support according to individual needs

Easily accessible service with close geographic proximity & flexible hours Increased training in elderly centers

Good quality care with minimal abuse / malpractice

Person-centred & family-centred care focusing on

meaning & quality

of life

Centralised care through building more dementia-

specific units

Strengthening home-based care 加強家居照顧

PwD have access to home assessment & improvement

Increased support for PwD who are living alone or double ageing PwD have access to daily living support

PwD have access to in-home training & treatment Achieving ageing-in-place

Need for **residential** care is minimised

5 支援家庭照顧者

Financial support are available for carers to use service

Carers have access to carer interventions & training

Carers have access to in-home service, transportation / escort & respite Carers are equipped with proper knowledge & skills

Carers are prevented from excessive stress, burden & isolation

Increased carer capacity

Proper **staff training** & development

Sufficient healthcare manpower

Sufficient long-term care manpower

Improved service coverage for young-onset & special groups

Review current service assessment mechanism

Broaden service application requirement

6 制定政策及長遠規劃

Increased support in research, innovative intervention & gerontechnology

Reduce service waiting time

The **Greater Bay Area** development of dementia care

There is close collaboration between medical & social care

Care coordination with case management There is seamless collaboration across wider sectors

"One-stop" service across dementia stages & varied needs Demonstrated effectiveness & cost-effectiveness of integrated care model

There is a dementia-specific policy & legal framework

