Consultancy Study on

Needs and Support Required of Carers of Elderly Persons and of Persons with Disabilities in Hong Kong

Main Report

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Executive Summary

Background of the consultancy study

1. Support and care for elderly persons and persons with disabilities constitute an important part of the social welfare system in Hong Kong. The Elderly Commission formulated the *Elderly Service Programme Plan* in 2017. In addition, the government released the new *Persons with Disabilities and Rehabilitation Programme Plan* in July 2020. Informal unpaid carers (such as family members, relatives and friends) play an essential role in the daily living, medical and social care, as well as social engagement of elderly persons and persons with disabilities to assist them to reside in the community. The well-being of elderly persons and persons with disabilities can therefore be significantly improved through the enhancement of support for carers. In view of this, the Labour and Welfare Bureau commissioned The Hong Kong Polytechnic University Consulting Team in July 2020 to conduct a consultancy study on the needs and support required of informal unpaid carers (carers) of elderly persons and persons with disabilities in Hong Kong.

2. The Consultancy Study's objective is to propose evidence-based and carer-centred recommendations to support carers of elderly persons and persons with disabilities, with the aim to enable carers to maintain a balance between their caring responsibilities and a life outside caring. Study findings will also facilitate integrating and prioritising resources injected by the Government, and examining relevant initiatives/programs by NGOs, social enterprises, academics, charities, and business sector, so as to provide effective, carer-centric and sustainable support to carers of elderly persons and persons with disabilities.

3. The consultancy study consists of eight component studies, aiming at obtaining empirical findings about the needs, strengths, and support required of carers of elderly persons and persons with disabilities through triangulation of the research methods and data sources. The eight studies include reviewing previous empirical findings and theories about carers' issues and service needs, using other economies as a reference, engaging with carers and various stakeholders so as to achieve an in-depth understanding of carers' needs and service expectations, as well as analysing pilot

schemes and exploring ways forward regarding providing resources and support to carers. (See details in **Chapter 1** and *Table 1.1*).

4. The consultancy study utilised both qualitative and quantitative methods. The qualitative research included 224 participants across focus groups and interviews, whereas the survey studies involved valid responses from 4 571 participants, making a total of 4 795 participants including carers, care recipients, and stakeholders (such as government officials, professional staff of elderly and rehabilitation services, service operators, representatives of private companies, etc.). The carer participants were selected from comprehensive user lists of elderly and rehabilitation services. In view of the varying degrees of nonresponses of questions among the returned cases in the survey studies, the Consulting Team reported the descriptive statistics and analysis based on response rates of the respective questions instead of the total returned number.

Findings from the review on literature and practices of other economies (Studies 1 and 2)

5. The Consulting Team reviewed 107 papers and categorised the findings into four areas, as follows: 1) concepts and models of caregiving, 2) care burden and risk, 3) existing services/support for carers, and 4) policies for carers. Factors associated with care burden and risk were identified as follows: care recipient conditions, caregiving role conflicts, caregiving tasks, socio-economic status, duration/amount of care, co-residency with care recipient, familial relationship, care competency, accessibility of community services/formal support, and social stigma.

6. Nine economies (Australia, Canada, the United Kingdom, the United States, Sweden, Guangzhou, Taiwan, Japan, and Singapore) were selected for the review. Four of them (Australia, the United Kingdom, Guangzhou, and Singapore) were then selected for in-depth analysis, with Singapore being chosen as the destination for a virtual field trip. Common carer support practices in these four selected economies include a clear definition of family carers, a national/regional care strategy plan, carer-supporting legislation (in Australia and the UK), financial assistance for carers, carer-friendly employment measures (e.g., paid leave and flexible work arrangements), tax discounts for carers, training/educational programmes, counselling, and respite care.

7. While most of the economies under our review have national or regional policies for family carers, these policy commitments are often faced by difficulties when being

translated into comprehensive support structures for carers, particularly financial assistance. Although direct financial support services for carers do exist in most economies, there are still barriers to their receipt. Eligibility criteria vary greatly and are complex; application procedure is lengthy; benefits often come with trade-offs in terms of restrictions on employment and means-testing.

Findings from the carers of elderly persons and persons with disabilities (Studies 3 and 4)

8. Thirty-one carers of elderly persons and 49 carers of persons with disabilities participated in the focus groups; over 70% were female in both types of carers, with an average age of 65.7 years. Seven themes emerged from the guided discussions of the focus group surrounding the needs, strengths and services expectations of the carers:

  1) *Role of carers:* The role of carers mainly includes caregiving tasks in ADL and IADL, accompanying care recipients to medical appointments, providing financial assistance, and providing emotional support. The carers shared that they engaged in multifaceted care provision activities depending on the care needs of their care recipients.
  2) *Care burden and its attributes:* The carers shared that they experienced an enduring and considerably heavy physical, mental, and financial burden of caregiving as well as role conflicts and relationship difficulties related to caregiving. The characteristics of both the care recipients and the carers contributed to this care burden.
  3) *Service expectations and needs:* Some carers suggested that building up a one-stop platform would be helpful for them to receive caregiving information for performing caregiving tasks. The carers raised the need for easily accessible information/resources and the adoption of case management approaches.
  4) *Strengths of carers:* The carers of elderly persons and persons with disabilities identified individual strengths in caregiving in terms of self-awareness, stress management skills, self-efficacy, problem-solving, help-seeking, enhancing family bonds, and fulfilling responsibilities. They also shared their appreciation of the support they received from their social networks. The majority of carers of elderly persons and persons with disabilities agreed that strengthening their

caregiving and cognitive skills (e.g., problem solving, memory, etc.) could help them handle the day-to-day challenges of caregiving more effectively.

5) *Facilitators of and barriers to service utilisation:* The carers of elderly persons and persons with disabilities shared that the accessibility of information, the application processes, and the availability of services are crucial factors in service utilisation. They also expressed that strict eligibility requirements, the complexity of application processes, and long waiting times are barriers to receive services or allowances.

6) *Characteristics of carers at high risk:* The carers of elderly persons and persons with disabilities reported that managing behavioural and psychological problems of care recipients is very stressful for them. The characteristics of carers at high risk include long and intensive caregiving tasks, history of domestic violence, behavioural disturbance of care recipients, lack of recognition and support from carers' immediate circle, caregiving for multiple dependents with disabilities, and having suicidal thoughts and/or murder-suicide thoughts. The partial disruption of community services and social isolation measures during the COVID-19 pandemic also further affected the mental health of carers.

7) *Use of technology to assist caregiving, and barriers to utilisation:* The carers shared that use of information and communication technology was conducive to seeking support services and promoting knowledge acquisition among carers. Insufficient/lack of knowledge, skills, and budget are barriers to using technology in caregiving.

9. A total of 966 carers of elderly persons and 1 307 carers of persons with disabilities were included for the quantitative analysis of Studies 3 and 4, respectively[1]. Most carers of elderly persons were female (74.5%) with an average age of 54.5 (*SD* = 18.1), who spent an average of 41.9 hours (*SD* = 52.4) on caregiving per week and most carers took care of their elderly parents (57.9%) or their spouse (22.6%). Likewise, the majority of carers of persons with disabilities were female (82.5%) with an average age of 51.3 (*SD* = 12.8), who spent an average of 77.2 hours (*SD* = 54.3) on caregiving per week, and most took care of their children with disabilities (87%).

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[1] Only percentages are shown in the descriptive statistics due to the different response rate of each questionnaire item.

10. In-depth statistical analysis of carers of elderly persons showed that being a spousal carer ($r = 0.074$, $p = 0.038$), being female ($r = -0.093$, $p = 0.005$), having a lower income level ($r = -0.098$, $p = 0.004$), and having a medical diagnosis of emotional issues ($r = 0.255$, $p < 0.001$), cancer ($r = 0.107$, $p = 0.001$), diabetes ($r = 0.073$, $p = 0.031$), or poorer perceived health status ($r = 0.298$, $p < .001$) were significantly associated with a higher care burden, whereas for carers of persons with disabilities, being a younger carer ($r = -0.13$, $p = 0.001$), being a male carer ($r = 0.14$, $p < 0.001$), and carers with a medical diagnosis of cardiovascular disease ($r = 0.083$, $p = 0.031$) and difficulty in mobility ($r = 0.261$, $p < 0.001$) were significantly associated with a higher care burden. The majority of both carers of elderly persons (87.6%) and carers of persons with disabilities (76.9%) perceived their health status as fair to very good.

11. Unlike in the case of carers of elderly persons, there is a coexistence of strength/positive aspects and care burden among carers of persons with disabilities. This seemingly contradictory finding may be attributed to the fact that carers with stronger carer strength may have greater expectations of themselves, leading to a higher level of care burden.

12. Both types of carers perceived the “Other services” (respite, emergency support, cash allowance and case management, etc.) as the most useful type of support (mean score = 3.81 and 4.18 out of 5, for carers of elderly persons and carers of persons with disabilities respectively), which is followed by “Support from family and friends” (mean score = 3.67) among carers of elderly persons, and “Centre-based services” (mean score = 4.09) among carers of persons with disabilities.

Findings from the stakeholders of elderly and rehabilitation services (Studies 5 and 6)

13. A total of 27 and 39 stakeholders from elderly and rehabilitation services, respectively, participated in the focus groups. Around 70% of these participants were female aged between 31 and 50 years. The two types of stakeholders had worked an average of 5.2 years (*SD* = 5.7) and 9.9 years (*SD* = 7.0) in the elderly and rehabilitation sectors, respectively. Five themes emerged from the guided discussions of the focus group surrounding the needs, challenges, and areas for improvement of carers, from the perspective of all stakeholders:

1) *Existing services:* The stakeholders pointed out there were services for carers of elderly persons, including role adaptation coaching, emotional support, peer support groups, training in caregiving skills, carer allowance, respite care, social activities, and stress reduction. The stakeholders considered that although financial assistance was one of the direct ways to support carers in carrying out their caregiving role, support services such as counselling, group activities, case management, and skills training were equally important.

2) *Carers' needs:* The stakeholders recognised carers' needs on two levels: individual and societal. Individual-level service needs include respite services, educational and caregiving skills training, financial assistance, one-stop information centres, transportation for care recipients, care planning for care recipients, and case management. Societal-level needs include social recognition and the establishment of carer-friendly working arrangements.

3) *Challenges faced by carers:* A lack of knowledge and of caregiving skills, inadequate support services during the pandemic, lack of recognition of carers in society, inadequate coordination of carer support services across different bureaux, and uncertain service continuity for care recipients.

4) *Factors affecting the needs of carers:* The traditional culture that it is an obligation to take care of elderly parents or children; sole carers of elderly persons or those with multiple caregiving roles; and carers' age, household income, educational attainment, social support network, etc., were found to affect the needs of carers.

5) *Areas for improvement:* Preventive measures rather than remedial action should be implemented to prevent carer burnout; collaboration among disciplines and between agencies and funding models should be strengthened; emergency support, such as different types of respite (home-based, residential, or centre-based) could be reinforced; formal services or allowances for elderly persons and carers were fragmented, limited, and inflexible; budget should be increased to provide additional manpower, space and service quota; and a more carer-friendly atmosphere should be cultivated in Hong Kong in the long run.

14. A total of 360 and 709 stakeholders from elderly and rehabilitation services, respectively, were included for quantitative analysis. About a third of the stakeholders

from elderly services were aged between 31 and 40 (32.8%), with the majority being female (75.6%) and social work being the major professional background among them (80.0%). On average, the stakeholders had been working in the elderly sector for 9.2 years (*SD* = 7.9), and 5.2 years (*SD* = 5.7) in services related to carers. Similarly, about one third of the stakeholders from rehabilitation services were aged between 31 and 40 (34.8%), with the majority of them being female (71.2%) and social work being their professional background (71.2%); on average, they had been working in the rehabilitation sector for 10.2 years (*SD* = 8.1), and 9.2 years (*SD* = 7.9) in services related to carers.

15. From the perspective of stakeholders, the carers of elderly persons most commonly faced a heavy psychological burden (61.3%), lacked professional support (58.5%) and lacked knowledge and skills on caregiving (54.6%), while the three most common issues faced by carers of persons with disabilities were heavy psychological burden (63.5%), being an old aged carer (58.1%), and the lack of community/professional support (48.5%). In addition, the carers of elderly persons with cognitive impairment were perceived by the stakeholders as the neediest group, followed by carers of elderly persons with poor health status and old aged carers next, whereas among carers of persons with disabilities, those who needed help the most were carers with mental/emotional problems, carers who take care of persons with serious emotional or behavioural problems, and carers in old age (aged 60 or above).

16. Post-hoc pairwise comparisons were performed on the stakeholders’ views on the usefulness of each type of support services among 14 types of carers of elderly persons; carers in poor health, carers caring for more than one person, carers for both the elderly and children, and carers caring for the elderly with Alzheimer’s disease rated residential respite service as more useful than novice carers and low-income carers ($p < 0.05$). With regard to the stakeholders’ views on the usefulness of each type of support services among 15 types of carers of persons with disabilities, carers with mental and emotional problems on average rated counselling services and home care services as most useful compared with other types of carers, such as on-the-job carers, old aged carers, frail carers, carers with disabilities and low-income carers ($p < 0.05$).

Findings from carers and stakeholders on the financial support to carers of elderly persons and carers of persons with disabilities

17. The aim of Study 7 was to explore the way forward with regard to providing financial support to carers of elderly persons. At total of 38 persons (government representatives/advisory committee = 5, stakeholders = 15, and carers = 18) participated in the focus groups. The stakeholders had an average of 13.9 (*SD* = 8.74) years of service in the elderly service sector and 11.4 (*SD* = 6.99) years in carer services. The participants expressed that the encashment of the Community Care Service Voucher for the Elderly (CCSV) would be advantageous in certain ways, such as enabling more flexibility in relation to caregiving-related expenses, catering for individual preferences in making caregiving arrangements, and being a form of recognition for carers. Some participants were also concerned that the encashed money may be prone to misuse and would cause family conflicts. Some opined that Carer Allowance is more flexible, a form of recognition, and compensation for carers not in employment due to their caregiving role, while both carers and stakeholders pointed out that CCSV encashment and Carer Allowance have their respective merits. There was a suggestion of offering one lump sum to carers and then splitting it into two parts: one part (a large part) for providing care expenditure to frail elderly persons, the other part (a small part) given to the carers. Some suggested relaxing eligibility criteria and raising the subsidy amount of both financial solutions.

18. A total of 376 carers and 421 stakeholders completed the survey in Study 7. Among the 376 carers, 275 were CCSV recipients and 101 were Carer Allowance recipients. Demographic information of carers is shown in Table 6.4. The majority of carers were aged 50 or above (80.1%) and were females (68.4%) with primary to secondary education (68.8%). The phenomenon of elderly doubleton families is very common almost half (45.3%) of the carers were aged 60 years or above; 30.9% of carers were young old (aged 61–70), 5.9% were aged 71–75, and 8.5% were aged 76 and above. About 40% were working (either full time or part time). The average number of years in caregiving was 8.4 (SD = 8.2). In the survey, 226 out of 328 carers (68.9%), regardless of their difference in demographics, agreed/strongly agreed with the idea of CCSV encashment, whereas 42.7% of stakeholders concurred. Moreover, carers who were more satisfied with CCSV centre-based services were more likely to support CCSV encashment ($B = 0.50$, $p < 0.01$).

19. As to the views on Living Allowance for Carers of Elderly Persons from Low-Income Families (Carer Allowance), 65.5% of carers and 55.1% of stakeholders

preferred this. The majority of the stakeholders and carers considered the Carer Allowance a better option because carers receive both services and cash (81.4% of stakeholders and 72.6% of carers), and the allowance recognizes carers' contribution (57.1% of stakeholders and 51.2% of carers). Stakeholders were inclined to believe that carers would choose the Carer Allowance rather than CCSV encashment due to the absence of co-payment, yet carers did not seem to agree (only 17.6 – 24.1% of carers shared this opinion).

20. The aim of Study 8 was to evaluate two pilot schemes, namely, the Special Care Subsidy for the Severely Disabled (Special Care Subsidy) and Providing Subsidy for Higher Disability Allowance Recipients in Paid Employment to Hire Carers (Subsidy to Hire Carers) and exploring their way forward. There were a total of 40 participants in the focus groups and interviews (18 persons with disabilities, 13 carers and nine stakeholders). Regarding the evaluation of the Special Care Subsidy, views were also collected via a survey among 388 carers and 44 human services professionals and SWD administrative staff.

21. In the evaluation of the Special Care Subsidy, the recipients and their carers made positive comments about the subsidy, which has improved their lives to a certain extent. Most of the beneficiaries were living with their carers, who might not be able to have a stable income, and this subsidy provided them with a certain amount of financial assistance. Also, the findings from both the focus groups and the survey indicated that the subsidy was used on care-related expenses such as medications and nutritional foods, which is in line with the intention of the scheme. Some recipients suggested lifting the current age limit of the subsidy from 60 to 65, and increasing the subsidy amount in view of inflation.

22. In the evaluation of the Subsidy to Hire Carers, the participants in the focus group were very positive about the assistance and care provided by domestic helpers. The scheme enables them to pursue their employment and live independently to minimise the informal care required from family members. The views on this pilot scheme were generally positive. Some participants suggested relaxing the eligibility criteria, increasing the amount and extending the current three-month grace period.

23. There were mixed views regarding the integration of the three pilot schemes explored in Study 8. Most of the participants in the focus groups and interviews were opposed to the idea of integrating the three pilot schemes, with concerns over their

eligibility after integration. As revealed in the survey, 78.6% of carers and 50% of human service professionals/SWD administrative staff considered that "unifying various subsidy schemes and using cash subsidies to facilitate carers/persons with disabilities to use the paid amount flexibly" would be an effective way to provide financial assistance to carers. However, given the very different natures, target beneficiaries, and eligibility criteria of the three pilot schemes, most participants did not understand the rationale or necessity of integration. Many participants expressed concern that some persons with disabilities or their carers who are receiving one of these subsidies would no longer be eligible for any if the three pilot subsidy schemes were integrated.

Formulation of Recommendations

24. At present, there are various types of government-funded services in Hong Kong, including regularised services and pilot schemes, which provide direct and indirect support to carers of elderly persons and persons with disabilities. These supportive measures include centre-based community care and support services (e.g. DECCs, NECs, DEs/DCUs, DSCs and PRCs), home-based community care services (e.g., IHCS(Frail Cases), EHCCS, HCS, ISS), respite services for elderly persons and persons with disabilities, and project-based services (e.g., Pilot Scheme on Living Allowance for Carers of Elderly Persons from Low-income Families, and Pilot Scheme on Living Allowance for Low-income Carers of Persons with Disabilities). In addition, there are innovative carer support programmes financed by charity funds e.g. regular in-home respite, carer café, training of graduated carers to become peer helpers to carers in need.

25. A policy framework and its recommendations for carers were developed based on four main directions. Drawing from the experiences of nine other economies, these directions, listed below, ensure that the policy framework developed is comprehensive, having the right focus and well-coordinated.

(1) **Support carers in the community:** This direction emphasises the need to see carers' roles and needs in the context of the communities in which they live by adopting a carer-centric approach in supporting them. The focus is not just to strengthen the carers' caregiving ability, but also to identify the holistic needs of and appropriate support for the carers themselves. A cost-effective way to do so is to expand existing services designed for care recipients to

simultaneously include carers. This ensures the involvement of the carers right from the commencement of the intervention. This direction also emphasises that carer support is a shared responsibility of family, community, business, and the Government.

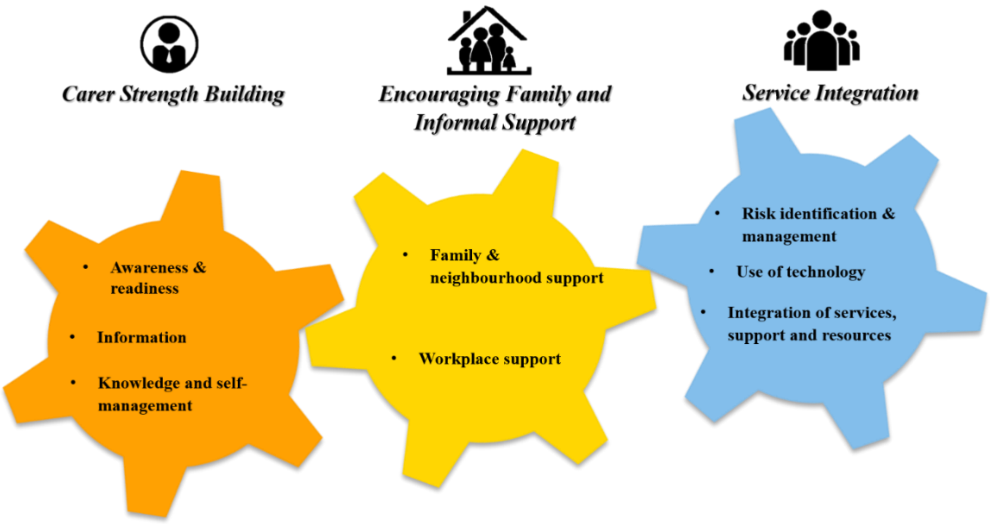
(2) **Capacity building of carers:** Carers should be empowered through the affirmation of their roles and abilities, and the contribution and enhancement of their personal strengths, confidence, and self-efficacy in coping with difficulties. This direction acknowledges the importance of promoting carers' psychological well-being.

(3) **Multipartite collaboration:** Support for carers should be provided through a joint effort by different stakeholders and sectors (e.g., the information technology industry; education, medical, health, and welfare sectors, housing, transportation, businesses, etc.). This direction also echoes the first direction in its emphasis on the development of a carer-friendly society.

(4) **Sustainability of carer support:** Support should be sustainable in terms of financial planning, workforce availability, and other resources. The business sector, social enterprises and charity funds are encouraged to provide carer support initiatives that follow a sustainable development model. This direction is important to ensure that different types of carers can continue to benefit from adequate support in the long term.

26. The Strength, Support, and Service Integration for Carers: A Collaborative Model (the Triple S Model) is the policy model proposed by the Consulting Team as an integrated framework for the policy recommendations of this consultancy study. The overall policy statement of this model is to provide effective and timely support to carers of elderly persons and persons with disabilities across their lifespans and at different stages of caregiving journey by building carers' personal strengths, encouraging support from their families and neighbourhood, and integrating support services. The focus of the Triple S Model should be on streamlining and integrating resources to achieve higher levels of efficiency, effectiveness and productivity. Triple S model is depicted below using a gear diagram, with the gear mechanisms representing collaboration between three main areas. These three areas are of equal importance and are as follows.

Strength, Support and Service Integration for Carers: A Collaborative Model (Triple S Model)



27. Under the Triple S Model, the Consulting Team is putting forward the following 11 recommendations pertaining to the three major gears of the model. Chapter 8, 9 and 10 of this main report introduced the needs, service gaps, and operational considerations of each recommendation in details.

Gear I: Carer Strength Building

1. Raise awareness of carers about the importance, availability, and access of information and increase the readiness of carers and intermediate parties to seek help from available services.

2. Examine existing websites and encourage NGOs/social enterprises/corporates to develop a carer-centric and sustainable information gateway to address carers' needs.

3. Provide carer-centric training and intervention to promote carers' wellbeing, self-management, ability to cope with stress, as well as to strengthen their caregiving capacity.

Gear II: Encouraging Family and Informal Support

4. Promote family-based support and mutual assistance among peer carers across their lifespan and at different stages of their caregiving journey.

5. Cultivate a carer-friendly neighbourhood.

6. Devise and promote a carer-friendly support environment in the workplace so as to help carers strike a balance between their work and their caregiving role.

Gear III: Service Integration

7. Develop a local self-administered assessment tool with the aim of increasing the knowledge of carers in terms of needs, risks identification and management, and potential support available.

8. Identify high-risk carers and provide timely support.

9. Better introduce, access and utilise assistive technologies to relieve care burden, enhance caring capability and improve carers' quality of life.

10. Increase accessibility and diversity of respite service to provide relief to carers with ad-hoc needs.

11. Provide good mix of services, voucher and cash to support carers.

Chapter 1. Introduction

1.1 Background

Support and care for elderly persons and persons with disabilities constitute an important part of Hong Kong's social welfare system. In 2017, the Elderly Commission formulated the *Elderly Service Programme Plan* (*ESPP*). In 2020, the Government introduced the *Persons with Disabilities and Rehabilitation Programme Plan* (*RPP*). Unpaid informal carers play an essential role in assisting frail elderly persons and persons with disabilities to carry out their daily activities, access medical and social care, and engage socially with other members of the wider community. Therefore, the well-being of elderly persons and persons with disabilities can be further improved through the enhancement of carer support by exploring carers' strengths and how these strengths contribute to their caregiving progress. In view of this, the Labour and Welfare Bureau commissioned the Hong Kong Polytechnic University Consulting Team in July 2020 to conduct a consultancy study on the needs and support required of informal carers of elderly persons and persons with disabilities in Hong Kong.

1.2 Objectives of study

The Consultancy Study's objective is to propose evidence-based recommendations to support informal carers of elderly persons and persons with disabilities, with the aim to meet carers' needs in carrying out their caregiving role, reduce caregiving distress and enable them to maintain a balance between their caring responsibilities and a life outside caregiving. Study findings will facilitate integrating and prioritising resources injected by the Government, and examining relevant initiatives/programs by NGOs, social enterprises, academics, charities and business sector, so as to provide effective support to carers of frail elderly persons and persons with disabilities.

Specifically, the consultancy study reviewed previous empirical findings and theories about carers' issues and service needs, used other economies as a reference, engaged with carers and various stakeholders so as to achieve an in-depth understanding of carers' needs and service expectations, and analysed pilot schemes and explored their ways forward regarding providing resources and support to carers.

1.3 Study deliverables of the main report

This report consists of eleven chapters. Chapter 1 is the introduction, while Chapter 2 discusses the current services for carers provided by the Government and NGOs, and a review of the literature and practices of other economies. Chapters 3 to 5 summarise the findings on carers' needs and service expectations from the perspectives of the carers and the stakeholders (i.e., component studies 3 to 6). Chapter 6 reviews existing financial assistance for carers. Chapter 7 depicts the Triple S Model of Carer Support and 11 recommendations proposed based on all study findings, and Chapters 8 to 10 elaborate each recommendation in details. Chapter 11 suggests the way forward, prerequisites for implementing the proposed recommendations and lists limitations of the consultancy study.

1.4 Study design

In order to enable carers to maintain a balance between their caring responsibilities and a life outside caregiving, the consultancy study obtained empirical findings regarding the needs and support required of carers of elderly persons and persons with disabilities through triangulation of both quantitative and qualitative data from a variety of different sources. Eight component studies were conducted, and data were analysed in an in-depth manner. The research topics of the studies are listed in *Table 1.1*. The data collection and analysis of these eight studies were completed by the end of May 2021. Studies 3 to 8 included both qualitative and quantitative approaches.

Studies 3 and 4 aimed to generate a profile of the carers of elderly persons and persons with disabilities, to understand their needs and strengths in carrying out their caregiving role, and to identify the kind of support carers need and the priority of carers' needs. Studies 5 and 6 aimed to develop a typology of the normative needs and service expectations of carers of elderly persons and persons with disabilities from the stakeholders' perspective. Study 7 aimed to explore (1) financial assistance for carers, including the pros and cons of encashing part of the Community Care Service Voucher for the Elderly (CCSV) to family members to take care of frail elderly persons at home, including engaging helpers to take up some of the caregiving tasks; and (2) the way forward for the Pilot Scheme on Living Allowance for Carers of Elderly Persons from Low Income Families (in short, the Carer Allowance). Study 8 focused on the evaluation of two pilot schemes—*Special Care Subsidy for the Severely Disabled* (Special Care Subsidy) and *Providing Subsidy for Higher Disability Allowance* (HDA) *Recipients in Paid Employment to Hire Carers* (Subsidy to Hire Carers)—and aimed to identify their way forward together with the *Pilot Scheme on Living Allowance for Low-Income Carers of Persons with Disabilities* (Allowance for Low-Income Carers).

Studies 3 to 6 adopted a mixed-methods design. Stage 1 was qualitative research with focus group interviews to explore various themes concerning carers of elderly persons and persons with disabilities, including their characteristics, needs, strengths, and service expectations. Stage 2 was a cross-sectional survey based on a conceptual framework derived from Stage 1. Stage 3 involved another round of qualitative data collection and consultation with the stakeholders concerned with a view to gaining better understanding of the practicality and priority of recommendations. Stage 3 was completed in May 2021.

The qualitative research involved over 220 participants across focus groups and interviews, and over 5,000 questionnaires were collected for quantitative analysis. There is a varying degree of completeness of variables in the returned responses of each study; thus, the numbers of valid cases for analysis are also shown in parentheses (*Table 1.1*).

However, the consultancy study was conducted amid the COVID-19 pandemic, which imposed great difficulties on data collection. Face-to-face interviews were changed to online or telephone format, leading to a considerable missingness in the survey data.

Table 1.1 Overview of eight studies

Study	**Research topic**	**Number of respondents in focus group/interview**	**Number of returned questionnaires (valid cases for analysis)**	**Total (valid cases for analysis)**
Study 1	A literature review of the needs and support requirements of carers of elderly persons and persons with disabilities	N/A	N/A	N/A
Study 2	A review and field study of carer support measures in other economies	N/A	N/A	N/A
Study 3	Identifying the needs, strengths, and service expectations of carers of elderly persons	31	1 112 (966)	997
Study 4	Identifying the needs, strengths, and service expectations of carers of persons with disabilities	49	1 756 (1 307)	1 356
Study 5	Developing a typology of normative needs and service expectations of carers of elderly persons from the perspective of stakeholders	27	421 (360)	387
Study 6	Developing a typology of normative needs and service expectations of carers of persons with disabilities from the perspective of stakeholders	39	745 (709)	748
Study 7	Exploring financial assistance to carers of elderly persons	38	797 (797)	835
Study 8	Evaluating two pilot schemes (namely, the Special Care Subsidy for the Severely Disabled, and the Pilot Scheme on Providing Subsidy for Higher Disability Allowance (HDA) Recipients in Paid Employment to Hire Carers) and exploring ways forward in coordination	40	432 (432)	472

Study	Research topic	Number of respondents in focus group/interview	Number of returned questionnaires (valid cases for analysis)	Total (valid cases for analysis)
	with the Pilot Scheme on Living Allowance for Low-Income Carers of Persons with Disabilities			
Total		**224**	**5 263 (4 571)**	**4 795**

1.5 Cross-reference with other data sources

The Consulting Team reviewed local literature, which is particularly relevant to the context of elderly and rehabilitation services, so as to grasp a more holistic overview of the existing services for people with long-term care needs, such as '*Evaluation Study of the Second Phase of the Pilot Scheme on the Community Care Service Voucher (CCSV) for the Elderly* (Sau Po Centre on Ageing, 2016), the *Elderly Services Programme Plan* (*ESPP*; Elderly Commission, 2017), and the *Persons with Disabilities and Rehabilitation Programme Plan* (*RPP*; Rehabilitation Advisory Committee, 2020).

1.6 Challenges in carer support in the coming decade

In Hong Kong, the number of elderly persons and persons with disabilities is growing, and a considerable number of these persons are being taken care of by their family members. The Government is committed to enhancing community care services for elderly persons to enable them to "ageing in place" and for persons with disabilities to develop the capabilities necessary to adapt to living in and integrate into the community, which also support carers. Community care services are important to enable elderly persons and persons with disabilities to live in the neighbourhood. Over the years, the government has strengthened community care and support services by, for example, establishing more community-based centres, enhancing home-based community care services and respite care, and providing financial assistance to carers. The following sections will centre on the pressing issues of population trends, carers' needs, and the challenges of delivering existing support for carers.

1.6.1 Projections of carer population and care recipient population

As the number of elderly persons increases in an unprecedented manner in Hong Kong following the ageing population trend, demand for long-term care will surge correspondingly. In many countries across the globe, such as the economies reviewed in this study, the long-term care system relies heavily on informal care from family members or friends. The increase in demand for long-term care also translates into an increase in demand for informal care. A projection of the supply of informal care is particularly important in Hong Kong. The existing formal care system is facing the shortage of manpower and space while family carers are often challenged by an overwhelming care burden. A projection of carer population is conducive to planning and reforming the long-term care system ahead in response to the ageing population, which also gives rise to an increase in persons with disabilities due to age-related frailty.

(i) Projection of the future population of elderly persons and their carers

According to Hong Kong Population Projections 2020 – 2069 (Census and Statistics Department, 2020), population ageing is expected to continue, with the number of elderly persons aged 65 and above nearly doubling in the next two decades. The number of elderly persons is projected to rise from 1.32 million (17.5 % of the total population) in 2019 to 2.07 million (26.1%) in 2029. Along with Hong Kong’s persistently low fertility rate, the change in the age structure of the projected population is also reflected by the variation in the dependency ratio. The elderly dependency ratio (per 1,000 persons) is expected to grow from 249 in 2019 to 408 in 2029 and to continue to rise to 606 by 2069. If the age of 60 is adopted as the threshold, the number of elderly persons is projected to increase from 1.91 million (25.2%) in 2019 to 2.61 million (33.0 %) in 2029.

To date, the number of elderly persons taken care of by carers was only recorded once, in the Thematic Household Survey Report No. 40 (Census and Statistics Department, 2009), which reported that 35.4% of elderly persons were looked after by unpaid carers (children, spouses, relatives, friends, or neighbours), and the data were not sufficient to calculate the varying growth rates. The Census and Statistics Department (C&SD) is conducting a territory-wide 2021 Population Census which will collate, for the first time, information on elderly persons requiring care and possibly other relevant data.

Due to lacking up-to-date and credible data, an accurate projection of future carer population for the elderly could not be done until all these results of the latest census are available.

(ii) Projection of the future population of persons with disabilities and their carers

Unlike the elderly population, the projection of persons with disabilities is less straightforward due to the varying prevalence rates of disability types. For persons with disabilities, C&SD conducted four rounds of territory-wide surveys[2] in 2000, 2006/07, 2013 and 2019/20[3], and the respective number of persons with disabilities were 269 500, 361 300, 578 600 and 534 200. Among the responding persons with disabilities in the four surveys, 75 400, 125 600, 203 700 and 204 200 persons respectively indicated that they had a person to take care of their day-to-day living as a result of their disabilities.

1.6.2 Carers' needs in view of socio-economic changes in Hong Kong

Since 1997, the principle of "ageing in place" has been persistently upheld in the development of long-term care services, emphasising that elderly persons should, as far as possible, live with their families or in a familiar environment as they age (Chui, 2008). This principle is further enshrined in the latest *Elderly Services Programme Plan* (ESPP), which sets out recommendations for the development of elderly services in Hong Kong (Elderly Commission, 2017). This principle reflects the pivotal role of family carers in keeping their frail relatives ageing well at home. The needs of carers cannot be intrinsically separated from the long-term care needs of care recipients. In a sense, carers may gain relief to a certain extent from their care responsibilities if formal care for elderly persons and persons with disabilities is adequately available in the community.

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[2] Referred to "Persons with Disabilities and Chronic Diseases in Hong Kong"

[3] In relation to the latest international development in collecting statistical data on disability, the definitions for selected types of disability have been updated in this round of the survey and hence the survey findings concerned are not directly comparable to past results.

However, there are some concerns regarding the inadequacy of supportive measures in addressing the needs of carers. Lou (2019), in a territory-wide survey of Hong Kong carers, revealed that many community carers (alternatively called full-time carers) and working carers highlighted the need for financial assistance, emotional/health support, and hotline services. While formal care services have improved, carers are still in need of financial assistance and support services to cope with psychological and care-related needs. In addition to this, carers were also found to be in need of caregiving training, support groups, and re-employment training and opportunities (Lou, 2019). The needs of local carers resemble those in foreign societies (e.g., the need for emotional and health support) (Stoltz et al., 2004).

Another challenge regarding the provision of informal care is the intertwinement of two ideologies — neoliberalism and traditional family values — in Hong Kong (Leung et al., 2020). The changes in older parents' filial beliefs have shifted eldercare responsibilities from families to individuals and the private market. The provision of physical care by adult children has decreased due to living arrangements and geographical distance. Therefore, most children tend to compensate for the lack of physical care by providing financial support (Lee & Kwok, 2005). It is common that care work has mainly been outsourced to the private markets such as private nursing homes and foreign domestic helpers (Chow, 2000; Legislative Council Secretariat, 2017). For low-income adult children who are unable to provide financial support to their older parents, financial assistance becomes increasingly important as an alternative approach to supporting carers to choose flexible care options and alleviate their burden of providing physical care.

Another noteworthy aspect is the needs of young people who provide care for their relatives who are elderly, ill, or persons with disabilities. Research of the characteristics and needs of young carers in Hong Kong is still limited compared to the older cohorts. Since the mid-1990s, there has been a growing awareness of the existence and specific life experience of young carers, notably in the West such as the UK, Australia, New Zealand, Germany, and Canada (Becker, 2005). Although the experience of young carers is not homogenous, international research suggests that caring can affect young people's physical and emotional well-being, connections with peers and the broader community, family relationships, educational and employment outcomes, their family's financial stability, and their opportunity (Aldridge & Becker 1997; Carers Australia

2002; Halpenny & Gilligan, 2004; Marsden, 1995), which may translate into relevant needs of young carers.

Chapter 2. Existing Support for Carers in Hong Kong, and Review of Literature and Practices of Other Economies (Studies 1 and 2)

2.1 Existing support for carers under various measures funded by the Government and other sources in Hong Kong

This section provides an overview of existing services in Hong Kong, including regularised services and pilot schemes, which directly and indirectly support carers of elderly persons and persons with disabilities. Services and programmes similarly supporting carers in other economies will also be illustrated in the following chapter to compare with those in Hong Kong in order to pinpoint the provision and good practices of relevant services.

2.1.1 Existing Government-funded measures for carers of elderly persons

The existing support services for carers of elderly persons are shown in *Table 2.1* below. The services are categorised into several aspects, including centre-based community care and support services, home-based community care services, respite services, and project-based services.

Table 2.1 Existing Government-funded measures for carers of elderly persons

Aspect	**Services/Programmes**
I. Centre-based community care and support services	**District Elderly Community Centres (DECCs) and Neighbourhood Elderly Centres (NECs)** • A total of 212 DECCs and NECs provide community support services for elderly persons and their carers across the territory. The services included, community education, health education, educational and developmental activities, reaching out and networking, volunteer development, provision of information on community resources and referral services, assistance in making long-term care service applications, arrangement of social and recreational activities, meal services, and carer support services

Aspect	Services/Programmes
	• The Support Teams for the Elderly (STEs) in the 41 DECCs identify potentially vulnerable elderly persons and their carers through various outreach services and community networks; • STEs show care for elderly persons through regular telephone contacts and home visits, provide them with emotional support, match suitable volunteers and encourage elderly persons of similar background to set up peer support groups, or refer those in need to other support or care services.
	Day Care Centres/Units for the Elderly (DEs/DCUs) • A total of 90 DEs/DCUs provide care services for elderly persons in need and support services for their carers; • Including information and counselling services, group activities and skill training, mutual support groups, and demonstration/ loan of rehabilitation-aid equipment.
II. Home-based community care services	**Integrated Home Care Services (Frail Cases) and Enhanced Home and Community Care Services** • A total of 13,365 service places are provided through the 61 Integrated Home Care Services (Frail Cases) service teams and 31 Enhanced Home and Community Care Services service teams for elderly persons in need and support services are also provided for their carers; • Services include personal care, basic and special care, rehabilitation exercises, counselling services, 24-hour emergency support, respite services, home environment safety assessment and improvement suggestions, housekeeping and meal delivery services, escort services, carer support, etc.
III. Respite services for elderly persons	**Residential respite and day respite for the elderly** • In addition to the 58 designated places in subvented RCHEs and contract homes, residential respite services are also provided in all

Aspect	Services/Programmes
	subvented RCHEs and contract homes through the use of casual vacancies. A total of 280 designated residential respite places are provided through 140 private homes participating in the Enhanced Bought Place Scheme (EBPS); • There are a total of 208 designated day respite places provided by 46 subsidised DEs/DCUs for elderly persons.
IV. Project-based services	• Integrated Discharge Support Programme for Elderly Patients; • Pilot Scheme on Support for Elderly Persons Discharged from Public Hospitals after Treatment; • Pilot Scheme on Community Care Service Voucher for the Elderly; • Pilot Scheme on Living Allowance for Carers of Elderly Persons from Low-income Families; • Support for Carers Project; • Pilot Scheme on Training for Foreign Domestic Helpers in Elderly Care; • Dementia Friendly Community Campaign; • Dementia Community Support Scheme.
V. Other support	**SWD hotline service** • The SWD hotline 2343 2255 provides information on welfare services in the form of voice messages or facsimile transmission to callers through a 24-hour interactive voice response system; • Social workers on duty also provide counselling, support and advice, and arrange appropriate follow-up services for those in need. **SWD websites/webpages on relevant carer support services** Information on the elderly services under SWD can be accessed via the below websites/webpages. • SWD elderly services www.swd.gov.hk/tc/index/site_pubsvc/page_elderly/ • SWD Elderly Information Website www.elderlyinfo.swd.gov.hk/tc

Aspect	Services/Programmes
	• Vacancy Enquiry System for Residential Respite Service for Persons with Disabilities, Residential Respite Service for the Elderly and Emergency Placement for the Elderly www.vesrrsep.swd.gov.hk/tc • Dementia Friendly Community Campaign www.swd.gov.hk/dementiacampaign/tc/index.html • Pilot Scheme on Training for Foreign Domestic Helpers in Elderly Care (On-line Training Videos) www.swd.gov.hk/tc/index/site_pubsvc/page_elderly/sub_online/

2.1.2 Existing Government-funded measures for carers of persons with disabilities

The existing Government-funded measures for carers of persons with disabilities are summarised below (*Table 2.2*).

Table 2.2 Existing Government-funded measures for carers of persons with disabilities

Aspect	Services/Programmes
I. Centre-based community support services	**District Support Centres for Persons with Disabilities (DSCs)** • 16 DSCs offer training, care, social, psychological, and personal development activities for persons with disabilities taking account of their needs, and provide support and training for their family members and carers (including care skills training, mutual support groups, relevant educational courses / seminars / workshops, and leisure and family recreational activities) for enhancing their caring capabilities and lessening their pressure; • The government has increased the number of DSCs from 16 to 18 in 2021-22, and will increase to 21 in 2022-23.
	Parents/Relatives Resource Centres (PRCs) • 19 PRCs help parents, family members, and carers in need to share experiences and strengthen their caring capabilities, as well as

Aspect	**Services/Programmes**
	attain mutual support, acquaintance, and acceptance of family members with disabilities.
	Social and Recreational Centres for the Disabled (S&RCs) • 16 S&RCs provide social, recreational, and developmental activities for persons with disabilities; • In 2020-21, SWD has increased resources for strengthening S&RCs' community support functions, particularly support for family members and carers, including: enhancing emotional support and counselling services for persons with disabilities and their family members and carers; getting in touch with less-motivated persons with disabilities and their family members and carers through outreach services, thus providing immediate assistance in bridging the needy to suitable community services; and strengthening the support networks of persons with disabilities and their family members and carers through volunteer services.
	Support Centres for Persons with Autism (SPAs) • 5 SPAs seek, through multi-disciplinary teams (comprising clinical psychologists, social workers, occupational therapists, speech therapists, etc.), to enhance the living, social, and job skills of young persons with high-functioning autism to help them cope with their needs in the transition to adulthood; • SPAs also provide support for parents and carers (including casework, group and programme support, and assistance in building mutual support networks) as well as advisory services and professional training for other subvented rehabilitation service units and frontline staff serving persons with autism.

Aspect	Services/Programmes
	Day Care Service for Persons with Severe Disabilities • Provides centre-based day care for persons with severe disabilities. It promotes care in the community by strengthening the caring capability of families or carers through provision of regular day care including nursing, rehabilitation, and social and personal care services so as to enhance opportunities of persons with severe disabilities to continue living in the community; • As of end April 2021, there were a total of 245 service places in the Care and Attention Homes for Severely Disabled Persons, DSCs, and Community Rehabilitation Day Centres.
	Self-help Organisations of Persons with Disabilities/Chronic Illnesses • The Financial Support Scheme for Self-help Organisations of Persons with Disabilities/Chronic Illnesses provides an annual amount of $21 million is provided as time-limited and project-based financial assistance to self-help organisations of persons with disabilities and their families/carers.
II. Home-based community support services	• Six service teams of the Home Care Service for Persons with Severe Disabilities (HCS) and two service teams of the Integrated Support Service for Persons with Severe Physical Disabilities (ISS) provide a range of integrated home-based services (including personal care, nursing care, and rehabilitation training) for persons with disabilities in need; • Carer support (including counselling services, care skills training, home respite services, and service referral).
III. Respite services for persons with disabilities	• As of end March 2021, there were a total of 160 day respite service places provided in the Day Activities Centres, DSCs, and Care and Attention Homes for Severely Disabled Persons, and 344 residential respite service places in different types of Residential Care Homes for Persons with Disabilities (RCHDs); • From 2021, SWD has purchased over 40 residential respite service places from RCHDs participating in the Bought Place Scheme

Aspect	**Services/Programmes**
	(BPS) for Private RCHDs to provide more service places and options for carers in need.
IV. Project-based services	• Pilot Scheme on Living Allowance for Low-income Carers of Persons with Disabilities – launched through the Community Care Fund (CCF) to provide a monthly allowance of $2,400 to carers from low-income families with persons with disabilities waiting for specified rehabilitation services subsidised by SWD, a special school with boarding placements under the Education Bureau or infirmary service of the Hospital Authority; • Pilot Scheme on Providing Subsidy for Higher Disability Allowance Recipients in Paid Employment to Hire Carers – launched through CCF to provide a monthly subsidy of $5,000 for eligible persons with disabilities to hire carers to assist them in travelling between their homes and workplaces, with a view to encouraging them to stay in employment; • Special Care Subsidy for the Severely Disabled – launched through CCF to provide a maximum monthly subsidy of $2,000 for eligible persons with disabilities to purchase care goods and services or for other purposes related to nursing care.
V. Other support	**SWD hotline service** • The SWD hotline 2343 2255 provides information on welfare services in the form of voice messages or facsimile transmission to callers through a 24-hour interactive voice response system; • Social workers on duty also provide counselling, support and advice, and arrange appropriate follow-up services for those in need. **SWD websites/webpages on relevant services** Information on the rehabilitation services under SWD can be accessed via the below websites/webpages. • SWD rehabilitation services www.swd.gov.hk/tc/index/site_pubsvc/page_rehab/

Aspect	**Services/Programmes**
	• SWD Information Website for RCHDs www.rchdinfo.swd.gov.hk/ • Vacancy Enquiry System for Residential Respite Service for Persons with Disabilities, Residential Respite Service for the Elderly and Emergency Placement for the Elderly www.vesrrsep.swd.gov.hk/tc

In general, it is noted by the Consulting Team that most of the current community care services primarily focus on serving elderly persons and persons with disabilities. While there are actually quite a number of community services that serve the carers (please see Table 2.2 above), they are still perceived by the carers who participated in the study to be scattered and difficult to access for reasons such as lack of adequate information on eligibility, time clashes due to employment or caregiving.

Carers' need for support can at times be episodic and urgent. For example, short respite care is often demanded by carers to take a few hours' break to attend to urgent matters. There do actually exist services that could address such needs, such as elderly sitting provided by service teams (e.g., Integrated Home Care Services Teams). Apart from the designated day respite service, all 90 DEs/DCUs can also make use of their casual vacancies to provide day respite service. There is also 24-hour emergency support under IHCS (Frail Cases) and EHCCS, which provide round-the-clock assistance and advice to service users and/or their carers in case of emergency. In the rehabilitation field, both the HCS and ISS, which currently serve persons with severe disabilities and their carers, are also providing home respite service, and in recent years, HCS has extended its coverage to persons at a moderate level of disability. As a matter of fact, from April 2020 to December 2020 (nine months), there were 7 996 instances of home respite services provided by HCS and 4 449 instances of home respite services provide by ISS, and the service has been actively used by PWDs in need. One of the focuses of the Consultancy Study was, therefore, to find the reasons why carers did not make good use of existing carer support services.

2.1.3 Other innovative programmes/projects funded by NGOs or charity funds

Currently there are several innovative programmes and projects funded by non-governmental organisations or charity funds in Hong Kong. Some of these are selected as examples and summarised below (*Table 2.3*).

Table 2.3 Programmes/initiatives funded by NGOs or charity funds (Selected)

Aspect	**Programmes / projects**[4]
Awareness and Information	• Carer EPS (BOKSS) • Big Silver Community (Big Silver Community Limited) • Resource and Support Centre for Carers (Caritas HK)
Carer training	• CARE College (BOK) • Jockey Club All Brilliant Carers Projects (HKFWC)
Family and neighbourhood support	• Elderly Sitters – Pilot Project on Community Support and Senior Employment (The Chinese Rhenish Church HK Synod) • Time bank projects (HKSKH Tseung Kwan O Aged Care Complex; BOK Lai Yiu NEC) • Community carer café/dementia café (AKA; HKFWC)
Workplace Support	• Flexible working hours, Parent Angel Team, regular talks and workshops for carers (Meiriki) • 2-day per year carer leave for staff, free 3-month trial for new users of Care-and-Call service, flexible working hours, free workshops for carers (Kerry Group)
Risk identification and management	• Multi-dimensional Risk Assessment Tool (HKCSS; HKU CoA)

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[4] AKA: Aberdeen Kaifong Welfare Association; HKFWC: Hong Kong Federation of Women's Centres; BOKSS: Baptist Oi Kwan Social Service; NEC: Neighbourhood Elderly Centre; HKSKH: Hong Kong Sheng Kung Hui; HKCSS: Hong Kong Council of Social Service; HKU CoA: Sau Po Centre on Ageing, The University of Hong Kong; HKAG: Hong Kong Association of Gerontology; CFSC: Christian Family Service Centre; SJS: St. James' Settlement.

Aspect	**Programmes / projects**[4]
	• Caregiver Support Model (CSM) and Psycho-education Program on Empowerment: Development and Validation (CityU)
Use of technology	• Gerontechnology Platform (HKCSS in collaboration with 9 organisations) • 656carer.com (SJS, HK Society for Rehabilitation, etc.) (stroke, dementia and fall) • WeRise Mobile Platform for Stroke Patients and their Caregivers (HKU Faculty of Medicine) • We60.com • Jockey Club Age at Home program (rental of gerontechnology products)
Respite service	• Jockey Club "Stand by U" Caregivers Community Support project (HKAG, CFSC, Salvation Army, HKSKH Lady MacLehose Centre & SJS) • Caregiver Companion Project (AKA) • Elderly Sitters – Pilot Project on Community Support and Senior Employment (The Chinese Rhenish Church HK Synod)

These support services for carers initiated by non-governmental organisations and charities have set good examples similar to those in economies with carer-friendly policies. However, most of these services are implemented on a pilot basis and may not be sustainable even if the outcomes are successful. Some measures, such as workplace support, are often ideal on a larger scale or in enterprises with sufficient resources and stronger emphasis on corporate social responsibility. Nonetheless, the designs of these innovative support services are noteworthy in terms of their promotion methods, service models and delivery channels when formulating carer-friendly measures in Hong Kong.

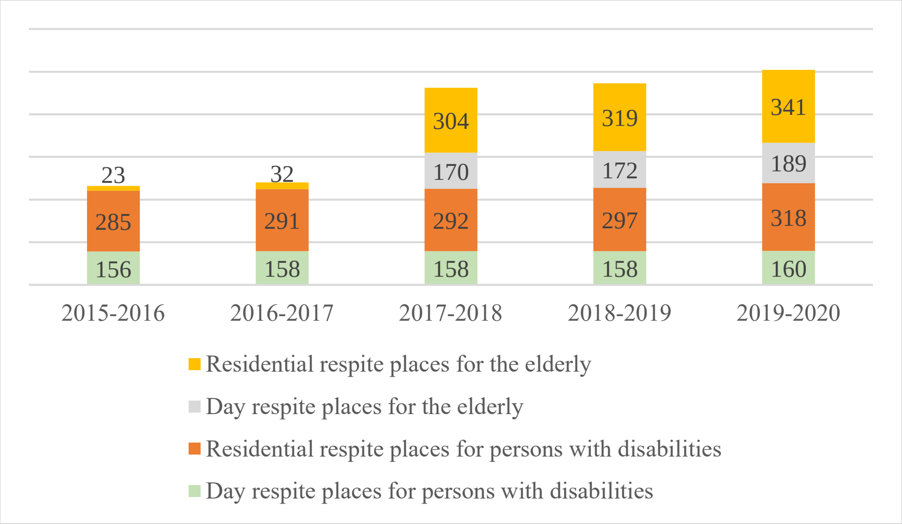
2.1.4 Further issues in the provision of carer support

In the past decade, the Hong Kong Government has successfully implemented a number of carer support initiatives in the areas of respite care, financial benefits, and community support services. However, some challenges are impeding the provision of carer support pertinent to service gaps and service utilisation.

Respite services

At present, government-funded respite services are provided as short-term care for elderly persons and persons with disabilities in need, as well as to relieve the stress of their carers. Since 2018, the Government has been purchasing elderly respite places from private residential care homes. The number of elderly residential respite places rose sharply from 32 in 2016-2017 to 341 in 2019-2020 (*Figure 2.1*). In 2017-2018, there were 170 designated day respite places in 39 subsidised day care centres/units for the elderly (DEs/DCUs), which increased to 189 as of 2020[5]. All DEs/DCUs can also make use of any of their casual day care vacancies to offer respite services. Similarly, for persons with disabilities, there are about 500 day and residential respite places as at the end of May 2021. The Government has purchased some 40 designated residential respite places from private RCHDs under BPS in 2021.

Figure 2.1 Number of respite places for elderly persons and persons with disabilities



Financial assistance

Since June 2014 and October 2016, respectively, the Government has rolled out two pilot schemes providing living allowances to ease the financial burden of carers from low-income families. In general, a carer may qualify for the monthly allowance, set at

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[5] No official data have been found on day respite places for elderly persons between 2015 and 2017.

HKD2 400, if he or she (a) provides at least 80 hours of care per month; (b) comes from a family with a monthly income at or below 75% of the median household income; and (c) takes care of an elderly person or a person with disabilities who has been on the waiting list for specified care services. If a carer has to take care of more than one elderly person or person with disabilities, and the carer is considered by the service unit to be capable of such concurrent care, a maximum allowance of $4 800 per month will be given. As of the end of December 2019, a total of 5 709 carers of elderly persons (out of a quota of 6 000) and 2 311 carers of persons with disabilities (out of a quota of 2 500) received the carer allowance under the two pilot schemes, and both have been extended to September 2023.

Table 2.4 Living allowance for low-income carers of elderly persons

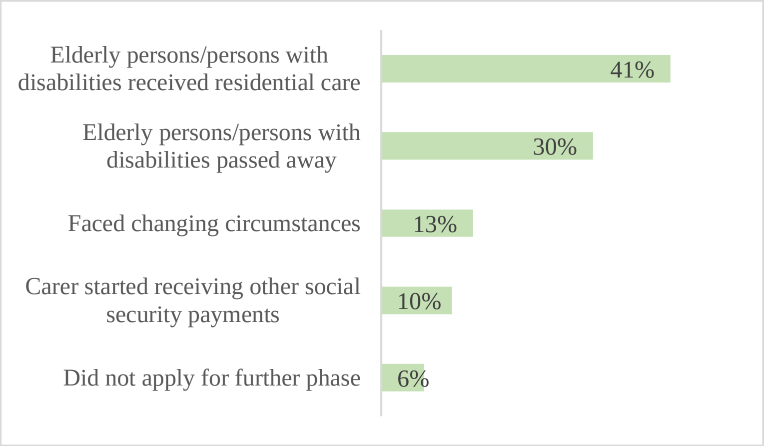
Living allowance for low-income carers of elderly persons				
	Phase I	**Phase II**	**Phase III**	**Total**
Period	**June 2014 – Sept 2016**	**Oct 2016 – Sept 2018**	**Oct 2018 – March 2021**	
No. of approved cases	2 001	1 968	1 740	5 709
No. of withdrawn cases	1 594	1 266	399	3 259
No. of current recipients				**2 450**

Table 2.5 Living allowance for low-income carers of persons with disabilities

Living allowance for low-income carers of persons with disabilities			
	Phase I	**Phase II**	**Total**
Period	**Oct 2016 – Sept 2018**	**Oct 2018 – March 2021**	
No. of approved cases	1 528	783	2 311
No. of withdrawn cases	366	80	446
No. of current recipients			**1 865**

Remark: The data were up to date as of the end of December 2019.

Figure 2.2 Reasons for withdrawing from the carer allowance schemes



As of the end of December 2019, there were 3 259 carers of elderly persons and 446 carers of persons with disabilities who had withdrawn from the schemes. Reasons for withdrawing included carers' dependents beginning to receive residential care or having passed away, carers facing changing circumstances (e.g., carers securing jobs or having passed away and elderly persons/persons with disabilities being taken care of leaving Hong Kong), carers starting to receive other social security payments, or carers choosing not to reapply (*Figure 2.2*).

Although the financial need of carers has been increasing, the Government is facing its resource constraint, in a way that it may not be sustainable in the provision of financial assistance to carers. Resources should only be used on supporting carers with the greatest financial needs. Enhancement of existing carer support services may be an alternative in addressing carers' and care recipients' needs.

2.2 Review of the literature and practices of other economies

This section aims to provide a review and summary of the findings of the literature and an examination of the nine selected economies[6] to draw on evidence-based and international experiences of carer support policies and measures. A theoretical model is therefore proposed, with features adopted from our findings, as the fundamental pillar guiding the support measures of this consultancy study so that the recommendations

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[6] The nine economies are Australia, Canada, the United Kingdom, the United States, Sweden, Guangzhou, Taiwan, Japan, and Singapore. See Chapter 3 of the Technical Report for detailed analysis.

proposed in the following chapters will be in alignment with compelling research evidence, international practices, and local socio-economic and demographic characteristics.

2.2.1 Review of relevant theoretical and conceptual models

Study 1, the scoping review, has identified several conceptual frameworks to guide the practices or services of carer support, including the dementia service centre model (Auer et al., 2015), the integration of the conceptual model of nursing and health policy with Roy's adaptation model (Garvey et al., 2019), the theory of change model (Abayneh et al., 2020), the timing it right model (Cameron & Gignac, 2008), the emotional vitality model (Barbic et al., 2014), and the stress-process model (Pearlin et al., 1990). Some of the highlights of these models are presented below.

In Auer et al.'s (2015) study, a comprehensive model was proposed to support carers of persons with dementia. In the model, a multidisciplinary approach is suggested in which medical doctors and other professionals (e.g., nurses) can refer carers to dementia centres to receive different supportive services, such as counselling, training modules, and support groups for carers (Figure *2.3*).

Garvey et al. (2019) proposed a conceptual model of nursing and health policy with Roy's adaptation model which supports carers of persons with dementia through home healthcare nursing services. In this model, informal carers receive a range of support through a one-stop home healthcare nursing system. The services include screening/assessment/identification and referral to healthcare professionals, identification of dementia caregiving turning points, educational support, emotional and psychological support, home health aide services, and referral to resources.

Under the theory of change model of service users and carers developed by Abayneh et al. (2020), carer support covers multiple levels, including the community level (e.g., community resources and strong political commitment), the health organisation level (e.g., health professionals and managers), and the service user level (e.g., carer).

The timing it right model and the emotional vitality model are used for carers of post-stroke patients. The timing it right model proposes that carer support should be tailored to phases following the disease trajectory from event/diagnosis and in-patient rehabilitation to community rehabilitation and adaptation in order to support carers (Cameron & Gignac, 2008). The emotional vitality model (Barbic et al., 2014) postulates that caregiving has a negative impact on the physical, mental, and social health of carers, suggesting that intrinsic (mastering skills/roles) and extrinsic (recognition and support) support should be provided.

The stress-process model is widely used cross-culturally for incorporating family and social contextual factors to operationalise several intervention strategies for dementia carers (Pearlin et al., 1990). This model considers access to and use of resources and programmes as important contextual elements of the stress process. These contextual elements are referred to as networks (including family) to which caregivers have attachments, the composition of the networks, and the nature and frequency of contacts with their members. Consequently, coping (i.e., individual behaviours and practice) and social support are the two major mediators of the model for directing interventions to relieve stress (*Figure 2.4*).

Moreover, the needs and support required for carers can be conceptualised from the perspective of multiple levels, and a holistic approach can help in the design and implementation of meaningful carer programmes and policies (Lee, 2007). The ecological system, as popularised by Bronfenbrenner (1977), proposes an approach for human development through the life span in formal and informal social settings, giving rise to the micro-system, meso-system, and macro-system, which respectively represent the individual, social, and systemic levels. Existing studies have also extended the ecological system to investigate the needs of carers of persons with disabilities (Williamson and Perkins, 2014) and persons with terminal illnesses (Lewis et al., 2013) (*Figure 2.5*).

In addition, Brown (2014) depicts the caregiving journey as having six stages[7]: (1) Expectant carers; (2) freshmen carers; (3) Entrenched carers; (4) Pragmatic carers; (5)

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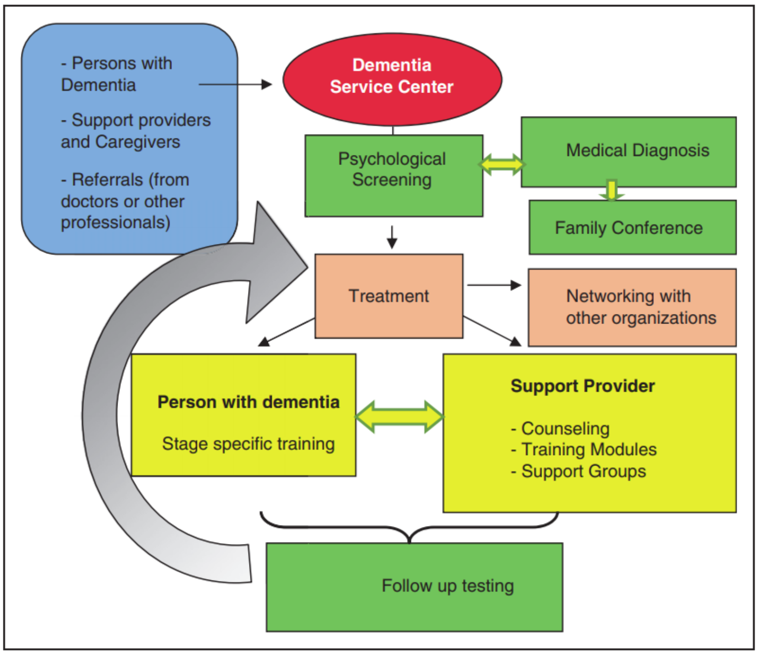
[7] According to Brown (2014), *Expectant carers* are those who expect to care for someone in the future but were not yet doing the caring tasks; *Freshman carers* are those who just started with the basic caregiving duties; *Entrenched carers* are those who are busiest with caregiving tasks; *Pragmatic carers* are those who are comfortable in their role as caregivers and have figured out how to manage all the tasks that nearly buried them in the third stage of caregiving (“entrenched stage”); *Transitioning carers* are those who are awaiting a time in the near term where they will no longer be caregiving; *Godspeed carers*

Transitioning carers; and (6) Godspeed carers. Other variations can be found with different stages but similar concepts, such as the five stages adopted by the Taiwan Association of Family Caregivers, or the four stages of the caregiving journey of American Senior Communities.

Overall, the review of relevant theoretical frameworks is conducive not only to conceptualising the characteristics of carers in Hong Kong, but also to deriving coherent theory-driven research components. Specifically, the caregiving journey is adopted in designing the questionnaire in a lifespan approach; and the ecological model with micro, meso and macro scope also inspires the formulation of recommendations that fall into the three domains of carer strength-building, encouraging family and informal support, and service integration. The stress-process model (Pearlin et al., 1990) also further ascertains coping and social support as two major mediators for directing interventions to relieve stress, together with evidence synthesised from local carers and professionals, to call for strategies with a focus on enhancing coping skills and social support (see Recommendation 3 in Chapter 8; and Recommendations 4 and 5 in Chapter 9).

Figure 2.3 Illustration of the flow through the services of a Dementia Service Centre (Auer et al., 2015)



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are those whose role of caregiving has concluded, and are now trying to find how to move on to the next stage in their life.

Figure 2.4 A conceptual model of Alzheimer's caregivers' stress (Pearlin et al., 1990).

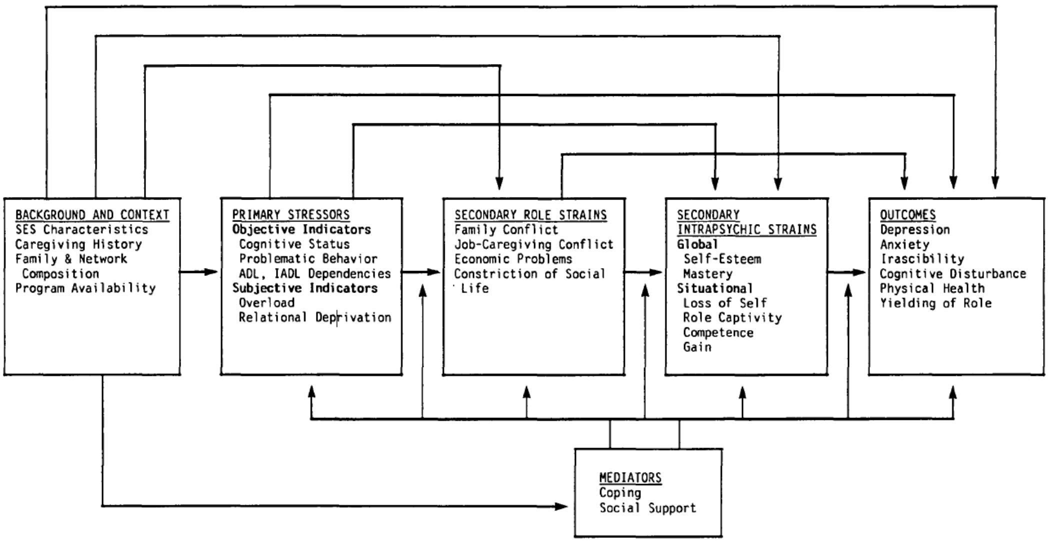
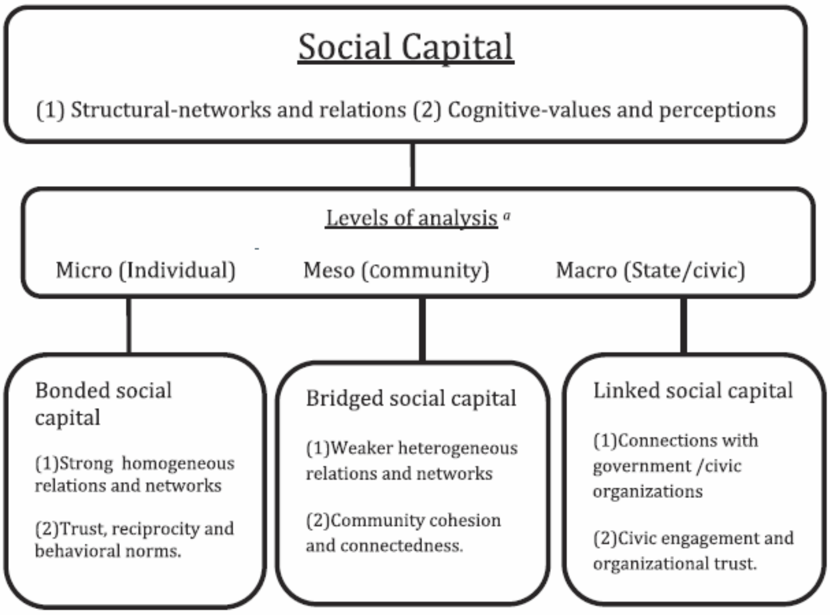


Figure 2.5 Social determinants of health: Theories of social capital situated in one or more of the levels of analysis (Lewis et al., 2013)



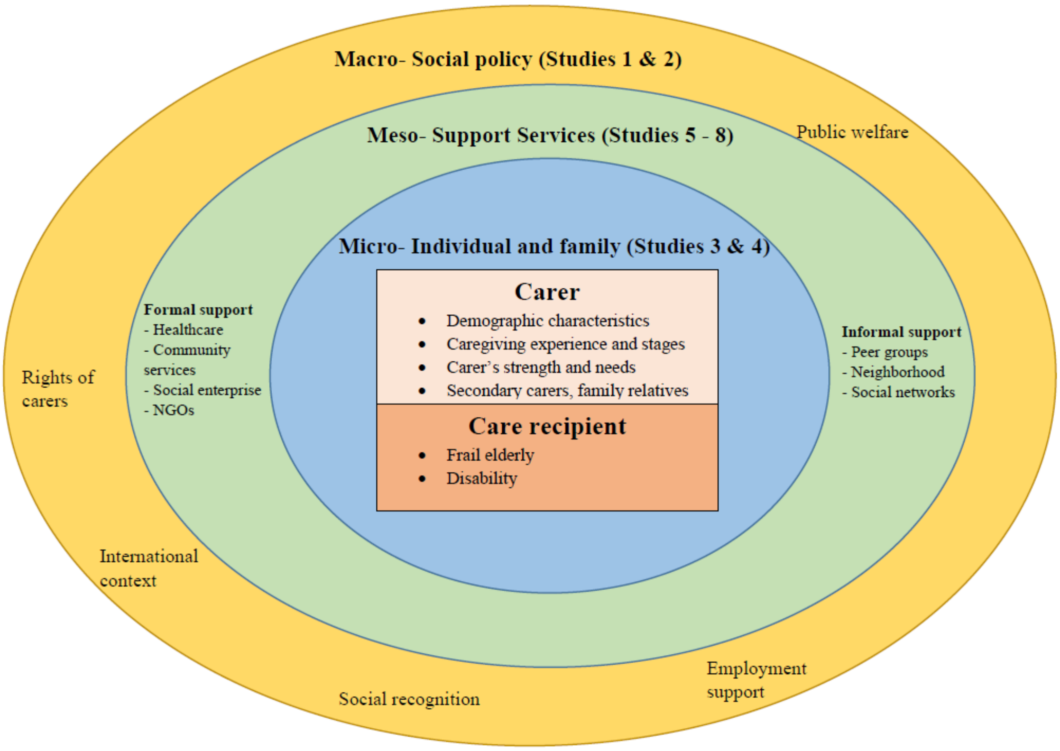
2.2.2 The models of carer support in Hong Kong

Drawing upon the conceptual models in our literature review, the overall consultancy study adopts a similar ecological approach, with study components corresponding to the micro, meso, and macro level systems of the investigation of carer-centric support (*Figure 2.6*).

The macro level is pertinent to social policy that centres on the welfare and support of carers from the perspectives of scholars, policymakers, and stakeholders. The meso level includes various organisations, groups, and social sectors that provide either professional or informal support for carers. Professional support includes support provided by healthcare professionals, community groups, social enterprises, and NGOs. Informal support includes carers' peer support and social support networks.

The micro level incorporates carers' individual characteristics (e.g., demographic information, caregiving experiences and stages, and care recipients' conditions) and needs. Carers have a wide range of needs: for example, informational/awareness needs, educational needs, financial needs, healthcare needs, support service needs, employment needs, and psychological needs. For each kind of need, different strategies should be adopted. The three levels of the socio-ecological system dynamically interact with each other. Each group of stakeholders plays a unique and supplementary role in supporting each other, ultimately fulfilling carers' needs.

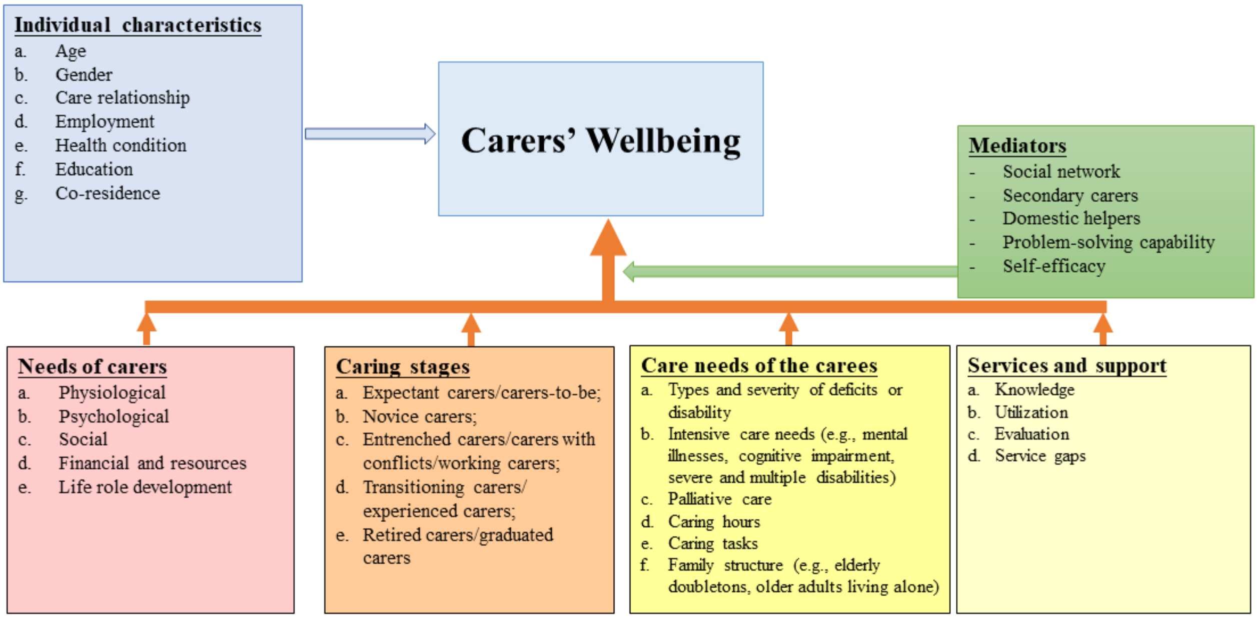
Figure 2.6 An ecological model of this consultancy study



Building upon the above ecological framework which guides the component studies of various research designs of this consultancy study, a theoretical framework is consequently proposed by consolidating the findings of the component studies to provide a holistic picture of the characteristics of carers specifically in the Hong Kong context.

As shown in *Figure 2.7* a carer-centred approach is adopted to illustrate the factors affecting, and potential strategies for promoting, carers' well-being. In this framework, carers are viewed holistically as independent persons rather than as subsidiaries to care recipients, and carers' well-being is affected by their individual characteristics, needs, caregiving stages, and services and support received, as well as the needs of care recipients. From a policymaking or service provision perspective, it is more pragmatic to prioritise resources to areas that can enhance carers' well-being (e.g., mediators and services/support). In addition to the above knowledge-driven process to facilitate our understanding of carers of Hong Kong, there is a need for a service framework which serve as a guide for policymakers and the social service sector to prioritise resources to address the pressing needs of carers. Such a service framework will be described in detail in Chapter 7.

Figure 2.7 Conceptual model guiding this study



2.2.3 Analysis of exemplar economies relevant to Hong Kong

Our review of the literature identified key areas for supporting carers, including service navigation, emotional/psychosocial support, knowledge/training programmes, use of technology, financial assistance, legislative recognition, and workplace accommodation.

In general, a holistic policy plan for supporting carers can be found in economies with a longer history of recognising the importance and value of family carers, notably Australia, Canada, and the United Kingdom, which share similarities in the designs of policies and specific action plans. Among the Asian economies in our review, national-level carer-centred policies can also be found in Singapore and Japan.

We have identified policy themes or main directions in economies with comprehensive carer support frameworks. In Australia, the National Carer Strategy 2011 contains six priority areas for action: (1) recognition and respect; (2) information and access; (3) economic security; (4) services for carers; (5) education and training; and (6) health and well-being. Under each of these priority areas, policy directions and areas for action in the shorter term have been identified. In 2015, the Australian government announced the development of an Integrated Plan for Carer Support Services (ICSS). This model identified eight service themes: awareness, information, intake, education, peer support, multi-component intervention, counselling, and need identification and planning. More recently, in 2020, new services were added to the ICSS framework, including peer support, self-guided coaching, phone-based counselling, a practical skills course, support planning, and emergency respite.

In the United Kingdom, the Standing Commission on Carers, established in 2007, has played a key role in advising the government on the progress of the delivery of national carer support strategies. Published in 2008, *Carers at the heart of 21st-century families and communities* is a 10-year cross-government strategy for ensuring that carers have increased choice and control and are empowered to have a life outside caring. The strategy sets out short-term commitments and identifies longer-term priorities, focusing on areas such as information and advice, respite care, expanded healthcare, employment support, emotional support, young carer support, enhanced service access, and financial assistance.

Policy plans for carers in other economies, such as the Canadian Carer Strategy, the United States' National Caregiver Support Program, Japan's Family Caregiver Support Manual, and Singapore's Caregiver Support Action Plan, are similar, with components resembling those listed under the Australian and British frameworks.

2.2.4 Summary of practices/support measures in other economies

The review of the economies in this study reveals a lack of comprehensive or comparable international evidence on carers due to the differences in service scope, eligibility criteria and service targets. Such a methodological challenge is also found in similar reviews (Colombo et al., 2011; Gardiner et al., 2019). While both merits and limitations are present in these services, as reflected in their evaluation reports, our review intends to focus on the typology (e.g., in-home care, respite care, financial support) and diversity of services that are common in designing carer-friendly policies in other economies. Some examples of support and services are summarised below to pinpoint the domains that are common in most of the economies, in an attempt to draw reference from them and compare them with similar existing services in Hong Kong (see also *Table 2.6*).

2.2.4.1 In-home care

In Australia, the Commonwealth Home Support Programme (CHSP) is an entry-level home support programme that helps elderly persons to live independently in their homes and communities. It also provides respite services to give carers a break. The CHSP is delivered by government-funded service providers, and users might need to pay a contribution or fee (which varies between providers) towards the cost of services. The in-home elements of the CHSP include help around the house, preparation of meals, personal care, and home modification. The CHSP also offers the Home Care Packages Programme as an enhanced version for more complex needs. The programme uses a consumer-directed care approach to make sure the support suits a person's needs and goals. Both the CHSP and the Home Care Packages Programme are available through the My Aged Care system[8]. As for in-home care of persons with disabilities, the National Disability Insurance Scheme (NDIS) provides funding to eligible persons for services that help with household tasks and home modification.

In Canada, Elizz, the First Nations Health Authority's Home and Community Care Programme (British Columbia), home care support services (Quebec), and the Home Care Program (Yukon) provide similar support for persons with care needs in terms of offering home respite and assistance with household tasks.

Home care in Sweden is regulated by the Social Services Act, as are most care services for elderly persons and persons with disabilities. Elderly persons and persons with disabilities who continue to live at home can obtain various municipally funded support, including home-delivered meals and healthcare assistance.

Our virtual field trip to Singapore also revealed good practices regarding in-home care. The Home Personal Care service is provided by trained care professionals to assist clients and their caregivers with activities of daily living (ADL; e.g., baths and light housekeeping), medication, mind-stimulating activities, elder-sitting, and other care tasks. This service is coordinated by the Agency for Integrated Care (AIC), with accessible information on the website that enables users to locate the nearest service provider.

2.2.4.2 Carer-friendly community support

Carer-friendly communities, as exemplified by the nationwide Carers Week in the United Kingdom, are places where carers feel supported to look after their family or friends and are recognised as individuals with needs of their own. The concept of a carer-friendly community encompasses areas of support such as community recognition, healthcare, employment, and education. Carers Week is also promoted nationally in Australia and the United Kingdom to foster carer-friendly communities. In addition to a comprehensive carer support framework, some economies have enacted carer-related legislation to recognise the value and contribution of carers, such as the Carer Recognition Act in Australia, the Care Act in the United Kingdom, the RAISE

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[8] My Aged Care is an online portal to access Australian Government-funded aged care services. The phone line and website can help older Australians, their families and carers to get the help and support they need.

Family Caregiver Act in the United States, the Social Services Act in Sweden, and the Long-Term Care Services Act in Taiwan. Recognition of carers in the community is achieved by methods such as the provision of carer ID cards (Australia) and carer passports (UK).

Another facet of a carer-friendly community is mutual assistance among peer carers. In Australia, the MyTime Peer Support Groups for Parents of Young Children with Disability programme provides a nationwide network of peer support groups for parents and carers of young children with a disability or chronic medical condition. In Canada, peer support for carers is mostly delivered in a group format and in collaboration with health-based and charity organisations that help to organise peer support groups, educational workshops, and activity-based support groups. For example, Baycrest Health Sciences (Ontario) offers an Online Caregiver Support Group for families and carers affected by a person with dementia. In Singapore, a number of community support groups provide carers with a platform to share their experiences, and some of these are peer-led groups. Another prominent example of the promotion of peer support is the carer café, an idea that originated with the French Association of Caregivers almost two decades ago. The concept has been popularised and the service model has been culturally adapted in other places, such as Japan, Taiwan, and, more recently, Hong Kong.

2.2.4.3 Respite care

Generally, respite care (or "short breaks") is one of the major services supporting families by providing carers with temporary relief from the continuous support and care they provide to elderly persons, persons with disabilities or persons who are dependent on others. The objective of such breaks is to increase or restore the carer's caregiving capacity (van Exel et al., 2006). The most common forms of respite care are day care respite, in-home respite, and institutional respite (depending on resource availability, level of urgency, and intensity of care) which are in place in all of the economies we reviewed. An important element in respite care is the length of respite. Some services offer short stays (e.g., day care services) and others offer longer periods of respite (e.g., vacation breaks for carers and emergency care).

From our review of the international literature, it appears that the evidence on the effectiveness of respite care is still controversial. While qualitative evidence shows that respite care is highly valued by carers, evaluative studies are often criticised for having a small sample size to allow statistically significant effects to be identified and thus provide little quantitative evidence to ascertain the cost-effectiveness of respite care (Colombo et al., 2011; Parker et al., 2010; World Health Organization, 2017).

Nonetheless, Sorensen's (2003) meta-analytic study reported that respite/day care interventions were effective for three outcomes: caregiver burden, caregiver depression, and caregiver well-being. Similarly, as shown in our qualitative and quantitative studies, respite service is an important way to relieve care burden and prevent the premature institutionalization of elderly persons or persons with disabilities. Respite care as a support for family carers is universal across the nine economies reviewed in this study.

In Australia, respite care is delivered under the policy frameworks governing disability and elderly care services, notably the NDIS and the CHSP. The Australian government pays providers a respite subsidy and supplement for providing respite care to eligible clients for up to 63 days annually.

To take Guangzhou as another example, respite care is provided through social centres as day and short stays for elderly persons and persons with disabilities. A monthly amount of ¥800 – ¥1 500 (around HKD 980–1 840) (depending on the household income) per person is provided as a respite subsidy to families of persons with disabilities aged between 16 and 59[9]. Respite care is also facilitated by municipal government and social organisations to provide short breaks for carers; for example, in 2020, the "Carers Haven" (照顧者的港灣) project, consisting of social workers and doctors, was established to provide home-based outreach services for families with frail persons, relieving the care burden of carers by more than 1 200 hours in a total of nearly 80 families within a half year project period.

In Singapore, information for accessing respite care is well integrated in the AIC. Carers in Singapore can use centre-based respite care at senior care centres for a few hours a day so that they can have time to attend to personal matters. Nursing home respite care is an option for overnight stays lasting from several days to a few weeks, providing

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[9] 广州市海珠区残疾人联合会关于印发《广州市海珠区重度残疾人托养服务资助管理办法》的通知

respite for carers who require longer breaks. A new initiative rolled out in 2019 is the provision of night respite to allow carers, especially those who are working or caring for an elderly person during the day, to catch some rest at night. Home-based respite is also available for carers taking care of end-of-life family members to receive support in custodial care, such as showering, dressing, and feeding. Another feature of Singapore's respite provision is Go Respite, a pre-enrolment programme that has been piloted since April 2019 to reduce the time required to activate respite care in senior care centres and nursing homes. Carers can register and complete some administrative processes in advance to reduce the activation time for respite care.

2.2.4.4 Financial assistance

Most of the economies reviewed in this study provide financial assistance to carers through cash benefits either paid directly to carers through a carer allowance or paid to those in need of care, part of which may be used to compensate family carers. The monthly amount ranges widely from SGD200 (HKD1 155) in Singapore to AUD2 064 (HKD12 384) in Australia. Carer allowance is not implemented nationally in the United States or China, but a few regional policies of subsidising family carers exist in both countries.

In Singapore, the Home Caregiving Grant provides an SGD200 (HKD1 155) monthly cash payment for carers who have to take care of persons with at least a moderate permanent disability (i.e., always requiring some assistance to perform three or more ADL) to defray their caregiving expenses, including the costs of elderly care and carer support services in the community or hiring a foreign domestic worker. The Caregivers Training Grant is an SGD200 (HKD1 155) annual subsidy for carers to offset the fees of training courses to equip themselves with the necessary skills to care for the physical and emotional needs of their care recipients.

In the United Kingdom, carers can be entitled to Carer's Allowance and Universal Credit as direct financial assistance when they need to provide care to a dependant. Carer's Allowance is a non-contributory benefit paid to persons who care full-time for someone who has severe disabilities. Carers must meet a list of eligibility criteria: for example, they must be aged 16 or above, spend 35 hours a week on caregiving, and have an income of £128 or less per week (HKD5 947/month) although it is still described as a non-means-tested benefit in the UK. The notion of "means test" in the UK usually covers tests on both income and capital. Apparently, the cap on earnings from paid employment in such case does not suffice to define it as "means-tested". Eligible carers can receive a weekly payment of £67.25 (around HKD 2 914/month). Also, if an individual is unable to work due to health problems or caring responsibilities, they may be entitled to Universal Credit, which provides a standard allowance of up to £594.04 (around HKD 6 296) per month per couple (or up to £409.89 or around HKD 4 344 for a single recipient). Where a person satisfies the care conditions for Carer's Allowance, a "carer element" is included in the calculation of the maximum amount of Universal Credit they can receive. This mirrors the carer premium/addition currently payable with means-tested benefits and is worth £162.92 (HKD 1 629) per month (2020/21 rate). For example, a couple taking care of a family member with disabilities may be eligible to receive Universal Credit of up to £756.96 (HKD 8 094) per month.

Measures to minimise the financial burden of carers in Canada can be found at the national and provincial levels. Nationally, Caregiver Recognition Benefit provides a non-taxable CAD1 000 (HKD 5 895) monthly benefit for carers of ill and injured veterans. A cash allowance to carers is not provided at the federal level, but various forms of cash-for-care programmes exist in provincial systems: for example, the Nova Scotia Caregiver Benefit (March 2018) provides CAD400 (HKD 2 358) per month to carers of low-income care recipients with a high level of disability.

In Sweden, the "Benefit for care of closely related persons" (*Närståendepenning för anställda*) provides carers with a little less than 80% of their regular income to care for a close relative who is seriously ill. Carers of children with disabilities can apply for a Car Allowance of up to SEK30 000 (HKD27 550) to purchase a car or use public transportation, and there are additional benefits for car acquisition or adaptation. In Taiwan, a monthly Care Allowance of NTD5 000 (HKD1 330) is provided for carers who dedicate their time to take care of elderly persons with a lower income.

2.2.4.5 Emotional support and training for carers

Training and emotional support can help family carers to gain relief and acquire the necessary knowledge and skills for care provision, and can enable them to protect themselves from burnout and other negative impacts on their physical and mental health.

Across the reviewed economies, emotional support and training are commonly embedded in the carer support framework.

In Australia, counselling, education, and training programmes for carers are delivered through the government-led Carer Gateway, an online platform where carers can access various supportive resources. The Dementia Education and Training for Carers programme and counselling, support, information, and advocacy services are also prominent services for supporting carers.

Counselling and training are also provided by the National Family Caregiver Support Program in the United States. In Singapore, the AIC has developed some community outreach teams to undertake a more focused approach to outreach and provide support for carers. These teams support carers in self-care through health and wellness activities, stress management, and future planning, as well as linking them up with support groups and counselling services where needed.

In China, the Guangzhou Civil Affairs Bureau has established social aid centres across the districts of the city (工療站); these centres are empowered by charities, social workers, and volunteers to provide community support for carers of elderly persons and persons with disabilities, including caregiving-related training, counselling, crisis intervention, real-time assistance, and case management.

2.2.5 Other relevant aspects

2.2.5.1 Employment/workplace support

Family carers require both time and flexibility when trying to reconcile employment and other responsibilities in their personal lives with often unpredictable care requirements. In some of the economies reviewed, family carers have a statutory entitlement to time off from employment; this entitlement ranges widely from a few days to several months (e.g., 10 days in Australia, 93 days in Japan, 100 days in Sweden, and 28 weeks in Canada). Flexible work arrangements, such as the possibility to reduce working hours or to work from home, can be instrumental in enabling working carers to remain in employment when faced with care duties. However, such arrangements are largely provided at the discretion of employers.

2.2.5.2 Identification and social statistics of carers

Identification of carers on a large scale is often achieved using population censuses or surveys. For example, in Australia, the main source of demographic and social data on carers is provided by the Australian Bureau of Statistics (ABS). In the UK, the nationwide census conducted every ten years provides the number of carers in the country by simply asking a question “Do you look after, or give help or support to, anyone because they have long-term physical or mental health conditions or illnesses, or problems related to old age?” Regular data on carers through censuses or other studies are essential for policy review and service development in carer support.

2.2.5.3 Holistic carer policy

In general, a holistic policy plan for supporting carers can be found in economies with a longer history of recognising the importance and value of family carers, notably Australia, Canada, and the United Kingdom, which share similarities in the design of policies and specific action plans. Among the Asian economies under review, national-level carer-centred policies can also be found in Singapore and Japan.

2.2.6 Summary of exemplary practices of other economies and Hong Kong

In addition to the above areas of support which are commonly observed across the economies under review, the table below summarises the major needs of carers and the types of support measures in other economies, so as to provide a comparison with those in Hong Kong, with observations on areas that deserve further attention. Instead of delving into the evaluation of these overseas examples, it is rather our focus to provide an overview of international practices in terms of the types of support provided to carers.

Table 2.6 Examples of supportive services or programmes for carers in other economies and Hong Kong

Needs	**Types of support measure**	**Examples from other economies**	**Examples from Hong Kong and observations**
Recognition and awareness	Defining family carers, responsibilities and entitlements	Australia – Carer Recognition Act, National Carer Strategy; Canada – Canadian Caregiver Strategy; UK – Care Act 2014; US – The RAISE Family Caregiver Act; Sweden – Social Services Act; Singapore – Caregiver Support Action Plan, National Guidelines for Palliative Care; Taiwan – Long-term Care Services Act	Observation: definitions of carers are relatively unclear in Hong Kong due to the lack of carer-specific legislation or action plan.
	Raising awareness about the challenges of carers	Australia – National Carer Awareness Campaign, Carers Week; Canada – National Caregiver Day; UK – Carers Week; US – National Family Caregivers Month	• Carer EPS, Carer Awareness Day (BOKSS); • Big Silver Community (Big Silver Community Limited); • Resource and Support Centre for Carers (Caritas HK)
	Official statistics on carers	Australia – Australian Bureau of Statistics; Canada – Statistics Canada; UK – nationwide census;	• Special Topics Report No. 63 (Census and Statistics Department) published in 2021; • Special Topics Report No. 62 (Census and Statistics Department) published in 2014.

Needs	Types of support measure	Examples from other economies	Examples from Hong Kong and observations
		Japan – “2016 Basic Survey on Social Life”; Singapore – data from the Ministry of Health	• Thematic Household Survey Report No. 40 (Census and Statistics Department) published in 2009. Observations: these reports focused more on care recipients while information on carers is comparatively less compared to that available in other economies. The 2021 Population Census included, for the first time, a few questions on elderly persons requiring care and their carers (e.g., relation of the carer and care recipients, time spent on taking care of the care recipient per week, etc.), while the 2019/20 Survey on Persons with Disabilities and Chronic Diseases also collected information on carers (e.g., hours of care service, level of stress and carers’ employment status).
	Care leave entitlements	Australia – National Employment Standards (10 days of paid leave, 2 days of unpaid leave);	Some corporates are starting to introduce carer-friendly measures, e.g.:

Needs	**Types of support measure**	**Examples from other economies**	**Examples from Hong Kong and observations**
Reconciling care with work and personal life		Canada – Compassionate Care Benefit (26 weeks of paid leave at 55% average earnings, 8 weeks of unpaid leave); Japan – Family care leave benefit (93 days of paid leave); Sweden – Carer paid leave (100 days of paid leave at 80% salary)	• Flexible working hours, Parent Angel Team, regular talks and workshops for carers (Meiriki); • 2 days per year carer leave for staff, free 3-month trial for new users of Care-and-Call service, flexible working hours, free workshops for carers (Kerry Group). Observation: workplace support of carers is still in the developmental stage in Hong Kong, where it is usually promoted by initiatives of private companies.
	Flexible working arrangements	Australia – Work and Care Charter; Canada – The Canada Labour Code; UK – Work and Families Act 2006; Acas Code of Practice; US – EEOC: Employer Best Practices for Workers with Caregiving Responsibilities	
Financial security	Cash benefits for carers (care allowance), social security	Australia – Carer Payment (HKD10,444 per month), Carer Allowance (HKD1,740 per month); Canada – Nova Scotia Caregiver Benefit (HKD2,358 per month);	• Pilot Scheme on Living Allowance for Low-income Carers of Elderly Persons (HKD$2,400 per month); • Pilot Scheme on Living Allowance for Low-income Carers of Persons with Disabilities (HKD$2,400 per month);

Needs	Types of support measure	Examples from other economies	Examples from Hong Kong and observations
		UK – Carer's Allowance (HKD2,914 per month), Carer Credit; Sweden – Benefit for Care of Closely Related Persons (<80% of individual income), Attendance Allowance (amount varies by individual); Singapore – Home Caregiving Grant (HKD1,155 per month), Caregiver's Training Grant (HKD1,155 per year); Taiwan – Special Family Care Allowance for Mid or Low-Income Elders (HKD1,330 per month)	• A maximum of HK$1,000 training fee throughout all phases of the Pilot Scheme (by reimbursement for participation in fee-charging training programmes and related expenses, e.g., respite care service); • HK$75,000 tax allowance for one dependant with disabilities. Observation: the subsidy amount in Hong Kong is comparable to that in some Western economies (e.g., the UK and Canada) and almost double that in some Asian counterparts (Singapore and Taiwan).
Access to services in the community	Access to respite care / respite locator	Australia – National Respite for Carers Programme (NRCP), Mental Health Respite: Carer Support (MHR:CP); Canada – At Home Program, Special Needs Assistance for Seniors; UK – NHS respite service locator; US – Eldercare Locator	• SWD's Vacancy Enquiry System for Residential Respite Service for Persons with Disabilities, Residential Respite Service for the Elderly, and Emergency Placement for the Elderly.

Needs	**Types of support measure**	**Examples from other economies**	**Examples from Hong Kong and observations**
			Observation: the paradox of perceived insufficient respite care and underutilisation is found in Hong Kong.
	Service information / navigation platform	Australia – Carer Gateway, Carers Australia; Canada – Canadian Caregiving Network, Elizz, Carers Canada; UK – NHS, Carers UK; US – National Alliance for Caregiving, CareRelay; Sweden – Carers Sweden (Anhörigas Riksförbund); Japan – Carers Japan; Singapore – AIC; Taiwan – Taiwan Association of Family Caregivers	• 656carer.com on stroke, dementia and fall (SJS, HK Society for Rehabilitation, etc.) • WeRise Mobile Platform for Stroke Patients and their Caregivers (HKU Faculty of Medicine) Observation: there are a few information platforms in Hong Kong for carers, but most of them are specific to certain types of care recipients and are initiated by NGOs.
Access to information and training	Information and counselling for carers	Australia – National Broadband Network, Carer Support Centres, MyAged Care; UK – Carers Trust counselling;	• SWD: Hotline Service <2343 2255> • Caritas Jockey Club Carer Support Hotline: <3892 0101>

Needs	**Types of support measure**	**Examples from other economies**	**Examples from Hong Kong and observations**
		US – National Family Caregiver Support Program; Singapore – Silver Line	Observation: Currently, some NGOs and the SWD are providing hotline services for people who have psychological distress and need instant support. While SWD's hotline operates round the clock, some services operate only during working hours and most other hotlines are not specially designed for and accessed exclusively by carers. Carers are not aware of many hotlines and they therefore do not access such hotlines when they encounter emergency circumstances.
	Training for carers	Australia – Dementia Education and Training for Carers, Carer Gateway self-coaching; Canada – MeSSAGES; UK – Skills for Care, Health Education England, START programme; Guangzhou – "social aid centres" (工療站), "Carer's Haven" (照顧者的港灣)	• All community centres (e.g., DECCs, NECs, DSCs, PRCs are expected to provide training to carers; • CARE College (BOKSS); • Jockey Club All Brilliant Carers Projects (HKFWC) Observation: many of them are time-limited and could only serve a small number of carers by the types of care recipients, due to the service scope of the organisations. Despite the well-intended designs of these

Needs	Types of support measure	Examples from other economies	Examples from Hong Kong and observations
			programmes, some carers are found to have little time to attend the activities, which are usually centre-based.
Health and well-being	Facilitating social relationships, peer support, and self-help	Australia – MyTime Peer Support Groups, Mental Health Support Services, the Weavers programme; Canada – Canadian Peer Support Network; UK – Carers UK Forum; US – Caregiver Action Network; Japan – NPO Caregiver Support Network Centre; Singapore – Caregiving Welfare Association; France – Carer café [carer café was initiated in France] Taiwan – Carer café	• Elderly Sitters – Pilot Project on Community Support and Senior Employment (The Chinese Rhenish Church HK Synod); • Time bank projects (HKSKH Tseung Kwan O Aged Care Complex; BOK Lai Yiu NEC); • Community carer café/dementia café (AKA; HKFWC). Observation: peer-support programmes are common in the economies under our review. Most of them received positive feedback because the programmes helped both the peer volunteers and carers realise their common experience and emotions, enabling them to share the difficulties and positive aspects. Some local NGOs in Hong Kong have demonstrated good examples although the scale of these programmes is relatively small.

Chapter 3. Summary of Findings from Carers on Needs and Service Expectations (Studies 3 and 4)

3.1 Summary of major aggregated and significant findings on both carer groups

Studies 3 and 4 and aimed to generate a profile of the needs and expectations of the carers of elderly persons and persons with disabilities, with an emphasis on understanding their major needs, challenges, burden, strengths, and service expectations. In Study 3, we gathered the views of service users (i.e., carers of elderly persons using existing government-subsidised services, including regular services and pilot schemes) and non-service users (i.e., carers of elderly persons who had never used any existing government-subsidised services or pilot schemes). Study 4 involved service users (i.e., carers of persons with disabilities who had used the direct support service, such as subsidies, training activities or education courses or talks or workshops or care skills courses, and enquiry or consulting service for carers) and non-service users (i.e., carers of persons with disabilities who had not used direct services in the past two or three years).

3.1.1 Demographic profiles of participated carers

In Studies 3 and 4, we adopted a mix-method design. In Stage 1, a total of 80 carers of elderly persons (*n* = 31) and carers of persons with disabilities (*n* = 49) were involved in focus group interviews. In Stage 2, a total of 2 868 questionnaires were returned for Study 3 (*n* = 1 112) and Study 4 (*n* = 1 756). After clearing missing cases and non-carers for Study 3 (*n* = 146) and Study 4 (*n* = 449), a total of 2 273 carers of elderly persons (*n* = 966) and persons with disabilities (*n* = 1 307) participated in a cross-sectional survey and thus the total number of valid questionnaires used in data analysis was 2 273. Among all 2 273 questionnaires, there were missing data in some question items for both Studies 3 and 4. Thus, the number of valid responses for data descriptive analysis of different questions was in fact different. From observation on all the question items, the minimum number of valid questionnaires used in data analysis for Studies 3 and 4 was 708 and 639, respectively. The inclusion criteria of carers of elderly persons were aged 15 or above and taking care of frail elderly persons (aged 60 or above) with various degrees of physical or cognitive impairment requiring assistance in their ADL or IADL. For the group of carers of persons with disabilities, they were required to be 15 years old or above and taking care of persons with any kind of disabilities as follows: (i) mental illness; (ii) visual, hearing, or speech impairment; (iii) intellectual disability, Down's Syndrome, attention deficit hyperactivity disorder, autism, or specific learning difficulties; (iv) physical, visceral, or multiple disabilities; and (v) other disabilities.

3.1.1.1 Demographic profiles of participating carers (Stage 1)

Regarding the demographic data of the 31 carers for Stage 1 (focus group) of Study 3, 71% were female, their average age was 65.7 (*SD* = 15.1), and the average age of the elderly persons they were taking care of was 80.8 (*SD* = 8.9). Similar demographic data were observed among the 49 stakeholders for Stage 1 (focus group) of Study 4, with 77.6% being female with an average age of 65.7 (*SD* = 15.1), while the age of their care recipients was 40.3 (*SD* = 24.6).

3.1.1.2 Demographic profiles of participating carers (Stage 2)

Regarding the demographic data of the respondents among 966 carers for Stage 2 of Study 3, most of them (74.5%) were female. Carers' average age was 54.5 (*SD* = 18.1), and the average age of care recipients was 82.0 (*SD* = 10.0). Less than half (40.1%) of the carers reported their self-perceived health condition as good/very good and most of the carers (57.9%) were taking care of their parents. Similar demographic data were observed among the respondent of 1 307 carers for Stage 2 of Study 4, 82.5% of the carers were female, they had an average age of 51.3 (*SD* = 12.8) and were taking care of persons with disabilities aged 27.5 (*SD* = 22.3). Only 28.4% of the carers reported their self-perceived health condition to be good/very good. Most of the carers were looking after their children with disabilities (87.0%).

3.1.2 Major qualitative findings on needs, challenges, burden, strengths, and service expectations

In Stage 1 of Studies 3 and 4 (i.e., focus group interviews), seven themes emerged representing the major needs, challenges, burden, strengths, and service expectations of carers: (1) role of carers; (2) care burden and its attributes; (3) service expectations and needs; (4) strengths of carers; (5) facilitators of and barriers to service utilisation; (6) characteristics of carers at high risk; and (7) the use of technology to assist caregiving and barriers to utilisation.

(1) Role of carers:

> The role of carers mainly includes caregiving tasks in ADL and IADL, accompanying care recipients to medical appointments, providing financial assistance, and providing emotional support. The carers shared that they engaged in

multifaceted care provision activities depending on the care needs of their care recipients.

Some carers pointed out that caregiving is a family issue and the responsibilities are shared with other family members. The carers often had to manage family issues as well as balance occupational roles to fulfil their caregiving duties.

(2) Care burden and its attributes:

The carers shared that they experienced an enduring and considerably heavy physical, mental, and financial burden of caregiving as well as role conflicts and relationship difficulties related to caregiving. The characteristics of both the care recipients and the carers contributed to this care burden.

(3) Service expectations and needs:

Some carers suggested that building up a one-stop platform would be helpful for them to receive caregiving information for performing caregiving tasks. The carers raised the need for easily accessible information/resources and the adoption of case management approaches.

(4) Strengths of carers:

The carers of elderly persons and persons with disabilities identified individual strengths in caregiving in terms of self-awareness, stress management skills, self-efficacy, problem-solving, help-seeking, enhancing family bonds, and fulfilling responsibilities. They also shared their appreciation of the support they received from their social networks. A majority of the carers of elderly persons and persons with disabilities agreed that strengthening their caregiving and cognitive skills (e.g., problem solving, memory, etc.) could help them handle more effectively the day-to-day challenges of caregiving.

(5) Facilitators of and barriers to service utilisation:

The carers of elderly persons and persons with disabilities shared that the accessibility of information, the application processes, and the availability of services are crucial factors in service utilisation. They also expressed that strict eligibility requirements, the complexity of application processes, and long waiting times are barriers to receive services or allowances.

(6) Characteristics of carers at high risk:

The carers of elderly persons and persons with disabilities reported that managing behavioural and psychological problems of care recipients is very stressful for them. The characteristics of carers at high risk include long and intensive caregiving tasks, history of domestic violence, behavioural disturbance of care recipients, lack of recognition and support from carers' immediate circle, caregiving for multiple dependents with disabilities, and having suicidal thoughts and/or murder-suicide thoughts. The partial disruption of community services and social isolation measures during the COVID-19 pandemic also further impaired the mental health of carers.

(7) Use of technology to assist caregiving and barriers to utilisation:

The carers shared that use of information and communication technology was conducive to seek support services and promoting knowledge acquisition among carers. Insufficient/lack of knowledge, skills, and budget are barriers to using technology in caregiving.

3.1.3 Major quantitative findings based on the in-depth statistical analysis

The majority of the carers of elderly persons and persons with disabilities at Stage 2 (i.e., the cross-sectional survey) were middle-aged adults with an average age of above 50. When it came to carers of elderly persons (n = 966)[10], most of them took care of their elderly parents (57.9%), followed by spouses (22.6%) and grandparents (15.7%). In the case of carers of persons with disabilities (n = 1307)[11], most of them took care of their children (87.0%), followed by spouses (22.2%) and parents (16.1%). The average caregiving hours per week for carers of elderly persons and persons with disabilities

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[10] There are missing data for some question items: some respondents did not provide answers, or provided irrelevant answers, so the total number of respondents answering each item might be less than 966 for carers of elderly persons.

[11] There are missing data for some question items: some respondents did not provide answers, or provided irrelevant answers, so the total number of respondents answering each item might be less than 1 307 for carers of persons with disabilities.

were 41.9 and 77.2, respectively. The difference in the average caregiving hours between the two carer groups is probably due to the caregiving tasks related to taking care of elderly persons and persons with disabilities being different. The majority of both carers of elderly persons (87.6%) and persons with disabilities (76.9%) perceived their health status as fair to very good, and over 50% of them did not have any diagnosed diseases. A total of 32.8% of carers of elderly persons and 18% of carers of persons with disabilities were full-time workers. Details of the demographics of carers of elderly persons[12] and carers of persons with disabilities[13] are listed in the footnotes.

The major findings at Stage 2 (i.e., survey) of Studies 3 and 4 fell into five areas: (1) role of carers and caregiving tasks; (2) service needs; (3) facilitators of and barriers to service utilisation; (4) facilitators of and barriers to technology utilisation in caregiving;

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[12] For the carers of elderly persons, the mean age of non-service users and service users was 44.0 (*SD* = 17.6; *n* = 434) and 64.0 (*SD* = 12.6; *n* = 486), respectively. Around one-third of all carers (33.3%) had a family income of less than HKD 9,999; 78% of service users and 33.7% of non-service users had a monthly household income of less than HKD 20,000. All carers, non-service users, and service users were mostly the children of care recipients (57.9%, 59.6%, and 56.4%, respectively) followed by spouses (22.6%, 4.1%, 37.6%) and grandchildren (15.7%, 2.0%, 33.7%). On average, all carers spent 5.6 days (SD = 2.0), non-service users spent 4.9 days (*SD* = 2.0), and service users spent 6.3 days (*SD* = 1.6) per week to take care of care recipients. Their average number of hours per week was 41.9 hours (*SD* = 52.4; for service users = 61.7±63.2; non-service users = 21.7±26.0 hours). Around one-third (32.8%) of all carers were full-time workers (49.7% of non-service users, 17.9% of service users), the main source of income of the participants was "own salary" (49.3% of all carers, 73.9% of non-service users, and 27.4% of service users), and 35.4% of all carers reported social security as their main source income (non-service users: 7.6%; service users: 60.2%).

[13] For the carers of persons with disabilities, the mean age of non-service users and service users was 52.9 (*SD* = 13.5; *n* = 168) and 50.7 (*SD* = 12.4; *n* = 503), respectively. Around one-fifth of all carers (21.6%) had a family income of less than $9,999; 52.7% of service users and 53.8% of non-service users had a monthly household income of less than $20,000. All carers, non-service users, and service users were mostly the children of care recipients (87.0%, 83.2%, and 88.3%, respectively), followed by spouses (22.2%, 23.8%, and 21.6%, respectively) and parents (16.1%, 18.8%, and 15.2%, respectively). On average, all carers spent 6.0 days (*SD* = 0.7), non-service users spent 5.8 days (SD = 3.0) and service users spent 6.0 days (*SD* = 0.8) per week to take care of care recipients. Their average number of hours per week was 77.2 hours (*SD* = 54.3) (service users = 77.5±54.7; non-service users = 76.3±52.8 hours). Around one-fifth (18.1%) of all carers were full-time workers (16.9% of non-service users; 18.5% of service users), the main source of income of the participants was "spouse's salary" (47.6% of total carers, 40.9% of non-service users; and 29.9% of service users), and 29.1% of total carers reported "Own salary" as their main source of income (non-service users: 28.7%; service users: 29.2%).

and (5) impacts of caregiving on carers and self-rated caregiving ability and burden. Major similarities and differences found between the two carer groups are reported in this and the next sections, respectively.

(1) Role of carers and caregiving tasks:

Consistent with the findings from the focus group interviews at Stage 1, the majority (91.7% of carers of elderly persons; and 93.3% of carers of persons with disabilities) of the carers believed that the major reason for taking care of care recipients was to fulfil the responsibilities of being a family member. The three main persons most frequently perceived as fulfilling these caregiving tasks were the carers themselves, family member/relatives, and domestic helpers. The needs of elderly persons most commonly reported by their carers were related to daily living (88.9%), followed by assistance with rehabilitation, medication, or treatment (76.7%), emotional support (68.7%), and personal care (64.2%). The findings were largely similar to those in Study 4 regarding carers of persons with disabilities. Daily living (87.3%) was the caregiving task reported by the largest proportion of carers of persons with disabilities, followed by emotional support (81.2%), assistance with rehabilitation, medication, or treatment (81.1%), and personal care (66.8%).

(2) Service needs:

Both the carers of elderly persons and the carers of persons with disabilities ranked “cash allowance” as one of the two most-wanted support. Among the carers of elderly persons, the top two support measures most frequently ranked 1 (most wanted) were “Cash allowance” (21.8%) and “Home care service such as meal service, general household or domestic duties” (20.7%). Among the carers of persons with disabilities, the top two kinds of support were “Cash allowance/financial assistance” (28.0%) and “Home rehabilitation (e.g., occupational therapy, physical therapy, speech therapy, etc.)” (11.5%).

(3) Facilitators of and barriers to service utilisation:

In general, the utilisation rate of existing services by carers of elderly persons was generally low, ranging from 4.2% (Pilot Scheme on Training for Foreign Domestic Helpers in Elderly Care) to 33.6% (Enquiry service for carers). On the other hand, the utilisation rate of existing services by carers of persons with disabilities was low to medium, ranging from 5.6% (Support for discharge from hospital) to 57.6% (Subsidies, e.g. subsidies for persons with disabilities from the Community Care Fund). The two most common reasons given for not using services were “I don’t know about the service” (carers of elderly persons: 11.5% to 44.7%; carers of persons with disabilities: 13.6% to 51.8%) and “I don’t need the service” (carers of elderly persons: 19.4% to 62%; carers of persons with disabilities: 12.2% to 59.1%). We want to caution about the interpretation of these findings since not all carers are eligible for some of these services (e.g., those who have not been hospitalised do not require support for discharge from hospital).

(4) Facilitators of and barriers to technology utilisation in caregiving:

More than one third of the carers of elderly persons and the carers of persons with disabilities had used IT products to assist caregiving. Most of the carers of elderly persons and persons with disabilities had used IT products for “obtaining online information” (77.1% of carers of elderly persons; 87.8% of carers of persons with disabilities), followed by “distant communication” (41.9% of carers of elderly persons; 43.9% of carers of persons with disabilities). More than a quarter of the carers of both elderly persons (35.6%) and persons with disabilities (22.7%) felt that IT products could be very/extremely helpful for relieving the care burden. The two measures most commonly indicated as being able to convince both types of carers to use IT products in assisting care were provision of an information platform on technology products (62.3% of carers of elderly persons; 50.3% of carers of persons with disabilities) and provision of assistance for usage of the technology products (54.5% of carers of elderly persons; 48.6% of carers of persons with disabilities).

(5) Impacts of caregiving on carers and self-rated caregiving ability and burden:

The two positive impacts most commonly selected by both the carers of elderly persons and the carers of persons with disabilities were “Gained caring knowledge and techniques” (mean score of 3.2 out of 5.0 in carers of elderly persons; mean score of 3.1 out of 5.0 in carers of persons with disabilities) and “Improved problem-solving ability” (mean score of 3.0 out of 5.0 in carers of elderly persons; mean score of 3.1 out of 5 in carers of persons with disabilities). Meanwhile, the majority of both groups of carers rated their caregiving ability as fair. Overall, both groups of carers showed moderate levels of care burden with a mean Zarit Burden Interview score (0 = no burden to 12 = the heaviest burden as carer) of 4.7 out of 12 for carers of elderly persons and 6.6 out of 12 for carers of persons with disabilities. Moreover, both carer groups reported an increase in caregiving pressure during the COVID-19 pandemic. The two main reasons were the behavioural and psychological problems of care recipients and the emotional problems of carers.

3.2 Summary of major differences between the two carer groups in terms of needs, challenges, burden, strengths, and service expectations

Based on the findings of studies 3 and 4, the needs, challenges, burden, strengths, and service expectations commonly found in the two carer groups have been reported in previous section. Below are several major differences between the two carer groups and the results of regression analysis on the two carer groups.

(1) Role of carers and caregiving task:

a. *Specific to carers of elderly persons:* Besides the general caregiving role, the carers of elderly persons specifically reported that they had to closely monitor various behaviour problems of their care recipients as most of the problems (e.g., wandering, agitation) were unpredictable.

b. *Specific to carers of persons with disabilities:* The needs most reported by carers were daily activities (including shopping, transportation, domestic cleaning, etc.), and these tasks were mostly taken care of by carers, family members, and domestic helpers. Other than closely monitoring the condition of their care recipients, the carers of persons with disabilities also need to provide emotional support and accompany their care recipients and take them to receive training, which were mostly provided by carers, family members, and social welfare/medical organisations.

(2) Service utilisation and barriers to service utilisation:

a. *Specific to carers of elderly persons:* The top three services that the carers of elderly persons used were enquiry service for carers, home visit rehabilitation service and day care service[14]. "I don't understand/know how to apply" (20.8%, 17.4% and 14.8%) was one of the main reasons for not using services. Carers of elderly persons specifically expressed that respite care is particularly difficult to access when carers encounter emergency events. Short-stay (e.g., 3 to 5 days) respite services are also scarce due to the unpredictability of casual vacancies and the overwhelming demand from carers who wish to take a break.

b. *Specific to carers of persons with disabilities:* The top three services that the carers of persons with disabilities used were subsidies, training activities/education courses/talks/workshops/care skills courses, and enquiry/consulting service for carers[15]. Regarding indirect support services for carers, most persons with disabilities did not use day care services, home rehabilitation services and nursing services, personal care and domestic cleaning services, escort services, discharge services, day respite services, residential respite services, home respite services, and emergency placement[16]. This result showed that more than three

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[14] The top three services that the carers of elderly persons used were "Enquiry service for carers" (total carers: 33.6%, non-service user: 23.7%, service user: 42.2%), "Home visit rehabilitation service" (total carers: 30.5%, non-service user: 25.5%, service user: 34.8%), and "Day care service" (total carers: 29.3%, non-service user: 24.5% and service user: 33.5%).

[15] The top three services that the carers of persons with disabilities used were Subsidies (e.g., subsidies for persons with disabilities from the Community Care Fund) (57.6% overall; 49.5% of the non-service user group and 50.5% of the service-user group), Training activities/education courses/talks/workshops/care skills courses (51.2% overall; 0% of the non-service user group and 71.2% of the service-user group), and Enquiry/consulting service for carers (47.3% overall; 0% of the non-service user group and 65.9% of the service-user group).

[16] Regarding indirect support services for carers, most persons with disabilities did not use day care services (78.6% overall; 85.5% of the non-service user group and 76.0% of the service-user group), home rehabilitation services and nursing services (81.1% overall; 85.9% of the non-service user group and 79.4% of the service-user group), personal care and domestic cleaning services (93.5% overall; 95.1% of the non-service user group and 92.9% of the service-user group), escort services (89.6% overall; 92.9% of the non-service user group and 88.4% of the service-user group), discharge services (94.4% overall; 95.7% of the non-service user group and 93.9% of the service-user group), day respite services (81.4% overall; 88.6% of the non-service user group and 78.8% of the service-user group), residential respite services (88.5% overall; 91.9% of the non-service user group and 87.3% of the service-user group) ,

quarters of the carers (from 78.6% to 93.5%) did not use any of the aforementioned indirect support services for carers. Also, more than two thirds of the carers (67.5%) did not use community support services provided by private or non-profit organisations. In general, the reasons why the carers did not use the services mentioned above included “I don’t need the service”, “I don’t know the service”, and “I am not eligible for the service”, depending on the type of direct and indirect support service for carers. On the other hand, quotas and the flexibility of service hours of respite care are the major concerns of carers in response to the unpredictable condition of care recipients, particularly persons with mental illnesses, special educational needs, or behavioural or emotional problems.

(4) Carers’ characteristics and their associations with care burden and risk level:

a. *Specific to carers of elderly persons:* The carers specifically expressed the huge burden of taking care of elderly persons with dementia who manifest behavioural and psychological symptoms and elderly persons with minimal self-care competencies at palliative stage. Some carers with high level of burden may not have time to take care of their personal health or even overlook their health problems. Results from multiple linear regression showed that carers with better perceived health status (subjective assessment of health status) ($B = 0.708$, $p < 0.001$), more emotional issues ($B = 1.304$, $p < 0.001$), and more needs for other services ($B = 0.478$, $p < 0.05$) had a higher care burden. Carers taking care of male care recipients ($B = 0.693$, $p < 0.05$) and those with a younger age ($B = -0.051$, $p = 0.01$) reported a higher care burden. The Consulting Team observed that carers who care for elderly persons with dementia and who have multiple caregiving tasks in various ADL are high-risk carers.

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home respite services (92.4% overall; 97.3% of the non-service user group and 90.6% of the service-user group) , and emergency placement (92.4% overall; 95.1% of the non-service user group and 91.4% of the service-user group) .

b. *Specific to carers of persons with disabilities:* Persons with disabilities having deficits in different areas (e.g., physical, cognitive, behavioural, and psychosocial functioning) make caring duties difficult and time consuming. Particularly, the carers of persons with physical disabilities, of children with special educational needs and of persons with mental illness expressed a high burden as their care recipients required close supervision and had intensive care needs. Results from multiple linear regression showed that carers with poor perceived health status were associated with comparatively higher care burden ($B = 1.665, p < 0.001$). Carers taking care of care recipients requiring assistance in all four needs were associated with comparatively higher care burden ($B = 0.769, p < 0.05$). The Consulting Team observed that high-risk carers have the following characteristics: old age, personal disabilities, unawareness of their own psychological status, low efficacy in handling behavioural issues of care recipients, lack of knowledge to access resources, requiring to take care of persons with disabilities with unpredictable emotional outbreaks.

(5) Carers' strength and its association with care burden and psychological well-being:

a. *Specific to carers of elderly persons:* The carers of elderly persons identified individual strengths in advanced care planning (e.g., scheduling their caregiving in advance). They found that scheduling and planning care in advance could help them to arrange caregiving tasks better. On the other hand, results from correlation showed that carers of elderly persons with better relationships with family members were associated with fewer perceived interruptions to social life due to caregiving tasks ($r = -0.075, p < 0.05$). The result also suggested that a better relationship with care recipients and other family members was associated with better well-being (*rs* between 0.099 and 0.138, all *ps* <0.05). Also, a higher satisfaction in care was associated with better well-being among carers (feeling cheerful, feeling active and vigorous, and feeling that life has been filled with things that are interesting; *rs:* 0.105, 0.084, and 0.72, all *ps* < 0.05).

b. *Specific to carers of persons with disabilities:* Some of the carers of persons with disabilities found that religious beliefs could help them face challenges. Some of the carers of children with special needs acknowledged that the knowledge and skills they had gained could benefit other carers with similar concerns. On the other hand, results showed that carers' strengths (i.e., "Gained satisfaction through care", "Gained caring knowledge and technique", "Improved problem-solving ability", "Met new friends/health care professionals", and "Had better relationships with persons with disabilities") had positive but weak associations with care burden (i.e., "Afraid of what the future holds for relative?", "Your health has suffered because of your involvement with your relative?", and "Your social life has suffered because you are caring for your relative?") (rs between 0.094 and 0.166, all ps < 0.05). The results suggested that better caring knowledge and skills as well as relationships with persons with disabilities were associated with higher care burden. A possible explanation for this seemingly contradictory finding is that the carers with stronger carer strength may have greater expectations of themselves, leading to a higher level of carer burden; or they are more likely to rely on themselves in caregiving and delay seeking help. The results also showed that "Gained caring knowledge and technique" ($r = 0.086$, $p < 0.05$), "Improved problem-solving ability" ($r = 0.109$, $p < 0.01$), and "Met new friends/health care professionals" ($r = 0.151$, $p < 0.01$) were associated with better well-being. The results suggested that better caring knowledge and skills as well as peer and professional support were associated with the well-being of carers.

(6) Carers' characteristics and their views on the usefulness of supportive services:

a. *Specific to carers of elderly persons:* Results from multiple linear regression showed that carers who were currently service users had a higher perceived usefulness towards home-based services ($B = 0.38$, $p = 0.001$), as did carers taking care of bedbound patients ($B = 0.285$, $p < 0.05$) and those with renal disease ($B = 0.440$, $p < 0.01$). Also, the carers who were currently service users had a higher perceived usefulness towards centre-based services ($B = 0.28$, $p < 0.05$) and family and peer support services ($B = 0.287$, $p = 0.001$). Carers whose main source of income ($B = 0.336$, $p < 0.01$) was from relatives had a high perceived usefulness towards family and peer support services. However, spousal carers ($B = -0.212$, $p < 0.05$) and carers with diabetes ($B = -0.355$, $p < 0.05$) had a lower perceived usefulness towards these family and peer support services. The results from multiple linear regression showed that carers taking care of elderly persons with Alzheimer's disease had a lower perceived usefulness towards services related to caregiving skills enhancement ($B = -0.206$, $p < 0.05$).

b. *Specific to carers of persons with disabilities:* Results from multiple linear regression showed that carers or care recipients suffering from mental problems ($B = 0.134$, $p = 0.009$), and carers not living with a domestic helper ($B = -0.114$, $p = 0.031$) perceived that they needed home-based services more. Carers depending on spouse's salary ($B = 0.097$, $p = 0.028$), carers who were service users ($B = 0.11$, $p = 0.018$), carers or care recipients suffering from mental problems ($B = 0.103$, $p = 0.018$), and care recipients living with grandchildren ($B = 0.086$, $p = 0.045$) perceived that they needed services for strengthening the ability of caregiving more. Also, male carers perceived that they need family and peer support services more than females ($B = 0.343$, $p = 0.011$).

3.3 Summary of potential demands and service gaps identified from studies 3 and 4

Based on the findings of Studies 3 and 4, similarities and differences between the two carer groups regarding needs, challenges, burden, strengths, and service expectations were found. Demand for various supportive services, including home-based services, centre-based services (e.g., respite service), financial assistance, and information seeking and training were shown. Insufficient knowledge of and accessibility to support service were identified as barriers to service utilisation. Supporting carers in daily caring duties and offering carers emotional support from their immediate circle (e.g., family members, peers, and professionals) are needed, but effective ways to offer support from carers' immediate circles is yet to be explored. The in-depth analysis and regression analysis based on the two carer groups showed that the characteristics of carers (e.g., gender, knowledge and skills in caregiving, utilisation of service, financial and health status) and care recipients (e.g. age, number of caregiving tasks required, physical and mental condition) were associated with the care burden, psychological well-being and/or risk level of carers. For example, emotional issues of carers of elderly persons were positively associated with perceived care burden. Carers of elderly persons with dementia and carers having multiple caregiving tasks in various ADL are identified as high-risk carers. When it comes to carers of persons with disabilities, high risk carers are characterised by old age, personal disabilities, poor health status, unawareness of their own psychological status, low efficacy in handling behavioural issues of care recipients, lack of knowledge to access resources, being required to take care of persons with disabilities with unpredictable emotional outbreaks and requiring intensive caring needs. However, carers with different characteristics have slightly different views of the usefulness of different kinds of carer support services. These results suggest that support should be offered according to the characteristics of carers and care recipients.

Chapter 4. Summary of Findings from Stakeholders on Carers' Needs and Service Expectations (Studies 5 and 6)

This chapter reports stakeholders' views on carers' needs, challenges, and service expectations collated through Study 5 which was on carers of elderly persons, and Study 6 which was on carers of persons with disabilities. These stakeholders work in both the elderly service sector and rehabilitation sector and included social workers, nurses, physiotherapist, agency administrators.

4.1 Summary of major aggregated and significant findings from stakeholders

4.1.1 Demographic profiles of participated stakeholders

Studies 5 and 6 adopted a mix-method design. In stage 1, a total of 66 stakeholder participants serving carers of elderly persons (n = 27) and carers of persons with disabilities (n = 39) were involved in focus group interviews. In stage 2, a total of 1166 stakeholder participants serving carers of elderly persons (n=421) and persons with disabilities (n = 745) participated in an online cross-sectional survey and thus the total number of questionnaires returned were exactly 1 166. Among all 1 166 questionnaires, there were missing data in some question items for stage 2 of Studies 5 and 6 and the number of valid responses for data descriptive analysis of different questions were in fact different. From observation on the responses of different questions, the number of valid questionnaires used in data analysis for stage 2 of Studies 5 and 6 were 360 and 709 respectively.

4.1.1.1 Demographic profiles of participating stakeholders (Stage 1)

Regarding the demographic data of the 27 stakeholders for Stage 1 (focus group) of Study 5, most of the interviewees were frontline professionals (51.9%), such as social workers (85.2%), and 44.4% of the stakeholders had worked in the elderly service sector for more than 10 years. The stakeholders had worked in carer services for an average of 5.2 years (*SD* = 5.7). Similar demographic data were observed among the 39 stakeholders for Stage 1 (focus group) of Study 6; most of the interviewees were frontline professionals (53.8%), such as social workers (92.3%), and 46.2% of the stakeholders had worked in the rehabilitation service sector for more than 10 years. The stakeholders had worked in carer services for an average of 9.9 years (*SD* = 7.0).

4.1.1.2 Demographic profiles of participating stakeholders (Stage 2)

Regarding the demographic data of the stakeholders for Stage 2 of Study 5, most of them were professionals (59.7%), with 80.0% (*n* = 168) of them were social workers. On average, the stakeholders had been working in the elderly sector for 9.2 years (*SD* = 7.9), and the average number of years working for carers was 5.2 years (*SD* = 5.7). Similar demographic data was observed for Stage 2 of Study 6, with the participants being mostly professionals (53.6%), of which most were social workers (71.2%). On average, the stakeholders had been working in the rehabilitation sector for 10.2 years (*SD* = 8.1), and the average number of years working for carers of persons with disabilities was 9.2 years (*SD* = 7.9).

4.1.2 Major qualitative findings on needs, challenges, burden, strengths, and service expectations

4.1.2.1 Carers' needs

The stakeholders considered that carers have needs on individual and societal levels. Individual-level service needs include respite services, educational and caregiving skills training, financial assistance, one-stop information centres, transportation for care recipients, care planning for care recipients, and case management. Societal-level needs, such as social recognition and the establishment of carer-friendly working arrangements, were also suggested.

Majority of the carers encountered by the stakeholders in the online surveys had at least 3 years of caregiving experience. According to the stakeholders, most carers of elderly persons and persons with disabilities generally reported that they lacked the knowledge and skills or support to take care of their care recipients. Hence, services related to the enhancement of carers' knowledge or skills should be strengthened.

The participated stakeholders expressed that carers of elderly persons with cognitive impairment and carers of persons with disabilities having mental or emotional problems are the two groups that seek help most frequently. The stakeholders were of the view that the following services appeared to be very useful: counselling, education, daytime respite services, and emergency residential services. Other services identified by (1) carers of elderly persons with poor health or (2) carers of persons with disabilities having severe emotional or behavioural problems, that need to be enhanced were escort services, safety assessments of the homes of elderly persons, home visits by trained health care staff, and hospital discharge services.

The stakeholders interviewed at Stage 1 of Studies 5 and 6 indicated that many factors might affect the needs of carers. The personal needs of carers depend on the care recipient's condition and its severity. For example, for frail elderly persons, persons with physical disabilities, or persons with severe cognitive impairment or intellectual disabilities, performing ADL can be very demanding, and therefore they require constant attention from carers.

The synthesised results of Studies 5 and 6 showed that traditional Chinese culture concerning the responsibility of taking care of family members originated from filial piety, the accessibility of information and formal services, and the demographic characteristics of carers (e.g., age, household income, and education attainment) have an influence on the needs of carers. Originated from the Chinese culture, some carers strongly believe that these are their duties to take care of their old parents or young children and should not make any complaints. Eventually they become reluctant to seek help. For the older carers with less education, they may have limited access to service information due to digital incompetence. They cannot easily access information and services.

4.1.2.2 Challenges faced by carers

The stakeholder participants stressed that carers face a wide variety of challenges and difficulties. The common challenges and difficulties which carers are facing are a lack of knowledge and caregiving skills, inadequate support services during the COVID-19 pandemic, and lack of recognition of carers in society. Many carers are hesitant to seek help and arrange appropriate services for their care recipients because they did not know what services were available or how to access them. The stakeholders reflected that it is too demanding and physically challenging when old-aged carers are required to take care of care recipients' ADL. Challenges specific to the rehabilitation sector mainly concern managing the care recipient's emotional stress and behavioural problems. The stakeholders in Studies 5 and 6 constantly commented that the current carer support services are not well-coordinated. Uncertainty regarding service continuity for care recipients creates anxiety among carers.

4.1.2.3 Service expectations of carers

The existing carer support services were classified into either direct (i.e., carer-oriented) or indirect (i.e., care recipient-oriented). The quantitative findings from stakeholders indicated that caregiving skills training, education, counselling, and recreational and social activities for carers were the major direct services for carers of elderly persons. It also indicated that referral services and disability caregiving skills training were the two pillars of service provision for carers of persons with disabilities. Referrals, recreational and social activities for elderly, equipment rental, and escort services were the more important indirect services in the elderly sector. The result also indicated that escort services, day respite services, and on-site rehabilitation/care services were more important in the rehabilitation sector.

Stakeholders considered that although financial assistance was one direct way to support carers in carrying out their caregiving role, support services such as counselling, group activities, case management, and skills training were also necessary. It was because they thought task shifting are not applicable for all the caregiving tasks and some responsibilities cannot be exempted. Many stakeholders reflected that most carers consider that both services and financial assistance are important. A mix of services and financial assistance provides better support to the carers. For some carers, they need some financial assistance so they could arrange the necessary services from different sources (e.g., private service providers, social enterprises). With some financial assistance, carers can get the necessary services in a shorter period of time, and this could reduce their instant stress.

4.1.3 Major quantitative findings based on in-depth statistical analyses

4.1.3.1 In-depth quantitative analysis of the usefulness of support services among different types of carers of elderly persons from stakeholders' perspectives

The results of Study 5 showed which kinds of support services were rated as most useful by stakeholders serving carers of elderly persons (from 0 = "not useful at all" to 2 = "very useful") (See *Table 4.1*). Stakeholders were of the view that different kinds of support services were useful for different types of carers, depending on the caregiving stages they were in, characteristics of carers and their care recipients, as illustrated in the table below.

For example, carers with low education levels perceived daytime respite services, caregiving training, carer allowance, and financial assistance for carers as the four most useful services (all mean scores = 2.0), whereas working carers perceived employer support for carers as the most useful service (mean score = 1.7). Carers caring for both elderly persons and children perceived daytime respite services and employer support for carers as the two most useful services (all mean scores = 1.7), whereas carers caring for more than one person perceived daytime respite services, escort services, carers allowance, and financial assistance as the four most useful services (all mean scores = 1.7). Low-income carers perceived carer allowance, financial assistance for carers, and employer support for carers as the three most useful services (all mean scores = 1.7), whereas carers of elderly persons with low self-care ability perceived home care services as the most useful service (mean score = 1.7).

Table 4.1 Stakeholders' views about the usefulness of the support services among the 14 types of carers of elderly persons

Types of carer of elderly persons	**Types of support service rated as the most useful by stakeholders**	**Mean Usefulness Score (SD)** (*0 = "not useful at all" to 2 = "very useful"*)
Carers-to-be (Those persons who will take up the role of carers soon)	Rehabilitation and healthcare for elderly persons	1.5 (0.5)
Novice carers (Carers whose caring period was less than one year)	Caregiving training	1.5 (0.5)
Experienced carers (Carers with a caring period of at least three years)	Daytime respite services, residential respite services, home care services, referral, rehabilitation and health care for elderly persons, counselling, carer allowance, financial assistance for carers, and employer support for carers	1.4 (0.5–0.6)
Carers at work	Employer support for carers	1.7 (0.5)
Graduated carers (Those who were previously	Daytime respite services, residential respite services, home	1.5 (0.7)

Types of carer of elderly persons	**Types of support service rated as the most useful by stakeholders**	**Mean Usefulness Score (SD)** (*0 = "not useful at all" to 2 = "very useful"*)
carers but not currently acting as carers)	care services, referral, and employer support for carers	
Old-aged carers (Carers aged 60 or above)	Home visits and escort services	1.6 (0.5)
Carers caring for elderly persons with cognitive impairment	Daytime respite services and counselling	1.6 (0.5)
Carers in poor physical health	Daytime respite services, home visits, and escort services	1.6 (0.5)
Carers caring for both elderly persons and children	Daytime respite services and employer support for carers	1.7 (0.5–0.6)
Carers caring for more than one person	Daytime respite services, escort services, carer allowance, and financial assistance	1.7 (0.5)
Low-income carers who are eligible to apply for carer allowance or financial assistance	Carer allowance, financial assistance for carers, and employer support for carers	1.7 (0.4)
Carers with low education levels (Carers with primary school education level or below)	Daytime respite services, caregiving training, carer allowance, and financial assistance for carers	2.0 (0)
Carers of elderly persons with low self-care ability	Home care services	1.7 (0.5)
Carers who do not live with elderly persons	Daytime respite services and home visits	1.6 (0.5)

4.1.3.2 In-depth analysis of the usefulness of support services among different types of carers of persons with disabilities from stakeholders' perspectives

The results of Study 6 showed which kinds of support services were rated as most useful by stakeholders serving carers of persons with disabilities (from 0 = "not useful at all" to 2 = "very useful") (See Table 4.2). Similar to the view of stakeholders related to carers of elderly persons, the results showed that different types of carers tend to rank different support services as most useful, as illustrated in the table below.

For example, low-income carers perceived financial assistance as the most useful service (mean score = 1.7), whereas carers not living with persons with disabilities perceived emotional support services and home personal care/homemaking services as the two most useful services (all mean scores = 1.7). Carers of persons with disabilities who have serious emotional or behavioural problems perceived day/residential respite services and respite services as the two most useful services (all mean scores = 1.7), whereas in-service carers perceived workshops and lectures as the most useful service (mean score = 1.6). Old-aged carers perceived escort services, emergency placement, home personal care/household cleaning and day care/rehabilitation services, carer allowance, and respite services as the five most useful services (all mean scores = 1.6), whereas frail carers perceived escort services, emergency placement, home personal care/homemaking services, and respite services as the four most useful services (all mean scores = 1.6). Carers caring for more than one person perceived day/residential/home respite services, emergency placement, and carer allowance as the three most useful services (all mean scores = 1.6), whereas carers with mental and emotional problems perceived day/residential respite services, emergency placement, and respite services as the three most useful services (all mean scores = 1.6). Carers taking care of persons with disabilities requiring service transition perceived counselling, emotional support, and emergency hotline/24-hour support as the three most useful services (all mean scores = 1.6.)

Table 4.2 Stakeholders' views about the usefulness of the support services among the 14 types of carers of persons with disabilities

Type of carer of persons with disabilities	**Types of support service rated as the most useful by stakeholders**	**Mean Usefulness Score (SD)** (*0 = "not useful at all" to 2 = "very useful"*)
Carers-to-be (Those persons who will take up the role of carers soon)	Counselling, emotional support, information or consulting services, workshops and lectures, carer-centred case management, respite services, accessibility of	1.4 (0.5–0.6)

Type of carer of persons with disabilities	**Types of support service rated as the most useful by stakeholders**	**Mean Usefulness Score (SD)** (*0 = "not useful at all" to 2 = "very useful"*)
	information, and employer support for carers	
Novice carers (Carers whose caring period was less than one year)	Carer allowance and employer support for carers	1.5 (0.5–0.6)
In-service carers (Carers whose caring period was between one and three years)	Workshops and lectures	1.6 (0.5)
Experienced carers (Carers with a caring period of at least three years	Escort services, day/residential respite services, home respite services, emergency placement, financial assistance, respite services, and employer support for carers	1.4 (0.5–0.6)
Graduated carers (Those who were previously carers but were not currently acting as carers)	Emotional support, information or consultation, workshops and lectures, carer-centred case management, and life planning services for persons with disabilities	1.4 (0.5)
Working carers	Employer support for carers	1.4 (0.6)
Old-aged carers (Carers aged 60 or above)	Escort services, emergency placement, home personal care/household cleaning and day care/rehabilitation services, carer allowance, and respite services	1.6 (0.5)
Frail carers	Escort services, emergency placement, home personal care/ homemaking services, and respite services	1.6 (0.5)
Carers with disabilities	Day/residential/home respite services, emergency placement, and financial assistance	1.5 (0.5–0.6)

Type of carer of persons with disabilities	**Types of support service rated as the most useful by stakeholders**	**Mean Usefulness Score (SD)** (*0 = "not useful at all" to 2 = "very useful"*)
Carers caring for more than one person	Day/residential/home respite services, emergency placement, and carer allowance	1.6 (0.5)
Low-income carers who are eligible to apply for carer allowance or financial assistance	financial assistance	1.7 (0.5)
Carers with mental and emotional problems	Day/residential respite services, emergency placement, and respite services	1.6 (0.5)
Carers not living with persons with disabilities	Emotional support services and home personal care/homemaking services	1.7 (0.5)
Carers of persons with disabilities who have serious emotional or behavioural problems	Day/residential respite services and respite services	1.7 (0.5)
Carers taking care of persons with disabilities requiring service transition from one service to a new service	Counselling, emotional support, and emergency hotline/24-hour support	1.6 (0.5–0.7)

4.1.3.3 Summary of in-depth analyses of carers of elderly persons and carers of persons with disabilities from stakeholders' perspectives

From the in-depth data analysis, it was found that carer type was one of the most important factors affecting carers' needs for different types of support services. In fact, carer type was not only categorized by caregiving stages like carers-to-be, but was also identified based on their needs, such as low-income carers, carers taking care of persons with disabilities requiring service transition, etc.

Common findings were observed regarding the support service needs of both carers of elderly persons and persons with disabilities. Counselling services, emotional support, and rehabilitation care were rated by stakeholders as the most important service needs of carers-to-be, whereas novice carers expressed service needs related to caregiving training and carer allowance as more important. Carers at work were more in need of employer support, whereas low-income carers rated allowances and financial assistance as most important.

On the other hand, a diversity of service needs was found between carers of elderly persons and carers of persons with disabilities. Carers caring for elderly persons with low self-care ability tended to desire home care services and escort services, whereas carers of persons with disabilities having serious emotional or behavioural problems more likely desired day respite services and emergency placement for persons with disabilities.

The stakeholders expressed that carers of elderly persons with cognitive impairment needed help the most, followed by carers of elderly persons with poor health status and aged carers next. The services that were commonly rated the most useful include daytime/residential respite services, escort services, and home care services. In addition, the top three types of carers of persons with disabilities who needed help the most were those in old age, with mental and emotional problems, or taking care of persons with serious emotional or behavioural problems. The services that were commonly rated the most useful include daytime respite services, and emergency accommodation services for persons with disabilities.

4.2 Summary of significant differences between the two stakeholder groups in terms of carers' needs, challenges, burden, strengths, and service expectations

The findings across Studies 5 and 6 were largely consistent. A careful comparison was conducted, and the following major differences were identified.

4.2.1 Carers' needs

Apart from the needs commonly shared between carers of elderly persons and carers of persons with disabilities, the stakeholders of persons with disabilities identified peer support groups and transportation allowance as their needs because wheelchair-bound care recipients may find it difficult to use public transport. They also emphasised that services for care recipients should not be disrupted even during the pandemic. The stakeholders of Study 5 tended to focus more on the other tangible needs, such as practical caregiving and respite care.

4.2.2 Challenges faced by carers

Other than the challenges commonly faced by the two groups of carers, stakeholders expressed that the duties of carers of persons with disabilities are challenging because caregiving tasks can be very complicated for those with severe disabilities. There is also societal stigmatisation of disabilities, which creates extra stress to the carers.

Chapter 5. Summary of Triangulated Findings on Carers' Needs and Service Expectations

This chapter summarises the findings of the triangulation process using the data from component Studies 1 to 6 to identify and explain carers' needs, burden, and challenges; carers' strengths; and awareness to the services, service utilisation, and service gaps. Triangulation refers to the use of multiple sources of data or approaches in seeking answers to specific questions, which leads to a more comprehensive understanding of the phenomenon and enhances the validity and credibility of the findings (Noble & Heale, 2019). Such triangulation has the advantage of providing a balanced view from multiple perspectives. We compared and contrasted the ideas generated from the two groups (carers and stakeholders) using both qualitative and quantitative data. The qualitative and quantitative findings were weighted equally, as they were conducted concurrently. On some occasions, qualitative findings can be further explained by quantitative findings and vice versa.

5.1 Carers' needs, burden, and challenges

Various data sources from Studies 3 to 6 consistently reported significant caregiving burden, needs, and challenges of carers.

5.1.1 Carers' needs and burden

Carers reported moderate levels of burden, with a mean score of 4.7 out of 12 for carers of elderly persons and a mean score of 6.6 out of 12 for carers of persons with disabilities (the surveys in Studies 3 and 4). In the qualitative interviews of Studies 3 and 4, carers further elaborated on the physical, mental, and financial burden they faced, and they also mentioned the challenges of balancing work, life, and caregiving (e.g., the role conflicts and the relationship difficulties related to caregiving).

On the other hand, stakeholders consistently echoed the significant burden encountered by the carers, especially regarding heavy workload, role conflicts, and psychological distress (the surveys in Studies 5 and 6). In addition, the stakeholders believed that this significant burden could arise from insufficient community/professional support (the qualitative interviews in Studies 5 and 6).

Both the carers and the stakeholders also shared how the disruption of community services and social isolation during the pandemic had hindered social support and increased mental distress of carers.

5.1.1.1 Characteristics of the carers and their burden

The characteristics of both care recipients and carers contributed to care burden. The characteristics of care recipients (e.g., the severity of and any change in the condition of their care recipients) were found to correlate with carers' burden. Both the carers of elderly persons and the carers of persons with disabilities expressed the huge burden experienced when taking care of care recipients with behavioural and psychological symptoms, having minimal self-care competencies that required close supervision or intensive care, and those at the palliative stage. They specified that some care recipients demand more care, which leads to a larger burden on them. These include elderly persons with dementia and persons with mental illnesses or autism (the qualitative interviews in Studies 3 and 4).

Stakeholders shared similar views and considered that complicated symptom management was the most challenging aspect of caregiving work. Stakeholders quoted the example of carers who had to take care of family members with intellectual disabilities, autism, attention deficit hyperactivity disorder (ADHD), and cognitive impairment (the qualitative interviews in Studies 5 and 6). There seems to be a consensus between carers and stakeholders that the demand of handling both care recipients' behavioural symptoms and self-care incompetence is the reason for carers' heightened burden.

In terms of the characteristics of the carers, when the carers perceived themselves as having poorer health conditions or mental problems, they were more likely to have a higher care burden. Carers who were younger reported a higher burden, and this may be because young carers are more likely to take on multiple carer roles (e.g., simultaneously being the carer of the next generation and the carer of elderly persons). In addition, carers of persons with disabilities who take care of care recipients that require assistance on personal nursing care, daily activity, emotional support/company, and rehabilitation activity/drug taking/therapy, or whose incomes rely on their children, were associated with high care burden (the surveys in Study 4).

Stakeholders further highlighted the characteristics of carers with care burdens. They considered that carers with low education levels, being single with low levels of self-efficacy, and co-residing with care recipients were more likely to have higher burdens. Carers with low socio-economic status and educational level tend to be less aware of the existing services and less likely to seek support or help. Working carers seem to be the most stressed group, as some may be unable to resign from their job due to economic pressure, though some eventually decided to quit their job to fulfil their caregiving duties (the surveys in Studies 5 and 6). Carers who are older and/or have health conditions may be less capable of assisting care recipients' ADL. Some carers, in particular those with lower education levels, encounter difficulties accessing information and community services (the qualitative interviews in Studies 5 and 6).

In addition, the stakeholders in Studies 5 and 6 also considered that there is insufficient community/professional support encountered by carers. Carers' caregiving loads are commonly heavy. Carers who are older and/or have health conditions may be less capable of managing manual work, such as ADL. Carers, in particular those with lower education levels, encounter difficulties when accessing community services and information. Carers also experience deficits in their knowledge and caregiving skills, as well as a lack of recognition of the identity of carers from society. Stigmatisation of disabilities by society creates extra stress for carers. Inadequate support during the COVID-19 pandemic and partial disruption and suspension of some formal services due to meeting the requirements of social distancing has exacerbated this, leading to a further insufficiency of community and professional support to caregivers.

5.1.1.2 Characteristics of high-risk carers

As carers' burden accumulates over time, some carers may experience substantial stress and become high-risk carers. The characteristics of carers at high risk include: long and intensive caregiving tasks, a history of domestic violence, behavioural disturbances of care recipients, lack of recognition and support from carers' immediate circle, caregiving for multiple dependents with disabilities, and having suicidal thoughts and/or thoughts of murdering care recipients. The partial disruption of community services and social isolation measures during the COVID-19 pandemic also further impaired the mental health of carers.

5.1.2 Carers' strengths

A variety of personal strengths, such as skill mastery, family bonds, and religious beliefs were highlighted as critical to offset care burden (the qualitative interviews of Studies 3 and 4). 'Affirmation from family' was considered as the most desired form of support from carers' point of view (the surveys in Studies 3 and 4). Several factors affecting the carers' needs burden were identified, including: 1) household income, 2) educational attainment, 3) social support network, 4) spirituality (e.g., religious support), 5) living environment; and 6) access to formal services (the qualitative interviews of Studies 5 and 6).

5.1.2.1 Individual strengths of carers

Carers of elderly persons and persons with disabilities identified individual strengths in regard to caregiving in terms of self-awareness, stress management skills, self-efficacy, capability of problem-solving and help-seeking, enhanced family bonds, and fulfilment of responsibilities. A majority of the carers of elderly persons and persons with disabilities agreed that strengthening their caregiving and cognitive skills, such as problem-solving and help-seeking abilities, could help them handle the day-to-day challenges they faced in regard to caregiving. Carers of elderly persons also identified individual strengths in advance preparation and planning for caregiving to care recipients. A few participants who cared for persons with disabilities shared the religious support they had received in regard to care provision. Enhancing carers' emotional bonds with their care recipients and building the actualisation of personal strength in assuming multifaceted roles will nurture the continuation of care provision.

5.1.2.2 Carer-friendly environment

In the focus groups in Studies 3 and 4, the participants described a carer-friendly environment as a motivator to assume a caregiving role to fulfil their social and occupational lives. The carers recognised that a conducive caregiving environment with social and community support fosters their personal strength development in terms of mastering skills and enhancing family bonds. Conversely, when carers lack support and resources, they reported high levels of burden and a decline in physical health and psychosocial well-being. Thus, the current findings propose that support measures should improve carers' strengths through building social networking and promoting carer-friendly community.

5.1.2.3 Formal services

Family support is essential to foster carers' strengths in the community. In Studies 3 and 4, carers ranked the support and affirmation from family members as the most wanted support. Carers with strong family support and positive caregiving experiences could be invited as role models to share their experience in carer supporting groups. Promoting family-based support and mutual assistance in the neighbourhood among peer carers across their lifespans and at different stages of caregiving journey can be adopted as ways to strengthen the carers' abilities.

Studies 5 and 6 echoed the importance of enhancing the carers' strengths through a series of services, such as the provision of training, enhancement of family support and affirmation, social networking, and the promotion of service information dissemination. Detailed information about these areas is presented in the following section.

5.2 Carers' service awareness and utilisation, and service gaps

Studies 3 to 6 consistently revealed the need to enhance carers' awareness and usage of services, as well as the need to address service gaps. The surveys from Studies 3 and 4 showed that carers with health problems, financially dependent on others, or taking care of highly dependent care recipients were associated with higher demand for services, ability strengthening, and social networking support. For carers of persons with disabilities, carers with mental health conditions were found to report a higher rate of perceived usefulness of support services. In the qualitative findings in Studies 3 and 4, the carers of elderly persons and persons with disabilities listed the usefulness of various support services, including home-based and centre-based services for care recipients, financial assistance, information provision, and training. In Studies 5 and 6, stakeholders proposed a set of strategies to support carers at both the individual and societal levels. The findings regarding carers' service awareness and use, and service gaps are summarised as follow: promoting service accessibility and utilisation, enhancing carer support services, and integrating service provision.

5.2.1 Promoting service accessibility and utilisation

Both the carers from Studies 3 and 4 and the stakeholders from Studies 5 and 6 expressed the importance of promoting service accessibility. The barrier to service utilisation is inadequate knowledge on the carer support services. Both types of carers highlighted the importance of service accessibility. This could be achieved by improving dissemination of information on services, increasing service places, and providing services in flexible hours. Regarding dissemination of information on services, some carers suggested that creating a one-stop platform for caregiving information and services would be helpful, with links to other relevant information such as waiting list information on individual support services. The stakeholders commented that the services for care recipients were scattered and that it was difficult for carers to search for the specific services they needed.

The carers of elderly persons and persons with disabilities reported that personal barriers, such as being unaware of existing services and lacking the time to understand and apply for the services, hindered service uptake. Carers also expressed that strict eligibility requirements, the complex application process, and long waiting times were barriers to receiving services or allowances. The stakeholders also suggested that the Government should consider raising service capacity to shorten the long waiting times for services. In recognition of the service accessibility issue, the stakeholders recommended that collaboration and coordination in the Government should be strengthened so as to streamline carer support services under purview of different bureaux/departments. In addition, the possibility of simplifying application procedures of formal services for care recipients should be explored. Collaboration among community-based service sectors, entrepreneurs, and public bodies would be helpful in terms of improving the diversity of services for care recipients and alleviating stress experienced by carers.

The literature further emphasises the importance of improving accessibility in several specific areas; carers being male, having a higher education level, a perceived higher care burden, and specific care needs are reported to be the determinants of higher utilisation of long-term care services by care recipients (Janssen et al., 2014; Lüdecke et al., 2012; Vandepitte et al., 2019). Many carers remain hesitant about seeking help from others or arranging services for their care recipients. They listed the barriers as follows: concerns about care recipients’ safety and adjustment in an unfamiliar environment, negative outcomes due to sub-standard services, overwhelmed by the information provided, uncertainty about the care given in long-term care facilities, and worry about social stigmatisation (Lüdecke et al., 2012; Robinson et al., 2012; Williams et al., 2018). To encourage carers to arrange formal services for their care recipients, a comprehensive service approach, which includes individual counselling and experiential education, service referral, and social support, are recommended (Alwin et al., 2010; Anderson et al., 2015; Chung et al., 2019; Górska et al., 2013).

5.2.2 Enhancing carer support services

In Studies 3 and 4, carers expressed that their mental well-being had been compromised, and stakeholders in Studies 5 and 6 proposed measures to improve mental health of carers. In Studies 3 and 4, the examples of useful services reported by carers of persons with mental illness, autism, intellectual disabilities, and dementia were centre-based services (e.g., respite services, day activity centres, rehabilitation training). Stakeholders shared that carers appreciate counselling sessions in which they can share their difficulties even though the immediate and tangible support was not the focus. They also recommended peer support groups at the community level. The participants from Study 6 expressed that peer support groups are important to carers because such groups allow carers to vent their emotions among those who understand them and to learn from other carers’ experiences.

To prevent burnout, carers suggested that preventive measures are more useful than remedial actions. For example, respite services are more helpful than emotional support groups or counselling when crises arise. Similarly, advanced planning based on carers’ anticipated needs is crucial. For example, the development of online services should be encouraged with the advancement of technology, because carers may rely more on online resources, to learn more about caregiving and know what to expect in future.

The carers of elderly persons and persons with disabilities expressed that respite care was particularly difficult to access when carers encountered emergency events. Short-stay respite services were also scarce due to the limited number of designated respite places, the unpredictability of casual vacancies, and the overwhelming demand from carers wishing to take a break. Stakeholders also echoed the urgent need for improved respite services because caregiving can be very time-consuming and often requires round-the-clock caregiving, hence, creating a huge care burden. These respite services could be short-stay residential services, centre-based services, or home-based services, and preferably could be arranged quickly under emergency situations. Some examples of support services reported by carers of elderly persons that could be used to relieve their burden are home-based services, such as personal care (e.g., homemaking, meal delivery, and home-based respite services) and centre-based services (e.g., respite services, rehabilitation training). Carers of elderly persons also mentioned the need of advanced care planning to improve their understanding of what will happen in the advanced stages of irreversible illness (such as advanced dementia), so that they can plan ahead for the death of care recipients and reduce their stress and anticipated grief.

Consistent with the opinions of carers of elderly persons and persons with disability, the stakeholders proposed other services to better support carers to deal with emergency events, such as providing hourly respite services to meet carers' needs in regard to managing their personal business (such as attending medical appointments), and providing training workshops and courses to prepare novice carers for their care recipients experiencing a sudden change in their health, and financial assistance such as the Pilot Scheme on Living Allowance for Low-Income Carers of Persons with Disabilities. The participants from Study 6 expressed that persons with disabilities usually require their carers to accompany them to medical or training appointments, because of which they incur additional costs.

The literature suggests that it would be crucial to coordinate the services provided to care recipients and support carers as they navigate the system, so as to ensure care continuity and individualisation (Lüdecke et al., 2012; Robinson et al., 2012; Williams et al., 2018). To effectively reduce care burden, comprehensive programmes delivered in a holistic approach and led by professionals are needed (Miao et al., 2019; Chan, Merriman, Parmenter, & Stancliffe, 2012; Chen, 2011).

5.2.3 Integrating service provision

The carers raised the need to ensure the continuity of support during service transitions (e.g., from preschool to school, from hospital to community care service, or when leaving special school) and the need for easily accessible support during sudden changes in the condition of their care recipients. Collaboration among disciplines and between agencies and funding models should be strengthened. In Study 5, the stakeholders suggested strengthening medical-social collaboration because they thought the health condition of elderly persons living in the community with minimal medical support was the primary stressor for their carers. Regarding services for carers of persons with disabilities, the stakeholders in Study 6 suggested enhancing the service interface between different sectors, for example, enhancing support for carers during the transition of their care recipient between education and social sectors, from pre-school rehabilitation to primary school, or when leaving school. Care recipients require different services to meet their unique needs; however, carers find it very difficult to identify and select appropriate services or support. Furthermore, needs change over time during the caregiving journey, which requires advanced planning. The stakeholders from Study 5 proposed that holistic care planning for care recipients would relieve the care burden associated with the changes in health conditions and care needs of care recipients. The stakeholders commented that formal services and allowances for elderly persons and carers were fragmented, limited, and inflexible. They suggested enhancing the services by improving their diversity, interface and flexibility.

While Rehabus service was provided for persons with disabilities who had difficulties using public transport services, and central bus service was provided for users of rehabilitation service centres, stakeholders proposed further enhancing transportation services for care recipients.

The carers expressed the need for their contributions to be recognised by society to enhance service integration through multi-partite collaboration among different sectors, professions, and public and private sectors. Some stakeholders stressed promoting recognition of the value of carers more broadly through public education, the introduction of carer-friendly legislation, and the formulation of a carer support plan. Stakeholders also suggested carer-friendly work arrangements; paid leave and flexible work arrangements would be helpful in allowing carers to fulfil their caregiving duties. The stakeholders hoped to cultivate a more carer-friendly atmosphere in Hong Kong in the long run by, for example, introducing a ‘carer card’ or ‘carer leave’ to support carers.

These findings are consistent with the guiding model (socioecological model) of this study, which indicated the multidimensional response to physical, psychological, and financial stressors associated with the caregiving experience (Chiao et al., 2015; Etters et al., 2008). The psychological burden of carers is associated with care recipients’ illness degeneration and the presence of symptoms, while carers often have limited knowledge and skills to cope with complex caregiving scenarios, and may experience anxiety, uncertainty, and even depression as a result. The psychological burden of carers is also caused by the role conflicts between caring for patients and fulfilling their own social roles; they have limited time for social engagement and interpersonal interactions (Queluz et al., 2020). Psychological distress is frequently reported by carers of persons with emotional and behavioural symptoms. Due to the chronic and progressive nature of some illnesses (such as dementia) and the challenges of symptom management, some carers experience more stress than others and become high-risk carers.

The findings of this study provide a context-specific understanding of the burden experienced by carers. Carers also have their own strengths and expectations of services. Their strengths and expectations deserve to be considered in the future planning of carer support services in Hong Kong.

Chapter 6. Review of Existing Financial Assistance for Carers, including Ways Forward for Related Pilot Schemes (Studies 7 and 8)

This chapter sets out the summary of major findings in Studies 7 and 8 regarding existing financial assistance for carers of elderly persons and persons with disabilities, and discussion of the way forward for financial assistance to carers.

6.1 Summary of major findings regarding financial assistance available to carers of elderly persons in connection with CCSV encashment and the living allowance for carers of elderly persons from low-income families

Study 7 examined financial assistance options for carers of elderly persons, including the Pilot Scheme on Community Care Service Voucher for the Elderly (CCSV) encashment, the ‘Living Allowance for Carers’, and other means, from the perspectives of carers and stakeholders. Study 8 evaluated the effectiveness of the two pilot schemes for persons with disabilities: namely the Special Care Subsidy for the Severely Disabled (i.e., Special Care Subsidy) and the pilot scheme on providing subsidies for Higher Disability Allowance recipients in paid employment to hire carers (i.e., Subsidy to Hire Carers).

6.1.1 Respondents’ views on CCSV encashment

CCSV encashment refers to allowing CCSV users to convert a designated portion of their CCSV voucher to cash with a view to providing them with flexibility in making caregiving arrangement. This allows CCSV users to “encash” part of the value of designated services provided by CCSV (e.g., meal services and escort to medical services) and use the encashed amount to make their own caregiving arrangements (e.g., hiring a part-time helper).

Generally speaking, the majority of carers (68.9%) opted for CCSV encashment but only 42.7% of stakeholders agreed with this approach. Carers (regardless of receiving CCSV or not) preferred CCSV encashment and this is significantly higher than the stakeholders.

All carers had similar preferences for CCSV encashment, regardless of age, gender, education level, marital status, employment status, duration of caregiving for elderly persons, and days spent on caregiving for elderly persons per week. The only determining factor of CCSV encashment was ‘carers’ satisfaction with CCSV service’.

This implies that, when the carers were satisfied with the CCSV service, they were more likely to support CCSV encashment.

Specific questions were asked to identify the pros and cons of the implementation of CCSV encashment, as follows.

Pros: It was generally agreed by both the carers of elderly persons and the stakeholders that CCSV encashment could reduce carers' financial burden and give carers greater flexibility in arranging their caregiving duties (e.g., hiring domestic helpers, arranging transportation to and from hospitals and homes). The carers agreed that CCSV encashment was a way to show that 'carers are sharing the responsibility of caregiving with the Government'. Carers also considered CCSV encashment as a kind of recognition of their caregiving work, and felt that CCSV encashment brought benefits to frail elderly persons because they did not need to wait for the subsidised services. More than half of the carers and stakeholders believed that CCSV encashment would attract more people to be carers, but the views from carers were much stronger than those of stakeholders.

Cons: Some carers of elderly persons and the stakeholders were concerned that CCSV encashment would induce family conflict. Stakeholders were also worried that carers would receive the cash but fail to provide proper care to elderly persons, but the carers did not fully agree with this worry. Moreover, carers who were receiving CCSV at the time were worried that there would be an increase in the number of carers joining the CCSV scheme and that this would increase the waiting time when applying for service vouchers; the stakeholders agreed with this point. Neither the carers nor the stakeholders really thought that some elderly persons and/or carers might not be able to make proper decisions due to the availability of more choices after CCSV encashment.

6.1.2 Respondents' views on the Living Allowance for Carers of Elderly Persons

In general, carers and stakeholders held different views when they were asked to indicate their preference of financial support options. Stakeholders preferred the Living Allowance (55.1%) to CCSV encashment (44.5%). On the contrary, relatively fewer carers (i.e., all carers regardless of receiving CCSV or not) preferred the Living Allowance (65.5%) to CCSV encashment (68.9%).

Regarding the Living Allowance for Carers, male carers were more likely to opt for this allowance than female carers. However, carers' age, education level, duration of caregiving for elderly persons, and days spent caregiving for elderly persons per week had no relationship with their preferences for this allowance. Carers who were receiving this allowance in the pilot scheme were more likely to favour it than those who had never received it.

Both the stakeholders and the carers shared some similar views about their reasons for considering the Living Allowance for Carers as a better option for supporting carers financially. In the survey, the majority of the stakeholders (81.4%) and carers (72.6%) felt that recipients of this allowance were in some way at an advantage, as they were receiving both services and cash; and about half of the stakeholders (57.1%) and carers (51.2%) considered this allowance as providing recognition to carers for their contributions to society and their families. Not many carers (25.6%) or stakeholders (37.9%) believed that carers chose Living Allowance for Carers because they were satisfied with the arrangement of the allowance. Some stakeholders (37.9%) held other views, believing that carers chose this allowance because there was no co-payment in the allowance. Only 21.9% of carers agreed with this.

6.1.3 Other resource-based support options for carers of elderly persons

Despite ‘carer’s allowance’ being ranked as the first choice among all the carers in the quantitative study, other resource-based options, such as carers’ healthcare voucher, discounts on medical fees for carers, travel allowances for carers when escorting frail elderly persons to and from hospitals and homes, and tax reductions, were agreed by carers as possible options to support them. In the qualitative study, some carers suggested increasing the quota in day care centres, as they asserted that formal services were most helpful in reducing their care burden. Stakeholders were of the view that services (in particular, professional services, such as physiotherapy or cognitive training) were still needed by frail elderly persons in the midst of requests for financial assistance from carers. Some stakeholders suggested setting up electronic platforms to help carers locate community resources in their neighbourhood, which would probably benefit those who are computer-literate or young. On the other hand, stakeholders expressed their concerns regarding spousal carers (particularly those in advanced age), as they are in greater need of supportive services due to being physically unfit to provide physically demanding care, such as bathing or mobilising, to their care recipients.

6.2 Summary of the major findings of the evaluation of the effectiveness of the two pilot subsidy schemes for persons with disabilities

6.2.1 Special Care Subsidy for the Severely Disabled (Special Care Subsidy)

Study 8 showed that the participants (i.e., persons with disabilities, their carers, and the human services professionals) generally held positive views of the Special Care Subsidy. In qualitative interviews, some carers expressed the need to review and increase the amount of the subsidy due to the increasing costs of daily supplies essential for caring for persons with disabilities, although there has been continuous enhancement in subvented services and financial assistance for persons with disabilities to meet their special needs. Some opined that the maximum age limit of 60 years old as one of the eligibility criteria should be reviewed. Some stakeholders pointed out that there are alternative ways of providing assistance to persons with disabilities and their carers, including the enhancement of community support services and their utilisation.

6.2.2 Pilot scheme on providing a subsidy for Higher Disability Allowance recipients in paid employment to hire carers (Subsidy to Hire Carers)

Generally speaking, the persons with disabilities, their carers, and the human services professionals held very positive views of the Subsidy to Hire Carers scheme. They pointed out that this scheme was useful in terms of providing financial assistance to persons with disabilities in the workforce. However, the persons with disabilities and their carers also opined that the eligibility criteria should be relaxed to allow more persons with disabilities to benefit (e.g., lower income threshold) and the amount of the subsidy should be increased because the initial costs involved in hiring a helper (e.g., agency fees, flight tickets, etc.) are substantial. The persons with disabilities and their carers stressed that providing a subsidy to hire a helper alone was not sufficient to encourage persons with disabilities to stay in the workforce. Providing more incentives for potential employers to offer more job opportunities to persons with disabilities is equally important. To this end, the Government has implemented various measures to promote the employment of persons with disabilities[17].

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[17] Including vocational rehabilitation and training services for persons with disabilities, job matching services in the open market for persons with disabilities, financial incentives to encourage employers to hire persons with disabilities, enhancing the abilities of and support for persons with disabilities, grants for NGOs to set up social enterprises, with the aim of creating more employment and on-the-job training opportunities for persons with disabilities, and promoting an inclusive culture.

6.3 Discussion of the way forward for financial assistance to carers

Integrating the qualitative and quantitative data from carers and stakeholders shows that financial assistance (in the form of cash) is an effective mean to support carers. Both carers and stakeholders agreed that cash has advantages, including flexibility of the use of money in different aspects of caregiving according to the needs and preferences of their care recipients, the reduction of carers' financial burden, and recognition of the contributions made by carers to their families and society. Since caregiving is diversified in nature and is constantly demanding, giving cash to carers directly allows carers to purchase different services; for example, hiring part-time helpers to carry out some personal care or relieving the carers for some time so that they can handle their own personal lives, such as going to the bank or attending their own medical appointments. In addition, cash allows carers to make decisions about the arrangement of some housework, meal delivery, or escort services for the care recipients. The flexibility of the use of cash may increase the efficiency of care and reduce some level of the care burden. However, monitoring the use of cash is practically challenging, as there is a possibility that the cash would be abused for non-caring related uses (as indicated by the stakeholders and some carers in Studies 7 and 8).

6.3.1 Discussion on CCSV encashment for carers of elderly persons

CCSV encashment is a potential form of financial assistance for carers of elderly persons. However, carers and stakeholders did not seem to reach a consensus on the feasibility and acceptability of CCSV encashment, and the support from stakeholders made up less than half of all the valid responses. In light of possible resistance from stakeholders, the Consulting Team is of the view that now may not be the best time to implement CCSV encashment (at the moment, only 6,000+ carers of elderly persons are using CCSV and 18,000 are using traditional care services). Nonetheless, CCSV encashment indeed has a great deal of potential for success when more carers receive services through CCSV in the coming future. Evidence has shown that carers (regardless of their status as CCSV recipients or non-recipients) are in greater support of CCSV encashment than stakeholders are. In this study, more than 80% of stakeholders predicted that the number of carers applying for service voucher would tremendously/slightly increase when CCSV encashment is implemented. This reflected a worry that the stakeholders had. To make CCSV encashment possible, efforts should be made to solicit stakeholders' understanding of the advantages of CCSV encashment.

At present, CCSV is open to elderly persons but not for persons with disabilities. Therefore, the implementation of CCSV encashment is considered in the context of supporting carers of elderly persons.

6.3.2 Discussion on integrating the three pilot schemes for persons with disabilities

In Study 8, the participants were asked whether it would be feasible to integrate the three pilot schemes: the Special Care Subsidy, the Subsidy to Hire Carers, and the Allowance for Low-Income Carers. The results were mixed. The persons with disabilities, their carers and the human services professionals in the focus groups were uncertain about the feasibility of integrating the three pilot schemes. On the other hand, according to the survey of Study 8, more than half (56.7%) of the carers of persons with disabilities believed that it would be feasible to consolidate the three pilot schemes into one single allowance under the Community Care Fund. The stakeholders agreed with this.

Potential advantages and disadvantages of the integration were raised by the study participants. In terms of the potential advantages, integration of the schemes may streamline the administration and make the application process easier. There seemed to be a consensus among the participants that, if there was a consolidated assessment to map out the needs of different target recipients, it might be possible to simplify the administrative process. Some participants with disabilities and their carers suggested drawing inspiration from the Comprehensive Social Security Assistance scheme in this respect. For example, there could be a standard allowance with additional supplements for different purposes (e.g., a Special Care Subsidy, etc.) under the same scheme.

Regarding the potential disadvantages of the integration, the carers were particularly concerned that the integration of the three pilot schemes might lead to some persons with disabilities and carers who are currently receiving one or more of the three subsidies being unable to obtain a similar level of financial assistance under the integrated scheme. Some participants with disabilities and their carers were also concerned that the amount received might be substantially reduced after consolidation of the three schemes. The carers also expressed concerns about the eligibility thresholds/criteria, the target recipients, the amount of subsidy, and the financing mode of the new scheme, as well as about how to provide suitable financial assistance according to different family conditions, different carers’ needs, and the different types and severity levels of disability of persons with disabilities. The stakeholders, on the other hand, were of a different view. They were concerned that the three schemes were used for different purposes and aimed at different target recipients. Some commented that, due to the different physical conditions of persons with disabilities and the different proportions of living expenses of a family, it would not be suitable to use one scheme to provide financial assistance to both carers and persons with disabilities. The subsidy amount of the new integrated scheme, if changed at all, should not be reduced.

If the subsidy schemes were to be integrated, the majority of the carers (61.1%) suggested that the best reference standard for the amount of allowance after the consolidation of the three schemes would be the severity of the disability of the person with disabilities, but the stakeholders suggested that the assets of both the carers and the persons with disabilities should be reviewed.

Chapter 7. Overall Recommendations

7.1 Is a carer policy necessary for Hong Kong?

In general, holistic policy frameworks for supporting carers can be found in economies with a longer history of recognising the importance and value of family carers, notably Australia, Canada, and the United Kingdom, which share similarities in the designs of their policies and specific actions plans. Among the Asian economies in our review, national-level carer-centred policies can be found in Singapore and Japan.

In Hong Kong, while carer support services are available in the forms of community care services and financial assistance, e.g., residential and day respite, centre-based care, home-based care, providing information and training, outreach, counselling, emotional support, etc., they are perceived by some carers and stakeholders as not well coordinated and difficult to access. A holistic carer-centred policy framework is therefore important to be formulated to integrate and prioritise support measures for carers in Hong Kong.

Having a holistic carer-centred policy framework would allow for the setting of priorities as well as the development and provision of services in a coordinated, comprehensive, and evidenced-based manner. Through the formulation and effective implementation of such a policy framework, it will be possible to better coordinate, facilitate, and ensure carers’ continued access to appropriate levels of resources and support. It would also be easier to communicate with the carers, the stakeholders, and the general public about the Government’s focus on carer support if a carer policy is in place. Due to the ageing trend and thus the increasing size of carer population, the demands of carers and care recipients might become more diverse and complex. A carer policy framework can help reduce the pressure on carers and improve their social, physical, and mental well-being in a well-coordinated manner.

At the community level, through the formulation and effective implementation of such a policy framework, carers may have access to appropriate levels of resources and support more effectively and efficiently. Resources could be better utilised to address carers’ diverse needs.

At the governmental level, a carer policy helps allocate resources in a cost-effective way and facilitate future service review. It also demonstrates the Government’s commitment to affirm the roles and contributions of carers.

Having a holistic carer-centred policy framework is only the first step. Carers may still be unaware of the available services even when such policy is formulated. Therefore, it is necessary for the Government to enhance service transparency and coordinate with different parties to improve the accessibility of available services by strengthening the communication between service providers and service users and promoting different services in appropriate channels.

7.2 Proposed definition of a carer

In this consultancy study, a carer is defined as a person who provides ongoing and regular unpaid care or support to a person who has illness, disability, frailty, mental health problem, terminal illness, or other special care needs. The carer may be a family member, partner, relative, friend, or neighbour, and may or may not live with the person receiving care.

Carers of elderly persons are defined as persons taking care of frail elderly persons who are of age 60 years and above, and who have different levels of physical and/or cognitive impairments (mild, moderate, or severe), and require assistance in their activities of daily living (ADL) or instrumental activities of daily living (IADL).

Carers of persons with disabilities are persons taking care of persons aged below 60 years who have various kinds of disabilities.[18]

For the purpose of service implementation, carers can also be defined by different categories including: (a) the age of the carer; (b) the age of the care recipient; (c) types of care recipients; (d) aspects of care needs; (e) intensity of caregiving; (f) the relationship between the carer and the care recipient, and (g) the stage of caregiving journey. These aspects may serve as references for the formulation of operational definitions or the eligibility criteria in the implementation of various services in the future.

In addition, there are subgroups of carers that deserve further attention. High-risk carers are usually those whose caregiving distress has increased suddenly and tremendously due to changes in some aspects of caregiving, such as facing service transitions (e.g.,

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[18] As delineated in the RPP, the types of disabilities include: (a) attention deficit/hyperactivity disorder (AD/HD); (b) autism; (c) hearing impairment; (d) intellectual disability; (e) physical disability; (f) mental illness; (g) specific learning difficulties; (h) speech impairment; (i) visceral disability; and (j) visual impairment.

from hospitals to community care services, or from special schools to adult rehabilitation services), changes in living environment, the health condition of care recipients or the carers themselves, or caregiving mode. They usually feel helpless and hopeless.

Hidden carers are ‘persons who provide unpaid care for a person with a disability, chronic illness or frailty due to old age but do not think of themselves as ‘carers’, and are therefore less likely to seek or access support’ (Knowles et al., 2016).

Young adult carers are “a distinct group of young persons aged between 18 and 24 who have caring responsibilities” (Becker & Becker, 2008).

7.3 Main directions for going forward

The findings of this consultancy study suggest that carers in Hong Kong experience inadequate recognition for the unique and crucial role they play in keeping their care recipients well and at home. As most existing community care services focus on elderly persons or persons with disabilities who have long-term care needs, Hong Kong lacks a holistic carer-centred policy framework for carers. Most of the data collected to date suggest that existing services can be integrated and prioritised so that they are more responsive to carers’ short-term needs (which may be episodic or urgent) as well as their long-term well-being (including their caregiving capability).

A policy framework and its recommendations for carers were developed based on four main directions. Drawing from the experiences of nine other economies, these directions, listed below, ensure that the policy framework developed is comprehensive, having the right focus and well-coordinated.

i. **Support carers in the community:** This direction emphasises the need to see carers’ roles and needs in the context of the communities in which they live by adopting a carer-centric approach in supporting them. The focus is not just to strengthen the carers’ caregiving ability, but also to identify the holistic needs of and appropriate support for the carers themselves. A cost-effective way to do so is to expand existing services designed for care recipients to simultaneously include carers. This ensures the involvement of the carers right from the commencement of the intervention. This direction also emphasises that carer support is a shared responsibility of family, community, business, and the Government.

ii. **Capacity building of carers:** Carers should be empowered through the affirmation of their roles and abilities, and the contribution and enhancement of their personal strengths, confidence, and self-efficacy in coping with difficulties. This direction acknowledges the importance of promoting carers' psychological well-being.

iii. **Multipartite collaboration:** Support for carers should be provided through a joint effort by different stakeholders and sectors (e.g., the information technology industry; education, medical, health, and welfare sectors; housing, transportation, businesses, etc.). This direction also echoes the first direction in its emphasis on the development of a carer-friendly society.

iv. **Sustainability of carer support:** Support should be sustainable in terms of financial planning, workforce availability, and other resources. The business sector, social enterprises and charity funds are encouraged to provide carer support initiatives that follow a sustainable development model. This direction is important to ensure that different types of carers can continue to benefit from adequate support in the long term.

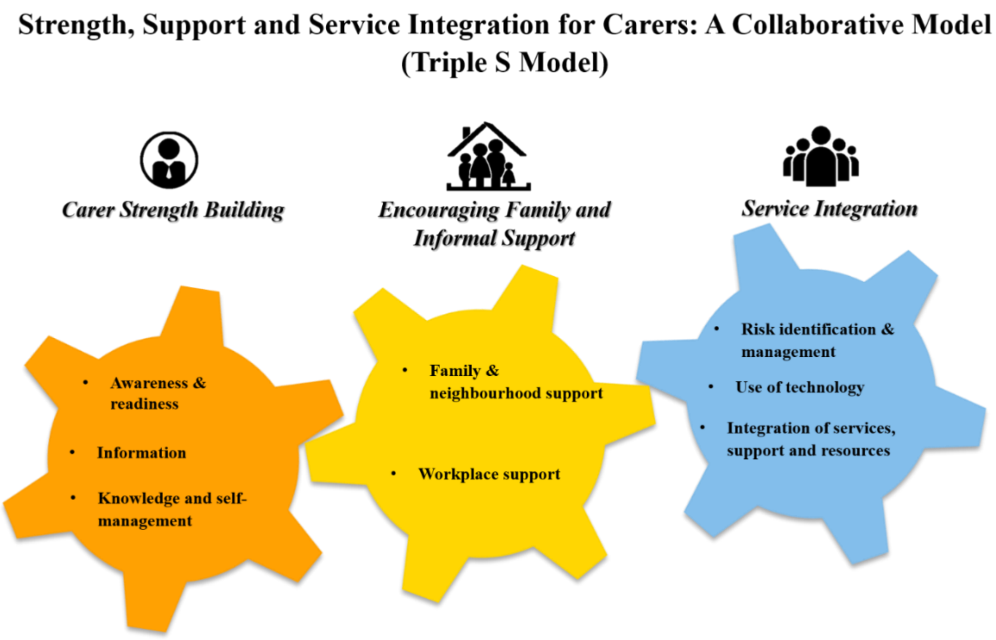
Nonetheless, it is noteworthy that these main directions may still face practical challenges. First, the enhancement of support services for carers in Hong Kong hinges on the availability of adequate manpower in relevant service sectors where social workers, therapists, psychologists, nurses, and frontline care workers are in short supply. Second, the collaboration among multiple parties, including government bureaux/departments, the welfare sector, and the medical sector should be enhanced. Finally, the recent pandemic, combined with the consequent economic downturn, may affect funding sources and lead to financial uncertainty for the sustainability of support measures for carers.

7.4 Strength, Support, and Service Integration for Carers: A Collaborative Model (Triple S model)

Strength, Support, and Service Integration for Carers: A Collaborative Model (the Triple S Model) is the policy model proposed by the Consulting Team as an integrated framework for the policy recommendations of this consultancy study. The overall policy statement of this model is to provide effective and timely support to carers of elderly persons and persons with disabilities across their lifespans and at different stages of caregiving journey by building carers' personal strengths, encouraging support from their families and neighbourhood, and integrating support services.

The focus of the Triple S Model should be on streamlining and integrating resources to achieve higher levels of efficiency, effectiveness and productivity. *Figure 7.1* presents the Triple S model using a gear diagram, with the gear mechanisms representing collaboration between three main areas. These three areas are of equal importance and are as follows.

Figure 7.1 The Triple S Model of Carer Support



The three gears of the model are carer strength building, encouraging family and informal support and service integration. Each gear has different functions (please see section 7.6 below). The Consulting Team suggests that the Government and the community should play different roles in each of these areas. The Government should facilitate social enterprises or NGOs to help carers build up their own strengths; facilitate the development of carer-friendly neighbourhoods in the community, and directly and actively provide suitable services and support to carers. The community should acknowledge and affirm the contribution of carers and establish a harmonious environment for carers to gain mutual support. All the gears must be working together in a dynamic mode, in which each area reciprocally helps the others, in order to achieve the best outcomes.

7.5 Formulation of the recommendations

The Consulting Team generated preliminary ideas based on observation and analysis of the major findings from Studies 3 to 8. Each of Studies 1 to 8 provided insights for the Consulting Team to make suggestions about some preliminary ideas that could be used for a third stage of consensus building, so that stakeholders, experts, and government officials could further analyse and consider them in terms of their feasibility and priority. In total, 96 preliminary ideas were generated from the available data of the component studies. All of these preliminary ideas were further condensed with respect to their importance and feasibility. The Consulting Team extracted 26 initial suggestions, which were further consolidated, giving rise to 11 policy and service recommendations. These 11 recommendations were further categorised into three main areas: carer strength building, encouraging family and informal support, and service integration.

In the third stage engagement of Studies 3 to 8, which aimed to bring forward the Triple S model and the 11 recommendations for discussion, seven sessions were held with stakeholders from both government and non-government sectors.

After taking into consideration all of the relevant and valid comments from the stakeholders during the engagement sessions after the interviews (Stage 1) and surveys (Stage 2), the Triple S model was fine-tuned, with eight domains across the three main directions and 11 policy and service recommendations (see Figure 7.1). These recommendations involve the individual, the family, and the community, and the support that can be generated through collaboration between these parties.

7.6 Three key main directions: carer strength building, encouraging family and informal support, and service integration

7.6.1 Carer strength building

Policy Objective: To build up the strength of carers of elderly persons and persons with disabilities through increasing their awareness and readiness to seek help, providing them with comprehensive information on available support resources, and upgrading their knowledge and self-management skills to enable them to better cope with challenges resulting from the process of caregiving.

Expected outcomes:

- Carers have increased and heightened awareness in recognising available resources and are more ready to seek help.
- Carers are provided with updated information and knowledge to provide quality care for the persons they take care of.
- Carers are equipped with more skills and strategies to manage their stress and crises and maintain their own emotional and mental health.

Specific recommendations:

- 1. Raise awareness of carers about the importance, availability, and access of information and increase the readiness of carers and intermediate parties to seek help from available services.
- 2. Examine existing websites and encourage NGOs / social enterprises / corporates to develop a carer centric and sustainable information gateway to address carers' needs.
- 3. Provide carer-centric training and intervention to promote carers' wellbeing, self-management, ability to cope with stress, as well as to strengthen their caregiving capacity.

7.6.2 Encouraging family and informal support

Policy objective: to encourage more family members to share caregiving duties; to strengthen mutual assistance in neighbourhoods; and to foster a carer-friendly support environment in the workplace.

Expected outcomes:

- Carers are recognised for their caregiving role within the family in the neighbourhood and workplace.
- Increased social connections for carers, including family and peer networks.
- Carers are supported in regard to spending time on personal activities, including family life, social networking, leisure activities, and educational or employment pursuits.

- Carers who are in productive life stages will be supported to reconcile work/education with their caregiving role.

Specific recommendations:

- 4. Promote family-based support and mutual assistance among peer carers across their life span and at different stages of their caregiving journey.
- 5. Cultivate a carer-friendly neighbourhood.
- 6. Devise and promote a carer-friendly support environment in the workplace so as to help carers strike a balance between their work and their caregiving role.

7.6.3 Service integration

Policy objective: To identify, in a timely and valid manner, carers at high risk, integrate carer-centric services, facilitate multi-partite collaboration among different sectors, professions, public and private sectors, and the adoption of flexible and innovative operation models (including promoting the use of technology) for sustainable carer support.

Expected outcomes:

- Carers who are at risk will be more quickly identified and provided with necessary and timely support.
- Carers can gain better access to and be better assisted by technology in their caregiving role.

Specific recommendations:

- 7. Develop a local self-administered assessment tool with the aim of increasing the knowledge of carers in terms of needs, risk identification and management, and potential support available.
- 8. Identify high-risk carers and provide timely support.
- 9. Better introduce, access and utilise assistive technologies to relieve the care burden, enhance caring capability and improve carers' quality of life.
- 10. Increase accessibility and diversity of respite service to provide relief to carers with ad-hoc needs.
- 11. Provide good mix of services, voucher and cash to support carers.

Chapter 8. Carer Strength Building

The caregiving journey may last for decades. Carers need to mobilise their resources and strengths, which can be leveraged in turn to strengthen their caregiving abilities and well-being. It is also important to build on carers' strengths to enhance their capacity to handle caregiving, well-being, or lifespan development challenges. Within the Triple S model, recommendations were formulated on the basis of the study's findings to address the following aspects: (1) raise awareness of the help available and readiness to seek help; (2) enhance the accessibility of information; and (3) promote self-management.

8.1 Awareness and readiness

8.1.1 Recommendation 1: Raise carers' awareness about the importance, availability and access of information and increase the readiness of carers and intermediate parties to seek help from available services

Carers are not aware of their own needs when they devote themselves to caregiving. It is observed from our study that many carers do not have sufficient awareness or knowledge of the available support services. Some of them are aware of the services but do not know whether they are eligible and how to apply. This recommendation aims to raise carers' self-awareness and promote their readiness of help-seeking as a preventive measure to minimise their risks of burnout. The measures required for the implementation of this recommendation should be regarded as a fundamental pillar in the overall support system for carers of elderly persons and persons with disabilities.

Self-awareness as a carer, the ability to identify risks, and readiness to seek help are crucial to upholding and building up carers' capacity to take care of the care recipients. These attributes are particularly vital among hidden carers, who regard caregiving merely to fulfil familial obligation and are less likely to seek help. If carers can identify their own risks and needs through awareness-building, they will be more proactive in obtaining further information (see Recommendation 2) and more willing to receive follow-up interventions, such as carer-centric training programmes and self-management programmes (see Recommendation 3).

Proposed initiatives, objectives, and target groups

This recommendation aims to increase self-awareness among carers, especially those who remain hidden and do not see themselves as carers, to increase their readiness to seek help, and to remind them of common situations or episodes that warrant proper attention.

Another facet of the awareness promotion campaign should be to raise the awareness of intermediate parties (e.g., significant others in the family, friends/relatives/ neighbours, social service providers, human service professionals, and frontline staff in housing estates and community units, as well as employers) regarding carers' issues, including their role and contributions, the challenges they frequently encounter, and the support available for their pressing needs.

Proposed content and operational considerations

(i) Dissemination of information

- **Community-based service centres:** Community-based centres with services targeting elderly persons or persons with disabilities provide ideal locations to put up posters and distribute pamphlets that assist carers in self-identifying and seeking further information. Information should be presented in a format that is easily understandable to the target audience by asking simple questions. For instance: 'Are you looking after, or giving help or support to, anyone because they have long-term physical or mental health conditions or illnesses, or problems related to old age?' Social workers in these community centres play a crucial role in the initial identification of carers. When attending community centres with their care recipients, carers can be further supported to increase their knowledge and awareness of available resources and support.
- **General practitioners' clinics**: Similar to dissemination of information at community centres, the content of posters in general practitioner's clinics should: (i) inform persons of identifying themselves as carers with slogans or questions, as above, to remind them of the role of carers and the support services available, in addition to simply being a family member; (ii) inform persons of acknowledging that they are entitled to support when in need; (iii) provide a location or online portal where carers and their families can seek further information and support; and (iv) provide information about opportunities for discussions with social

workers. Practitioners in health sector should be encouraged to support carers in the community. Relevant information about carer supportive services should be regularly given to the medical and health practitioners by the Department of Health or Hospital Authority with regular updating of information on carer support. Professional development training on the importance of carer support should be given to medical and health practitioners in the community.

- **Mass advertising strategies:** Mass advertising strategies should be employed to reach out to wider audiences, for example, through billboards, TV shows, and social media.
- **Outreaching:** Outreach activities should be organised regularly and deployed by relevant community centres in communities, districts, or public housing estates with a high proportion of persons with long-term care needs (and potentially a large number of carers). Outreach services could be conducted by community centres for persons with disabilities (e.g., social and recreational centres for the disabled) and for elderly persons (e.g., DECCs) to get in touch with less motivated persons in need of care and their family members, providing them with immediate assistance to connect those in need to suitable community services. These serve as practical examples of how to extend similar outreach services to carers on a larger scale.
- This recommendation of awareness-building strategies should be implemented in tandem with other initiatives, such as a self-administered assessment, an information gateway, timely support for high-risk carers, and stress management interventions (as detailed in the subsequent recommendations).

(ii) Carer Awareness Week

A ‘Carer Awareness Week’ or similar campaign could be organised in collaboration with the elderly and rehabilitation service centres as an opportunity to promote the recognition and importance of carers, what they do, and the services and support they need. Events (such as family workshops or tea sessions with refreshments) could be organised to allow carers from different backgrounds to gather and share their stories. Stakeholders from other sectors (e.g., employers) could also be involved to maximise the awareness-building impact of the events. The Carer Awareness Week could be hosted by NGOs with funding from charity funds. Taking the Carers Week 2021 in the UK as an example, a headline supporter is the main organiser, usually an enterprise from the public sector or a non-governmental organisation, who connects other joint charities and social organisations. The Government could also promote the concept of Carer Awareness Week by encouraging the business sector to expand their efforts in corporate social responsibility.

Souvenirs, such as tote bags, umbrellas, and T-shirts, could be distributed to participants during events to further spread the message of support for carers to the general public. The above activities could be carried out in conjunction with a media campaign before and during Carer Awareness Week, to reinforce the information on the role and contributions of carers, and the support they need. Information disseminated through the above channels may also facilitate other supportive measures listed in subsequent recommendations, such as an information gateway, carer-centric training programme, respite services, and carer-friendly neighbourhoods.

(iii) Enhancing awareness of available community support services

Professional input to identify carers and offer support in a neighbourhood is very important. Currently, the case management approach is applied by rehabilitation service providers (including DSCs, HCS and ISS), under which case managers coordinate necessary services for service users and make timely and suitable service referral. The responsible social workers of elderly services also co-ordinate necessary services for elderly persons and their carers to make timely and suitable service arrangement and referral. Specifically, case managers / responsible social workers will collaborate with other social workers and allied health professionals in the service units to draw up individual care plans with persons with disabilities or elderly persons concerned and/or their carers/families, monitor the implementation of the care plans, and coordinate with relevant social and medical service units that accept referrals to enable service users and their families to obtain appropriate services. Given the one-stop and comprehensive services provided through the case manager / responsible social worker, it is recommended to enhance the awareness of the above case management approach and encourage carers to seek assistance when needed.

8.2 Information

8.2.1 Recommendation 2: Examine existing websites and encourage NGOs / social enterprises / corporates to develop a carer centric and sustainable information gateway to address carers' needs

Information to support caregiving is available from various online platforms and community-based service centres. However, carers encountered difficulties in understanding information and determining which particular carer support services fit their needs. In some cases, the information may not be comprehensible, updated and readily accessible to carers. Some information is not tailor-made to address the needs of the carers. This recommendation calls for the examination of available sources of information and the development of a more carer-centric sustainable information gateway.

Proposed initiatives, objectives, and target groups

To encourage NGOs / social enterprises / corporates to operate a comprehensive information gateway for carers in a sustainable model.

Proposed content and operational considerations

To avoid conflicts of interest among different service providers and build up a sustainable model, a standalone social or private enterprise operating the proposed gateway is preferable. Support from charity foundations and public funds could be solicited as seed money to set up the gateway, which should adopt a business/sustainable operation plan to ensure sufficient capital to cover recurrent costs of IT as well as manpower for the gateway. The content of the information gateway should be comprehensive, covering aspects such as disease-specific information, patient care information, service-related information, and carer self-care. Carer service providers may update its own information and inform the gateway operator to ensure carers can receive the latest information. The gateway operator would be responsible for checking the validity of weblinks.

A challenge for the information gateway is to tackle the low access rate as reflected in some of the local information platforms. A very important strategy is to make it as user-friendly as possible by developing a simplified app version to facilitate access by the younger generation. The gateway should also be compatible with various types of smart devices so that carers can access information at their preferred times and places. Other suggested functions include an easy search function (e.g., keyword search functions), and an artificial intelligence chatroom which could attend to carers' enquiries and to provide information on carer support services. While this one-stop gateway is not meant to replace professional staff who can provide face-to-face consultations in DECCs, NECs, PRCs, and DSCs, carers with more complicated and individualised queries can even engage in interactive dialogue with trained peer helpers or professionals to seek timely initial advice. Service matching could then be arranged so that carers could get into contact with the relevant service providers in their district. Moreover, videos of carer training sessions operated by DECCs/ NECs/DSCs and other carer projects can be incorporated into the gateway.

A local information gateway established for Tai Po carers is presented below for reference. The carer-focused ap*p* <<照顧達人>> operated by a non-subvented organisation, the Hong Kong Federation of Women's Centres, provides information on upcoming activities for carers (e.g., opening hours of a carer café, mindfulness training for carers), and information provided by district-based or territory-wide service providers. Carers can apply to attend these activities via the app. The app is user friendly and was designed by a commercial IT company after consultation with various stakeholders. According to the Hong Kong Federation of Women's Centres, its annual operating cost is around HK$1 million. Reference can also be made from exemplar information platform(s) in other economies such as the Caregiver Alliance Limited (CAL) in Singapore, which is very user-friendly and brings together relevant support and resources for carers. It presents information according to what the carers are concerned about systematically, and provides links to relevant resources (e.g., service providers) as well. There are also exemplar information platform(s) on other user groups (such as family carers of children), which adopts a business model for sustainable development.

The long-term goal of the one-stop information gateway is to identify high-risk carers and offer immediate help to them, after getting their consent, through a built-in self-assessment function (See Recommendation 7 for details of the assessment tool).

8.3 Knowledge and self-management

8.3.1 Recommendation 3: Provide carer-centric training and intervention to promote carers' wellbeing, self-management, ability to cope with stress, as well as to strengthen their caregiving capacity

Caregiving responsibilities can result in overwhelming levels of stress. Many carers are not aware of support services specifically targeting carers. Their personal needs and well-being are perceived as being ignored. Our review on literature has underscored the importance of psycho-educational programmes targeting carers as one of the most effective interventions. In fact, this type of programmes is not uncommon in Hong Kong. Yet many of them are time-limited and could only serve a small number of carers by the types of care recipients due to the service scope of the organisations. Despite the well-intended designs of these programmes, some carers share that they have very little time to attend the activities which are usually centre-based.

This recommendation calls for restructuring and enhancing of existing support and training services, so as to more actively engage carers who lack the motivation and readiness to seek help and enhance their personal capacity. Moreover, training-based intervention such as psychoeducational groups has become increasingly popular to enhance the capacity of family caregivers. Therefore, this recommendation also calls for the design of a carer-centric psychoeducational program to promote carers' wellbeing and caring capacity. The carer-centric psychoeducation programme is not teaching the carers how to care the care-recipient. Instead, the programme should pay attention to the differences in needs among carer types (e.g., young carers, carers at work, older carers, etc.), and remove the barriers of learning (e.g., mixed modes of learning, distance learning, etc.).

Proposed initiatives, objectives, and target groups

Psychoeducation programmes such as the Resources for Enhancing Alzheimer's Caregiver Health (REACH) are found to be effective in improving the perception of caregiving, and reducing depressive symptoms and subjective feelings of burden (Cheung et al., 2015). To build up carers' self-management, stress-coping skills, and caregiving capacity, we propose to introduce a short psychoeducational programme for carers by making good use of current training resources.

Carers participating in training programmes could be identified and approached by social workers in community centres, school teachers (or school social workers if relevant) for younger carers who are still in school, or healthcare professionals when the care recipient is going to be discharged from the hospital. The selection of carers for participation should be based on professional judgments, with the optional aid of assessment tools. Priority should be given to carers who have shown to be exposed to heightened risks due to their care burden, emotional issues, or family conflicts.

Proposed content and operational considerations

Carers should be encouraged to receive training on stress management and caregiving techniques through existing community-based service centres (such as DECCs, NECs, integrated family service centres, PRCs, and DSCs). Other existing courses and resources could also be adapted to serve the purpose. These existing courses and resources include teaching materials of the relevant Employees Retraining Board courses, courses of the Capacity Building Mileage Programme, and an online psycho-educational programme to empower carers developed and validated by a research team of the City University of Hong Kong, and a 8-session psycho-educational programme developed by a team of local researchers (Zhou et al., 2020).

On the other hand, it is recommended to design a new short-term psychoeducational intervention programme specifically for carers. It might include components of behavioural therapy, psychosocial/problem-solving skills, and caregiving techniques via a computer-mediated platform; and would be preferably designed according to theoretical learning models such as the Self-Efficacy Model (Bandura, 1994), which suggests the adoption of strategies including mastery, modelling, social persuasion, as well as managing stress and emotional responses. Training areas may include the roles and responsibilities of peer supporters, stress management, the positive aspects of caregiving, crisis/change management, experience sharing, and help-seeking awareness. Specific guidance should be provided to carers to cope with care recipients with different characteristics, including elderly persons with dementia, persons with intellectual disabilities or mental illnesses, and children with special educational needs.

As carers often reflect that they are fully occupied with caregiving duties, they could also be encouraged to complete web-based tasks, such as watching short self-coaching videos that feature scenarios similar to their own caregiving situations, so that they do not have to frequently attend service centres. This psychoeducational intervention programme could be delivered on a pilot basis and in a hybrid model (including web-based, centre-based, and at-home components). The core sessions of centre-based training workshops could then be delivered weekly for a certain period. The total duration of the programme will be time-specific so that an evaluation of its effectiveness can be easily implemented and more people can benefit from it if it is proven to have long-lasting beneficial effects. Upon completion of the programme, carers will be reassessed for stress and self-efficacy using the same tool to evaluate the programme’s effectiveness. Certificates could be awarded to carers who have completed training courses/programmes to recognise their enhanced caregiving capability.

It is suggested that graduated carers should be recruited and trained as peer support workers and take on the role of group activity mentors or course instructors as volunteers. Peer support workers can also help carers to establish an informal peer support network in the community, promote mutual assistance across families of similar backgrounds, and foster a carer-friendly atmosphere (see Recommendations 4 and 5).

Chapter 9. Encouraging Family and Informal Support

Caregiving is one of the most important functions of family which provides practical and emotional support for its members. In the surveys of Studies 3 and 4, respondents regarded "serving the role of a family member" as the main reason of taking up caring responsibilities. However, there has not been sufficient recognition and support for carers from their immediate circle. The care burden is often put on the shoulders of one family member. Carers of elderly persons and persons with disabilities considered that the responsibility of caregiving should be shared among family members, NGOs and government bodies. Even though most families in Hong Kong today are nuclear families, it is still possible to release manpower, including young family members, for intergenerational assistance.

The establishment of an informal network system is also proposed to strengthen the support for carers. Stress can be alleviated through interactions with family and friends residing nearby, and this in turn can enhance the quality of carers' caregiving work. In addition, it is suggested that support groups should help carers throughout the different stages of the caregiving journey. Facilitating community-based peer support can be an effective way of pooling knowledge and experience among carers with different levels of caregiving experience, and can be instrumental to offering timely sources of practical and emotional support. There is a need to raise the awareness and ability of community care services and people in the immediate circle of carers, including other family members, to identify the needs of carers and offer support to them.

Although there is an awareness of the need to support employees who care for infants and young children, many workplaces may not understand the need to support employees who care for someone with disabilities, chronic illness, age-related frailty or in mental recovery. There are two main reasons why workplaces should be made carer-friendly. From a business perspective, showing support for working carers is likely to enhance the reputation of an organisation in the eyes of all employees and customers. It can help to attract and retain staff who might otherwise quit their jobs due to the heavy care burden. Offering support to staff to execute their caregiving role may reduce their perceived care burden, stress levels, and subsequent health issues. The reduction of employees' sick leaves would increase the firm's productivity. From the perspective of human resource management, employers should provide the best possible support to their employees, particularly if they are experiencing challenges outside of work that will have an impact on their well-being in the workplace. In addition to employer support in the workplace, indirect peer group support and school support should be provided to young adult carers. For these reasons, it is crucial to create a carer-friendly atmosphere in the workplace and in educational institutes such as tertiary education institutes so as to help carers maintain a balance between their dual roles of being an employee or a student and a carer.

9.1 Family and Neighbourhood Support

9.1.1 Recommendation 4: Promote family-based support and mutual assistance among peer carers across their life span and at different stages of their caregiving journey

Elderly and intergenerational-focused promotional/educational activities have been implemented through NGOs or tertiary institutions. These actions could encourage the younger generation to be more aware of the needs of the elderly and to appreciate intergenerational interaction and assistance. On the other hand, peer support programmes have been delivered in community care service units in Hong Kong. Carers with similar experiences in their caregiving journey could be a channel to provide emotional support for their peers. Peer-to-peer support can also enable young carers and peers to establish informal social support networks that help to build up skills, knowledge, and reciprocity, and reduce stress in the long run. More peer-to-peer support engaging carers at different stages of their caregiving journeys is needed. One of the peer support activities is the pilot carer café programme which is a global exemplar successfully launched in France and then in other economies, including Taiwan and Hong Kong. Some peer support programmes have reported positive outcomes. However, there are service gaps in these projects in terms of locations, hours, and membership eligibility. This recommendation therefore calls for enhanced efforts in family education and community support projects in order to promote understanding and support from family members, neighbourhood and the community.

Proposed initiatives, objectives and target groups

The Consulting Team proposes that more family members should be involved in sharing caregiving duties through family education, strengthening social support networks in the neighbourhood so as to facilitate mutual assistance among carers, and encourage knowledge-sharing among carers at different stages of the caregiving journey.

Proposed content and operational considerations

(i) To provide promotional/educational activities and family education

Family members are either carers themselves or provide essential support to carers of elderly persons and persons with disabilities in their families. Thus, enhancing family members' involvement in caregiving is most important. To promote family-based support, it is suggested to normalise the caregiving role and promote intergenerational assistance through public education. For example, activities featuring themes such as 'everyone could be a carer at different stages of their life' and 'appreciation of reciprocal assistance between the generations' could be implemented. More emphasis will be placed on the younger generation and family education. Promotional/educational activities may include a carer week, campaigns, and roadshows with related themes. These activities can be implemented through NGOs, charitable organisations, educational institutes, and business sectors in the form of educational/promotional programmes and production of educational/promotional materials.

The development of new educational programmes or modules on family education is also recommended. Tertiary institutions could consider developing new educational programmes (e.g., undergraduate or postgraduate) or modules (e.g., general education programmes for undergraduate studies) under family studies or increasing the elements of family support in as many courses as possible since everyone could be a carer at different stages of their lifespan development. This could be done through flagging up family education as manpower remarks for universities' attention in the UGC triennial planning exercise of academic programmes.

In terms of primary and secondary education, relevant learning elements about family care/education have already been included in their curriculum. For example, both Primary General Studies and junior secondary Life and Society include elements such as the responsibilities of an individual toward family, while senior secondary Health Management and Social Care includes family relationships and care provided by family. However, since family-based support and sharing of caregiving responsibilities are important, more could be done to nurture students' readiness and capacity to support and take care of their family members.

Through these educational programmes and modules, the younger generation could be educated on different areas of family functioning/values (e.g., the family system/subsystem, the function of family, roles and responsibilities in the family across one's lifespan, risk and resilience factors as well as traditional Chinese thinking related to family and interpersonal relationships). It would encourage the younger generation to be carers or offer support to the primary carers of elderly persons or persons with disabilities.

Family education could be implemented by family education centres, educational institutes, schools, universities, the mass media, and other organisations related to family education. Staff may also need to receive training about family education. To achieve the above, a training package with educational materials should be produced for use in Hong Kong. It is recommended that experts be invited to produce such educational materials, particularly tapping into the interests and needs of the younger generation and nuclear families.

(ii) To enhance carer café programmes

The Consulting Team suggests introducing more carer café programmes. It is suggested that professional staff (e.g., social workers and counsellors) be assigned to plan and carry out the carer café programmes.

To leverage the extensive networks of existing centres in elderly and rehabilitation services, it is suggested that carer cafés[19] programmes could be implemented through DSCs and district-based elderly centres. For example, in these centres, a corner could be set aside for the setting up and running of a café, and another corner for parallel activities for the service recipients. Alternatively, and more desirably, carer café programmes could be held in other places with a relaxing, comfortable and café-like environment, such as restaurants, bistro or studios. In addition to services units

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[19] The carer café was first introduced by The French Association of Carers (FAC) in France in 2003 to address carers' social and emotional needs. FAC promotes and ensures the program's consistency and quality by developing a fundamental philosophy, delivery model, tool kit and training that must be followed by local organisations conducting carer cafés. Hong Kong may draw reference from this.

providing elderly and rehabilitation services, other service units (e.g., other welfare service units, community halls/centres, integrated services centres, etc.) may be engaged to operate carer cafés. Extending existing services in this way would be less costly than setting up new carer cafés. It could also avoid overlap of services, increase its scope and ensure the services could reach more carers.

(iii) To promote the development of community-based peer support programmes

The content of such programmes may vary and should be implemented by trained social workers and/or relevant professionals. Volunteer peers should receive training as peer specialists to support other carers at different stages of their caregiving journeys.

Some success factors from previous studies and existing programmes are identified. For example, during group sessions, participants could acquire various skills that may help them achieve their different objectives, such as self-exploration, enhancement of their well-being and self-efficacy, and strengthening their peer support network. Carers with similar experiences in their caregiving journey could be a source of emotional support for their peers. Peer support can also enable young carers to establish informal social support networks that help build up skills, knowledge, and reciprocity and reduce stress in the long run.

To promote peer support, the carer café programmes and community-based peer support programmes will require the involvement of NGOs. Various community centres may consider organising these programmes as part of their regular service.

9.1.2 Recommendation 5: Cultivate a carer-friendly neighbourhood

Some pilot projects supported by public funding and charity funds have been successful in cultivating carer-friendly neighbourhoods. However, there is a gap in the awareness of and ability to identify the needs of carers and offer support to them in their immediate circles. Some carers do not identify themselves as carers or are not recognised as such by service providers. Some carers are unwilling to receive services, some lack knowledge and skills to seek help, and some frontline staff may lack knowledge and skills to deal with carers. Support from the daily contact point of carers is required. This recommendation aims at building on success factors of local projects on building supportive neighbourhoods, and at strengthening support to carers from various community groups and local stakeholders, including the business sector.

Proposed initiatives, objectives and target groups

The Consulting Team proposes to encourage various community groups and the business sector to contribute to cultivating carer-friendly neighbourhoods. Within a carer-friendly neighbourhood, carers can be identified and recognised. Raising awareness, sensitivity, and readiness to provide support for carers in neighbourhoods is also recommended.

Proposed content and operational considerations

(i) To encourage the business sector to be carer-friendly

This initiative could be implemented by connecting and encouraging the business sector to offer discounts, support, and services. For example, NGOs or social enterprises may consider issuing a carer identity card to affirm the contributions of carers, and encourage the business sector to collaborate and contribute. Beyond corporate social responsibility, the business sector should be encouraged to consider carer support as a way to achieve the 'Environmental, Social, and Governance (ESG) criteria', which is an increasingly common way for investors to evaluate companies in which they might want to invest.

(ii) To promote the concept of carer-friendly neighbourhoods

NGOs could offer publicity, educational and training activities to different parties (e.g., private practitioners, security guards and managers of housing estates, restaurant staff, etc.) to increase sensitivity and readiness of supporting carers in their neighbourhoods. Various charity funds could show support to such activities or campaigns through funding NGO's innovative projects in order to develop service models. Building a harmonious neighbourhood requires the collaborative efforts of different parties surrounding carers and the utilisation of the strengths of different parties. Social enterprises and NGOs could organise annual events with awards to honour carers' contributions.

(iii) To integrate and enhance the types and availability of community care services

In Hong Kong, there are different types of community care services. Considering the financial constraints and availability of many existing services, it is advised to enhance the integration among different service types and enhance the availability of community care services. For example, the development of carer-friendly neighbourhoods could be implemented by promoting existing measures implemented by NGOs, e.g., block warden projects, elder-sitters, encouraging the greater use of time banks and creating reward systems to affirm the contribution of carers by the business sector. There may be room to better integrate elderly and rehabilitation services in support of carers since carers may share similar needs and require a similar form of support during their caregiving journey.

9.2 Workplace Support

9.2.1 Recommendation 6: Devise and promote a carer-friendly support environment in the workplace so as to help carers strike a balance between their work and their caregiving role

By devising and promoting a carer-friendly support environment, this recommendation aims to encourage more workplaces to adopt proper measures to cultivate a carer-friendly environment by themselves or through collaborations with human service professionals and community groups. Thus, it will, in turn, raise awareness, sensitivity, and readiness to provide support and recognition to carers, which was also highlighted under Recommendation 5. Given the challenges presented to young adult carers, work organisations should proactively advocate employer support to carer employees. Good practices from individual corporations should be shared so other workplaces can draw reference to help their carer employees or students strike a balance between their work or study and their caregiving role.

Proposed initiatives, objectives and target groups

The objective of this recommendation is to promote a carer-friendly support environment in the workplace, so as to help carers strike a balance between their work or study and their caregiving roles.

Proposed content and operational considerations

(i) To help organisations retain talented employees who might otherwise quit their jobs due to their heavy care burden

While many organisations have been promoting a family-friendly work environment to their employees, this recommendation calls for a special focus on carer-friendly measures to support employees who are informal carers of elderly persons and persons with disabilities. The introduction of carer-friendly measures could be promoted as an effective way of helping organisations to retain talented employees who might otherwise quit their jobs due to heavy care burden. Employers should be encouraged to recognise the role of carers by providing a supportive environment that can help relieve carers' stress through measures such as leave/time off to accompany care recipients to medical appointment, and flexible working arrangements, so that carer employees can carry out their caregiving duties while being able to remain in employment. Large/public enterprises (e.g., listed companies, universities and quasi-governmental organisations) could also be encouraged to operate corporate-owned day care centres for frail elderly relatives of their staff, similar to child carer centres run by some banks. The promotion/encouragement can be done through media campaigns targeting the employers. This could also build on the Labour Department's efforts to promote good human resource management (GHRM) culture, including the implementation of family-friendly employment practices (FFEPs) by employers for their employees.

In the longer term and upon the availability of resources, the government might explore the feasibility of providing incentives to motivate the business sector to create a carer-friendly atmosphere tailor-made for their employees who have a caregiving role.

(ii) To encourage carer-friendly work arrangements

It is recommended that private organisations or associations should be encouraged to create carer-friendly workplaces. Having gathered experience, these organisations or associations may share their best practices with different sectors and organisations so as to motivate the employers to provide cross-sectoral support to carers. Recognition of these organisations is recommended. This could draw reference from the Good Employer Charter (GEC) 2018 and GEC 2020, which are organised by the Labour Department to recognise good employment practices implemented by employers.

It would also be worthwhile to take reference from other economies with experience in promoting carer-friendly workplaces through the provision of flexible work arrangements, such as working from home, part-time work, flexible working hours and re-employment of graduated carers.

(iii) To strengthen peer group network support and provide a channel for young adult carers to voice their concerns

Young adult carers who are current students may face challenges in handling their academic work while taking care of family members. This may lead to distress, affecting their learning, and even leading to taking leave from school due to their heavy caregiving duties. It is essential for their teachers and student affair offices to take early notice and provide academic and other relevant support to them. It is thus important to provide training for teachers and student affairs officers so as to increase their awareness of the potential problems and the related needs of young adult carers. Peer group network support could relieve the burden of young adult carers, or at least provide them with a channel through which they can voice their concerns.

Some workplaces provide childcare centres for their staff but there is no such care centre for elderly persons in Hong Kong, which could help relieve the burden of their staff who are carers of elderly persons. Hualien Tzu Chi Hospital in the city of Hualien in Taiwan has a Geriatric Day Care Centre targeted at elderly family members of the hospital staff, which is supported by the Buddhist Tzu Chi Medical Foundation. This could be a worthwhile reference for Hong Kong.

(iv) Other considerations

There has been an increasing demand for business corporations to adopt socially responsible practices. Companies are accountable to their various stakeholders, such as investors, customers, employees, and collaborators. Thus, ESG criteria, which is an increasingly common way for investors to evaluate companies in which they might want to invest, could be taken as a reference in regard to Recommendation 6.

Chapter 10. Service Integration

The following recommendations focus on the integration of existing carer support services, covering areas such as risk assessments for carers, emergency support services, respite services, the use of assistive technology, and financial assistance.

10.1 Risk identification and Management

10.1.1 Recommendation 7: Develop a local self-administered assessment tool with the aim of increasing the awareness of carers in terms of needs, risks, and potential support available

Many carers are not aware of the severity of their own health problems although some of these conditions have persisted for a long time. Little attention has been given to carers' health and little information has been given to restore their well-being. By now, there are no particular initiatives to encourage carers to assess their health status periodically.

The needs of carers vary considerably and are individualised and complex, as they are determined by various factors, including the individual circumstances of each care recipient. Assessment for carers in Hong Kong often adopts existing psychometric tools which have been validated, for example the Caregiver Strain Index (Chan et al., 2013; Robinson, 1983), Depression Anxiety Stress Scale-21 (Wong et al., 2019), Positive Aspects of Caregiving (Lou et al., 2015), and Zarit Burden Interview (Tang et al., 2016). The Consulting Team is aware that some service organisations also employ the validated instruments as their screening tools for carer-related service admission. The tools per se are scientifically rigorous although the validation process is usually specific to certain types of care recipients. Moreover, a Multi-dimensional Risk Assessment Tool has been developed and validated by the University of Hong Kong and the Hong Kong Council of Social Services to assess the risk levels of carers of elderly persons (Lou, 2021). In the meantime, another 'Caregiver Support Model' is being developed and validated via randomized control trial by the City University of Hong Kong to assess the needs of carers. However, both are for carers of elderly persons and are for the use of social workers.

In view of the changes in services of the social setting, development of a decision-support tool to assess the risk of care burden, with built-in service mapping functions specific to the local society and carers, is more desirable as a proactive and efficient approach compared to adopting the traditional assessment methods. This recommendation calls for the development of an easily accessible assessment tool which offers opportunities for carers of both the elderly persons and persons with disabilities to self-evaluate their risk level and, as required, connects them with service providers to follow up on their needs. Higher service priority should be given to high-risk carers as identified by the assessment tool so that they can receive timely support, thus reducing the risk of tragedies befalling them or their care recipients.

Proposed initiatives, objectives and target groups

The recommendation proposes the development of a self-administered assessment tool that evaluates the needs and risk levels of carers of both persons with disabilities and elderly persons. The objectives of developing the assessment tool are to: 1) increase the self-awareness of carers; 2) identify high-risk carers and their needs; and 3) match needy carers with appropriate service providers.

Proposed content and operational considerations

(i) To develop a self-administered assessment tool to evaluate the needs and risk levels of carers

The assessment tool should be easily accessible to carers so that they are motivated to make use of it. An online assessment tool would be preferable, as this would allow carers to access it regardless of time or place. The tool should be easy to use because some carers may not be familiar with using computers. It is also important to design a simple and user-friendly interface so that a wide range of carers, including elderly persons, are able to benefit from it. Regarding the content of the assessment tool, it should cover all aspects of carers' needs, including physical, psychological, and other needs. Finally, the assessment tool should be tested and shown to have good reliability and validity before launching it to the public. An existing website for carers (656carer.com) provides information on stroke, dementia, and fall. However, it only targets carers of persons suffering these three illnesses/impairments. There is an icon showing 'self-assessment' but it can only be accessed by registered members. While this is a good start to encourage carers to conduct self-assessment, an accessible, simple and user-friendly self-assessment tool which covers all aspects of health of a carer should be developed. Regardless of whether the assessment tool is the digital or paper version, some carers may still have difficulty in self-administering the assessment by themselves, so there should also be an introduction video about the tool in Chinese and English, and potentially in other languages for ethnic minorities.

(ii) To enhance awareness and usage through promotion

Increasing self-awareness of good health among carers is crucial and may be regarded as the first step of illness prevention. Good health is not only limited to physical health but should also include mental health, social health, and spiritual health. Through mass media and social media, carers should be educated to increase their awareness of good health. With good health, carers can provide a better and sustainable care to the care recipients.

To optimise the usage of the self-assessment tool among carers, the assessment tool is proposed to connect with the carer-centric information gateway (Recommendation 2) and helplines which help identify high-risk carers (Recommendation 8). The self-administered nature will allow carers to heighten their awareness of burnout due to caregiving. Part of the assessment can be illustrated as short questions for display on promotional posters and leaflets distributed during the awareness building activities described in Recommendation 1 so that more carers, particularly those who remain hidden or unaware of their caregiving role, can actively identify their risk factors and scenarios that require professional attention.

(iii) To match carers with appropriate service providers

While the assessment tool could identify the needs and risk levels of carers, matching carers with appropriate service providers is also important. Linked with the information gateway, the assessment tool can enable carers to obtain information about and resources from appropriate service providers. With the consent of carers concerned, the assessment tool may pass information about carers' background and needs to service providers, which can approach carers for follow up. Carers should be able to choose their preferred service providers within their service district and opt to let the latter access the results of their assessments. While carers of all risk levels will have the option to send their contact information to service units of their choice at the end of the online assessment, the service matching function is especially important for carers who are identified as at high-risk so that individualised care plans could be devised to address their needs. Some carers may need further in-depth assessments conducted by service providers in person. The host of the digital assessment platform should exercise strict data protection measures (such as firewalls and data encryption) to prevent the data from any form of cyberattack. Furthermore, data access should be restricted to high-privilege administrative users.

It is suggested that the assessment tool should be developed by tertiary institutions to ensure the sensitivity, reliability, and validity of the tool. The development of the assessment tool should involve input from carers of elderly persons and persons with disabilities, as well as service providers. After the assessment tool has been validated, a link could be added to the SWD website to promote the use of the tool. Service providers could also promote the use of the assessment tool to potential service users. The tool should be promoted and accessible to all NGOs and carers.

10.1.2 Recommendation 8: Identify high-risk carers and provide timely support

Carers may encounter physical and mental distress arising from caregiving at any time. Unexpected difficulties and challenges related to caregiving may leave carers feeling helpless. It is crucial to provide timely support for high-risk carers. High-risk carers are characterised by suicidality, long and intensive care needs of care recipients, severity of health condition of care recipients, history of domestic violence, behavioural disturbance of care recipients, lack of recognition and support, and feeling affected by partial service disruption during the COVID-19 pandemic. Some of them may not be motivated to seek help by themselves. Neighbours/friends/relatives should be educated to help identify these high-risk carers and provide support (psychological and/or tangible support) to them.

Although there have already been several emergency hotlines available in Hong Kong, not many carers are aware of these and some may not consider that these hotlines are for their use. The Consulting Team notes that the scope of service of these hotlines may not be sufficiently promoted to carers in need.

Currently, some NGOs and the SWD are providing hotline services for people who have psychological distress and need instant support. While SWD’s hotline operates round the clock, some services operate only during working hours and most other hotlines are not specially designed for and accessed exclusively by carers. Carers are not aware of many hotlines and they therefore do not access such hotlines when they encounter emergency circumstances. It is noted that a new 24-hour hotline service for carers of elderly persons, adopting a case management approach, will shortly be launched by a social enterprise in two districts. Subject to the review of its effectiveness, it is worth exploring expanding this hotline to other districts for operation in the longer term, and serve carers of persons with disabilities. The potential long-term development of this hotline service is a step in the right direction and is in line with this recommendation.

Proposed initiatives, objectives and target groups

This recommendation on enhancing existing hotlines aims at effectively helping carers who are in urgent need of support, especially high-risk carers whose caregiving distress has surged suddenly or tremendously due to challenging caregiving situations or changes in some aspects of caregiving episodes.

Proposed content and operational considerations

(i) To enhance existing hotlines

It is suggested that the existing 24-hour SWD hotline or other hotline operated by NGOs/social enterprises should be enhanced by, for example, setting up special services for carers and strengthening their capacity to address the needs of the carers, especially the high-risk carers. The hotline aims to provide carers with a sense of security, in that they could access instant and professional support irrespective of geographical location, time, health, or financial status. It would also remove the technical barriers to accessing services since calling via the telephone is relatively straightforward.

Given that the target users of this service would be carers who are in urgent need of support, especially high-risk carers, it is suggested that the service content might cover: 1) instant and individualised needs assessment; 2) instant referral to crisis interventions to prevent self-harm and suicidal behaviours; 3) timely counselling services; and 4) service matching and referral. Emergency respite and emergency elder-sitter services could also be further strengthened. It is worth collaborating with existing call centres for persons in need (e.g., Senior Citizen Home Safety Association's care on-call service and the Carer Support Hotline operated by Caritas Jockey Club Resource and Support Centre for Carers).

In the longer term and when resources are available, the Government may explore the setting up of an emergency centre, similar to existing Caritas Family Crisis Support Centre or CEASE Crisis Centre operated by the Tung Wah Group of Hospitals, which combines hotline and other emergency support services to meet the emergency needs of high-risk carers in a timely and holistic way.

(ii) To form a team of professionals and high-quality volunteers for emergency support services

It is crucial that the service is supported by a team of professionals, especially social workers who are trained to be sensitive to carers' needs and who are experienced in handling carer cases. Trained social workers should have caregiving-related knowledge and be able to provide professional advice and support to stressed carers. Meanwhile, it is equally important to train a group of volunteers to operate the hotline. It would be beneficial to encourage volunteers who have caregiving experience (i.e., graduated carers) to serve as call receivers, since they often have some experience of dealing with particular situations. To ensure service quality, substantial training will be needed for these volunteers. A guiding system (including a monitoring system and pre-service and in-service training) will be essential to ensure the smooth operation of the hotline. All volunteers will need to go through a selection process and attend pre-service training, which will help them to develop the necessary listening skills and gain the knowledge and confidence to support callers. In-service training, including special case handling workshops, case sharing, and discussions, will also have to be provided regularly. On some occasions, call receivers (volunteers) may be exposed to complex cases that they are unable to handle. Under such situations, professionals (e.g., social workers) should serve as the key counsellors. It is also necessary to explore ways to motivate and retain these devoted volunteers such as providing a certificate.

(iii) To raise awareness and usage through promotion

This hotline service for carers should be promoted regularly through various methods to remind carers of its existence and of how to use it. Real-life scenarios can be used in promotional materials to raise carers' awareness of using the hotline to seek timely support.

10.2 Use of technology

10.2.1 Recommendation 9: Better introduce, access, and utilise assistive technologies to relieve the care burden, enhance caring capability and improve carers' quality of life

Although the majority of the carers regarded assistive technology as a useful tool to reduce stress, only 37% of the carers had the experience of using assistive technology. Many carers encountered difficulty when they used the technological products and did not seek help or make enquiries immediately. Some carers, particular those in advanced age, were not aware of the availability of these technological products. They had reservation to use these products due to the lack of knowledge and training. Many of them were concerned about the rental cost of these products, as these could potentially be a heavy financial burden.

By better introducing and utilising assistive technologies, this recommendation aims to enable more carers of elderly persons and persons with disabilities to acquire the capacity and opportunity to use assistive technologies for caregiving and, ultimately, to bridge the assistive technology gap between carers and the rest of the community. Given the rapid development of technology, carers should be empowered to search for technological assistance and be supported in using it. It is expected that the demand for assistive technologies will escalate over the coming years, and the cost of individual technological devices is likely to reduce in tandem with the development of the mass production of products.

Proposed initiatives, objectives and target groups

Assistive technology will be an important element in the overall drive to strengthen the caregiving capacity of carers. Our analysis in the previous sections has shown the need to better introduce and utilise assistive technologies to relieve the care burden and improve carers' quality of life. Therefore, the Consulting Team recommends the following short-term and long-term objectives on assistive technology to relieve the burden and improve the quality of life of all carers of elderly persons and persons with disabilities.

1. Short-term objective: To enhance the accessibility and use of assistive technologies among carers of elderly persons and persons with disabilities, thus improving their caregiving competencies.
2. Long-term objective: To bridge the service gap between carers and the assistive technologies that are available in the community.

Proposed content and operational considerations

(i) To introduce assistive technologies and strengthen referrals through online and offline platforms

There are several existing online platforms featuring assistive technologies (e.g., the Gerontechnology Platform[20], the Jockey Club Smart Ageing Hub, the Social Enterprise Intelligent Hub under the LU Jockey Club Gerontechnology and Smart Ageing Project). Their accessibility and referrals should be strengthened; for example, the Gerontechnology Platform may expand its scope to serve younger persons with disabilities and their carers, and change the name of the platform accordingly to cover persons with disabilities as well. The usability of these platforms should be enhanced through the development of mobile Apps. More functions, such as providing solutions for carers in regard to technical issues arising from the use of assistive technology products should be embedded. Moreover, a business model is recommended to ensure regular updates and the sustainable development of assistive technology products. Information and referrals in regard to using assistive technologies for caregiving should also be strengthened through the support and promotion of such technologies (e.g., pop-ups and regular exhibitions of assistive technologies) in district-based elderly and rehabilitation community centres (e.g., DECCs, NECs, DSCs, and PRCs).

(ii) To provide better access to renting assistive technologies for individuals

To encourage more service units to provide assistive technology products to help carers with their caregiving tasks, consideration could be given to expanding the service scope

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[20] In 2020, the Social Innovation and Entrepreneurship Development Fund has appointed a collaborative coalition of ten organisations led by the Hong Kong Council of Social Service as an intermediary to design, develop and operate an inclusive one-stop Gerontechnology Platform. The Platform is to link up different stakeholders on the supply and demand sides and enhance synergy by way of engagement, cross-sector partnership and collaboration.

of the CCSV to the rental of assistive technologies products. Ideally, such rental services should be available in different districts and providing different types of products to meet the needs of different carers. Upon evaluation, consideration should also be given to extending the Jockey Club ‘age at home’ Gerontech Education and Rental Service to persons with disabilities, taking reference from the relevant recommendations of the RPP.

(iii) To promote the confidence and motivation of carers and care recipients in the use of assistive technologies

It is also recommended that training should be provided to carers so that they can interpret online information correctly and make informed decisions about which products are suitable to their caregiving tasks. Training workshops on digital health literacy could be organised by community-based service centres so that carers are better equipped to distinguish which online information is appropriate and could be used in caregiving.

10.3 Respite services

10.3.1 Recommendation 10: Increase accessibility and diversity of respite services to provide relief to carers with ad-hoc needs

Although the non-means tested respite services were considered as the second most useful service to carers, the usage of respite servicers is not high. The utilisation rate of designated day respite service for the elderly in 2019/20 was 45.78%. The relatively low usage may reflect issues on awareness and accessibility of respite services. Some eligibility criteria might have complicated the application procedures. On the other hand, respite services should not be fully utilized, otherwise there is no capacity for emergency use.

This recommendation addresses the carers’ concern on the accessibility of existing respite services through public education about the usefulness and availability of respite services. Variation in respite services to address individual needs and enhancing accessibility of services are highly recommended. Carers with different caregiving situations should be able to find the most suitable types of respite services to fit their needs.

Proposed initiatives, objectives and target groups

This recommendation aims to enhance carers' knowledge of and readiness to utilise respite services. It also aims to motivate and monitor respite service providers to provide a prompt response to carers in urgent need of respite services.

Proposed content and operational considerations

(i) To provide information and education to carers about respite services

Utilisation rate of existing respite services are found to be relatively low. This may be related to carers being unaware of their own needs and their knowledge deficit about respite services. Sufficient information on the availability and application procedures of respite services in their neighbourhood and education on the use of respite service (e.g., there is no conflict with filial piety (and no guilt) when carers ask for help), should be promoted among carers. It is noteworthy that SWD's existing vacancy enquiry platform for respite services (https://www.vesrrsep.swd.gov.hk/en/content/preface) already enables users to look for available designated places of residential respite services and emergency placement by district.

(ii) To motivate and monitor respite service providers

Service providers are important stakeholders that need to be motivated and monitored in order to encourage the use of respite services. For example, it is suggested to require the service providers to keep records of both successful and unsuccessful service application for monitoring. Administrative procedures should be reviewed to see if there is room for streamlining so that carers can use respite services in a timely manner. That said, some eligibility criteria, such as 'the elderly person has to be physically and mentally fit for communal living to receive respite service in residential care homes', are necessary to ensure the health and well-being of existing residents in residential care homes. Training should also be provided to staff so that they could deal with behavioural problems of persons with disabilities or persons with dementia.

To facilitate timely admission of care recipients to respite services, the Government may promote and facilitate social workers and other human service professionals to actively connect care recipients to designated service providers in their districts through the use of information technology. Moreover, a pre-registration mechanism might be set up to expedite the use of respite service by elderly persons or persons with disabilities (such as applicants on Central Waiting List for Subsidized Long Term Care Services and Central Referral System for Rehabilitation Services might be considered as being qualified for respite services). For example, The Agency for Integrated Care in Singapore allows carers to apply for pre-enrolment respite care. Whenever there are unexpected respite care needs, the time required to access the service is minimised. Since 2019, SWD has rolled out a measure that elderly persons and their families can contact the private residential care homes for the elderly under EBPS for urgent use of respite care during non-office hours. Similarly, persons with disabilities and their families/carers can contact directly the private homes participated in "Designated Residential Respite Service for Persons with Disabilities" under Bought Place Scheme for use of respite care during non-office hours. This measure might be explored to expand to subvented residential care homes for the elderly persons and to residential care homes for persons with disabilities.

(iii) To increase diversity of respite services

Despite the fact that SWD has been providing home-based respite, centre-based respite, and residential respite through subsidising various service operators, facilitating the use of respite services of greater diversity may help carers to change their attitudes toward help-seeking. Several types of respite services such as emergency respite, regular respite and night respite as well as better connecting carers with service providers should be considered.

(iv) To coordinate and integrate existing services & resources to increase service capacity

To increase the capacity of respite services, the Government could consider integrating the existing services (such as casual vacancy of various day and residential service units) and resources (such as bought place in private residential care homes) to increase the overall capacity to provide respite services in Hong Kong. Coordination is needed to facilitate the provision of respite places by existing service providers to the care recipients.

(v) To facilitate provision of respite services by private sector, social enterprises and charities

The role of the self-financed sector or private sector in home-based respite should not be overlooked, as they are, in general, more flexible in arranging workforces. CCSV might be a possible channel to connect these self-financed / private service providers with carers in need.

10.4 Financial assistance

10.4.1 Recommendation 11: Provide good mix of services, voucher and cash to support carers

The Consulting Team is of the view that all-round support should be made available to carers because caregiving tasks are always physically, mentally and financially demanding. The combination of services to care recipients, services to support carers, vouchers and cash assistance to low-income carers should be viewed in a holistic manner when considering support to carers of different needs. A good mix of services, voucher and cash allowance provides a direction for providing sustainable support to both carers and care recipients.

Services: Existing services to the elderly and persons with disabilities have been evidenced as one of the ways to reduce carer burden and long-hour direct care. The existing services should be made available to carers where appropriate. With the existing service centres in the community (including DECCs, NECs and DSCs), services to support carers could easily be initiated and implemented. While financial assistance is considered by carers to be a kind of ‘important support’, services are regarded as equally important by stakeholders.

Voucher in the form of CCSV: Although CCSV only targets elderly persons and is at a pilot stage, its potential for expansion is well supported by both carers and stakeholders. CCSV, as a voucher system with the co-payment arrangement based on the “users pay in accordance with affordability” principle, offers an alternative choice for carers to accommodate the care recipients in non-traditional subsidised services. Carers have similar level of satisfaction to the CCSV home care/centre services, when compared to the satisfaction level to traditional subsidised home care/centre services. It is therefore worthy to explore the possible flexible use of CCSV to provide support to carers (for example, to provide voucher for in-home respite, allow carers to receive psycho-emotional interventions, and cover carers’ transportation and meals when companying care recipients to medical appointments). There may be a need to streamline the CCSV administration so as to save cost and expedite the service provision. In the long run, it is suggested to increase the quota of CCSV for both elderly persons and persons with disabilities when resources are available.

Cash allowance: Cash allowance to carers does not seem to be the only solution to resolve the issue of care burden while it is recognised as an important part to support both carers and care recipients who are frail elderly persons and persons with disabilities. Consideration should be made on its long-term sustainability and practicality in implementation as Hong Kong adopts a low-tax system. Cash allowance is one form of financial assistance while CCSV encashment is another. While it is understandable that some carers face a financial burden and need some level of financial assistance, CCSV encashment may be a better choice compared to cash allowance with respect to sustainability and practicality. CCSV encashment may encourage collaboration among social enterprises, private companies, charities, and non-government organisations based on their own expertise and resources to provide necessary services for CCSV users.

Proposed initiatives, objectives and target groups

a) Objectives of the recommendation

The objectives of providing financial assistance to carers include:

- Objective 1: To reduce financial burden of carers with low income.
- Objective 2: To support the care needs of frail elderly persons and persons with disabilities living in the community.

b) Target groups

Financial assistance for carers of elderly persons and persons with disabilities should target those who are waiting for long-term care services.

- *Carers of elderly persons:* Carers providing care to elderly persons with impairments, who are eligible for subsidised long-term care services (community care or residential care services as assessed by SCNAMO-ES) and who are residing in their own homes in Hong Kong.
- *Carers of persons with disabilities:* Carers providing care to persons with disabilities, who are on waiting lists for specified rehabilitation/residential services subsidised by the SWD, for special schools with boarding placements under the Education Bureau, or for infirmary services provided by the Hospital Authority, residing in their own homes in Hong Kong.

Proposed content and operational considerations

(i) For carers of elderly persons

The Consulting Team has studied two options in providing financial assistance to carers of elderly persons: CCSV encashment and cash allowance. Findings on these two options are set out in the following paragraphs. The Consulting Team is of the view that the Government should only choose to implement one form of financial assistance to avoid confusing the frail elderly persons and their carers and inducing the possible duplication of resources. Comparing the two options, CCSV encashment is considered as having higher potential, which provides more flexibility to carers in the long run and makes care support more efficient in a person-centred manner.

Option 1: CCSV encashment - as certain home-based care services can be provided by informal carers, this option allows CCSV users to "encash" part of the value of certain designated services and use the encashed amount to make their own arrangements.

We developed the following suggestions for considerations and actions:

(a) CCSV encashment is not intended to replace professional supportive services (such as physiotherapy, wound dressing, cognitive training, day care service, etc.) provided by recognised service providers. Hence, encashment should be limited to designated services which can be provided by carers (i.e., home making, meal service, and escort service), and those which support the caregiving tasks (See more details in part (b) below). Once the user chooses to "encash" these designated services, they will not be eligible to receive them from the subsidised sector to avoid duplicating the benefits.

(b) CCSV encashment should allow flexibility for carers to determine how the cash should be spent in a reasonably manner on the condition that the "encashed" amount is for carrying out the caregiving tasks (e.g. hiring a part-time domestic helper, arranging centre-based respite, in-home respite, etc.) or supporting expenses of the carers (e.g. allow carers to receive psycho-emotional interventions and cover carers' cost of transportation and meals incurred when accompanying care recipients to medical appointments).

(c) Principle of "co-payment" should be maintained in the CCSV encashment. It is suggested that consideration should be given to simplify the CCSV administrative system to reduce cost and speed up the vetting process of the applications as well as the service provision.

(d) Evaluation of pilot scheme on CCSV encashment should be made after its implementation for a considerable period of time, say three to five years, when meaningful empirical data and users' feedbacks could be collected. The scope of evaluation might cover cost effectiveness and operational arrangement of the scheme

(e) The number of CCSV should be increased when resources are available.

Pros of CCSV encashment

The Consulting Team is of the view that this option has the following advantages:

(a) CCSV encashment gives flexibility to carers to determine who provides the needed service to frail elderly persons. Carers may opt to use the encashed amount to engage other persons (e.g. part-time domestic helper) to carry out these tasks which may be more efficient and cost effective.

(b) CCSV encashment may be a more sustainable way of providing financial assistance to carers, as resources are redistributed to carers who may arrange caregiving tasks in a way that is efficient and timely to meet the needs of the frail elderly persons.

(c) In addition, since the principle of co-payment is to be maintained in the CCSV encashment scheme if implemented, this would help promote the wider acceptance and application of the principle in the long run.

(d) CCSV encashment enables the private sector, social enterprises and even individuals to provide services for elderly persons. This cultivates an environment in which there are different helping hands in society to support carers and care recipients.

(e) CCSV encashment potentially provides opportunities for carers to develop tailor-made care plan for care recipients according to the latter's preferences. This would support care recipients and reduce care burden.

(f) CCSV encashment allows carers to purchase services outside the services provided by Recognised Service Providers (such as renting assistive technology/devices) and this could serve as pilot testing for new service items of care support to both carers and care recipients.

(g) CCSV encashment may help development of new services to both carers and care recipients. CCSV encashment may attract private sectors and social enterprises to become CCSV recognised service providers. Their business model may bring about greater flexibility and creative deployment of resources, both human and others.

Cons of CCSV encashment

The Consulting Team is of the view that this option has the following drawbacks:

(a) Encashment may generate demand on CCSV. Frail elderly persons who previously did not opt for CCSV or even did not take SCNAMO-ES for subsidised long-term care services may be attracted to the CCSV scheme mainly because of encashment. If the generated demand cannot be met by supply (for example, in case no additional vouchers are issued), it may create a waiting queue for the voucher which will defeat the current key advantage of CCSV as a quick solution to meet the need for community care services. Greater demand on CCSV would also lead to higher public expenditure.

(b) It will have unfair and different treatments for those elderly persons using or choosing subvented community care services since no encashment provision will be provided for them though their frailty and care need are the same as those CCSV users. Currently, there are around 18,000 users of traditional DEs/DCUs, EHCCS and IHCS (Frail Case) services.

The Government may need to consider soliciting buy-in of stakeholders, especially carers and human service professionals. As CCSV itself is still at the pilot stage, not many carers (especially those non-CCSV users) and human service professionals are fully aware of the features of CCSV and they may have difficulty understanding the potential benefits of CCSV encashment. While CCSV encashment may be an option to provide financial assistance to carers in a sustainable manner, publicity and promotion is required in getting more carers and human service professionals to understand the rationale and benefits of this option.

CCSV encashment is a new and complex model. Its advantages and disadvantages, eligibility criteria, operational details, monitoring and importantly, resource implications, should therefore be examined in details. A service model should be tested as a pilot scheme and such implementation is subject to availability of resources.

Option 2: Cash Allowance – this option provides direct cash assistance to carers. One example of its implementation is the Pilot Scheme on Living Allowance for Carers of Elderly Persons from Low-income Families.

We developed the following suggestions for consideration:

(a) Cash allowance to carers is not a compensation for job loss (e.g., quitting a job for caregiving or changing from full-time employment to part-time employment) due to caregiving.

(b) Each care recipient may choose to allow only ONE carer to receive cash allowance on the care recipient's behalf. Family members of care recipients should agree among themselves about who should apply (which follows the principle of claiming tax reduction for supporting dependent parents/grandparents).

(c) Cash allowance should only be eligible to carers of frail elderly persons who are waiting for but not yet receiving any subsidised long-term care services (including traditional community care service or CCSV).

(d) When the frail elderly persons start to receive subsidized long-term care services, carer would NOT be eligible for this cash allowance, to avoid double benefits and being unfair to others on the waiting list.

(e) Recipients of cash allowance should be subject to means test and the allowance should not duplicate with other means-tested social security schemes.

Pros of Cash Allowance

The Consulting Team is of the view that this option has the following advantages:

(a) The Pilot Scheme on Living Allowance for Carers of Elderly Persons from Low-income Families has been implemented since 2014. Both carers and stakeholders are familiar with the concept of carer allowance and only minor adjustments may be required to improve its implementation.

(b) Carer allowance is not tied with a particular mode of service delivery and hence it is equitable to the targeted carers.

Cons of Cash Allowance

The Consulting Team is of the view that this option has the following drawbacks:

(a) Cash hand-out may not be a sustainable measure of support in the long run. While carers naturally hope for a higher amount and more relaxed eligibility (e.g., more relaxed means test, concurrent benefits with other social security payments, etc.), the Government only has limited resources especially with the rapidly ageing population.

(b) Cash allowance may create conflicts within the family as only ONE carer may receive it.

(c) To avoid possible abuse of the given cash, monitoring system should be in place. This requires considerable administrative cost.

(ii) For carers of persons with disabilities

Similar to carers of elderly persons, optimising support for carers of persons with disabilities also requires a good mix of service provision and financial assistance. This is in line with the view of the majority (75.2%) of carers in our survey who expressed that “partial service support and partial financial assistance” was a very effective/effective means in supporting them. In terms of service provision, it should be carer-centric. The existing services for carers of persons with disabilities can be consolidated and strengthened, which has been highlighted in the previous chapters.

Existing CCSV scheme for the elderly could serve as an example to explore the feasibility of introducing a similar measure for persons with disabilities. However, the consultancy team is aware that the principle of “co-payment” used in CCSV for elderly services is not generally accepted by persons with disabilities and their carers. Compared to the services for the elderly, the existing relatively limited pool of private service providers for persons with disabilities could not readily cater for the diverse needs of persons with different types and levels of disabilities and at different stages of life. Therefore, the feasibility and acceptability of CCSV for persons with disabilities and their carers requires further exploration and examination, preferably by the working group proposed to be established above, drawing reference from experiences gained from the elderly field and having due regard to stakeholders’ views as well as services available in the market in a holistic manner.

There are three pilot schemes that provide financial assistance to persons with disabilities or their carers (Allowance for Low-income Carers, Special Care Subsidy, Subsidy to Hire Carers). These three cash allowances are all means-tested, with different eligibility criteria. The carers of persons with disabilities and human services professionals surveyed all held a very positive view on these schemes. The majority of carers of persons with disabilities (78.6%) welcomed the concept of unifying the various subsidy schemes. Integrating various subsidy schemes for persons with disabilities and their carers may enable them to use the cash subsidy to meet their needs in a flexible manner. Moreover, the application procedures can be simplified for the applicants, and the related administrative work for the staff handling the applications can be streamlined as well. As the purposes, eligibility criteria and number of beneficiaries differ among the three pilot schemes, the working group proposed to be established above should further review the details holistically and examine the way forward.

If cash allowance is to continue to be provided, the Consulting Team suggests that the amount be determined with reference to both the household income as well as severity of disability of the care recipients.

Concluding remarks

A mix of services (including professional services for care recipients and the carer-centric support recommended in Chapters 8, 9, and the rest of this Chapter 10), voucher and financial assistance have good potential to provide sustainable support to both carers and care recipients. Financial assistance for carers does not seem to be the only solution to the issue of care burden, but it is an important component of support for both carers and care recipients. Consideration should be given to the mix of services, vouchers and cash allowance to carers and/or care recipients, the potential of CCSV encashment, as well as the long-term sustainability and the practicality of implementation.

To examine the feasibility of CCSV encashment as a long-term option to support frail elderly persons and their carers, a service model should be tested subject to availability of resources. Drawing reference from experiences in the elderly field, the Government should also examine the feasibility and acceptability of a similar scheme for persons with disabilities and their carers, taking into consideration the views of relevant stakeholders and the way forward for the three existing pilot schemes, which provide financial assistance to persons with disabilities and their carers.

Chapter 11. The Way Forward and Implementation Plan

11.1 Prerequisites for consideration

This consultancy study aims to formulate evidence-driven recommendations for the support of informal unpaid carers of elderly persons and persons with disabilities in Hong Kong. The subsequent phase of translating the recommendations into action is essential to the delivery of the desirable outcomes. Therefore, considerations should be given to the below suggestions or prerequisites that are pivotal to the carrying out of all proposed recommendations.

1 **Funding and resources:** First of all, additional Government funds should not be regarded as the only funding source. Other non-governmental funds and existing resources should be mobilised and appropriately deployed, which include but are not limited to the followings:

1.1 To integrate and re-engineer existing services (e.g., community centres, respite care operators) to achieve better coordinated and cost-effective mode of service delivery, free up more space/resources for carer-centred support to carers. Various community service units (e.g., day care centres, home service units) are suggested to extend their services or support to the carers.

Most community centres are closed and the spaces are not fully utilised at the weekends. Thought should be given to make good use of this space to organise carer support programmes for carers (particularly for working carers).

1.2 To explore non-government funding sources (e.g., charity trusts, private initiatives under corporate social responsibilities, making good use of ‘Environmental, Social, and Governance (ESG) criteria’, etc.) to help finance and implement the various recommendations; and to encourage private and social enterprises to adopt a sustainable/business approach to carry out some of the recommendations, such as Recommendation 2 which encourages NGOs / social enterprises / corporates to develop a carer-centric information gateway to address carers’ needs; as well as Recommendation 5 which is to cultivate a carer-friendly neighbourhood. Other recommendations which can be addressed by non-government resources can be found in **Annex.**

1.3 To explore government funds: including resources from SWD/LWB and other bureaux/departments, public funds, for example, Social Innovation and Entrepreneurship Development Fund (SIE Fund), Mental Health Initiatives

Funding Scheme, Community Investment and Inclusion Fund and other funds under the Innovation and Technology Bureau (ITB); and

1.4 To optimise the current CCSV by adopting more flexible use of voucher to support carers, for example, the cost of psycho-emotional interventions for carers should be covered. Other long-term and sustainable options, for example, launching a pilot scheme on CCSV encashment, should also be considered.

2 **Service package to serve the need of care recipients as well as their carers:** One way to ensure that all three gears of the Triple S Model work seamlessly together is to provide a better fit between services for care recipients and support for their carers. At present, there is a wide range of community services targeting only frail elderly persons or persons with disabilities. In view of the important role of carers in helping to implement the intervention plan for care recipients and in promoting the latter's well-being, there is room to explore the inclusion of carers right from the start of intervention so appropriate support are given to them for performing the caregiving tasks. Additional support options, for example, expanding the coverage of CCSV to services supporting carers should be explored to provide carer-centric services as mentioned under the Recommendations.

This notion does not mean to reallocate resources from care recipients to carers. As shown in this study and overseas experiences, services for care recipients should have carers' perspective, taking into consideration the role of carer in facilitating the service provision, as some support to carers is also essential for smooth implementation of the service delivery to care recipients.

3 **Addressing holistic needs of carers:** At present, professionals and even carers themselves mainly focus on the well-being of the care recipients and tend to neglect the personal needs of carers per se. The objective of carer support is not only to enhance the carers' caregiving role, but to identify and address the holistic needs and well-being of the carers.

4 **Engage more service providers:** private sector and social enterprises should be engaged in the field of rehabilitation and eldercare for service provision.

5 **Sustainable manpower provision:** diverse options for the supply of manpower in the services to support carers should be explored (e.g., mobilising peer helpers/volunteers, building up support network through carer café, etc.).

6 **Multipartite, cross-sectoral collaboration:** the integration and re-engineering of existing services may involve various stakeholders from multiple societal sectors. The Government should work closely with these stakeholders, especially among

the healthcare, social welfare, business, education and housing sectors to strengthen service coordination and utilisation of resources.

7 **Knowledge dissemination and exchange:** NGOs are encouraged to organise knowledge transfer sessions to share good practices of experimental / innovative projects under public or non-public funds so as to benefit the whole welfare field.

8 **Continuous data collection:** regular surveys, or research studies should be conducted in collaboration with local universities to construct a database on the needs and expectations of carers of different characteristics (*See also Section 11.2*).

9 **Evidence-informed decision making:** this study constitutes a starting point of a systematic review of carers' needs and service expectation in Hong Kong. Further study may be invested as a foundation to continue the momentum of decision making well informed by empirical evidence.

11.2 Knowledge gaps

While this study provides the basis for the recommendations, including the integration and prioritisation of services for carers, a number of knowledge gaps are identified.

(1) *Under-study of non-service users and hidden carers*: In the qualitative research in Studies 3-8 (focus groups and interviews), invitations were sent to participants mainly through non-governmental organisations and service providers. It is possible that some carers of elderly persons or persons with disabilities living in the community, particularly non-service users and hidden carers, were not reached.

(2) *Lack of longitudinal data:* The surveys conducted in Studies 3 – 8 were cross-sectional in nature, so could only capture the viewpoints of study participants in a snapshot. There is a lack of longitudinal data on the expressed needs of carers for long-term projections in terms of service demand and associated workforces.

(3) *Lack of data on informal caregiving:* Our study revealed a lack of census data in relation to informal caregiving. For example, from our literature review, we found that the number of elderly persons taken care of by informal carers had only been recorded once in Hong Kong's historical census data. This prevented us from making projections about the number of informal caregivers in Hong Kong. There is also a lack of existing data related to informal caregiving costs. This includes tangible costs (e.g., financial caregiving costs) as well as intangible costs (e.g., emotional and mental costs). This

data inadequacy prevented us from estimating the service demand and cost of caregiving support services.

(4) *Inadequate data for workforce and budget projections:* Our study was unable to estimate the workforce and budget required for each caregiving support service (e.g., home-based services, including meal delivery, home-based respite services, and centre-based support, including respite services and rehabilitation training) and its economic impact, due to data inadequacy.

In summary, continued research is important to facilitate the further development of carer support services, and explore the effective and innovative approaches to service delivery. It is important to obtain updated empirical data to inform policy-making, service planning and service design, so that services that better meet the needs of diverse carers can be formulated while limited resources can be utilised more effectively. In this regard, C&SD's 2019/20 Survey on Persons with Disabilities and Chronic Diseases, published in December 2021, collected information on carers of persons with disabilities. It would be important for similar studies in future to develop evidence-based support to carers.

On the other hand, researchers, academics and research centres are encouraged to apply research funds (such as various research grants under University Grants Committee (UGC), Public Policy Research Funding Scheme (PPR), Strategic Public Policy Research Funding Scheme (SPPR), etc.) to conduct studies to identify carers' needs and further the development of carer services. In connection with this, it is recommended to update the themes and indicative research areas of various research grants to include carer studies.

A related issue is to ensure that data from government bureaux/departments and from publicly-funded research studies should become open for public use as well. At present the Government has an Open Data Policy in place, requiring all government departments to publish annually their open data plans for the coming year. Such an open data pool could facilitate secondary analysis of data to inform policy and service planning instead of having to conduct data collection every time when data are required.

Annex

Recommendations with potential to be funded by charity trusts and non-government funding sources as well as recommendations which carry potential for sustainable/business model

1. Charity Trusts and Non-government Funding Sources may Consider Contributing to the Implementation of the Following Recommendations

Recommendation 1: Raise awareness of carers about the importance, availability, and access of information and increase the readiness of carers and intermediate parties to seek help from available services;

a. Disseminate information
b. Launch the "Carer Awareness Week"
c. Enhance awareness of available community support services

Recommendation 2: Examine existing websites and encourage NGOs / social enterprises / corporates to develop a carer-centric and sustainable information gateway to address carers' needs;

Recommendation 3: Provide carer-centric training and intervention to promote carers' wellbeing, self-management, ability to cope with stress, as well as to strengthen their caregiving capacity;

a. Design a new short psychoeducational intervention programme specifically for carers
b. Provide carer training on stress management and caregiving techniques through existing community-based service centres, or existing training resources.

Recommendation 4: Promote family-based support and mutual assistance among peer carers across their lifespan and at different stages of their caregiving journey;

a. Provide promotional/educational activities and family education
b. Enhance carer café programmes
c. Promote the development of community-based peer support programmes

Recommendation 5: Cultivate a carer-friendly neighbourhood;

a. Encourage the business sector to be carer-friendly
b. Promote the concept of a carer-friendly neighbourhood
c. Integrate and enhance the types and availability of community care services

Recommendation 6: Devise and promote a carer-friendly support environment in the workplace so as to help carers strike a balance between their work and their caregiving role;

a. Retain talented employees who might otherwise quit their jobs due to their heavy care burden
b. Encourage carer-friendly work arrangements
c. Strengthen peer support of young adult carers and provide a channel for them to voice their concerns

Recommendation 7: Develop a local self-administered assessment tool with the aim of increasing the knowledge of carers in terms of needs, risks identification and management, and potential support available;

a. Develop a self-administered assessment tool to evaluate the needs and risk levels of carers
b. Promote service awareness and usage of the tool
c. Match carers with appropriate service providers

Recommendation 8: Identify high-risk carers and provide timely support;

a. Enhance existing hotlines to support carers, especially high risk carers.
b. Form a team of professionals and high-quality volunteers for emergency support services
c. Raise awareness and usage of hotline through promotion

Recommendation 9: Better introduce, access and utilise assistive technologies to relieve care burden, enhance caring capability and improve carers' quality of life;

a. Introduce assistive technologies and strengthen referrals through online and offline platforms
b. Provide better access to renting assistive technologies for individuals

c. Promote the confidence and motivation of carers and care recipients in the use of assistive technologies

Recommendation 10: Increase accessibility and diversity of respite service to provide relief to carers with ad-hoc needs.

a. Provide information and education to carers about respite services
b. Motivate and monitor respite service providers
c. Increase diversity of respite services
d. Facilitate provision of respite services by private sector, social enterprises and charities

2. <u>Recommendations with Potential to be Implemented Through a Sustainable/Business Model</u>

Recommendation 2: Examine existing websites and encourage NGOs / social enterprises / corporates to develop a carer-centric and sustainable information gateway to address carers' needs;

Recommendation 3: Provide carer-centric training and intervention to promote carers' wellbeing, self-management, ability to cope with stress, as well as to strengthen their caregiving capacity;

c. Provide carer training on stress management and caregiving techniques through existing community-based service centres, or existing training resources.

Recommendation 5: Cultivate a carer-friendly neighbourhood;

a. Encourage the business sector to be carer-friendly
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a. Retain talented employees who might otherwise quit their jobs due to their heavy care burden
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  a. Provide information and education to carers about respite services
  b. Increase diversity of respite services
  c. Facilitate provision of respite services by private sector, social enterprises and charities

Glossary

ABS	Australian Bureau of Statistics
ADL	Activities of Daily Living
AKA	Aberdeen Kaifong Welfare Association
BOKSS	Baptist Oi Kwan Social Service
C&SD	Census and Statistics Department
CCF	Community Care Fund
CCSV	Community Care Service Voucher for the Elderly
CHSP	Commonwealth Home Support Programme
DE/DCU	Day Care Centre/Unit for the Elderly
DECC	District Elderly Community Centre
DSC	District Support Centre for Persons with Disabilities
EHCCS	Enhanced Home and Community Care Services
ESPP	Elderly Services Programme Plan
GRF	General Research Fund
HCS	Home Care Service for Persons with Severe Disabilities
HDA	Higher Disability Allowance
HKCSS	Hong Kong Council of Social Service
HKFWC	Hong Kong Federation of Women's Centres
HKSKH	Hong Kong Sheng Kung Hui
IADL	Instrumental Activities of Daily Living
ICCMW	Integrated Community Centre for Mental Wellness
IHCS	Integrated Home Care Services
ISS	Integrated Support Service for Persons with Severe Physical Disabilities
LWB	Labour and Welfare Bureau
NDIS	National Disability Insurance Scheme
NEC	Neighbourhood Elderly Centre
NGO	Non-government Organisation
PPR	Public Policy Research
PRC	Parents/Relatives Resource Centre
RCHD	Residential Care Homes for Persons with Disabilities
RCHE	Residential Care Homes for the Elderly
RCS	Residential Care Services
RPP	Persons with Disabilities and Rehabilitation Programme Plan
S&RC	Social and Recreational Centre for the Disabled
SJS	St. James' Settlement
SMD	Standardised mean difference
SPA	Support Centre for Persons with Autism
SWD	Social Welfare Department

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