Gratia Christian College
宏恩基督教學院

To explore the caregivers' perspectives on future planning for their adult children with intellectual disabilities in Hong Kong

An Undergraduate Honours Project

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By

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Abstract:

This research project aims to investigate the perspectives of caregivers regarding future planning for their adult children with intellectual disabilities in Hong Kong. The study seeks to describe the process and perspectives of caregivers' future planning, explore the aspirations and barriers they encounter in their planning efforts, and identify the types of support caregivers require for active engagement in the decision-making process related to future planning.

The research questions guiding this study are as follows: How do caregivers of adult children with intellectual disabilities perceive and approach future planning? To what extent have caregivers' expectations for support, both formal and informal, been met in fulfilling the needs of their adult children with intellectual disabilities? What are the aspirations of caregivers for the future of their adult children with intellectual disabilities, and what barriers do they encounter in making future plans?

The proposed methodology for this study involves qualitative research through in-depth interviews with caregivers. This approach allows for a comprehensive exploration of their challenges, experiences, and opinions on the study. The study's main finding is that caregivers strongly hold the belief that residential care is the primary and often the sole option for their adult children with intellectual disabilities when planning for their future. They perceive their children as incapable of living independently in the community without parental care and view residential care as the only feasible choice. The availability of formal and informal care influences the decision-making process, with those receiving support from family and domestic helpers preferring to keep their children at home. However, challenges such as a lack of guidance from social workers and limited government support impede the implementation of long-term plans.

A comprehensive understanding of caregivers' perspectives and needs is of utmost importance in developing effective support systems and policies for individuals with intellectual disabilities and their families. The findings of this study have significant implications for the design of support systems that address the unique needs of caregivers and their adult children with intellectual disabilities in Hong Kong. It highlights the critical need for increased support and resources for caregivers of individuals with severe intellectual disabilities. Person-centered care within residential services and fostering collaboration between caregivers and staff are

indispensable. Policy changes and appropriate allocation of resources are imperative to enhance the quality of care provided. Social workers play a crucial role in transition planning, and there is a need to enhance the knowledge and skills of professionals in the social work field. Moreover, ensuring continuity in schooling and residential services is vital for the well-being of individuals with intellectual disabilities and their caregivers. By addressing these implications, individuals with intellectual disabilities and their caregivers can receive comprehensive support, leading to an improvement in their overall well-being. Furthermore, further research is recommended to explore community care options that are specifically tailored to individuals with mild intellectual disabilities.

In conclusion, this study contributes valuable insights into the experiences and challenges faced by caregivers in future planning for their adult children with intellectual disabilities in Hong Kong.

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LIST OF ABBREVIATIONS

Abbreviation	**Full Form**
ID	Intellectual disabilities

CONTENTS

Chapter ONE: INTRODUCTION AND BACKGROUND

In recent years, future planning for individuals with intellectual disabilities (ID) has gained significant attention worldwide. Studies by Casale et al. (2021) and Burke et al. (2018) highlight the increasing longevity of individuals with intellectual disabilities, which means they are outliving their parents. This situation raises concerns for parents, especially as they face their own health problems and aging. It becomes crucial to establish emergency plans for adult children with intellectual disabilities, including living arrangements and identifying successive caregivers.

In the context of Hong Kong, statistics from special topic reports estimate that the total number of individuals with intellectual disabilities is around 77,000 to 90,000, indicating a prevalence rate of 1.0% to 1.2%. Mimi et al. (2018) notes the positive developments in medical interventions that have led to increased longevity for individuals with intellectual disabilities in Hong Kong. However, Pang (2015) stated that they are prone to various long-term diseases and physical dysfunctions earlier than the general population, with an average life expectancy of 50 to 60 years. Consequently, caregivers of adult children with intellectual disabilities face increasing challenges and stress.

Furthermore, older parents of adult children with intellectual disabilities face the dual challenges of aging and illness, as noted by Weeks et al. (2009), with a growing number of older parents providing care at home for their adult children with intellectual disabilities, there is a pressing need to support these families in their caregiving responsibilities. Chou et al. (2009) suggested that future care plans become especially important for elderly parents, who must consider their own aging while arranging for their adult child's future care. Similarly, Lee et al. (2021) mentioned the importance of addressing future planning when adult children with intellectual disabilities continue to live with their parents without any plans for when the parents can no longer provide care.

To alleviate the burden on caregivers, future planning on the persons who are caring has emerged as a solution. By proactively addressing the needs and concerns of caregivers and establishing clear plans for the future, the well-being of both caregivers and individuals with intellectual disabilities can be better supported.

The primary objective of this research is to delve into the experiences and processes of family caregivers as they navigate the challenges of addressing the caregiving needs of their adult children with ID. The study aims to capture caregivers' perspectives on the support they have received, their hopes for the future, and their plans to continue providing care for both themselves and their adult children with ID as they enter later stages of life.

Having worked in the service for individuals with ID for the past 14 years, the researcher has developed a close working relationship with people with ID and their caregivers. Many caregivers have expressed their fervent desire to outlive their children, enabling them to provide care until the end of their own lives. However, reality often deviates from their wishes, necessitating the need for caregivers to proactively plan and arrange for the future care of their adult children while they themselves are still physically and mentally capable. This includes considerations such as living arrangements, identifying successive caregivers, establishing special trusts, and addressing personal and leisure plans, daily training, activities, and fostering friendships for their adult children with ID.

According to the study by Walker and Hutchinson (2018), there is a mention of Table 2, which provides an overview of 14 research studies conducted in foreign contexts on future planning for caregivers of adult children with ID. There is a dearth of relevant researches directly related to the similar societal condition in Hong Kong. Therefore, the researcher aims to explore the unique perspectives of caregivers in Hong Kong and identify any service gaps and needs that exist to better support and address the concerns of caregivers of adult children with ID. By filling this research gap, the study aspires to explore to the development of more tailored and effective services for relevant caregivers in Hong Kong.

Aim: To understand how the caregivers plan the future planning for their adult children with intellectual disabilities in Hong Kong.

Objectives:

1. To describe the process and perspective of the future planning of caregivers for their adult children with intellectual disabilities.
2. To explore the aspirations and barriers that caregivers encounter in their efforts to plan for the future of their adult children with intellectual disabilities.
3. To identify the types of support that caregivers require to actively engage in the decision-making process related to future planning.

Research Questions:

1. How do caregivers of adult children with intellectual disabilities perceive and approach future planning?
2. To what extent have caregivers' expectations for support, both formal and informal, been met in fulfilling the needs of their adult children with intellectual disabilities?
3. What aspirations do caregivers have for the future of their adult children with intellectual disabilities, and what barriers do they encounter in making future plans?

Chapter TWO: LITERATURE REVIEW

Conceptual framework

To better understand future planning for caregivers with adult children with intellectual disabilities (ID), the literature review will refer to relevant foreign studies to understand the definition of the scopes of future planning for them, the benefits and barriers of future planning, and the types of services and supports that will meet the caregivers' needs, it is expected that this research can understand the views of caregivers on future planning in Hong Kong.

The Framework of Future Planning

Future planning for caregivers with ID is essential to ensure that adult children with special needs continue to receive the necessary support and care throughout their lives. There are some aspects to consider when planning for the future planning.

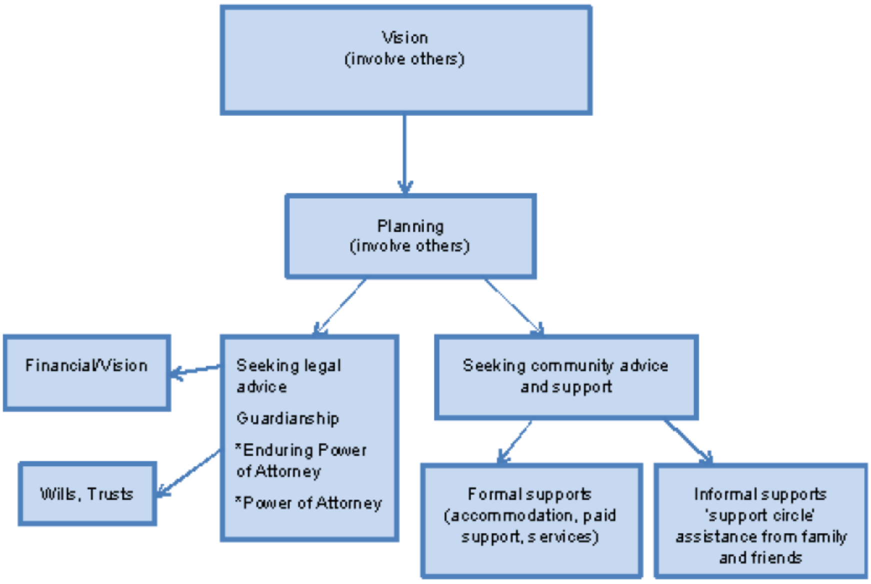
In the context of individuals with intellectual disabilities, future planning encompasses various domains as highlighted by Lee et al. (2021), Burke et al. (2018), and McCausland et al. (2019). These domains include residential, legal, and financial considerations. Additionally, Casale et al. (2021) and Burke et al. (2018) emphasize the importance of involving the entire family in discussions about the future. Developing succession plans is also mentioned by Grey et al. (2015), Burke et al.

(2018), and Taggart et al. (2012). Furthermore, Lee et al. (2021) and McCausland et al. (2019) emphasize the significance of creating plans for leisure and social activities.

Furthermore, Thakkar (2018) pointed out that the parents' other suggestions include preparing the child; preparing the informal network; securing the child's financial future; creating a life plan and a training manual; and preparing the community.

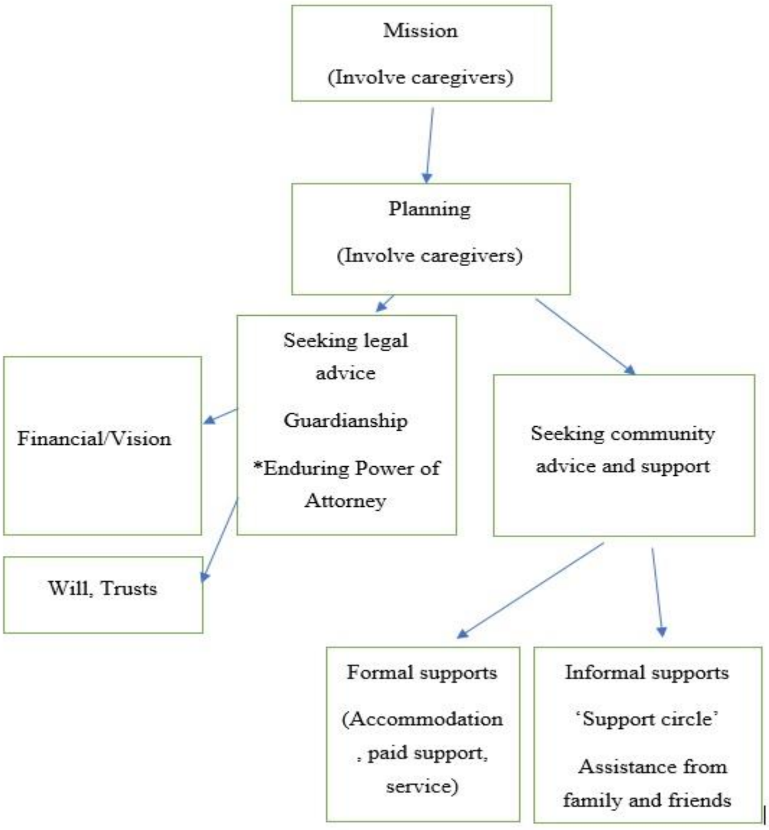
In addition, a resource booklet has been developed by the Australian Government of Social Services (2014) to assist caregivers of people with ID in planning for the future, it provides the planning process and content to help caregivers with their children with ID, including vision of caregiver, planning of legal, finance, community support of both formal and informal support.

Planning Process



* Important, especially for parents of young children with disability

Australian Government of Social Services (2014) to assist caregivers of people with disability in planning for the future of the above planning process.



Based on the planning process by the Australian Government of Social Services (2014), the researcher proposes the framework to investigate the planning for persons with intellectual disabilities as above. The researcher modified the planning process by changing the vision statement to a mission statement. This change was made because a mission statement typically encompasses the caregiver's purpose, direction, and operations, whereas a vision statement primarily focuses on forward-looking aspirations and future state. Another modification was made to involve caregivers, which further enhanced specificity.

Benefits of the future planning

Caregivers have their own experiences, perspectives, and opinions on caring for their children, so it would be useful to be able to develop a care plan for the successive caregivers, and to give children with ID the opportunity to maintain more similar habits to continue living, Taggart et al., (2012) mentioned that preparing future plans early would be more helpful for developing the individualized future care plans, rather than waiting for a crisis to occur, and Walker & Hutchinson (2019) point out when parents to put some firm plans into place for the future may help to alleviate the emotional and practical day-to-day demands they face as aging carers, and be beneficial for their family member with ID in the longer term by avoiding decisions at a time of crisis.

On the other hand, preparing to accept the transition with successive caregivers is important. According to Boeije et al., (2022), The study showed that Interviewees reported that talking about the future and possibly asking for help created openness about the situation and sometimes created space to consider long-term planning together. Some successive caregivers stated that they had arranged a gradual takeover of care tasks, which often turned out well and gave them more confidence in sharing the care with others, with professionals, and with their social networks. And some successive caregivers also reported sharing mentorship and trusteeship with their partner or with their children. And Lee et al., (2019) mentioned siblings expressed a desire for more family communication about future plans. Lee and Burke (2020) also pointed out that implementing future plans can help siblings who need to become successor caregivers to anticipate their own future plans, which can reduce their pressure to become caregivers, and specifically, siblings are willing to take care responsibilities when discussing future plans with their families. Moreover, Burke et al., (2012) point out that if siblings are not included in future caregiving plans, individuals with disabilities may receive inadequate or inappropriate support when their parents can no longer care for them. It is crucial to identify which siblings anticipate taking on future caregiving responsibilities in order to effectively support their ability to provide care for their ID brother or sister.

Barriers to the future planning

Synthesis of some studies help to identify the following barriers to future planning:

The emotional nature of future planning

McCausland et al. (2019), Burke et al. (2018), Boeije et al. (2022), Grey et al. (2015), and Taggart et al. (2012) acknowledge the emotional nature of future planning for caregivers of adult children with ID. These studies highlight that the process of making a future plan can evoke complex emotions among caregivers, such as feelings of guilt for abandoning a family member, sadness of death, and no longer being able to care for their children.

Boeije et al., (2022) reported future planning was an emotional topic, and the sadness and feelings of guilt of abandoning a family member could get in the way, and Taggart et al., (2012) mentioned the interviewees of the study reported not having explored future planning options because carers reported that they avoided making plans as this was a very painful journey. Moreover, caregivers may not make plans as a result of denial about the inevitability of their own mortality and the realization that they will not be able to provide care indefinitely. They have difficulties in letting go of their loved ones because it may result in more loneliness and the termination of their position in life. They find the subject too painful to broach and do not make firm plans until it becomes unavoidable.

Lack of support and guidance

According to Taggart et al. (2012), caregivers of adult children with ID often face a lack of support and guidance when it comes to future planning. Several studies, such as those conducted by Walker & Hutchinson (2018), Lee et al. (2021), Davy et al. (2015), McCausland et al. (2019), and Burke et al. (2018), have highlighted the barriers to future planning, including the lack of relevant information and appropriate service provision.

Taggart et al. (2012) found that caregivers expressed interest in future planning; however, the study highlighted a lack of knowledge regarding accessible sources of information and practical support for exploring future care options. This indicates that there is a need for accessible resources and guidance to help caregivers navigate the process of future planning for their adult children with ID.

Dissatisfaction with and lack of confidence in current services

According to Walker et al. (2018), Baumbusch et al. (2017), Boeije et al. (2022), Lee & Kim (2021), caregivers of adult children with ID often express dissatisfaction with and lack of confidence in current services. This dissatisfaction can stem from negative experiences and a mistrust of residential care services, leading to resistance in future planning.

According to McCausland et al., (2019); Burke et al., (2018); McCausland et al., (2019); Boeije et al., (2022), they highlight the importance of establishing residential options for individuals with intellectual disabilities, especially in situations where there is a lack of family members available to be caregivers. However, caregivers may hesitate to plan for the future due to their mistrust of residential care services and negative past experiences.

Baumbusch et al., (2017) point out many aging parents take the view that they alone can provide proper care for their adult-child with ID, a belief that may result from their experiences with low-quality services or institutionalization when their child was younger.

Given the benefits and barriers surrounding future planning for individuals with intellectual disabilities in foreign countries, it would be valuable for the researcher to conduct interviews with caregivers in Hong Kong. By gathering insights from these caregivers, the researcher can gain a deeper understanding of their perspectives, suggestions, and emotions regarding future planning. This qualitative approach will provide valuable firsthand accounts, allowing for a comprehensive and in-depth examination of the topic.

The perspectives of current family care and community care of caregivers of

adult children with intellectual disabilities

Current family care entails parents assuming the duty of caring for individuals with ID in the familiar surroundings of their own family. Parents have a deep understanding of their children's physical condition, emotional behavior, lifestyle, and habits, which makes them the best suited to meet their unique needs. This arrangement allows parents to offer personalized care and support, ensuring the overall well-being of their children. The familiarity and comfort of the home environment can greatly contribute to the individual's sense of security and happiness. Brennan et al., (2020) mentioned that the majority of families intend to provide lifelong support at home for their adult children with ID and that people with ID themselves largely wish to remain in the family home. According to the findings of Boeije et al. (2022), most interviewees were scared that no one else could provide the same level of care that they did because they knew exactly what their family members required.

According to the Social Welfare Department, HKSAR (2022), Community support services include social and recreational centers, day care services for individuals with severe disabilities, residential respite services, and emergency placement services for those without caregivers. These services are financed by the

Social Welfare Department and are designed to provide necessary support and care for individuals with intellectual disabilities.

In the context of this study to investigate caregivers' perspectives on the community care services currently available in Hong Kong. It aims to understand whether parents prefer to care for and train their children with ID on their own or if they prefer utilizing community care services. This research will shed light on the preferences and experiences of caregivers and contribute to the ongoing development and improvement of community care services in Hong Kong.

Expectations of the services and supports

When it comes to future planning for individuals with intellectual disabilities, caregivers have certain expectations for the services and supports available. These expectations revolve around ensuring long-term care, independence, and a secure future for their adult children. Indeed, the researcher's suggestion of utilizing case management services for individuals with intellectual disabilities can be highly beneficial in meeting their needs and assisting their families in making comprehensive plans for the future. Case management services involve a coordinated approach to support, where a designated case manager works closely with the individual and their family to assess their unique needs, develop a personalized plan, and connect them with appropriate resources and services.

According to Taggart et al., (2012), the findings highlighted the importance of recognizing the emotional aspect of future planning and the need for individualized support. By providing a "personal touch" through one-to-one support, statutory and voluntary services can effectively assist families in navigating the complexities of future planning for their adult children with intellectual disabilities. This personalized approach can help alleviate the emotional burden and facilitate a smoother transition into the future. Ryan et al., (2014) also proposed that ID services have a key role in brokering services for their older ID clients, and continued planning and collaboration between ID and older people services can benefit all older people.

Chapter THREE: METHODOLOGY

Research design

The proposed methodology for exploring caregivers' perspectives on future planning for their adult children with ID in Hong Kong with the goals of understanding their lived experiences and subjective viewpoints. Conducting qualitative research through in-depth interviews allows for a deeper exploration of their struggles, experiences, and opinions on the topic.

Phenomenology, as described by Sundler et al. (2019), is an appropriate approach for this study. It focuses on understanding the essential structure of phenomena based on the lived experience of insiders. By conducting in-depth interviews, the researcher can delve into the unique perspectives of each caregiver, taking into account their life journeys, cultural backgrounds, social discourses, and other factors that shape their views on future planning. Thematic analysis, as a descriptive approach with a focus on lived experience, is well-suited for this study. It allows for the exploration of the caregivers' experiences and the identification of common themes and patterns that emerge from the data. This analysis will help shed light on the factors that influence their perspectives and opinions.

In line with the principles of phenomenology, the researcher is going to conduct the data analysis process with a critical stance and strive to set aside their own assumptions and preconceived notions. This involves questioning and reflecting on their understanding of the data and the phenomenon under investigation. By maintaining an open and unbiased mindset, the researcher can gain a more comprehensive and nuanced understanding of the caregivers' perspectives.

Sampling method: purposive and snowball sampling

The sample for this study will consist of eight caregivers who have adult children with intellectual disabilities. The inclusion criteria for the parents are that they must be over the age of 55, while the children must be over 18 years old. To ensure diversity in the sample, half of the caregivers as interviewees do not receive residential services for their children, while the other half do receive residential services.

To recruit the specific target groups, the researcher will collaborate with organizations that provide support to caregivers of adult children with intellectual disabilities. This collaboration will facilitate the identification and recruitment of potential interviewees who meet the desired criteria.

The sampling method applied in this study will be purposive and snowball sampling, as suggested by Naderifar et al. (2017), will be utilized to access hidden populations through referrals. This method is particularly useful in qualitative research when other sampling techniques may not be feasible. The sample size will gradually increase, akin to a rolling snowball, as each interviewee refers others who may fit the criteria.

Data collection

In this study, the primary method for data collection will be in-depth individual interviews. Each interview will follow a predefined interview guideline to ensure consistency and capture the necessary information. The interviews are expected to last between 60 to 75 minutes, providing ample time for interviewees to share their experiences and perspectives.

The interviews will be conducted either in the organization setting or the interviewees' home environment, depending on their preference and convenience. Throughout the interview, detailed notes will be taken to capture key points and important insights shared by the respondents.

Before commencing the interview, written consent will be obtained from each interviewee, ensuring their voluntary participation and consent to record the interview. The interviewees will be assured that their responses and identities will be kept confidential and treated with utmost respect. The recorded data will be stored securely and only accessed by the researcher and authorized personnel involved in the study.

This study will utilize a semi-structured interview approach, according to Barriball & While, A. (1994). The semi-structured interviews were selected as the means of data collection, they are well suited for the exploration of the perceptions and opinions of respondents regarding complex and sometimes sensitive issues and enable probing for more information and clarification of answers. It aims to gather rich and authentic data that reflects the caregivers' experiences and perspectives on future planning for their adult children with intellectual disabilities.

Data analysis

The researcher in this study will utilize thematic analysis as a method for analyzing interview data, as described by Braun and Clarke (2006). Thematic analysis is a process of identifying, analyzing, and reporting patterns or themes within the data. It involves organizing and describing the data in detail and interpreting various aspects of the research topic.

There are three key concepts in thematic analysis: code, category, and theme. Codes are descriptors assigned to segments of data that assign meaning. Categories are derived from codes and are more abstract and conceptual. Themes, on the other hand, are theoretical constructs that explain similarities or variations across the data.

Braun and Clarke (2006) outline six stages that describe the process of thematic analysis:

1. Familiarizing with the data: This involves transcribing the data, reading and re-reading it, and noting down initial ideas.
2. Generating initial codes: Interesting features of the data are systematically coded across the entire dataset. Data relevant to each code are collated.
3. Searching for themes: Codes are collated into potential themes, and all data relevant to each potential theme are gathered.
4. Reviewing themes: Themes are reviewed in relation to the coded extracts and the entire dataset. A thematic "map" of the analysis is generated.

5. Defining and naming themes: Ongoing analysis is conducted to refine the specifics of each theme, ensuring clear definitions and names for each theme.

6. Producing the report: This stage involves final analysis, selection of vivid and compelling examples, relating the analysis back to the research question and literature, and producing a scholarly report of the analysis.

Confidentiality and ethical issues

The researcher guaranteed interviewees confidentiality and received written informed permission. interviewees were free to leave the interview at any time during the procedure. An information document will be created so that interviewees would know exactly what they agree to share with the researcher. Ethical approval of the research must be proceeded by Gratia Christian College's Research Office.

CHAPTER FOUR: FINDINGS AND ANALYSIS

In this study, the researchers invited a number of self-help groups for people with ID to participate in the study by email, and one of the self-help groups serving people with severe ID was willing to participate in the study, including six parents, one couple (C1 &C2) who had full-time jobs and needed to be interviewed after work, so the interviews with C1 and C2 were conducted via Zoom, while the other parents were interviewed face-to-face. The seventh interviewee was introduced by the social worker of the home help service for interview, and the last interviewee was introduced by the researcher's church friend for interview, and finally 8 parents, 5 of whom took care of their children on their own and 3 parents whose children were admitted to residential care.

Profiles of the interviewees

Family demographic information							
Interviewees code	Parent	Parent's age in years	Family members	Son or daughter's gender	Son's/daughter's age in years	Son's/daughter's diagnosis	Living situation
C1	Father	63	Father, mother and son	Son	28	Severe intellectual disability, hemophilia, cerebral epilepsy, blindness, paralysis	Home
C2	Mother	56					Home
C3	Mother	58	Father,mother,son(ID)and younger sister	Son	25	Severe intellectual disability and cerebral epilepsy	Home
C4	Mother	62	Father, mother and son(ID)	Son	32	Severe intellectual disability, cerebral epilepsy, and scoliosis	Home
C5	Mother	62	Father,mother,older brother and daughter(ID)	Daughter	24	Severe intellectual disability, cerebral epilepsy and paralysis	Residential service
C6	Mother	60	Father, mother,older sister and daughter(ID)	Daugther	24	Severe intellectual disability, cerebral epilepsy and autism	Residential service
C7	Father	73	Father, mother and son(ID)	Son	31	Down syndrome,Moderate intellectual disability and sleep apnea	Home
C8	Mother	63	Father,mother,older brother and daughter(ID)	Daughter	33	Severe intellectual disability	Residential service

Theme1: Future Planning

Perspectives on residential care as the main option

The interviewees in the study believed that residential care is the primary and often the only option for their adult children with ID when considering future planning. They expressed the belief that their children are unable to have their own daily life in the community without parental care, leading them to view residential care as the sole viable choice. This perspective may stem from a perceived lack of alternatives and the challenges associated with providing adequate care and support for individuals with ID in the community.

"We actually have to think about the future for our son, therefore we will first choose a residential service with a longer waiting time. "-C2

"In fact, there is nothing that can really help, social services are only residential services are the only help, and my friend's network, maybe because my son is severely intellectually disable. If it is mind intellectual disability, the network of friends or family can also help you live in the community, but severe intellectual disability is really very difficult in this situation."-C3

"Since my daughter was 13 years old, I already knew that I would have to arrange residential service for my daughter in the future, because I knew that my daughter might live longer than myself, and there would be no one to take care of her. "-C5

"So, at the age of 15, the teacher encouraged us to arrange the hostel as early as possible, I also think it makes sense. "-C6

The interviewees' statements reaffirm their firm belief in the importance of residential care for their adult children with intellectual disability. They take a pragmatic approach, considering their children's long-term prospects and care needs. The above highlights the interviewees' practical approach to planning for their children's future and their firm belief that residential care is the primary, and often the only, viable option for addressing their children's ongoing care needs.

Perspectives on formal and informal care

The distinction between formal and informal care emerges as a key element influencing caregivers' decisions about placing their adult children with intellectual disabilities in residential services. The interviewees' experiences highlighted the importance of family support and the caregiver's circumstances in determining the time and need for residential care.

C2 express their preference for keeping their child at home due to the support they receive from each other and their foreign domestic helpers. They rely on this network of support to provide care for their child. Therefore, option for putting their child in the inactive team for residential care, which has a longer waiting time. This decision reflects their belief that they are currently capable of taking care of their child's needs. Similarly, C3 also emphasizes the support of her husband and desires to keep her son at home for a longer period. She also chooses to place her son in the inactive team for residential care, indicating that she believes she can manage his care needs for the time being.

"When one of us has no ability, or the financial ability and physical function cannot be taken care of, we actually have to think about the future for our son, therefore we will first choose a residential service with a longer waiting time, because we felt that we were able to take care of him for the time being, so we were reluctant to let him go to residential service.''-C2

"I don't really care when the hostel is assigned. If it is assigned to me now, I will not let him move in, so we will continue to wait it slowly, and see if my husband and I will change in a few years when our physical condition will change, at least we are queuing for the hostel.''-C3

C4's husband's decision to resign from work and care for his son reflects the impact of changed circumstances. After his son suffered an injury, the father recognized the higher importance of intensive care required and chose to prioritize his son's needs. This decision is influenced by the support from the father and their belief that they can manage the care at home for now. And since C4 has a husband to help take care of his son, C4 chose a designated hostel, even if it takes a longer time to wait, Husband's support enhances C4's confidence in taking care of his son at home. C7's situation is similar, with the wife being the primary caregiver while the husband manages his own health condition. The division of care work between the couple allows them to manage their son's needs at home, leading to their placement in the inactive team for residential care.

" I was like crazy, thinking that it was my hand that injured my son, and then father immediately applied for leave from the company, thinking that even if he was fired, he would immediately support me, and the he also decided that he needed to resign, if he did not support me, I could not hold on, this family will be scattered''-C4

"My wife and I are the only force who take care of our son, so the care work is shared by us solely. Because I am easier to be in asthma even if walking and light exercise, so my wife is mainly responsible for taking my son out.''-C7

When caregivers lack support from their families, they are more inclined formal care instead of informal care. C5, as a sole caregiver, recognizes the need for residential services, considering the future when she may not be able to provide care. The lack of suitable alternatives within the family motivates her decision to arrange for her daughter's placement in a hostel while she is still healthy. And C6 highlights the stress and burden of becoming the sole caregiver after her worker's sister resigned from helping with her daughter's care. The absence of suitable respite services further adds to her challenges, leading her to urgently apply for residential services. C8's decision is influenced by the inconvenience of taking care of his daughter due to the opposite gender. This consideration, along with the responsibility falling mainly on the mother, leads to the decision to place the daughter in a residential setting.

"Because I am the only one who is familiar with taking good care of my daughter. If I die, my husband and son are not suitable to continue to take care of my daughter, so I have to arrange for my daughter to live in the hostel while I am still healthy.''-C5

"Before my daughter moved into hostel, the worker's sister was my biggest helper,

because I was the only one who could not take care of my daughter, and my daughter was vigorous.’’-C6

" I found that my son couldn't take care of it, because he is the opposite sex, and my daughter had grown up, so it was inconvenient to take care of it, and the care of daily life was handled by me, so my son didn't need to pay attention to it.’’-C8

Overall, the perspectives on formal and informal care highlight the critical role of family support, changes in circumstances, and the caregiver's ability to continue providing care. These factors play a significant role in determining the timing and necessity of residential services for adult children with ID.

Long-term planning for adult child's living arrangements, healthcare, and financial stability

Although the interviewees expressed during the interview that they had no specific future plans other than residential care, it is evident that the parents in the study are actively engaged in planning for their adult child's future in various aspects. C1, for instance, mentioned the economic pressure of employing two foreign domestic helpers and relying on them to assist in their child's care, diet, and training. This indicates that the parents are actively seeking solutions to ensure their child's well-being and support.

Additionally, the parents have considered the possibility of establishing a special needs trust to secure funds for their child's future. C1 mentioned their efforts to keep a sum of money for their child's benefit and explore the option of finding a trustworthy person to manage it. It demonstrates their proactive approach to financial planning and their desire to improve their child's material life.

However, the implementation of the special needs trust plan has been hindered by challenges, as mentioned by C3. The high entrance fees and other associated costs imposed by the government have made it unfeasible. According to Social Welfare Department, HKSAR (2022), the annual fee for each trust account is HK$20,000. This highlights the financial obstacles and limitations faced by the parents in executing their long-term plans.

"Many people retired at the age of 60, and I am still working in my 60s now. In fact, I have not thought about retirement... because the economic pressure of employing two ‘sisters’ (foreign domestic helper) is very great... so we rely on these two sisters to help us take care of our son, as well as his diet and training."-C1

"We also thought about whether there will be a fund for the child, and also asked some insurance brokers to understand, we are hard working for able to keep a sum of money for the child, if I find a person I trust to help me operate. "-C1

"At that time, the special needs trust was discussed... even if it was only hundreds of

thousands, it could be spent slowly... and the goal was that their material life would be better in the future... but then the government came out of this SNT and his entrance fee and other fees were so high, so in the end, it didn't work."-C3

The interviewees' statements highlight the challenges faced by individuals with disabilities and the importance of considering their specific needs in terms of living arrangements and healthcare. C1 describes the struggles their son faces with encephalopathy and the reliance on his hearing, emphasizing the need for a supportive environment. C4 expresses the desire for a hostel close to Queen Mary Hospital of Hong Kong for ongoing consultations. However, C5 expresses a lack of trust in hospitals and the hope for family accompaniment during hospital stays. These statements underscore the need for inclusive healthcare settings that address sensory needs, offer continuity of care of their children, and involvement of their family members in the care of individuals with disabilities.

"He suffers from encephalopathy, and he relies on his ears to identify the environment, you can imagine that you close your eyes and turn off all the lights. In the state of not knowing anything, it will be very wandering and panicked, my son in this situation, you will find that if you can't see things, and if there is a voice around you, so how frightened my son will be, he will cramp every time. "-C1

"I also wanted to choose the hostel in Wong Chuk Hang, because I wanted him to continue to have follow-up (medical)consultations at Queen Mary Hospital, and the

visiting doctor of the hostel was sent by Queen Mary Hospital to provide consultation services."-C4

" I don't trust the hospital... I hope that when disabled individuals are hospitalized, their family members can stay with them, just like in pediatric wards. So, my current strategy is to avoid my daughter's admission to hospital."-C5

To ensure effective care management, C6 maintain meticulous records of their child's condition and communicate this information to relevant parties. And C7 actively visit different hostels to find suitable living arrangements and prioritize facilities that can assist with specific needs, such as laundry services. C8 has to monitor her child's health condition for exercise and training programs at the hostel to address weight gain and edema of her child.

"Just because I am experienced so many years of caring my daughter, I have a habit of writing records... and record them and let them know my daughter's condition, only so."-C6

"In terms of children's living arrangements, I often visit the hostel, hoping to find a better hostel... I hope to pick him up after work on Friday, and send him back to the hostel on Sunday night or Monday morning... I decided to choose other hostel because the most important thing is whether they can help me wash the machine."C7

"She is in the hostel I also pay attention to her physical condition, she has gained a lot of weight, edema, I have proposed to the hostel whether there is some training to be exercised, because they will not take the initiative to exercise. *"C8*

Despite initially claiming to have no future plans, the parents demonstrate a proactive approach to securing their child's living arrangements, healthcare, and financial stability. They recognize the importance of ongoing planning to improve their child's health, mental state, and overall quality of life.

Succession of planning in caregiving

Succession planning in caregiving is a critical aspect of ensuring ongoing care for individuals who require support. This examines the perspectives of interviewees regarding their succession plans for caregiving and highlights the challenges and considerations they face.

The pressure and responsibility of caring for an ID child is enormous, and each interviewee will not consider transferring the responsibility of caring for an ID sibling to a normal child, so even if some ID children have siblings, the parents will eventually decide to regard the residential care as the final destination of the ID child, and they only hope that other children will be able to visit the ID siblings after the death of their parents.

"Absolutely no more, because this responsibility is too heavy, except for me and my husband, there is no possibility that no one else can take care of him. "-C3

"We don't want to have such a heavy responsibility on someone else, so why don't I think about having another child, because my son needs a lot of attention from me, and if I have another newborn baby, I should take care of that? "-C4

"As for my son, I only hope that he can visit his sibling with disability once a week to let her know that her brother is still around. "C5

"My preparation is that when father and I pass away, elder sister will go to see her younger sister. It is because if my daughter has no one to visit, her life will be so bleak. -"C6

"My son's life is always very busy, I used to think he could take care of it when he was a child, but when he was older, I found that he couldn't take care of it, because it was the opposite sex, and my daughter had grown up, so it was inconvenient to take care of it- "C8

Overall, the interviewees' perspectives highlight the immense pressure and responsibility of caregiving for an ID child. They often see residential care as the eventual outcome, with hopes that their other children can provide support through regular visits. These considerations inform the interviewees' succession plans for caregiving.

Theme2: Aspiration for the future

Hopes for parental involvement and care quality in residential settings

While interviewees expressed their belief that residential care is the main option for their adult children with ID, they also shared similar aspirations for their children's future well-being and training routines.

C1, C2, C4, C5 and C6 expressed the hope that they would be able to participate in their children's care even after they entered residential care. They desired the opportunity to accompany their children during meals, engage in conversations, and ensure that their children's daily routines, such as drinking milk and changing diapers, were properly followed. They viewed this level of involvement as necessary for their children's well-being and ideal.

Additionally, C1, C2, C3, C5 and C6 expressed a desire for more opportunities to visit their children in the residential settings. They emphasized the importance of proximity to the residential care, even if they were not able to accompany their children for extended periods. Having a visitation was seen as crucial for maintaining a connection with their children.

" I hope that after working hours, I can go to the hostel to accompany my son to have dinner or lunch. Chatting, leaving before going to bed at night, and making sure at night what time he drinks milk and what time he changes the diaper; we can let go, and it would be ideal if they could do that."-C1

" I heard some parents also talked that after their children were admitted to the residential care, it seemed to be released, but in fact it was not, just because parent really wanted to visit their children"-C3

" I need to be close to home for me to visit, even if the hostel cannot let me accompany him for a long time, but it can also give me a room for me to visit, bring some food for him to eat"-C4

"In terms of aspiration for future care, I hope that the residential service will be open for parents to help with feeding and (personal hygiene) care "-C5

" When I really take her to the hostel, I am also wandering near the hostel, will I move here near it, can I get close to my daughter. "-C8

While some interviewees viewed residential care as the primary option for their children's future, they shared similar aspirations for parental involvement and care quality. They hoped for opportunities to participate in their children's care, maintain regular visits, and ensure that their children's needs were met.

Importance of increasing staffing levels and stability

The interviewees in the interview emphasized the hope for increasing staffing levels and ensuring stability in residential care settings to address the complex needs of individuals with ID. They expressed concerns about the current manpower shortage of the service agencies and its impact on the quality of care provided.

" We all know that manpower is very tight, we think if there is a residential service that makes us feel confident, we will want to try. "-C1

" I hope that the number of manpower can be increased a little, because the staff of the residential service is relatively small compared to the school (of disable children).."-C3

" I am most concerned about the manpower in the residential care, especially the 3T, 3T are including speech therapy, physiotherapy and occupational therapy training, because therapists and nurses are now working in several homes, maybe cannot provide the enough training for our child. "-C4

" And now I only hope that the staff of the hostel can be stable, so I also encourage

them more, I hope they will not often have changes in their manpower."-C6

C7's case highlighted a specific example of the impact of manpower problems. His child requires a ventilator for sleep apnea, which needs regular cleaning and maintenance. However, due to the manpower shortage, the residential care facility was unable to provide this assistance. It led C7 to try teaching his child to clean themselves, but ultimately, he had to give up the hostel. His wish was for the hostel to be willing and able to help maintain the ventilator.

" Therefore, in the future, I hope that the hostel can maintain the function of this Ventilator. "-C7

It pinpoints the interviewees' concerns about the shortage of staff and the need for increased staffing levels and stability in residential care settings. They recognize that manpower issues can affect the quality and effectiveness of care, particularly in terms of specialized training and meeting specific needs. The specific case of ventilator maintenance further emphasizes the importance of having sufficient staff to provide essential medical support.

Theme3: Barrier to the future

Lack of Government Support and Limited Services

The barriers in future planning for adult children with ID revolve around the lack of government support and limited services. Families feel the need for a reliable residential service that can instill confidence and provide appropriate care. However, they struggle to find suitable options and express frustration over the lack of support from the government. Even if they have financial resources, they are unable to find alternative solutions. The focus is on the well-being of the child with ID. Overall, there is a sense of helplessness and a need for better support and options in planning for the future.

"So, I think that on the part of the government, since there is not enough residential service unit that it leads to long waiting times (of residential care), coupled with the shortage of manpower, etc.,."-C2

"In fact, there is nothing to plan, because there is no way out, actually, there is only one way out is residential service, if you want to help them live in the community, I don't see any support from the government, even if you don't say the future, even now, I can't see what support the government has given us."-C3

"Why doesn't the government care about our care needs. If the welfare of the disabled can comparable to the welfare of the elderly, it can reduce our burden, is it possible that the elderly contribute to society, but our children with intellectual disabilities do not, so they are not valued? "-C5

"Even if I know that the residential service is not a good choice, but I can't think of

any other way out, even if I have money, I can't think of any other way out."-C6

There are many things that have been said for many years and many years, that is, it is so simple, the responsibility is shirked between government departments, and the same is true for different departments, complaints are accepted, but the practice is the same”. -C7

The barriers identified by interviewees highlight the lack of government support and limited services in future planning for adult children with ID. They express frustration over the shortage of residential services, long waiting times, and insufficient manpower. They question why the government does not prioritize the care needs of individuals with ID and compare it to the support provided for the elderly. Despite having financial resources, these families struggle to find viable alternatives to residential services. There is a sense of helplessness and disappointment with the government's lack of attention to their needs. The interviewees also emphasize the need for better coordination and communication between government departments to address these challenges effectively.

Disappointment of support from social worker

The dissatisfaction with social workers represents a significant barrier in the future caregiving process for families with adult children with ID. Most of the interviewee’s express frustration with social workers, highlighting their lack of understanding and knowledge. They feel that social workers do not provide adequate support and guidance, which hampers their ability to effectively plan for the future. They also mention that social workers may not have detailed information about available services and may be new comers of social welfare service with limited understanding of the field. The lack of personalized support and home visits further adds to their dissatisfaction. They feel that social workers primarily focus on administrative tasks such as managing waiting lists and arranging visits, rather than actively assisting families in their unique situations. Such dissatisfaction with social workers creates a barrier in the overall process of future planning, as families do not feel adequately supported or understood in navigating the challenges associated with their child's ID.

"Which is actually just that they help me manage the records of the waiting list of residential service, and if the place is assigned, they will notify me through them. Every six months, they were called to ask if there was any special incident, and they didn't even visit my home. " C3

"Social workers in the field may not have detailed information, and I have also found that many social workers are new recruits, and many of them are not clear about the services. "-C4

"But as a parent, I really look forward to how the social worker can help the members, in fact, you can't help me with anything, I think I want her to know, this is good for her, I completely feel that she is just do a job, so disappointed. " -C8

The dissatisfaction with social workers creates a barrier in the future planning process, as families do not feel adequately supported or understood in their caregiving journey for their adult children with ID. This highlights the need for improved training and support for social workers to better meet the unique needs of these families.

Lack of confidence in current services

The caregivers in the interview expressed deep concerns about the inadequate services and care provided for their children with ID. They highlight issues such as lack of meaningful activities, limited support for individual needs, negative experiences with services. These worries underscore the urgent need for improved services that cater to the unique requirements of individuals with ID, ensuring their well-being and overall development.

"When my son graduated, I used the service of P L K Day Centre in Sham Shui Po, and I found that he was only sitting, and there was no training provided, just sitting in the center and watching TV. Also, if my son needs to do sports, they would give you a mat to do it by yourself, I thought if no one can help him to do sports or exercises, I can also do it at home. " -C2

"There were ten intellectual disabilities people, a few tables and a tutor, everyone was forced to sit together, but their ability should be better, maybe they could hold

a glass of water to drink, but my son can't, give some toys they can know how to play (This means that the ID person at the centre has a higher ability to play with toys on his own, while C3's son does not). At least they will know how to do it, or if you ask him to go to the toilet, they will know how to do it themselves, but my boy's ability is not to do these things, plus severe cerebral ringworm, so I was thinking that if he went to these places, he might just sit there all day. " -C3

"I have tried a respite service to make my son's mood was bad, he has to sit in a safety chair because of cramps, and the seat belt is in the position of the navel so that his whole person is close to the back of the chair, and he can go to the toilet by himself, but the respite service requires him to wear diapers to make his mood bad, and then I went to visit him in the respite service, he has ignored me. " -C4

"After my daughter lived in the school dormitory for more than a year, my daughter had a severe cramp that was so serious that it was a life-threatening situation, I thought it was because of the school's poor care. "-C5

"I found that my daughter's towel was moldy, and when I told the staff of the hostel, they only responded that they would change it once every 3 months. " -C6

Indeed, the worry about the poor service provided for their children with ID can have an impact on parents' confidence in planning for the future. When parents witness or experience inadequate care and support, it can lead to a sense of disillusionment and mistrust in the system. This lack of confidence may deter parents from actively engaging in future planning.

The concerns about the quality of service may make parents hesitant to rely on existing resources or services for their child's long-term care. They may question the effectiveness and reliability of available service, leading to doubts about the feasibility of future planning. The fear of making the wrong decisions or being let down by the system can erode parents' confidence in their ability to plan effectively.

Theme4: Expectation to the service

Based on the concerns and expectations expressed by the interviewees, it can be summarized that they desire improved services in residential care. They find the current system lacking and compare it to a prison-like atmosphere. The family members seek more flexibility in visitation, increased activities, and better reputation for the hostels. They also emphasize the need for continued learning and training for individuals with disabilities, personalized care based on individual needs, and improved dental care. Overall, they hope for a more supportive and comprehensive care system that addresses the specific needs of their family members as well as their children with disability.

"The growth center just has a teacher, an assistant, a cleaner and a social worker. In fact, the manpower is very limited. Each student is accompanied by a worker ‘sister’ (foreign domestic worker) or parent. They accompany the students to class,

play and do sports. If this mode of operation can be applied to the residential care. It is actually a win-win situation. "-C1

"Hostel limited them to visit once a week, each time for 45 minutes, so theoretically it should be safe to let the children into the hostel, but actually it is not, in fact, the residential service is just an accommodation arrangement, but we feel that it is more pitiful than visiting the prison, and entering the residential service is like sitting in prison. So, I often feel that if we can improve the service, we can feel more at ease. " -C3

"Parents have seeked for lifelong learning of their children. When the graduates (their children with disability) leave school and stop training, they are prone to degradation, it is hoped that they will continue to receive training before articulation to adult services, that is, at least there is muscle training. -"C4

"My only wish is how to help her get her teeth right, how to help her be willing to eat, I hope she can sleep well. "-C6

"I hope that the hostel will have a better reputation and more activities. The hostel that is closer to home can at least have some entertainment after work or meals. If you like to sing, you can sing. and you can watch TV if you like to watch TV. It is because if the place is too small, life will not be comfortable. "-C7

"Roughly following the care of the current hostel is good, we sometimes do not take her home leave for vacation, they take good care of her, the diet and other things are satisfactory, the only thing the dental care is a little worse. " -C8

Most of the interviewees reveal a common desire for improved services in residential care. They emphasize the need for a supportive and engaging environment, with could increase visitation flexibility, could enhance activities, better reputation, lifelong learning opportunities, improved dental care, and support for healthy eating habits. These findings highlight the importance of addressing these concerns to provide a comprehensive and satisfactory residential care experience for individuals with disabilities and their families.

CHAPTER SIX: DISCUSSION AND CONCLUSION

The findings of this study shed light on the perspectives of caregivers regarding future planning for their adult children with ID. The interviewees in the study expressed a strong belief that residential care is the primary and often the only option for their children's future. The interviewee' statements demonstrate their pragmatic outlook and consideration of the long-term future and care needs of their children. One key factor influencing this perspective is the belief that their children are unable to have their own daily life in the community without parental care. The interviewees express concerns about the level of support and specialized attention required for individuals with ID, which they perceive as difficult to provide within a community setting. This perception may stem from a perceived lack of suitable alternatives and a recognition of the challenges associated with providing adequate care and support in the community.

The findings also revealed that the parents in the study were actively engaged in long-term planning for their adult children's living arrangements, healthcare, and financial stability. Firstly, the interviewees demonstrated a high level of engagement by frequently visiting residential and day service facilities, carefully evaluating whether the locations and activities offered met the specific needs of their children with ID. Secondly, they explored options such as consideration of special needs trusts to secure funds for their children's future. However, challenges such as high fees and limited government support hindered the implementation of these plans. Furthermore, the interviewees also considered the location of medical facilities as an important factor in their planning. They recognized the need for accessible healthcare services and emphasized the importance of family accompaniment during hospitalizations. Their advocacy for family involvement in medical situations reflects their desire to ensure the best possible care and support for their adult children with ID.

The finding related to succession planning in caregiving for individuals with ID suggests that the interviewees prioritize residential care as the final destination for their ID children. They express concerns about burdening other family members with the responsibility of caregiving and believe that their ID children require specialized attention that may not be feasible for other siblings or family members to provide. Instead, they envision that their other children can maintain a connection with their ID siblings through regular visits after the parents pass away. This approach reflects the interviewees' understanding of the challenges and limitations of caregiving for individuals with intellectual disabilities and their efforts to ensure ongoing care and support for their ID children even when they are no longer able to provide it themselves.

The category of formal care and informal care emerged as an important factor influencing the decision-making process of caregivers regarding the placement of their adult children with ID into residential services. The interviewee' experiences highlighted the significance of family support and the caregiver's circumstances in determining the timing and necessity of residential care. Caregivers who received adequate support from their families expressed a preference for keeping their children at home and relied on this network of support to provide care. On the other hand, caregivers who lacked support from their families were more inclined towards formal care options. The decision to option for residential services was influenced by changes in circumstances, such as the caregiver's ability to continue providing care and the availability of respite services.

On the other hand, informal care refers to the support provided by family members, friends, and other close individuals within the caregivers' social network. Informal care can encompass emotional support, assistance with daily activities, and respite care. The findings of this study highlighted the importance of informal care in the decision-making process. Caregivers who had sufficient support from their families expressed a preference for keeping their adult children with ID at home, relying on this network of support to provide care. They recognized the value of familial relationships and the positive impact of family involvement on their children's well-being.

However, it is important to note that informal care also has its limitations. Caregivers who relied solely on informal care may face challenges such as caregiver burnout, lack of respite, and limited access to specialized services. These challenges can lead to increased stress and strain on the caregiver, potentially compromising their ability to provide optimal care.

The discussion highlights the aspirations expressed by caregivers regarding the future care of their adult children with ID in residential settings. While acknowledging that residential care is often the main option, the caregivers expressed a strong desire to remain involved in their children's care. They hoped for opportunities to participate in activities such as meals, conversations, and ensuring proper routines for their children's well-being. Maintaining regular visits was also seen as crucial for maintaining a connection with their children, even if they couldn't accompany them for extended periods.

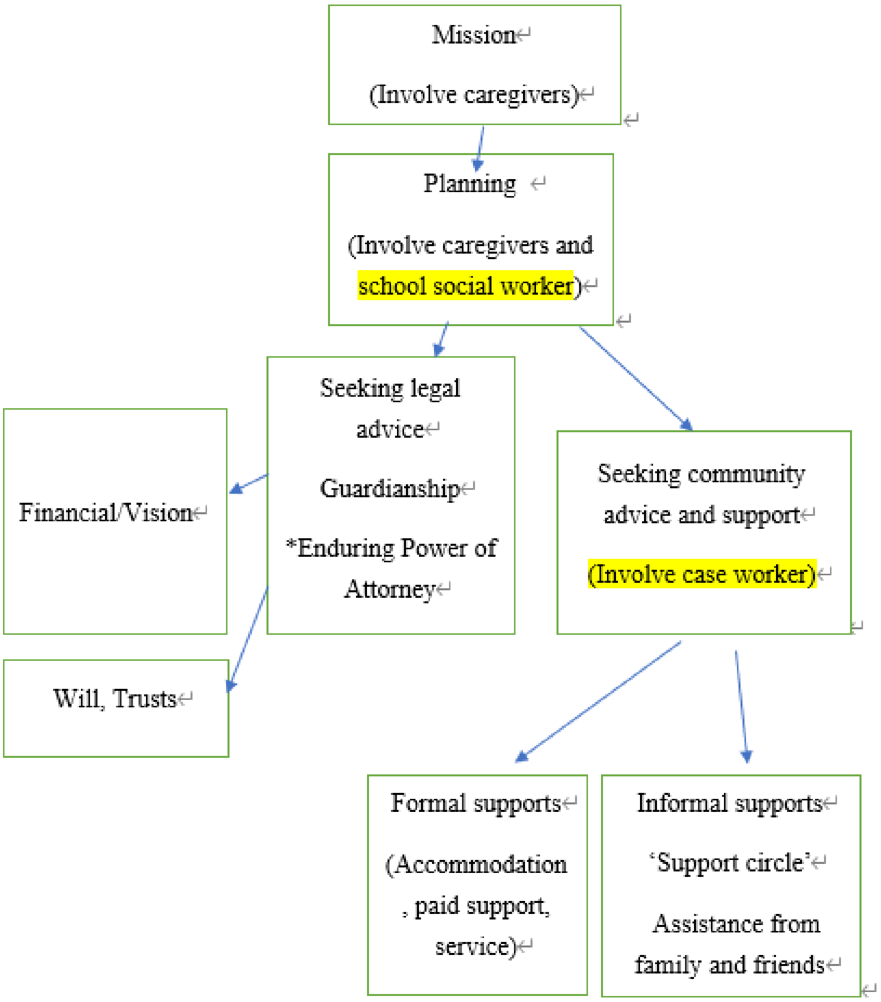
The aspiration for parental involvement underscores the caregivers' deep concern for their children's well-being and their desire to continue playing an active role in their care, even after they enter residential settings. It highlights the need for residential care facilities to create an environment that allows parents to contribute to their children's care and be involved in decision-making processes.

Another important aspect raised by the caregivers is the importance of increasing staffing levels and ensuring stability in residential care settings. They expressed concerns about the current shortage of manpower in service agencies and its impact on the quality of care provided. Caregivers stressed the need for more staff to address the complex needs of individuals with intellectual disabilities and to provide specialized training, such as speech therapy, physiotherapy, and occupational therapy. The case of C7, whose child requires a ventilator for sleep apnea, further emphasizes the impact of manpower problems. The shortage of staff prevented the residential care facility from providing necessary assistance, leading C7 to ultimately give up on the hostel. This highlights the urgent need for sufficient staff to provide essential medical support and maintain specialized equipment.

Moreover, barriers expressed by caregivers for the future of their adult children with ID. One of the barriers is lack of information among social workers about the services available in the field of social work is a significant issue that needs to be addressed. It is crucial for social workers to be well-informed about the services and resources available to effectively assist and support individuals in need. One of the contributing factors could be the lack of training and professional development opportunities provided to social workers. It is essential for social workers to receive ongoing training and education to enhance their knowledge and skills. This includes staying informed about the latest developments in the field and being aware of the available services and resources. Furthermore, it is crucial for social workers to establish strong networks and partnerships with various service providers to ensure that they have access to accurate and up-to-date information about available. services.

Another significant barrier identified in the study is the lack of confidence in the current services. Caregivers of adult children with ID express concerns about the inadequate support, limited activities, and negative experiences they have encountered with existing services. These concerns have a profound impact on their ability to engage in future planning for their children. The lack of confidence stems from their perception of a lack of meaningful activities, insufficient individualized support, and negative experiences with the services provided. As a result, caregivers fear making wrong decisions and being let down by the system, which ultimately erodes their confidence in their ability to plan effectively. To overcome this barrier, it is essential to prioritize improvements in the quality and reliability of services. This includes providing comprehensive staff training, ensuring the availability of adequate resources, and fostering transparent communication with caregivers. These measures are necessary to instill confidence among caregivers and empower them to effectively plan for the long-term care of their adult children with intellectual disabilities.

A Conceptual Framework



The study emphasizes the importance of starting future planning during the school stage for individuals with ID. This is attributed to the fact that individuals with ID can start considering adult residential services at the age of 15. School social workers are in a position to play a vital role in assisting caregivers in systematically contemplating future care arrangements during this stage. Moreover, this stage serves as a starting point for preparing parents to transition and let the caring task to residential care. School workers can organize workshops to familiarize parents with the planning process for their children with ID, thereby alleviating their concerns and anxiety. These workshops can cover various aspects, including applying for residential services, discussing successor caregivers within the family, and addressing training, recreational activities, and socialization opportunities for their adult children with ID. By offering caregivers an initial plan, school social workers can actively participate in the future planning process.

Furthermore, the interviewees expressed disappointment with social work services, stating that caregivers experience significant care pressure and have urgent case management needs. The researcher suggested that the existing case management services at District Support Centre for Persons with Disabilities should assist caregivers in planning and managing the social services they require, such as home help training and respite service. The involvement of a case social worker can help coordinate with service providers and address issues faced by caregivers. For example, in the case of C7, a case social worker could potentially mediate with the hostel to ensure the cleaning of the ventilator, thereby increasing the willingness of the hostel to provide necessary support.

To address the difficulties faced by caregivers, the future planning framework should include the involvement of social workers in the planning process. This would help reduce parents' sense of isolation and ensure they receive the required services. Therefore, in the column of seeking community advice and support, the addition of a case worker is recommended.

Conclusion:

In conclusion, the perspectives of caregivers regarding future planning for their adult children with ID demonstrate a strong belief in the necessity of residential care as the primary option. The decision to option for residential services is influenced by factors such as the availability of family support, changes in circumstances, and the caregiver's ability to continue providing care. Caregivers actively engage in long-term planning for their children's living arrangements, healthcare, and financial stability. However, challenges such as limited government and dissatisfaction with and lack of confidence in current services support hinder the implementation of these plans. These findings highlight the importance of understanding caregivers' perspectives and providing adequate support and resources to meet the future care needs of individuals with intellectual disabilities. Further research is needed to explore alternative options and strategies for future planning in order to improve the overall well-being and quality of life for individuals with ID and their caregivers.

CHAPTER SEVEN: IMPLICATION ON THE STUDY

Support and resources

The need for greater support and resources for caregivers of individuals with severe ID. The challenges faced by these caregivers, including the extensive care responsibilities and the impact on their own well-being, indicate a need for comprehensive support systems. This could include access to respite care, counselling services, and educational programs to assist caregivers in managing their roles effectively and maintaining their own physical and mental health.

Person-centered care in residential service

The importance of person-centered care in residential service for individuals with intellectual disabilities. The interviewees expressed the expectation for high-quality care that meets the specific needs and preferences of their children. This suggests a need for staff training and development to ensure that caregivers in residential service have the necessary skills and knowledge to provide individualized care that promotes independence, dignity, and overall well-being for the residents. Additionally, the study highlights the significance of collaboration and partnership between caregivers and residential service. The interviewees expressed the desire for more involvement and time with their children in the facilities, as well as the importance of trust and communication between caregivers and staff. This implies a need for strategies to foster meaningful engagement and collaboration between caregivers and residential service, such as regular family meetings, shared decision-making processes, and open lines of communication.

Policy changes and resource

Furthermore, the study suggests the need for policy changes and resource allocation to enhance the quality of residential care services. This includes government support in terms of funding, staffing, and regulatory frameworks to ensure that residential care service meet the necessary standards and provide optimal care for individuals with severe intellectual disabilities. It also calls for ongoing evaluation and monitoring of these facilities to ensure continuous improvement.

The knowledge and skills of social work profession

Social workers play a crucial role in transition planning for individuals with ID. They need to have a deep understanding of the transition process, including knowledge of relevant laws, policies, and available resources. By staying updated on best practices, social workers can provide accurate information and guidance to caregivers, empowering them to make informed decisions.

The research also emphasizes the importance of collaboration and coordination for social workers. They need to work closely with various services involved in the future planning process, such as caregivers, home help services, residential services, day training services, and medical follow-up. Social workers should possess networking, communication, and teamwork skills to facilitate effective collaboration among these stakeholders. By building strong partnerships and fostering a coordinated approach, social workers can ensure that individuals with ID receive comprehensive and seamless support throughout the planning and implementation stages.

The continuity of schooling and residential service

The continuity of schooling and residential service emerges as an important aspect in the future planning for individuals with ID. The research highlights that the school stage serves as a starting point for future planning. It is during this stage that individuals with ID, together with their caregivers, can consider applying for adult residential services starting from the age of 15. Therefore, ensuring continuity in schooling becomes crucial for a smooth transition into adulthood and future care arrangements. Social workers can play a vital role in advocating for appropriate educational programs and services that support the developmental needs and goals of individuals with ID. They can collaborate with teachers, occupational therapists, physiotherapists, educational psychologists, etc and other relevant stakeholders, such as Day Training Centres, Workshops and Respite Services to ensure a seamless transition from school to adult life.

The research also underscores the significance of residential services in future planning for individuals with ID. Caregivers may have concerns about securing residential placements for their adult children with ID. Social workers can assist in navigating the process of applying for and accessing suitable residential services. Additionally, they can help coordinate with residential service providers to address specific needs or challenges, such as ensuring the provision of necessary medical care or individualized support. By promoting continuity in residential services, social workers contribute to the overall well-being and stability of individuals with ID.

Overall, the study highlights the need for greater support and resources for caregivers of individuals with severe intellectual disabilities. Person-centered care in residential services and collaboration between caregivers and staff are essential. Policy changes and resource allocation are necessary to enhance the quality of care. Social workers play a crucial role in transition planning and ensuring continuity in schooling and residential services. By addressing these implications, individuals with ID and their caregivers can receive comprehensive support and improve their overall well-being.

CHAPTER EIGHT: LITMITATION ON THE STUDY

The study acknowledges several limitations. Firstly, it focuses on individuals with moderate to severe intellectual disabilities, which may limit the generalizability of the findings to individuals with mild intellectual disabilities. The unique needs and requirements of individuals with different levels of intellectual disabilities should be recognized and considered in future research and planning efforts.

Secondly, the study acknowledges the researcher's lack of experience in conducting interviews, which may have resulted in suboptimal questioning techniques. This limitation could have impacted the depth and quality of the data collected from the interviews, potentially leading to gaps or missed opportunities for valuable insights.

Lastly, the study recognizes the researcher's lack of experience or understanding of the specific needs and services required for individuals with severe intellectual disabilities. To address this limitation, it is important to allocate more time during interviews to gain a better understanding of the physical and mental needs of individuals with severe intellectual disabilities and the specific services they require.

These limitations highlight the importance of considering the full spectrum of intellectual disabilities, ensuring researcher competence and experience, and deepening the understanding of the needs and services required for individuals with severe intellectual disabilities in future research and planning endeavors.

CHAPTER NINE:

REFLECTIONS AND RECOMMENDATIONS

Through this study, the researcher gained a deep understanding of the challenges faced by caregivers of individuals with severe ID. These parents start their involvement in their children's lives from their school years, as some special schools' welcome parents or foreign domestic helpers to assist in implementing the content taught at school. Since individuals with severe ID require significant assistance in their daily lives, parental involvement ensures better care for their children. The parents of children with severe ID dedicate their entire lives to caring for their children.

They diligently care for these children with multiple disabilities and illnesses, often hovering on the edge of life and death, ensuring that they grow up successfully. Now, these caregivers are facing their own aging and decline. They know that the ultimate destination for these children is residential care service. Their wish is that even when their children are about to enter residential care, the hostel will allow them more time to accompany their children. If the hostel can adopt the practices of special schools, allowing parents to participate in their children's care and gradually withdraw from their caregiving roles after establishing trust with the hostel, would this be a solution?

C8 shares her satisfaction with the hostel where her daughter resides. She believes that the hostel takes on the role of caregiver while the parents become guardians. This allows parents to feel at ease leaving their daughters in the care of the hostel. Moreover, her daughter is always happy when returning to the hostel, and the staff warmly greets her, enabling C8 to take better care of herself. This experience has made C8 willing to share her story. In fact, there are some high-quality residential care services in Hong Kong. Although there are also disappointing ones, as mentioned in the interviews. This is an area where social workers must strive together in the future. Social workers must work hard to improve residential care services. The researcher views this as a divine mission and hopes that the industry will continue to improve, while the government can increase resources to develop and enhance the quality of residential care services.

The researcher proposed the establishment of a parent mutual support group at the district support center, where parents sharing similar backgrounds can provide support, encouragement, and exchange experiences in caring for children with ID. This platform would also enable parents to share information about the social services they are utilizing. In an interview, C8 expressed her desire for a channel to share information about excellent hostels, organizations, and structures, as it would contribute to the happiness of parents and residents alike. She hoped that this positive influence could spread, motivating other residential service providers to improve. If the district support center initiates a parent mutual support group, more parents would become aware of their rights, and fellow parents would be able to establish trust, support, and reduce isolation among each other. Ultimately, this would enhance community support for families.

Further research is indeed recommended to explore community care options specifically for individuals with mild intellectual disabilities. While the current study focused on residential care as the primary option. It is important to investigate alternative models of care that can support individuals with mild ID in living independently within the community. This research could examine the effectiveness of community-based support services, including vocational training, educational programs, and social integration initiatives, in promoting the autonomy and well-being of individuals with mild ID. Additionally, studying the experiences and perspectives of caregivers and individuals with mild ID in accessing and utilizing community care services would provide valuable insights for developing tailored support systems. This research would contribute to a more comprehensive understanding of the range of options available for future planning and promote inclusivity and independence for individuals with mild ID.

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Appendix:

Interview Questions (In English)

Interview Question

1. **How do caregivers of adult children with intellectual disabilities perceive and approach future planning?**
   1.1 Can you tell me about your role as a caregiver for your adult child with ID?
   1.2 How do you approach long-term planning for your adult child's living arrangements, healthcare, and financial stability?
   1.3 Who are the main people who help you support to care for your adult children, and what are their roles?
   1.4 If you are no longer able to fulfill your caregiving role, is there a plan in place for a successive caregiver to take over? Why do you feel they would be suitable?
   1.5 Have you ever discussed a successive care plan with your family members?
   1.6 Have you sought any professional guidance or support in developing strategies or plans for your adult child's continued care? If so, what resources or services have been helpful in this process?
   1.7 Based on the family member’s current care needs, what concerns do you have about his/her future care?
   1.8 What type of long-term care(original family care or residential care) do you feel would best suit your adult child's needs and desires in the future?
   1.9 Do you have any views, feelings, or concerns about residential service?
   1.10 What are your thoughts and feelings when the news reports about the inappropriate care of people with intellectual disabilities in residential service?

2. **To what extent have caregivers' expectations for support, both formal and informal, been met in fulfilling the caregiving needs of their adult children with intellectual disabilities?**
   2.1 Describe the types of support you have received and would expect to help take care of your adult child with ID?
   2.2 Who are the main people/organizations who help you support your adult child? Paid or unpaid? formal (social service) or informal (family, friends, or neighbors)?
   2.3 What degree of support does your adult child currently require and where

do you expect that will come from (e.g. family, friends, and social services)?

2.4 Based on your experiences, what recommendations or suggestions would you make to improve the social service to caregivers of adult children with ID? How do you think these improvements would positively impact the caregiving journey?

3. **What aspirations do caregivers have for the future of their adult children with intellectual disabilities, and what barriers do they encounter in making future plans?**

3.1 How do you envision the future for your adult child with ID? What are your hopes for them?

3.2 What are some of the barriers or challenges you have encountered in making future plans for your adult child with ID? Can you provide specific examples of the barriers you have faced?

Appendix:
Interview Guidelines/ Questions (In Chinese)

訪談問題

1. **智障成年子女的照顧者如何看待和處理未來的規劃？**
   - 1.1 您能告訴我您作為智障子女的照顧者的角色嗎？
   - 1.2 您如何為智障子女的生活安排、醫療保健和財務穩定性進行長期規劃？
   - 1.3 誰是支持你照顧成年子女的主要幫手，他們的角色是什麼？
   - 1.4 如果您不再能夠履行您的照顧角色，是否有計劃讓繼任的照顧者接任？為什麼你覺得他們適合？
   - 1.5 您是否曾經與家人討論過繼任照顧計劃？
   - 1.6 您是否在為成年子女的持續照顧制定策略或計劃時尋求任何專業指導或支援？如果是這樣，哪些資源或服務在此過程中有幫助？
   - 1.7 根據家庭成員目前的照顧需求，您對他/她未來的照顧有什麼顧慮？
   - 1.8 您認為哪種類型的長期照顧 (傳統家庭照顧或院舍照顧) 最適合您成年子女未來的需求和願望？
   - 1.9 你對院舍服務有什麼看法、感受或疑慮嗎？
   - 1.10 當新聞報導智障人士在院舍服務中受到不當照顧時，你有什麼想法和感受？

2. **在滿足智障成年子女的照顧需求方面，照顧者對正式和非正式支援的期望在多大程度上得到滿足？**
   - 2.1 描述您獲得的支持類型，並希望幫助照顧您的智障子女？
   - 2.2 誰是支持你照顧智障子女的主要人物/機構？有償或無償? 正式 (機構)或非正式(親朋戚友或鄰居)。
   - 2.3 您的智障子女目前需要多大程度的支援，您期望這些支援來自哪裡（例如家人、朋友和社會服務）？
   - 2.4 根據您的經驗，您會提出哪些對於社會服務的建議來改善對智障成年子女的照顧者的支援？您認為這些改進將如何對照顧過程產生積極影響？

3. **照顧者對智障成年子女的未來有什麼期望，他們在制定未來計劃時會遇到哪些障礙？**
   - 3.1 您如何設想智障子女的未來？你對他們的希望是什麼？
   - 3.2 在為智障的成年子女制定未來計劃時，您遇到了哪些障礙或挑戰？您能舉例說明您面臨的障礙嗎？

附件1

宏恩基督教學院 社會工作學院

探討香港照顧者為成年智障子女進行未來規劃的看法

參與研究同意書

本人 ____________________ 備悉上述研究計劃目的在了解照顧者如何為成年智障子女進行未來規劃。本人亦知悉此研究負責人來自宏恩基督教學院之社會工作學士學位課程學生鄭淑英。

本人知悉所提供的資料將根據香港法例第486 章 《個人資料(私隱)條例》加以保護。而此研究所得的資料將會被錄音及可能被用作日後的研究及發表，但該研究及發表中亦不會包含能夠識別本人身份的細節。本人的私隱權利會得以保留，本人的個人資料不會被公開，明白本人提供的資料及錄音會在研究計劃完成後銷毀。

研究人員已向本人清楚解釋列在所附研究程序上的資料，本人明瞭當中涉及的利益及風險；本人自願參與研究項目，並同意參與提供個人意見。

本人知悉本人有權就程序的任何部分提出疑問，並有權隨時退出而不受任何懲處。

參與者簽署 ：____________________________
參與者姓名 (正楷) ：____________________________
家長或監護人 (如適用) 簽署 ：____________________________
家長或監護人 (如適用) 姓名 ：____________________________
研究人員簽署 ：____________________________
研究人員姓名 ：____________________________
日期 ：____________________________

備註： 就有關上述研究細則，可聯絡宏恩基督教學院社會工作學院陳家傑博士電話：5804 4140

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