



FUTURE CARE PLANNING

for persons with
intellectual
disability

WHAT WOULD YOU DO?



James is a 48-year-old male with Down syndrome. He has moderate intellectual disability (ID), suffers from obstructive sleep apnea and has limited mobility. James lives with his parents who are in their 70s, each having health conditions of their own. He has a younger sister who is married with two children and lives separately from James and his parents.

James' parents are worried about his well-being once they pass away. They hope their daughter will be able to help take care of her brother. They have heard from friends that they need to apply for a deputyship so that she can take on this role in future. They have come to you to seek your help in this application. How would you respond to this request?



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IMPORTANCE OF FUTURE CARE PLANNING

As persons with intellectual disability (ID) live longer and their caregivers age, questions surrounding who will take on the care of these individuals with ID and how they will be cared for come to the fore. Uncertainty about the future is a source of significant amounts of stress for caregivers and their families. Caregiver stress has a negative impact not only on the health of caregivers themselves, but also on the care recipient.

From a national perspective, addressing this issue of planning for the future care of persons with ID is also of concern. Neglecting this issue is likely to result in higher healthcare and social costs due to long-term hospital admissions and premature institutionalisation.

Given the nature of the healthcare profession, it is not uncommon for clinicians to find themselves facing questions from patients related to future care planning. Individuals may request for memos to withdraw money from their care recipients' bank accounts. They may ask for assistance with deputyship applications or for help with securing accommodation for their loved ones.

This booklet aims to provide a framework for approaching future care planning for persons with ID. In addition, it will provide guidance on how to respond to requests for deputyship applications and where to direct patients to for further assistance.



GOAL OF FUTURE CARE PLANNING

Uncertainty over the future of the person with ID contributes to caregiver burden, and neglect to plan for the future may result in significant cost to both the individual and the country. However, the primary goal of future care planning is not to reduce caregiver stress nor to save cost, important as these goals are.

The primary goal of future care planning is to ensure that individuals with ID receive the support and care they need to lead happy, healthy, and fulfilling lives. With this goal in mind, the overarching questions of the future care planning process should be “What is in the best interest of the patient today and in the future?”

What can we do today to safeguard the future biological, psychological and social health of the individual with ID in the eventual passing of his current caregiver?”

Answering these questions will require consideration of factors in different domains of an individual’s life and care needs.



FUTURE CARE PLANNING FRAMEWORK

The following diagram illustrates the various aspects of care that need consideration in the future care planning process.



Fig 1: Aspects of care.

A. Mental Capacity

Applying a person-centred approach, the person with ID is placed at the centre of the FCP framework. The mental capacity of the PWID to make decisions for himself will influence decision making in all the other domains of care. It is important to have a good grasp of what mental capacity is, how it is determined and the implications of certifying an individual to lack mental capacity.

Therefore, familiarity with the Mental Capacity Act in Singapore and how it is applied is necessary when approaching FCP. This will be covered in more detail in the next section of the booklet.

B. Personal Welfare

Personal welfare encompasses the individual's:

- Ability to manage daily living tasks
- Housing and living arrangements
- Education and employment
- Recreation
- Social relationships
- Safety

FUTURE CARE PLANNING FRAMEWORK

The ability of the individual to make and execute decisions in this domain of his life will influence other areas such as, whether or not he or requires a caregiver and/or deputy, and if so, the role of these individuals. The factors are also inter-related. For example, where a person lives will likely influence who he socialises with, access to employment and his personal safety.

In this area, personal values also come into play as the individual or his caregiver may prioritise certain aspects of personal welfare over others. For example, regular visits to siblings may contribute more to an individual's well-being than being employed in a sheltered workshop. An intellectual disability does not impair an individual's desire for relationship, meaning and purpose in life. It is important to take time to explore what brings the individual most joy and meaning. Plans for his future should protect and preserve these things.

C. Finances

Sufficient money is required to finance the daily living expenses as well as care needs of the individual with ID till his end of life. The amount required and source of these funds are matters of concern that may require the advice of experts in legal and financial institutions. In addition, the finances available for the individual with ID is also influenced by the financial needs of their caregivers as they too age and develop higher care needs. This must be considered and planned for carefully.



FUTURE CARE PLANNING FRAMEWORK

D. Legal considerations

In addition to the mental capacity act, laws surrounding ownership of property and the use of CPF monies and other financial assets have the potential to significantly influence the care decisions made for the person with ID. Seeking legal advice may be beneficial to the future care planning process. This is important as the choice of the donee(s) for the caregivers' lasting power of attorney and the contents of his/her will has to be congruent with the plans that are being made for the individual with ID in the event of the caregivers' loss of capacity and death.

E. Health and medical needs

Individuals with ID may require ongoing medical and health interventions. This likelihood increases with age especially

as persons with ID tend to age earlier than people in the general population and thus experience the medical conditions associated with aging earlier too. Thus, it is important that arrangements are made to ensure that they have access to the appropriate healthcare services. They may also require someone who can advocate for their medical needs. If so, an appointment of a deputy is required. The appointed person must have the ability to speak on behalf of the person in this area.



FUTURE CARE PLANNING FRAMEWORK

F. People

The future care planning process is often complex not merely because many factors have to be considered, but also because often many people have to be involved, consulted and at the minimum, considered. In particular, the values, needs and preferences of the current caregiver must be accounted for in the future care plan. This is because the well-being of the caregiver has direct implications for the well-being of the individual with ID. The caregiver must also be led to consider how their own functional decline and demise may affect the care recipient. We cannot overemphasise that future care planning for the individual with ID and their caregiver(s) must occur concurrently.

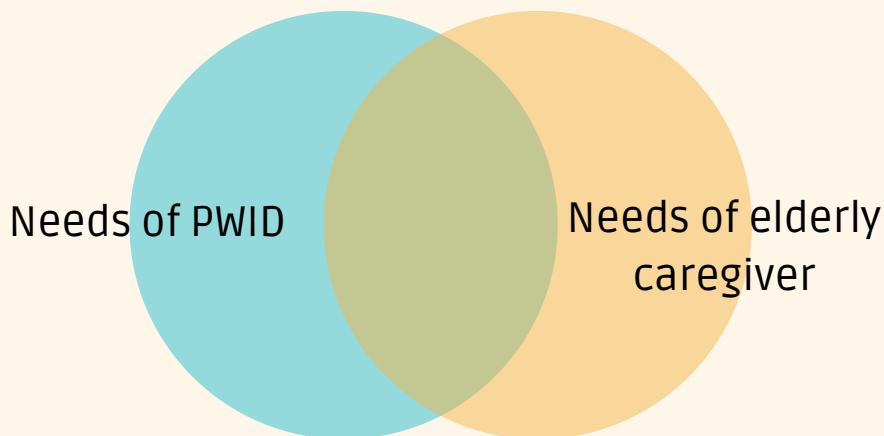


Figure 2: Interdependence of PWID and caregiver

During the process of discussion with various stakeholders, varying and sometimes conflicting opinions may be raised. It is important for the person facilitating the FCP process to remain objective and neutral as they listen to and facilitate conversation between multiple individuals. As strong opinions and emotions arise, the facilitator helps to focus the conversation on what will ultimately be in the best interest of the individual with ID. Selection and appointment of future caregivers and deputies should be made after careful consideration of all factors, and most importantly the relationship these individuals have with their future care recipients.

MENTAL CAPACITY ACT

The Mental Capacity Act (MCA) is a legal framework in Singapore that outlines how decisions should be made on behalf of individuals who lack mental capacity, including individuals with ID. It aims to protect the rights and welfare of these individuals and to support decision-making that is in their best interests.

The Act defines mental capacity as the ability to make decisions for oneself. An individual is considered to lack mental capacity if they are unable to make a specific decision at the time it needs to be made. This can be due to various factors such as illness, injury, or disability. Important to note in this definition that a judgement on the presence or lack of mental capacity is specific to what the decision is, and when it needs to be made.

In the context of FCP for persons with ID, the clinician's role is to determine whether or not the individual has the mental capacity to make decisions with regards to things like housing and living arrangements, health and medical needs, and the management of financial assets to meet their daily living needs. The clinician needs to keep in mind that the lack of men-

tal capacity to make one or one type of decision, e.g., how to manage one's money, does not automatically imply lack of mental capacity for decision making in another area e.g., housing and living arrangements. The clinician also needs to consider that the mental capacity of the individual with ID may decline in the future.



MENTAL CAPACITY ACT

When attempting to determine whether the individual with ID has the mental capacity to make particular decisions, the MCA states that the following principles be employed:

- **A person is assumed to have capacity unless it is established that he has no capacity.**

It is not uncommon that persons with ID are assumed to lack mental capacity to make any decisions for themselves. This is especially so because persons with ID often have expressive communication deficits that cause them to appear to understand less than they actually do.

- **A person is not to be treated as unable to make a decision unless all practical steps have been taken without success.**



With appropriate accommodations, many people with ID can be assisted to make decisions for themselves. These accommodations may include the use of visual aids, demonstration or simply slowing down one's speech.

MENTAL CAPACITY ACT

- A person is not to be treated as unable to make a decision merely because he makes an unwise decision.

Just like persons without ID, persons with ID may make unwise decisions, despite understanding the potential negative consequences of their actions. An unwise decision must not be taken as evidence of mental incapacity.

If the individual is deemed to lack the mental capacity to make decisions with regards to any area of his personal welfare, health and/or finances, it will need to be decided whether a deputy needs to be appointed to act on behalf of the individual. The MCA outlines that the deputy must act in accordance with the following two principles:

- An act done or decision made for or on behalf of a person who lacks capacity must be done or made in his best interests.
- Before the act is done or decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.



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WHEN IS DEPUTYSHIP NECESSARY?

In recent times, the deputyship application process has garnered a lot of attention. It is a misconception that a deputyship application is always necessary for individuals who do not have mental capacity to make decisions with regards to their future care. This is not true. According to Singapore law, a deputy is only one of four groups of people who can make decisions on behalf of a person without mental capacity. Importantly, the MCA makes provision for caregivers, doctors and nurses to make decisions on the care of the individual without mental capacity and on necessary medical treatment.

The future care planning process should begin with and focus on the patient and family's needs and values. These will then direct decision-making on the strategies and tools to be employed. The deputyship application is just one of many tools that might be employed in future care planning. Other tools include CPF nominations, wills, advance care plans and LPAs. With careful planning and creativity, a deputyship application may not be necessary.



So how is the decision for a deputyship application made?

WHEN IS DEPUTYSHIP NECESSARY?

Step 1

The key issue is whether there are decisions that need to be made by the individual with ID at that point in time or in the near future. Ask, "Does ___ need to make any decisions now or in the near future?"

Step 2

If there are indeed decisions to be made, the next step is to determine what they are. Ask "What decision does ____ need to make?"

Step 3

Determine if the person with ID has the mental capacity to make these decisions. Ask "What types of decisions is ___ able to make now?"

Step 4

Determine if there are alternative pathways to achieve the same goal. Ask "What options have you considered to achieve your goal of ___?"

WHEN IS DEPUTYSHIP NECESSARY?

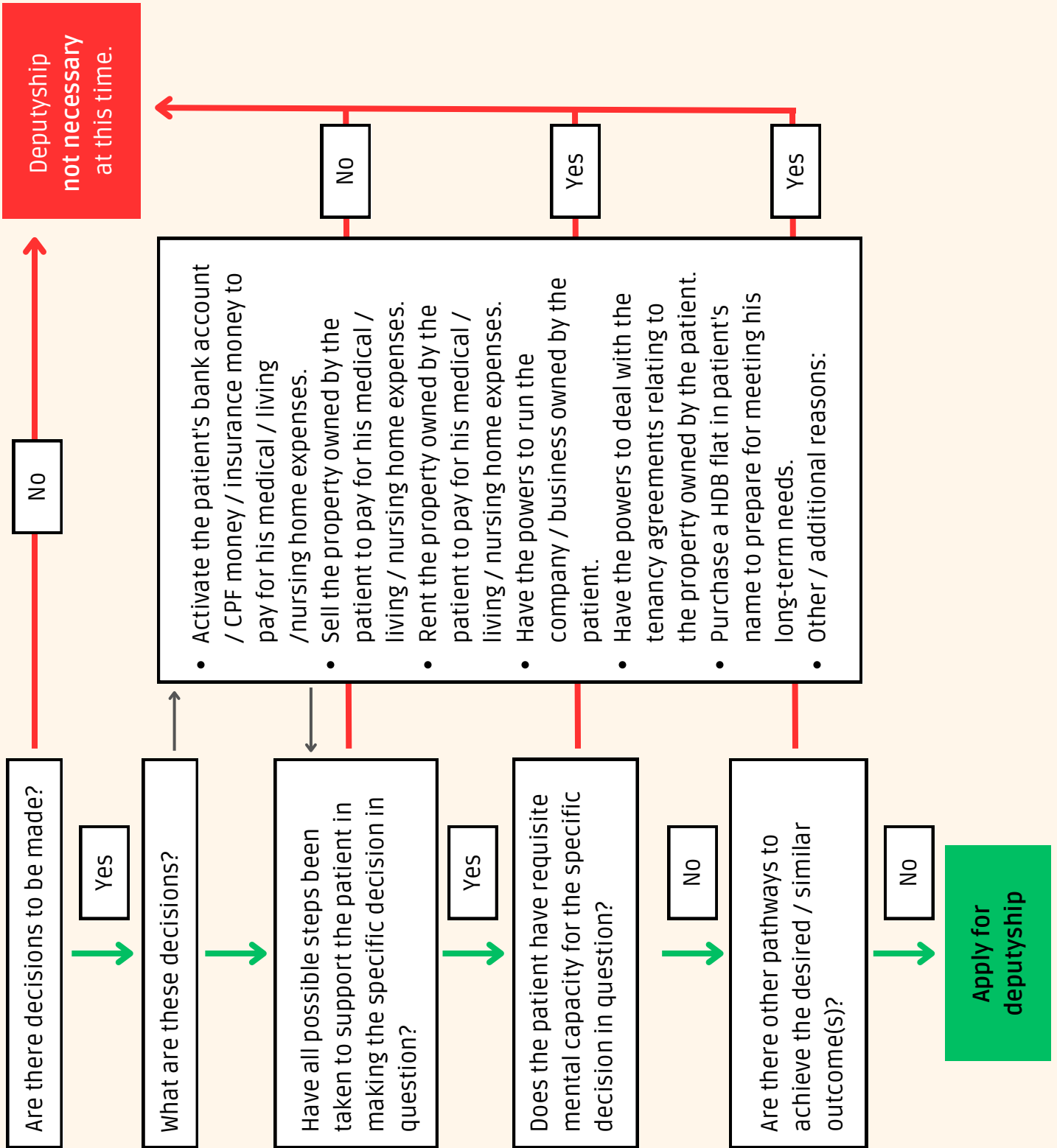


Fig. 3 Deputyship decision making algorithm



RESOURCES & REFERRALS

Recognising that clinic visits are often short, clinicians may not have the time to perform an in-depth assessment of the future care needs of the client, or make an appropriate judgement with regards to whether or not a deputyship application is required. In such scenarios, the clinician can consider referring the patient to the following organisations for assistance.

a. MINDS

MINDS has developed an online tool that guides caregivers to explore the legal, financial, health and accommodation options available when planning for their family member's future. Under the Assisted Deputyship Application Programme (ADAP), MINDS is also able to facilitate the simplified (online) deputyship application which limits the powers of the deputy to assets of less than \$80K.

MINDS – Caregivers Support
Services Centre
Telephone: 6547 8503
Email: cssc@minds.org.sg

MINDS – Disability Case
Management Programme
Telephone: 6547 8503 /
6805 1646
Email: dcmp@minds.org.sg



MINDS – Future Care Planning
Telephone: 6547 8503
Email: fcp@minds.org.sg

MINDS Hub Central @MINDS
clinic
Telephone: 6805 1643
Email: hub@minds.org.sg

RESOURCES & REFERRALS



b. IDHealth

IDHealth is a community-based integrated healthcare team that serves the healthcare needs of adults with intellectual disability. Refer a patient to this team for assistance with future care planning if the patient has at least one health condition (physical, mental or oral health) that requires management. Other common reasons for referral include behaviours of concern, difficulty performing medical procedures and high levels of caregiver stress.

IDHealth

Telephone: 6239 5770

Email:

info@happeehearts.com

Website:

www.happeehearts.com

RESOURCES & REFERRALS

c. Special Needs Trust Company (SNTC)

SNTC is Singapore's only non-profit trust company set up to provide affordable trust services for Singaporeans and its permanent residents with special needs.

SNTC's trust fees are highly subsidized by the Ministry of Social and Family Development. They partner with the Public Trustee to invest and safeguard the trust fund; therefore, the principal sum is guaranteed by the government. SNTC works with the caregivers to develop a financial care plan for the special needs beneficiary. This care plan is reviewed periodically to capture changing needs. An initial capital of \$5,000 is the minimum required to kick-start an SNTC trust account. The said trust can then be topped-up via moneys from estate planning. Guided by the wishes of the settlor (caregiver), SNTC will use the money in the trust account to provide for the special needs beneficiary.

SNTC journeys with the special needs beneficiary from the time the trust account is set up till termination of the account.



SNTC
Telephone: 62789598
Email: enquiries@sntc.org.sg
Website:
www.sntc.org.sg
www.facebook.com/SNTCSG

RESOURCES & REFERRALS

d. Kith and Kin Law Corporation

Kith and Kin's team of lawyers are committed to journeying with their clients across the lifespan. They specialise in succession, trusts, estate planning, mental capacity and later life. They are committed to understanding their client's unique needs and take a multidisciplinary approach to finding solutions.

Right: Tan Shen Kiat, CEO, founder and director

Kith & Kin
Email: hello@kithkinlaw.com
Website:
www.kithkinlaw.com
www.facebook.com/kithkinlaw
IG: @kithandkinlc



RESOURCES & REFERRALS



SG Enable
Telephone: 1800 8585 885
Email: contactus@sgenable.sg
Website:
www.sgenable.sg
www.enablingguide.sg

e. SG Enable (SGE)

SGE is the focal agency for disability in Singapore. They have developed the **Enabling Guide** which is a one-stop portal for all resources and services for persons with disability and their caregivers.



GUIDANCE FOR CAREGIVERS

The following are some practical suggestions for caregivers beginning the future care planning process.

1 Consider who your child is.

How would you describe your adult child? What are his/her likes and dislikes? Does he/she have preferences for food, living space, leisure etc.? What is most important to him/her? **Who** your child is will influence **what** your plans will be.

2 Plan for yourself.

Your health and well-being directly influence the health and well-being of your adult child. Caring and planning for your own needs is one of the most loving things you can do for your child.

3 Discuss with family & friends.

Involving family and friends in the process of planning for the future will help ensure that the concerns of all important members of the community surrounding your adult child are considered and addressed. It is not uncommon to discover that many in your community are willing and eager to journey with you. Future care planning can be an emotional process. Support is beneficial to help keep you persevering.

GUIDANCE FOR CAREGIVERS

4

Get help from professionals.

Professionals like lawyers, social workers and health professionals can assist you in understanding the legal, health, financial and social policies that may influence your care decisions. Where appropriate, they may help with applications for support services and subsidies.

5

Document.

Documenting your decisions is the process of putting your decisions in writing. Documentation can be formal e.g., will, LPA, deputyship court order or informal e.g., communication passport. This is done so that if or when you are unable to speak for yourself and your child, others in your support system can act in accordance with your wishes. This is one way you can protect your child from possible abuse.

6

Don't give up!

The process of planning and putting in place the necessary support structures for your child's future can be long and tedious. Think of it as a journey rather than a task. Persevere, taking just one step at a time. Your peace of mind and your child's welfare are worth the time and effort. Don't give up!

WHAT WOULD YOU DO?

Let's return to the case study on James, a 48-year-old male with Down syndrome whose parents are approaching their primary care physician for help with a deputyship application. What might be an appropriate response?

In response to James' parents, it may first be necessary to educate the parents that a deputyship on its own is not sufficient preparation for James' future. More information needs to be gathered. Questions may include:

- What aspects of care does James require?
- What decisions need to be made now or in the near future?
- To what extent can James be involved in decision making?
- What financial and other resources are available for James' care and that of his parents?
- Has James' sister agreed to care James in the future, and what does she understand that to mean?

The above are just some of the questions that need to be answered before a future care plan can be made.

Though they may not be part of the entire process of future care planning, primary care physicians, can assist families to begin the journey of future care planning for persons with ID by providing appropriate education, asking pertinent questions and referring them to the right service.

WHAT WOULD YOU DO?

As James had a health condition, he was referred to IDHealth where his immediate health needs were addressed. The IDHealth staff also facilitated a discussion with James' family about his future care. James' sister expressed that she was willing to care for James and have him live with her when their parents pass on. As James had no assets to manage and plans for his care in future was already clearly established, a deputyship application was not required. However, it was necessary to make LPA applications for both his parents.



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(MINDS)



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