CARING FOR PERSONS WITH INTELLECTUAL DISABILITIES

INTRODUCTION

This booklet is the first in a series on healthcare for persons with intellectual disability (ID). It is an introduction to how persons with ID might be received and cared for in a medical clinic.

Through the series, we aim to provide clinicians with relevant knowledge and practical suggestions on how to approach the care of people with ID. The series will include topics such as:

- Common genetic syndromes
- Overcoming communication barriers
- Approaches to behaviours of concern
- Physical health conditions in persons with ID
- Mental health disorders in persons with ID
- Aging in persons with ID
- Mental capacity and future care planning
- Managing polypharmacy in persons with ID

WHO WE ARE

IDHealth is an initiative of Happee Hearts Movement (a registered charity). It is a clinic and home-based service that addresses the complex healthcare needs of adults with ID and their caregivers. We cannot do this alone, so IDHealth works closely with many other health and social service partners.

In addition, the IDHealth team is committed to support and build capability within the healthcare ecosystem to serve this unique population. In writing this booklet, we hope that we will encourage you and many other health providers to open the doors of your clinics to people with ID. In doing so we believe that both your professional practice and your personal life will be enriched.

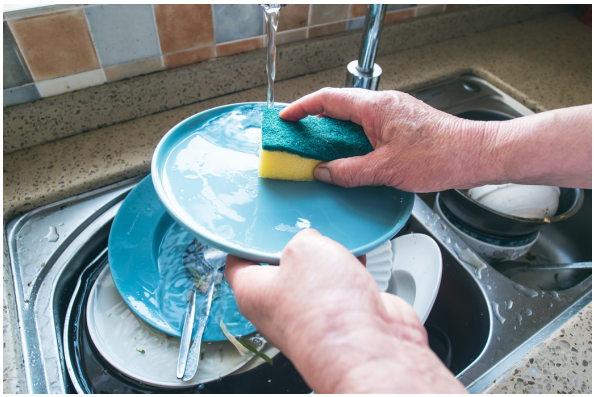
If you need support in the care of your patients with intellectually disability, please feel free to reach out to us at 62395770 (tel no.) or email info@happeehearts.com.

WHAT WOULD YOU DO?

John is 56 years old and has Down syndrome. He has also been diagnosed with hypertension and hyperlipidemia. He has been working as a dishwasher at a coffeeshop for the past 10 years. He is a reliable worker and has good relationships with everyone else at the coffeeshop.

Over the past half a year, his supervisor has reported to John's family that his performance has declined. The dishes are not cleaned well, and he has been dropping and breaking more plates. At times he seems confused. As a result, John lost his job.

Today John and his sister come to your clinic to seek your help with regards to his functional decline. How would you approach John? What are your immediate thoughts on this situation? What questions do you have? What assessments might you perform?



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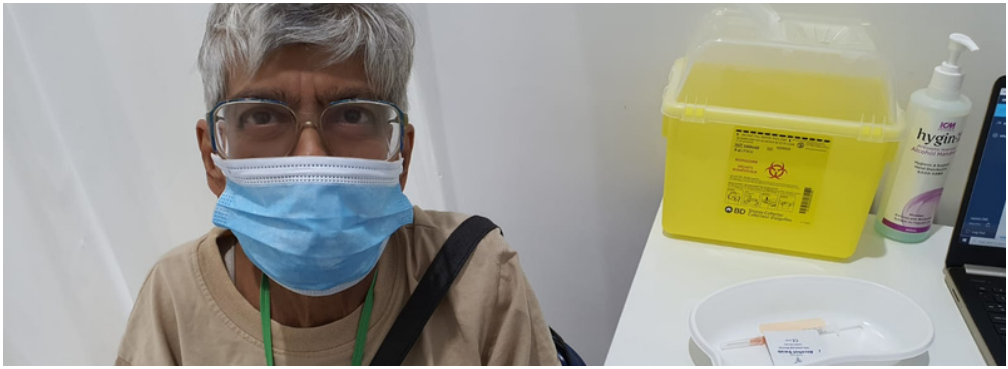
WHO ARE PEOPLE WITH INTELLECTUAL DISABILITIES?



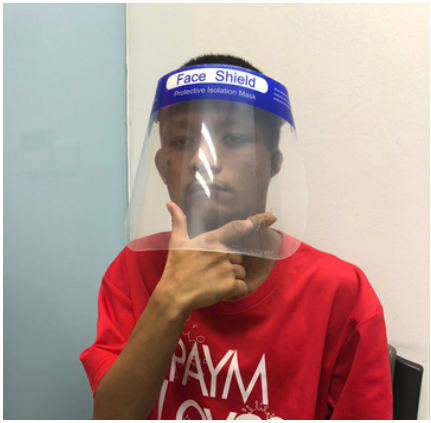
People with ID have difficulties with learning, reasoning and problem solving (cognition) as well as with daily living skills like self-care, communication and socialization (adaptive behaviour). These problems present in infancy and childhood and have implications for almost all areas of life throughout the lifespan. The IQ of < 70 was previously essential in the diagnosis of ID, however there's a gradual move away from relying on IQ and looking instead at overall function.

What does this mean practically?

People with ID tend to have limited vocabulary. They use simple rather than complicated words.
Therefore, use simple words and avoid medical jargon when speaking with them. For example, say "high blood pressure" instead of "hypertension".

Who are people with ID?

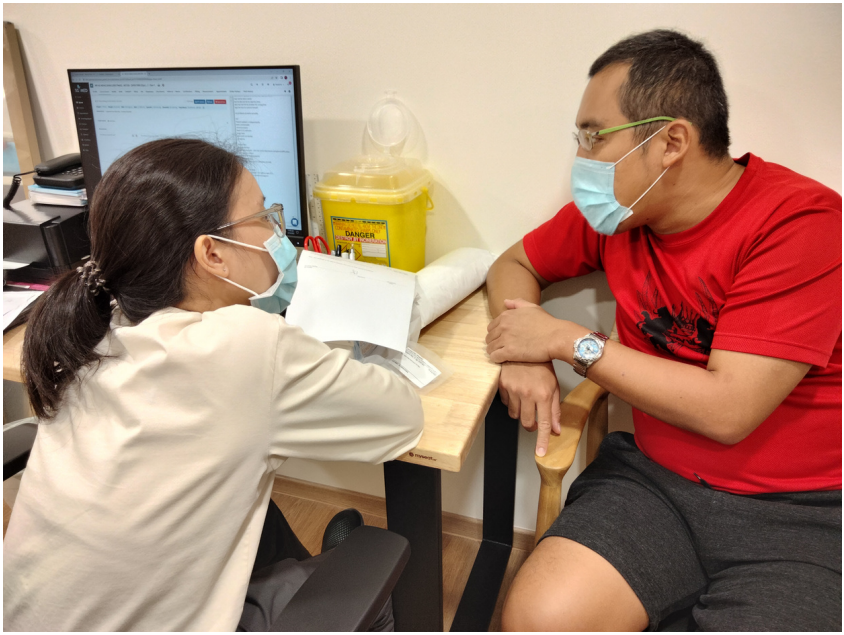
People with ID often take longer to process information and learn more slowly.
Speak slowly and allow for longer pauses between chunks of information. Be prepared to repeat things as necessary. Try not to bring up too many new topics or ideas in one conversation.



It is common for people with ID to have problems with speech, making it difficult to understand them.
Instead of ignoring them and speaking solely to their caregiver, you could suggest another way for them to let you know what they mean e.g., with action. Getting their caregiver to translate their speech is another option.

People with ID often have motor problems, making their physical movements awkward or uncoordinated.
Be aware of areas in your clinic that might increase the chances of bumps, bruises and falls e.g., narrow walkways or steps. Be prepared to respond to unpredictable movements.

Who are people with ID?



Some physical and mental health problems are found more frequently among people with ID than the general population. Please *refer to Appendix A* for a list of these and some suggestions on how to approach them.

People with ID may present with behaviours that are socially awkward or unacceptable for a variety of reasons.
These behaviours are not inherent to people with ID. Approaching the person with ID calmly, with curiosity and care will help in the process of discovering the reason(s) for these behaviours.

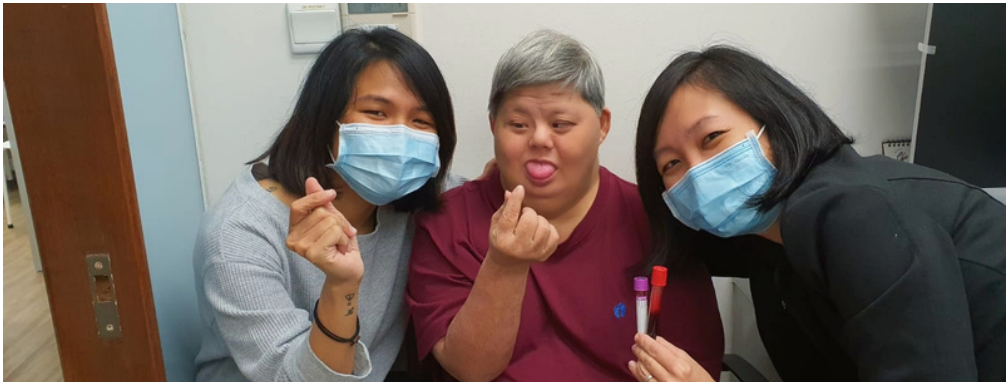
Who are people with ID?

Up to 9 in 10 people with ID are classified in the ***mild*** range. This means they are largely independent in daily living and have the academic ability of a primary school child. They can acquire simple job skills and use public transportation. However, they are likely to have difficulties with complex reasoning, judgement and in handling finances.

People with ***moderate*** ID's ability to read and write is likely limited to recognition of simple words and numbers. They require more vocational support as well as some assistance with practical daily living skills e.g., meal preparation.

People with ***severe*** and profound ID rarely acquire any academic skills. They typically require high levels of support from caregivers.

In your general practice, it is most likely that you will serve people who have mild to moderate ID. Despite having classifications, it is important to note that people with ID are a heterogenous group and their *abilities vary across a spectrum.* .



WHAT CAUSES INTELLECTUAL DISABILITY?

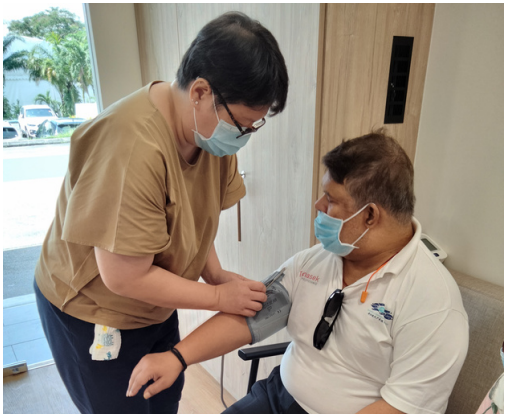
Intellectual disability can be a result of gene defects and syndromes, maternal infections during pregnancy, exposure to toxins, extreme malnutrition etc. However, in most cases of mild ID we often do not know the cause. On the other hand, for most cases of severe and profound ID, the cause is often genetic or related to structural brain anomalies.

As you prepare to receive people with ID in your clinic, it might be helpful to think about the patient visit in 5 stages:

1. Pre-visit preparation
2. The welcome
3. Assessment
4. Procedures and treatment
5. Follow-up

PRE-VISIT PREPARATION

1 **Make an appointment.**



This allows you to choose a time of day that will be most conducive for you and the individual with ID. You may want to pick a time slot where the clinic is least busy as people with ID may sometimes have difficulties waiting for a long time. You may also want to allocate more time for the individual than you normally would since every stage of the visit will likely take longer than a typical patient visit.

2 **Bring existing medication.**

If it is the patient's first visit, ask the individual to bring along samples of all the medication they are taking since it may be difficult for them to recall the names of the medication.

3 **Bring information regarding past health records and existing service providers.**

If it is the patient's first visit, ask the individual to bring along any health or social records. This can give you important information that the patient may not be able recall or communicate to you.

THE WELCOME

Consider what the individual experiences as they enter the clinic. What do they see, hear, smell and feel? People with ID may have sensory preferences and find it more difficult to transition between different environments. Environmental factors that may be adjusted to make transitions less stressful for these individuals might include:

- **Lighting:** Warm lighting may be more soothing than white light.
- **Sound:** Keep background music soft so it does not distract.
- **Smell:** You may want to consider keeping your clinic environment fragrance free by using cleaning products and toiletries without perfumes.

ASSESSMENT

The individual with ID is now in your consultation room. What should you keep in mind as you attempt to understand his or her complaint and figure out the cause behind it?

1 **Speak to the person with ID first.**

Until assessed otherwise, assume that the person with ID can understand you and respond appropriately to your questions. Often persons with ID have better comprehension than expressive ability. This is particularly so in persons with autism. Consult caregivers to corroborate what the patient says or to obtain clarification and more details.

2 **Be aware of atypical presentation.**

The person with ID often presents differently from a patient without ID with the same condition. This is often due limitations in their ability to verbally express their symptoms. For example, a person with ID may be unwilling to get out of bed, refuse meals or even present with agitation because of constipation.

3 **Beware of diagnostic overshadowing.**

Many health conditions in people with ID go undiagnosed because the signs and symptoms that they present with are wrongly attributed to the ID diagnosis when in fact they indicate a comorbid condition. For example, confusion could be a symptom of dementia or an infection.

ASSESSMENT

4 **Be mindful of common medical conditions.**

Some physical and mental health conditions are more common among people with ID than in the general population. Some genetic syndromes are also associated with increased prevalence of certain conditions. It is helpful to be aware of and look out for signs and symptoms of these. *Refer to Appendix A for a list of these common conditions.*

5 **Consider effects of aging.**

People with ID show signs and symptoms of aging earlier in life than people in the general population. Problems that arise among those in their 60s in the general population may begin to surface in people with ID who are in their 30s and 40s.

6 **Take a biopsychosocial approach.**

People with ID adapt less easily to changes in their physical and social environments. It would be helpful to ask about changes in routine, people and places in their life.

ASSESSMENT

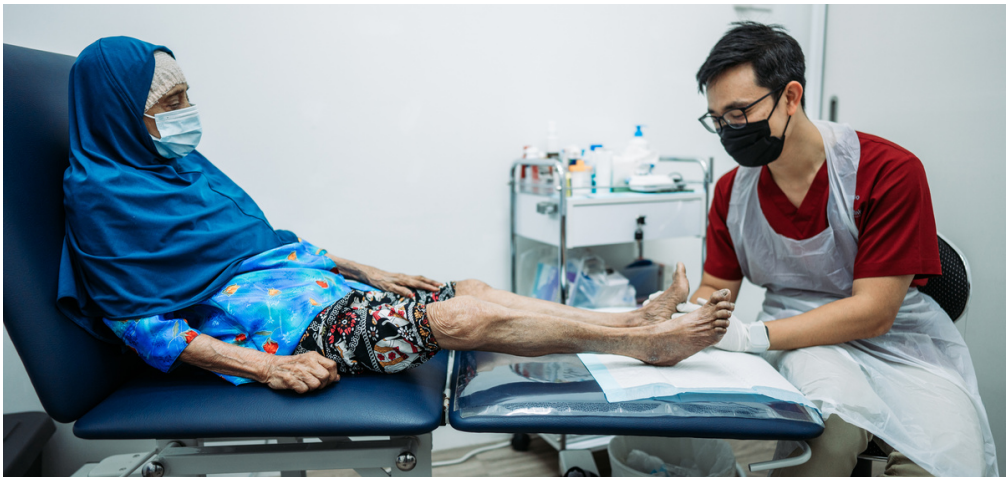
7 **Diagnose psychiatric conditions last.**

Before suspecting a diagnosis of a psychiatric condition, it is first necessary to address and eliminate physical, psychosocial and environmental reasons for signs, symptoms and behaviours of concern.

8 **Review patient medications.**

Polypharmacy is common in people with ID. Their presenting condition may be associated with side effects from existing medication and drug interactions.

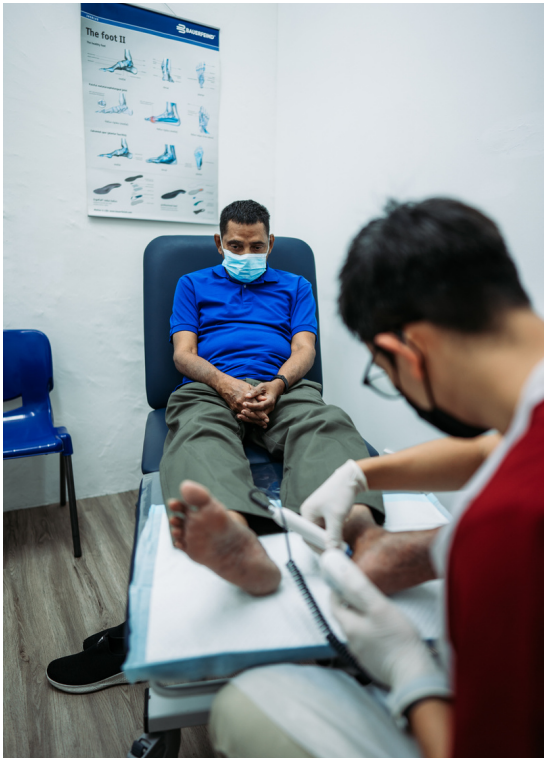
PROCEDURES AND TREATMENT



1 **Explain simply.**

Before starting an assessment or treatment procedure, tell the patient what you are about to do. Find out how the person with ID usually communicates. Where appropriate, use easy-to-read material or pictures to assist with explanations *(refer to Appendix C for an example)*. Ensure that you communicate with both the person with ID and their caregiver (if they are accompanied).

PROCEDURES AND TREATMENT



2 **Hesitate to prescribe medication for behaviours of concern (BOC).**

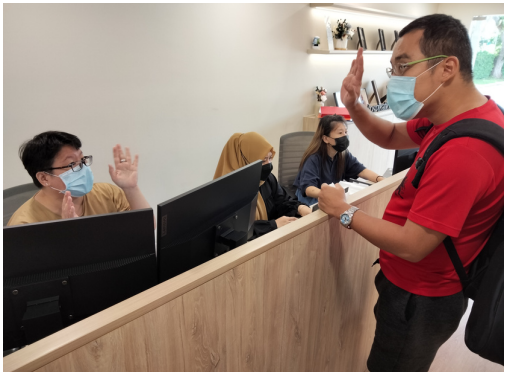
BOC are "behaviours of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy, or behaviours which are likely to seriously limit or deny access to the use of ordinary community facilities."

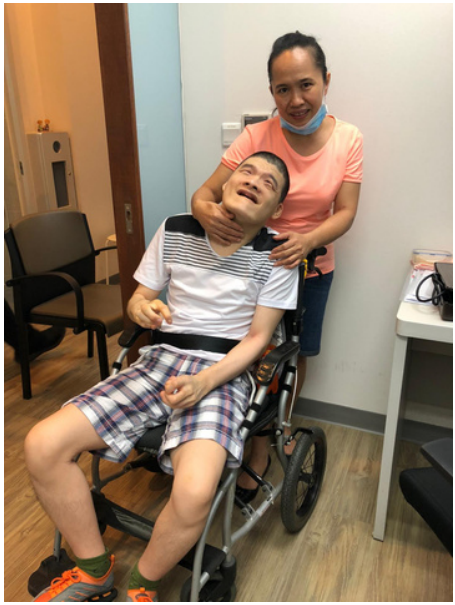
When addressing BOC always consider *non-pharmacological* interventions before prescribing medication. If medication is needed, it should be prescribed at as low a dose for as short a time as possible. *Refer to Appendix B for more details.*

FOLLOW-UP

1 **Monitor for effectiveness.**

Schedule a follow up appointment to monitor the effectiveness of treatment since response may be atypical and require timely modification.





2 **Consult other service providers.**

Consider communicating with other health or social service professionals who also care for the client. They can assist in monitoring and ensuring compliance with treatment.

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APPENDIX A: COMMON HEALTH CONDITIONS

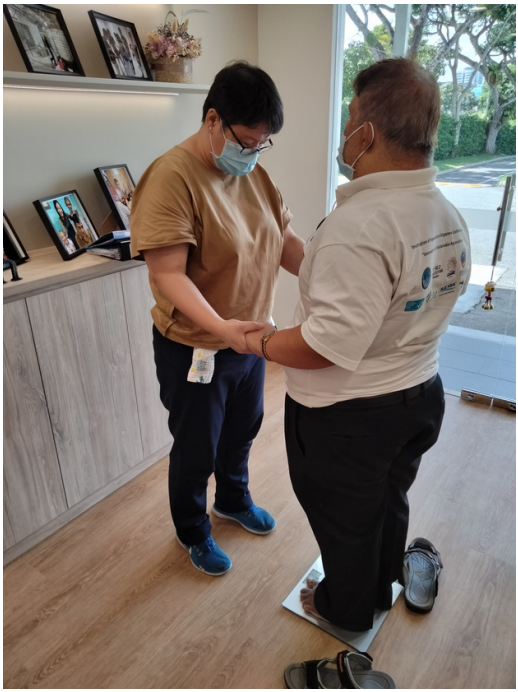
Health Condition	Suggested Action
Physical inactivity and obesity	Monitor weight trends and BMI.
Vision and hearing impairments	Perform annual clinic-based screening (e.g., Snellen eye chart and whisper test). Functional tests and questions can be used as well (e.g., Can the individual pick up small objects?)
Oral disease	Monitor oral health and ask about their diet.
Cardiovascular disease	Screen for CV risk factors (e.g., Hypertension, hyperlipidemia, diabetes) as you would in the general population. However, consider screening earlier if there are higher risks such as increased BMI and high fat diets. Promote prevention.
Respiratory disorders	Assess for swallowing difficulties which can lead to aspiration related chest infections
Gastrointestinal problems	Ask about GERD symptoms and bowel movements.
Women's gynecologic and reproductive health	Ask about menstrual-related symptoms and concerns regularly. Pregnancy should be considered in females with ID if there are suggestive symptoms.

APPENDIX A: COMMON HEALTH CONDITIONS

Health Condition	Suggested Action
Neuromuscular and skeletal disorders	Promote mobility and regular physical activity. Screen for osteoporosis when there is risk for falls or conditions that increase risk of osteoporosis such as thyroid disease and long-term usage of antiepileptic medications.
Epilepsy	Review frequency of seizures and the usage of antiepileptic medications.
Endocrine disorders	Monitor thyroid function in patients with elevated risk (e.g., screening in people with Down syndrome every 1-2 years).
Infectious disease	Include patients with ID in routine immunization programmes such as influenza and pneumococcal vaccines.
Sleep problems	Screen regularly for sleep problems including obstructive sleep apnoea and associated caregiver stress. Review medications and other factors that might affect sleep.
Psychiatric disorders	Screen for antecedents, life events and other triggers of mental distress. Consider depression, anxiety and psychosis as they are more common in persons with ID compared to the general population.

APPENDIX A: COMMON HEALTH CONDITIONS

Health Condition	Suggested Action
Dementia	Assess for progressive cognitive and functional decline. Particularly in persons with Down Syndrome, symptoms of dementia can start as early as 30s and 40s.
Dermatological conditions	Assess for eczema and dermatitis. Examine their nails and assess their foot health (e.g., Calluses, bunions, bony deformities). Check that footwear fits well.



APPENDIX B: BEHAVIOURS OF CONCERN

Behaviours of concern are “culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities.” (Emerson & Bromley, 1995)

A thorough and holistic assessment of the patient with ID, considering all biological, psychosocial and environmental factors, is an absolute pre-requisite in the management of BOC.

Clearly document details about the BOC.

- List the target BOC to be managed with a precise description of each.
- Document the frequency and severity of the BOC.
- List possible causes (biological, psychological and environmental) of the BOC.
- Evaluate triggers and outcomes of the BOC. This can be done using the ABC recording method:

APPENDIX B: BEHAVIOURS OF CONCERN

Antecedent (A)	Behaviour (B)	Consequence (C)
What happened directly before the behaviour occurred.	Specific behaviour of interest.	What happened directly after the behaviour occurred.

It is helpful to view BOC as a form of communication of need, desire or discomfort. After determining the purpose of the BOC, a useful principle of management would be to replace the functional but inappropriate behaviour with one that is more appropriate. For example, teaching the person with ID to point to a picture or an object to express need instead of shouting.

Below are some situations where clinicians may consider using medication to manage BOC:

- To treat an underlying mental health disorder
- Failure of non-pharmacologic interventions
- Significant risk/evidence of harm/distress to self, others, or property
- To calm the person to enable implementation of non-pharmacological interventions
- Risk of care or placement breakdown

APPENDIX C: EXAMPLE OF EASY-READ MATERIAL

We are working on a series of similar material to assist you in communicating with patients with ID.

Taking your blood pressure

Taking your blood pressure tells us how well your heart and blood vessels are working.

Step 1: I will put a cloth cuff on your upper arm.

Step 2: I will connect the cuff to a machine.

Step 3: When I press the button on the machine, air will be pumped into the cuff and squeeze your arm **tight**. There will be **no pain**.
After a few seconds the cuff will loosen.

APPENDIX D: RESOURCES

- **SG Enable** is the focal agency for disability and inclusion in Singapore. Their website provides links to various resources for people with disabilities, including those with intellectual disability. https://www.sgenable.sg/

- **The Enabling Guide** produced by SG Enable lists services and resources for persons with ID. https://www.enablingguide.sg/disability-info/intellectual-disability

- **The Adult Neurodevelopmental Service (ANDS)** is a service in the Institute for Mental Health (IMH) for adults with ID and/or autism spectrum disorder (ASD), with co-occurring mental health conditions.

- **MINDS Developmental Disability Clinic** provides comprehensive health screening for persons with ID. They are also able to make referrals to and connect patients with other medical services. Each of their patients will also receive a health passport that details their medical conditions, communication skills, mobility needs and BOC. Tel: 68051643 Email: mddmc@minds.org.sg

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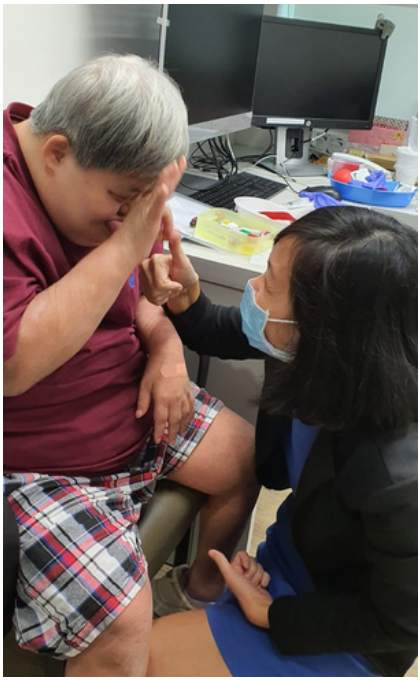

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We would like to thank all the persons with intellectual disabilities and their families who have allowed us the privilege of serving them and being a part of their lives. Our lives have been enriched because of them. We'd like to specially thank the following patients and caregivers who have allowed us to use their photographs in this booklet:

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CARING FOR PERSONS WITH INTELLECTUAL DISABILITIES

Pre-visit

Make an appointment.

Welcome

Warm light. Soft music. Fragrance-free.

Assessment

Assume understanding. Speak to patient first.

Beware of diagnostic overshadowing.

Think outside the box. Query atypical presentation of common conditions.

Take a biopsychosocial approach.

Treatment & Procedures

Explain using simple words.

Use easy-to-read material, pictures or diagrams.

Hesitate to medicate for behaviours of concern.

Follow up

Monitor for effectiveness.

Consult other service providers.

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MOVEMENT

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