OVERCOMING
COMMUNICATION BARRIERS

Healthcare for
People with Intellectual Disability

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VISITING
THE DOCTOR

Alan is 50 years old. He has mild intellectual disability (ID). He works at a supermarket, helping in the storage area and ensuring that the shelves are always restocked. Today, Alan has taken leave to see a GP near his home because he is running low on his hypertension medication. The GP clinic is busy as usual, and he waits for 30 min before the doctor sees him. Dr. Tan has been seeing him for many years. With a quick, "How are you?" he takes Alan's BP and finds that it is higher than normal for the third visit in a row.

Dr. Tan: Your BP is high. I'm going to give you another medicine ok.

Alan: Ok.

Dr. Tan: You take and monitor. If any side-effects, let me know, but there shouldn't be any problem.

Alan: Ok.

Dr. Tan: So, any other issues? Any dizziness recently? Headache? Sleeping ok?

Alan: Ah... ok.

Dr. Tan: Great! I'll see you in 3 months' time! Just wait outside. The nurse will give you the medication.

VISITING
THE DOCTOR

Alan collects his medication and heads home. He has been thinking about what the doctor said about starting a new medication. He wonders if he should start the new medication immediately or if he should wait till he finishes the existing lot of his 'old' medication before starting the new one. But now he's home, he has nobody to ask. Also, he wonders what side-effects are. And he remembers that he forgot to tell the doctor about the knee pain that he's been having when climbing the ladder at work. He shrugs his shoulders; he'll just have to remember the next time.
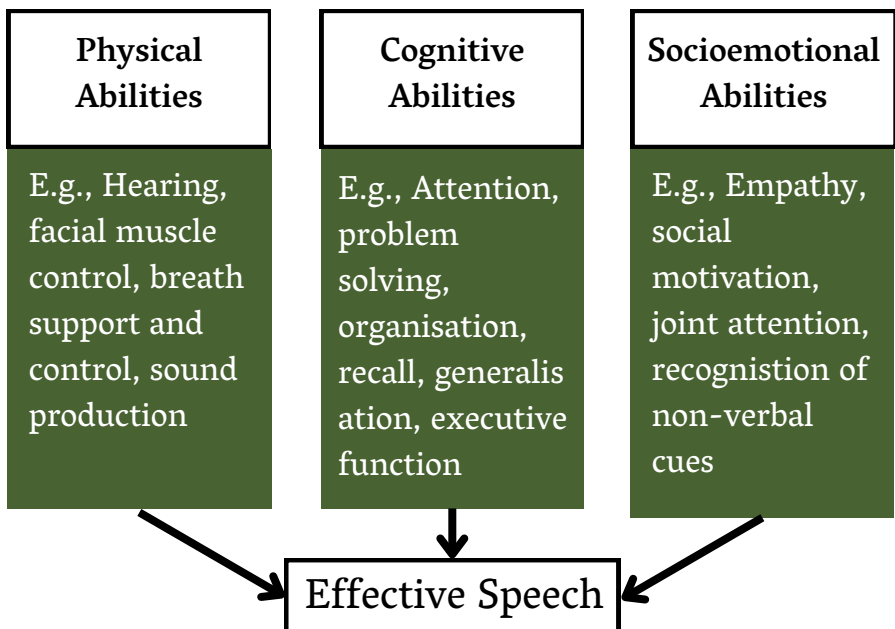
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INTRODUCTION

The above scenario describes a typical interaction between a patient and their GP. The outcome of such an interaction would be acceptable if not for the fact that the patient has ID. Appropriate and effective healthcare delivery is dependent largely upon obtaining and delivering accurate and reliable information between doctor and patient. Health professionals use information from patients to form and test hypotheses before making diagnoses. Patients act on the advice given by their health professionals. Barriers to effective communication prevent people with ID from accessing appropriate healthcare and thus contribute to the overall poorer health status of this group of individuals compared with the general population. This resource will:

- Describe common communication difficulties faced by people with ID.
- Describe three communication profiles among people with ID.
- Suggest strategies that can be employed to improve communication with persons with ID in a healthcare setting.
- Describe communication tools developed by IDHealth and guidelines on how use them.

COMMUNICATION
DIFFICULTIES

Communication is a broad term used to refer to the exchange of information between two parties. This exchange can be achieved in various ways, of which speech is one. Speech is the verbal expression of language. Language is a structured system of symbols used to express meaning. Most of us are unaware of the complexity surrounding the ability to understand spoken language and the ability to speak effectively. It in fact requires a combination of biophysical, cognitive and socioemotional abilities.

Physical Abilities	Cognitive Abilities	Socioemotional Abilities
E.g., Hearing, facial muscle control, breath support and control, sound production	E.g., Attention, problem solving, organisation, recall, generalisation, executive function	E.g., Empathy, social motivation, joint attention, recognition of non-verbal cues

Effective Speech

COMMUNICATION
DIFFICULTIES

People with ID often have deficits in more than one of the above-mentioned categories of abilities though by definition their main deficits are in their intellectual functioning i.e. cognition.

For example, people with Down Syndrome, in addition to their intellectual deficits, often have auditory deficits. Their tongue is often large in comparison to the size of their mouth, and this affects the intelligibility of their speech. Consider also people with ID who have co-occurring autism spectrum disorder. In addition to their reduced cognitive skills, they also have deficits in social skills and an inflexibility in the way they process and respond to information. In combination these would make communication using speech a significant challenge, depending on the severity of their ID and ASD.

COMMUNICATION
DIFFICULTIES

By now it may be apparent that the ability of people with ID to learn and use speech is varied given that there are unlimited ways and degrees to which an individual may be affected by their disability. However, limitations in speech do not equate to an inability or a lack of desire to communicate. Communication is far more than the ability to speak words and string sentences together. Reuel Howe said that "It is false to assume that if one can talk he can communicate." The opposite is also true – that it is false to assume that if one cannot talk that he cannot communicate.

It is the premise of this resource that people with ID, no matter their ability, desire to communicate as an overflow of desire to connect with other human beings. It is the desire to understand, and to be understood. Therefore, it is imperative that appropriate support is provided to enable them to do so.

> "
> ...it is false to assume that if one cannot talk that he cannot communicate.
> "

COMMUNICATION PROFILES

Based on assessments done by speech therapists on a group of patients with ID who attend the IDHealth clinic, the communication ability and support needs of people with ID can be categorized into three communication profiles.

Profile by Ability		
Adequate Ability	Limited Ability	Limited Engagement
Profile by Support Need		
Easy Read	Visual Support	Communication Passport

NB. The fourth section of this booklet will describe in greater detail what Easy Read Materials, Visual Supports and Communication Passports are and provide guidelines on how they should be used.

COMMUNICATION
PROFILES

Adequate Ability / Easy Read

- Usually able to say at least one word.
- Sufficient ability to understand basic information and instruction.
- Adequate ability to communicate health-related signs and symptoms through speech with high level of accuracy.
- Difficulty with higher level reasoning or memory.
- Either able to read and comprehend text themselves or can understand information read to them.

Alan, who was mentioned in the above case study, would be categorized as having "Adequate Ability" and would benefit from Easy Read materials to support his understanding of his health condition and the steps he needs to take to care for his health. Overall, he understands that he needs to take medication but he may have trouble making the lifestyle changes necessary to prevent worsening of his hypertension.

Limited Ability / Visual Support

- Limited receptive and expressive ability.
- May or may not use speech or spoken language to communicate.
- Inconsistent and thus less reliable responses to verbal questions and instructions. Have relative strengths is visual rather than auditory processing
- Visual abilities sufficient to discriminate between small pictures and motor abilities sufficient to point to pictures.

Cheryl, a 25-year-old lady with Down syndrome and moderate ID. She is very sociable and chatty, however much of her speech is difficult to understand. She responds to questions with single words or short phrases. Sometimes she echoes the last word of the question asked. Her mother, who is her main caregiver, indicates that at least half of her answers to questions are incorrect. In addition, Cheryl easily gets distracted by objects in the clinic. She repeatedly reaches out to touch the BP machine and the doctor's stethoscope. Cheryl would meet the criteria for the "Limited Ability" communication profile. Visual supports would help Cheryl focus on the conversation and increase the accuracy of her responses.

COMMUNICATION
PROFILES

Jedidiah, 30-year-old man with cerebral palsy and severe ID. Jedidiah is a wheelchair user and is dependent on helper for all his activities of daily living. When spoken to, he inconsistently turns his head towards the speaker. He does not respond to touch. When shown pictures he appears to look past them. As a result of his cerebral palsy, Jedidiah's arms are often in a flexed position. His helper reports that sometimes he will be observed to be kicking his legs and smiling. She also reports that he cries when the television is on too loud at home. A communication passport that describes Jedidiah's typical responses to particular stimuli would help health professionals understand how best to approach Jedidiah and what kind of responses they should expect and how to interpret them.

Limited Engagement / Communication Passport

- Minimal to nil response to various stimuli (auditory, tactile, visual).
- May vocalise (i.e. produce sounds) but generally do not use speech.
- Often have associated sensory (e.g. visual or hearing impairment) or physical limitations (inability to point).

COMMUNICATION
STRATEGIES

Every individual with ID will have traits unique to their style of communication. However, there are general strategies that can be employed in most situations to improve understanding and facilitate more reliable responses in this population. Even if a caregiver is present, begin by speaking first to the individual with ID before speaking with the caregiver. This demonstrates respect for and value of the individual. The strategies presented in the following pages can be applied to people with ID as well as those with autism.

COMMUNICATION
STRATEGIES
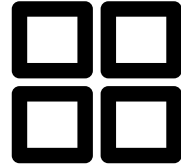
Strategies to improve UNDERSTANDING

Assess readiness to receive information:
Is the patient calm and paying attention?
Can the patient hear and see clearly?

Organise information:
Help patients to group or categorise
information. Explain the relationship
between individual pieces of information.

Speak slowly and clearly:
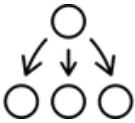Slowing down gives time for the patient to
process what you are saying.

Use simple language:
Speak in short sentences and avoid the use
of jargon.

COMMUNICATION
STRATEGIES

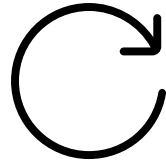### Strategies to improve UNDERSTANDING

Use multiple modes of communication: Information may be presented through speech, gestures, images etc.

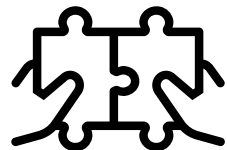**Use repetition:** Ask for the same information in different ways.

Use concrete examples: Concepts like time are abstract. Using events like breakfast, lunch and dinner may help with understanding of routine.

Check understanding: Asking the patient to explain what they heard you say will help you assess how much they understood.

COMMUNICATION
STRATEGIES

Strategies to improve RESPONSE

Ask one question at a time:
Asking multiple questions in succession may confuse patients. It may not be clear which question they are answering.

Double confirm responses for reliability:
You may do this by repeating the question or asking it a different way.

Facilitate transitions between topics:
Inform the patient that you have finished talking about the current topic and are moving to the next.

Wait!:
Give time (10 sec) for the patient to respond after asking a question. Allow them to finish their sentences.

COMMUNICATION
STRATEGIES

Strategies to improve RESPONSE

Be investigative:
Asking multiple questions in succession may confuse patients. It may not be clear which question they are answering.

Use visual aids:
Provide an alternative to point to a word, image or object to express themselves.

Provide binary choice (choice between 2 options):
Choosing between 2 options may be easier than answering Y/N.

COMMUNICATION TOOLS

The following communication tools were developed by IDHealth to address the communication barriers to appropriate healthcare for people with ID. The tools were designed to be used in healthcare settings in Singapore. In particular, they were designed with the IDHealth clinic, GP clinics and polyclinics in mind.

Recognising that clinicians require accurate and reliable information from their patients to guide their clinical reasoning, diagnosis and treatment decisions, these tools have been developed with the aims of:

1. Facilitating understanding of health-related questions.
2. Obtaining accurate and reliable health-related information.
3. Facilitating health-related procedures.
4. Facilitating understanding and application of health education.

HEALTH ID

My Health ID

IDHealth
AN INITIATIVE BY
HAPPEE HEARTS
MOVEMENT

I have an
intellectual disability.

I communicate differently from you.
Please speak slowly and in a calm tone.

Please call my care team
Main line: 6239 5770
Nurse:
Social worker:

600 Upper Thomson Road Blk E #01-43
Upper Thomson Community Hub S574421

● **Purpose**

- To identify patients with ID who are under the care of the IDHealth team.
- To provide a means to contact the identified nurse and social worker for more detailed information where necessary.

● **Description**

The Health ID is a wallet-sized card that:

- indicates that the patient has an intellectual disability.
- has the contact numbers of the IDHealth nurse and medical social worker caring for the patient.

HEALTH ID

● **Guidelines on use**

The Health ID is issued to all patients under the care of IDHealth. It is kept by the patient or caregiver. It is presented to the attending clinician in settings such as a GP clinic, polyclinic or even an emergency room, usually during acute medical situations. This will highlight that the patient has an intellectual disability and may require necessary adjustments to the assessment and treatment process. If the clinician requires more information on the patient's medical history and finds it difficult to obtain from the patient or caregiver, they may call the phone number(s) on the Health ID to contact a IDHealth team member who will be able to provide him with the relevant history.

● **Benefits**

The Health ID facilitates communication between healthcare providers of the patient with ID. Sharing of information allows for a more complete picture of the patient's health status and thus more accurate diagnoses can be made and more effective interventions can be implemented.

COMMUNICATION PASSPORT

● **Purpose**

To provide GP or other health professionals with information on the communication profile of the patient in relation to how he or she may present in a healthcare setting.

● **Description**

The Communication Passport is a 1-2 page document that includes information on:

- How the patient usually responds during medical procedures and the type of support needed to facilitate the procedure.
- Receptive ability:
  - Language the patient understands best
  - What the patient can and cannot understand
- Expressive ability:
  - The reliability of responses e.g., yes / no
  - Form of expression e.g., speech, gestures, writing
  - Meaning of behaviour unique to the individual

COMMUNICATION PASSPORT

● **Guidelines on use**

The communication passport is filled in by the IDHealth team in consultation with the patient and/or caregiver. In order for the information to be accurate and beneficial, it needs to come from people who know the patient well and have experienced performing medical procedures on the patient.

This document will be handed to the healthcare provider who will either be sharing care with IDHealth or taking over the care of the patient (e.g., a GP). The communication passport will complement a memo written by the IDHealth physician that will contain the patient's medical history and suggested follow up plans. During handovers, a IDHealth team member will usually accompany the patient and bring along the two documents. The receiving healthcare provider will be encouraged to contact the IDHealth team for more details if necessary, or for support if the patient's health status changes.

COMMUNICATION PASSPORT

- **Benefits**

This document provides clinicians with information that will help them to communicate in a way that reduces distress and confusion, while developing understanding, trust and rapport with the patient. The latter goes a long way in obtaining the patient's cooperation with medical procedures that might be uncomfortable but necessary so that measures can be taken to improve the patient's health. Though designed initially for patients who have "Limited Engagement", it can also be used for patients in other communication profiles for when their ability to communicate is impaired (e.g. when they are unwell or dysregulated) or as supplemental information when handing over care from one health provider to another.

AUGMENTATIVE & ALTERNATIVE COMMUNICATION (AAC)
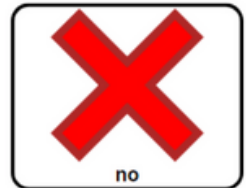# VISUAL SUPPORT

● **Purpose**

- Increase patient's engagement and involvement with the healthcare encounter.
- Increase understanding of healthcare related questions.
- Obtain more accurate and reliable information that form the basis of diagnosis and intervention.
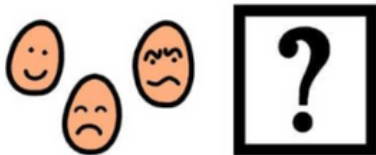
How are you **feeling?**

pain

no pain

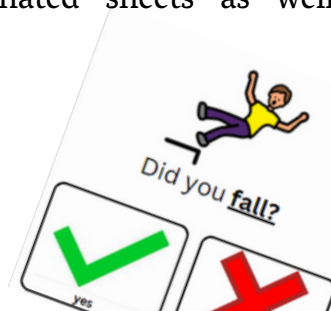Did you take **medication?**

yes

no

AUGMENTATIVE & ALTERNATIVE COMMUNICATION (AAC)
VISUAL SUPPORT

● **Description**

Augmentative and Alternative Communication (AAC) are all the ways that someone communicates apart from talking. AAC either adds to the speech that the individual has or provides another means of communication. There are different forms of AAC. The IDHealth team has developed two types of AAC – visual support, communication board and easy-read materials.

The visual support is a series of images that are designed for use in a healthcare setting by a doctor or other healthcare professional to complement the verbal questions asked and to provide an alternative means for the patient to respond to these questions i.e. to point to images or words instead of speaking. The visual support comes in both laminated sheets as well as electronic (PDF) form.

AUGMENTATIVE & ALTERNATIVE COMMUNICATION (AAC)
VISUAL SUPPORT

● **Description**

The first few pages of the visual supports orientate the patient to person and place. Going through these few pages with the patient also serves as an assessment for the receptive and expressive ability of the individual.

The following pages of the visual support are categorized according to topics, such as feelings, pain, bowel and bladder habits, food, falls and exercise. They are then arranged according to frequency of use. The order of the pages can be rearranged to fit the questioning style of the user. Pages can be easily added or removed from the tool as appropriate.

AUGMENTATIVE & ALTERNATIVE COMMUNICATION (AAC)
VISUAL SUPPORT

● **Guidelines for use**

The visual support is kept in clinic or other healthcare setting. It is meant for use with patients who are categorized within the 'Limited Ability' communication profile. As the clinician speaks, he/she points to the image(s) that complement his verbal question. The patient is encouraged to point to the image(s) that correspond(s) to their answer. The following are some guiding principles behind using the visual support.

- Model with the intent to connect.
  - The clinician must model how the visual support is used. Learning to use the visual support is like learning a language. The patient needs to observe and practice the use of the visual support many times before becoming competent. [Video: https://happeehearts.com/resources/]
  - Initially, focus first on connecting with the client through the visual support. With connection, collaboration becomes possible.

AUGMENTATIVE & ALTERNATIVE COMMUNICATION (AAC)
VISUAL SUPPORT

● **Guidelines for use**

- Guide patient to the correct answer for the orientation questions [Add link to video example]
  ○ Is your name _____?
  ○ Are you a boy or a girl?
  ○ How did you come here?
  ○ Where are you now?
- Give the patient sufficient time to respond to each question.
- Check for reliability of responses by rephrasing questions. [Video: https://happeehearts.com/resources/]
- If you suspect that the patient has difficulty attending to many visuals, physically cover some of the answer options to reduce the number of options visible.
- If you suspect the patient has difficulty understanding what each answer option represents, point to and label each one for them.

AUGMENTATIVE & ALTERNATIVE COMMUNICATION (AAC)
VISUAL SUPPORT

● **Benefits**

Individuals with ID process visual stimuli better than auditory stimuli. The visual support helps the patient to attend to the questions and thus increases understanding. With better understanding, and the option of an alternative way to express oneself, the accuracy and reliability of the patient's response is likely to improve.

AUGMENTATIVE & ALTERNATIVE COMMUNICATION (AAC)
EASY READ - HEALTH ED.

● **Purpose**

To enhance understanding and facilitate application of health education in relation to dietary choices to manage weight and diabetes.

● **Description**

"Easy Read" refers to the presentation of text/information in an accessible, easy to understand format. The principles of Easy Read design include:

- Use short sentences. Each sentence should only contain 1-2 points of information.
- Each image should be explained by one simple sentence.
- Simplify language.
- Explain necessary terminology.
- Use large font sizes.
- Place images on the left; text on the right.
- Avoid fancy fonts and italics.
- Minimise design elements.

AUGMENTATIVE & ALTERNATIVE COMMUNICATION (AAC)
EASY READ - HEALTH ED.

● **Description**

Applying these principles, IDHealth has produced written material in the Easy Read format on two topics to date.

- Healthy Eating for Weight management
- Diabetes

These topics were chosen to begin the Easy Read series because obesity and diabetes are common conditions among adults with ID with significant negative implications for the health of the individual. In addition, these patients often have unhealthy dietary habits which contribute to the development and worsening of obesity and diabetes.

The educational material include:

- 2 booklets

AUGMENTATIVE & ALTERNATIVE COMMUNICATION (AAC)
EASY READ - HEALTH ED.

● **Guidelines for use**

The Easy Read material are designed to be used with patients who are categorized to have an 'Adequate Ability' communication profile. Even though the material has been designed to make understanding easier, independent understanding should not be assumed. Wherever possible, the clinician or health professional should read through the material with the patient and check understanding with questions. Not everyone in this category will be able to read text so it is important for someone to go through the material with them and explain the images using the text provided.
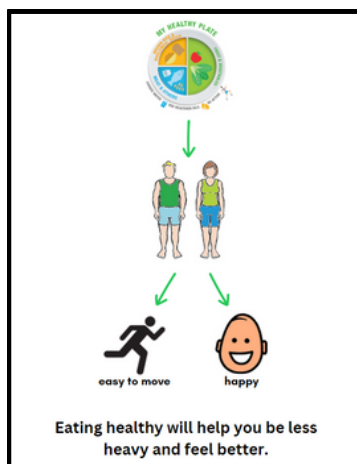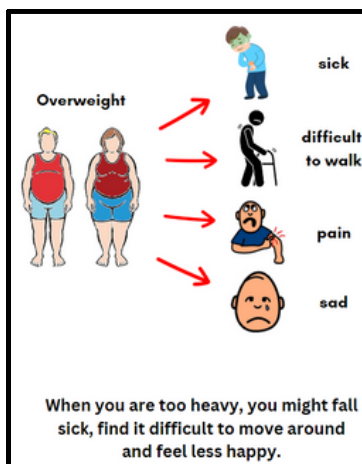
The healthy plate and food models can be used to illustrate dietary concepts such as portion sizes, proportion of a meal, and categories of food and nutrients. The health professional can also check for understanding of the education given by asking the patient to select 'foods' to fill the 'plate'.

AUGMENTATIVE & ALTERNATIVE COMMUNICATION (AAC)
EASY READ - HEALTH ED.

● **Benefits**

People with ID are often a neglected target audience of national health promotion initiatives. Thus, they lack the knowledge and skill to make healthy lifestyle choices to support their well-being. The Easy Read material addresses this lack of appropriate health education resources for this population in Singapore. With appropriate adjustments made to the presentation of health education, people with ID will have better understanding and recall of the information received. As a result, they may be able to make more informed health choices.

Overweight

sick

difficult to walk

pain

sad

When you are too heavy, you might fall sick, find it difficult to move around and feel less happy.

MY HEALTHY PLATE

easy to move

happy

Eating healthy will help you be less heavy and feel better.

AUGMENTATIVE & ALTERNATIVE COMMUNICATION (AAC)
EASY READ - PROCEDURAL SUPPORT

● **Purpose**

To facilitate cooperation with blood taking.

● **Description**

Short video clips have been created to show patients the steps involved in having a blood test. Go to https://happeehearts.com/resources/ to find video clips on:

- Steps involved in the blood test.
- How patients can indicate feelings about the blood test and choose to request for help or support through the process.

To complement these videos, steps for the blood test have been written in Easy Read format.

AUGMENTATIVE & ALTERNATIVE COMMUNICATION (AAC)
# EASY READ - PROCEDURAL SUPPORT

● **Guidelines for use**

These video clips can be shown to patients who resist the blood test procedure. They can be sent to patient or caregiver to view prior to the clinic visit. They can then be shown again on arrival at the clinic before the blood test. The caregiver and clinician should talk through the video with the patient, emphasizing what the patient needs to do at each step and how they should ask for help.

At the start of and during the procedure, the nurse can use the written steps to guide the patient through each step and obtain consent to the blood taking.

● **Benefits**

Providing the patient with information so that he or she can anticipate what will happen during the blood test reduces fear and anxiety. In addition, providing the patient with the means to express the type of support or help he or she needs gives the patient some control and the ability to regulate his emotions.

COMMUNICATION TOOL ACCESS
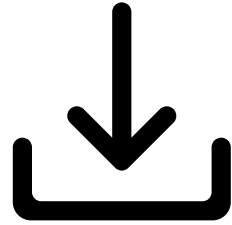
IDHealth strongly believes that knowledge should be shared across professions and sectors for the benefit of patient care. Thus, we have made available the Visual Support and Easy Read material on our website:

https://happeehearts.com/resources/

Feel free to download and use the material as necessary. If you have questions on how to use any of the material, please feel free to **contact us**. We will be willing to provide training and support in this area.

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Paul R, Norbury CF. Language disorders from infancy through adolescence: listening, speaking ,reading, writing and communicating (4th ed). St. Louis: Elsevier Mosby; 2012

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Perry Goh

We would also like to thank the speech-language therapists from AWWA for their help in the development of the communication tools and their contribution to the expert content of this booklet.

IDHealth

AN INITIATIVE BY
HAPPEE HEARTS
MOVEMENT

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AUGMENTATIVE & ALTERNATIVE COMMUNICATION (AAC)
COMMUNICATION BOARD

● **Purpose**

To provide an alternate means of two-way communication between the patient with ID, their caregiver and other important individuals in the patient's life. Only a select group of IDHealth patients will have communication board.

● **Description**

Communication boards are individualized sets of images that the individual with ID and their communication partner can use to express themselves as well as respond to others. They are designed for use in multiple contexts. Therefore, they will contain vocabulary that are common to multiple contexts as well as vocabulary that are unique to each context (e.g., home, school, clinic). The communication boards have been designed in the form of laminated sheets. However, if appropriate, they can be made for use in electronic form too.

AUGMENTATIVE & ALTERNATIVE COMMUNICATION (AAC)
COMMUNICATION BOARD

● **Guidelines for use**

The communication board is kept by the patient with ID. He or she should bring the communication board with him to medical appointments. The content of the communication board will be decided on by the IDHealth team in consultation with the family. The vocabulary selected should reflect the patient's interests, wants and needs in different contexts.

When using the communication board:
- Model the use of the board by pointing to relevant symbols while speaking because this is how we want the patient to use the board too.
- Use simple language. Start with 1 symbol per statement before combining more symbols to form a longer message. When people learn a new language, they start with learning single words, then short phrases before forming long senteces.

AUGMENTATIVE & ALTERNATIVE COMMUNICATION (AAC)
COMMUNICATION BOARD

● **Guidelines for use**

- Wait for the patient to respond. The patient may require up to 45 sec to do so.
- Acknowledge all communication attempts even if you suspect they pointed to the incorrect symbol. This reinforces their understanding of the cause-and-effect relationship between the use of their communication board use and the response of others.

● **Benefits**

The communication board helps the user to develop language skills – vocabulary and grammar. More importantly, it provides the user with an alternative means to express themselves when speech is difficult, so that they can be understood. It is a tool that allows the back-and-forth interaction with others that is necessary for connecting and building relationships.