- **These flashcards contain information about working with people with Intellectual Disability in low resource areas.**
- **These Flashcards are made for the use by fieldworkers.**
- **These flashcards are based on the information about Intellectual Disability from the RehApp.**

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The goals of the flashcards are:

- To meet the needs of people with disabilities and their families.
- To improve knowledge and skills of fieldworkers in providing basic (functional) rehabilitation services for people with disabilities and their families.
- To enhance participation in daily, family and community life.
- To improve the quality of life of people with disabilities and their families.
- To support you (as fieldworker) in the process of guiding a family by providing you with a resource you can keep with you on your phone (offline) or in your bag.

What can you do with these flashcards:

- To help guide your visits to families that have a family member with **Intellectual Disability.**.
- Make an inventory of the needs of the person with **Intellectual Disability** and his/her family.
- Learn about the implications of a disability for the person and their family.
- To do an assessment.
- To set goals for a person with **Intellectual Disability**.
- To help you discuss interventions with the family.
- To help you keep client records.
- To help you monitor process.

Index:

Note: These flashcards contain information about intellectual disability*. The content is organised according to the International Classification on Functioning, Disability and Health domains of the World Health Organization (2012). These cards don't replace the knowledge and skills of doctors and therapists. We advise you to seek their advice first.*

Index

Intellectual Disability

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❑ Puberty

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❑ Self esteem and abilities

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❑ Family pressure

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Let's first discover some (of still so many) inspirational stories by someone with Intellectual Disability

Introduction

ABC; Nurina Savitri

**Introduce Stephanie Handojo,
The Swimming Olympic Champion!**

The doctor's diagnosis of down syndrome and intellectual disability have **never limited** Stephanie **from living her dream**!

1. Her outstanding ability in swimming has made she won gold medal in various special olympic championship!

1. Her name has been written in Indonesia Record Museum for her music ability playing 22 songs for 2 hours non stop!

**Instagram.com/
@ivangunawan**

**Introduce Windi Setyoningsih,
The Famous Fashion Designer!**

Intellectual disability **have never limited** Windi **from shining** in the fashion design field!

1. She is widely recognized by her outstanding wedding or party dress and also Moslem's headscarf (hijab).

1. One of the well-known designers in Indonesia recognized Windi's abilities and used her designs for his hijab products.

Why Intellectual Disability ?

Intellectual Disability is often confused with other mental illnesses or any other stigmas such as "idiot" which finally bring mental breakdown to person with ID and family.

Field workers' and caregivers' life are also often impacted by the complexity of the condition and the lack of practical caring solutions for ID in the community. **You are not alone.**

How could these flashcards help?
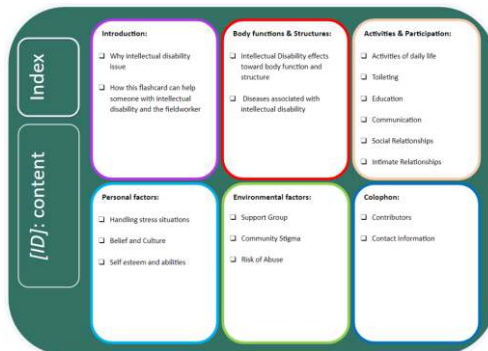
1. **Go to Index**
2. **Choose the section**
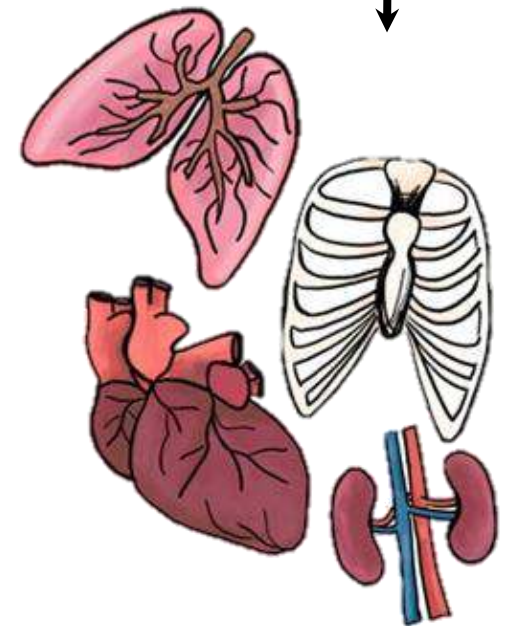3. **Apply any relevant "Actions to Take" in the journey of caring**

"Be Patient and Consistent"

Through RehApp Flashcard, let's solve the journey of caring puzzle together!

Body functions and structures:
Information and
Actions to take

Card 3

Body functions & structures: Diagnosis

How does Intellectual Disability affect development?

The organ that is mostly affected is the brain, as it is a **neurodevelopmental disorder** that begins in childhood. People with intellectual disability will need support for optimal daily participation, compared to others in the same age.
Diagnosis of Intellectual Disability requires limitations in both adaptive skills and intellectual skills:

Adaptive Skills

Intellectual Skills

Social Domains
- **Empathy**
- **Social perspective**
- **Interpersonal communication**

Conceptual Domains
- **Math**
- **Writing**
- **Language**
- **Reading**

Practical Domains
- **Self management**
- **Personal care**
- **Job responsibility**
- **Organizing task**

Intellectual Disability

Learning

Problem Solving

These skills will be affected based on ID severity.
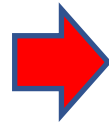
Reasoning

Judgement

Notes: ID severity is no longer classified by an IQ score, but measures of intellectual impairment may be considered as being in these ranges: Mild (IQ 50 to 69), Moderate (IQ 35 to 49), Severe (IQ 20 to 34, or lower)

Body functions & structures: Comprehensive Check

Actions to Take :

EARLY DIAGNOSIS IS CRUCIAL

- History of ID in family?
- Any suspected growth and developmental differences compared to others in same age group?

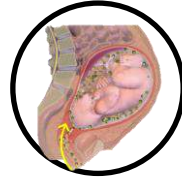**Early Comprehensive Medical Check Up**

Pediatrician | **Psychologist**

What are the causes of intellectual disability ?

There is a higher chance that underlying conditions are present and important to be identified early (not only limited to these):

Down syndrome or other genetic disorder

Birth infection

Head injury and stroke

Birth defects

Are there any associated conditions related to intellectual disability ?

Yes, there is also a higher chance (approximately 30-70%) that other neurodevelopmental disorders are present (not only limited to these):

Autism, depression, anxiety, and other mental diseases

Eating disorder

Movement disorder

Visual impairment

Activities & Participation:
Information and
Actions to take

Why are Activities of Daily Living important?

Activities of Daily Living (ADL) are activities and routines commonly conducted in normal daily lives such as eating, getting dressed, moving (body movement from one place to another without aid), and connecting with others (family and community).

The ability to perform ADL as good as possible is **crucial for person with ID's identity and developmental independence**
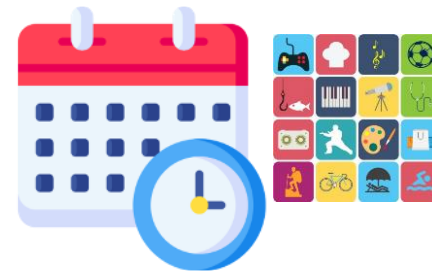
Actions to Take :

Consider what kind, and how much, of appropriate support will most likely help this person with ID become more **independent!**

Break a task into small steps and teach the person one task at a time at the place where the task will be done e.g., the bedroom.

Provide a picture agenda with additional information in short, simple sentences for supporting the person to remember tasks. Use videos and simple-to-use websites, when available, to support their learning process.

How toileting can be practiced?

The person may need support in toileting, especially if they don't have any sufficient training as a child. A person with intellectual disability **may need to be reminded when it's time to go the toilet.** A person with moderate or severe intellectual disability **may need more comprehensive instructions.** Toileting skills are also important to **promote autonomy and dignity** in a person with intellectual disability. Provide support if independent toileting is not possible.

Actions to Take :

Make a list of the person's abilities.

Find out what they've mastered and what they haven't.

Arrange the routine schedule **consistently** for their toileting in order to train their discipline of toileting.

Apply "Toileting Task Analysis" (e.g., breakdown the toileting tasks into **smaller tasks**, and explain it **one step at a time**)

Praise attempts and achievements.
Repeat the same tasks to help a person **understand better.**

Support in taking care of hygiene and self care ?

Maintaining personal hygiene is one of the things that can be very difficult to do for person with ID, who might lack a sense of awareness and the importance on maintaining personal hygiene. Some persons **may need support to follow hygiene rules and routines.**

Some persons with ID tend to struggle reading social cues and knowing when to fix hygiene issues. They may need extra help with personal care such as brush their teeth, shave, comb their hair or put on make-up.

Actions to Take :

Use **picture** agendas to remind them when to manage their hygiene and self-care

Explain it one step at a time with **visual** example

Appraise small achievements

Follow the same routines consistently can make great impact

Make and use personal hygiene smart box (box containing **complete equipment for hygiene**) if necessary.

Communication

What a person with ID can or has difficulty with to communicate and understand what is said, depends on the severity of ID. Persons with severe ID often have difficulties to communicate clearly or understand what is asked of them or said, which can lead to misunderstandings. It's necessary for adults to **communicate properly with persons with ID, to make them feel heard and appreciated.**

A person with ID might have difficulty in interpreting social cues and social situations. This might lead to difficulties in responding to other people appropriately, taking appropriate action, and having difficulties in problem solving.

Actions to Take :

Make time and give your full attention daily to listen and **make a person with ID feel that their opinion and stories are heard.**

Prepare a person if needed on **how to deal with certain difficult situations such as bullying.**

Train the person on how to **understand someone's intention better. Use stories to explain situations such as asking someone for help.**

Communicate using some pictures or picture stories to make the person **understand better about various social situations.**

Education

Education for a person with ID may vary based on the level of the ID. Persons with mild intellectual disability might participate in an inclusive school with some support, while a person with moderate or severe level might need more support or benefit from a special education school.

Effective forms of education and awareness-raising about ID can help them tremendously. **They are designed to fit their special learning needs.**

Actions to Take :

Provide experts (e.g., psychologist) to assess the **capabilities, needs, and interests** of a person with ID and type of education needed

Adapt and modify the school curriculum or create a **personalized** educational program to **fulfill individual needs**

Arrange the study routine schedule **consistently** to help a person **memorize** each task better

Provide media and technology, explore personal interests that help a person with ID with learning and

Social relationships

Person with ID have the right for a 'normal' life, like any other person, where they can **make friends** and **engage in community activities**. But social circumstances might create boundaries for them such as being bullied or discriminated.

The person, or caregivers, might have **little peer contact**, when kept at home and not in school. This makes learning, social interaction and making friends harder because of their lack of social experiments.

Actions to Take :

Help and teach the person to **make friends** by **using social stories and some pictures**

Develop, apply and evaluate **bullying interventions to create more acceptance in the classroom and in the community**

Explain the person that **their uniqueness makes them special** if they feel frustrated

A buddy-system can be used, **linking a peer to a person with ID to give them more stability in school and support their social life**

Is a person with intellectual disability able to experience an intimate relationship?

Absolutely yes, like everyone else, and **it's their right to have healthy sexual and intimate relationships.** Unfortunately, they can have difficulties in forming these relationships because of:

Lack of privacy: usually over caring by family in the personal life or not have their own room

Social judgement & stigma that might say a person with ID is childlike or asexual

Poor knowledge on sexual education, low self-esteem and lack of experience in intimate relationship

Actions to Take :

Giving private space if possible when age appropriate

Facilitating having a group of friends

Allowing personal intimate relationship and giving mental support

Providing sexual education according to their age maturity

Advocating sexual needs and rights for a person with ID

Card 11

Activities & Participation: Intimate Relationship

How puberty develops in a person with ID?

Due to hormonal changes, a person with ID may develop mood problems (anxiety, aggressive, or lack of interest) or even depression and social withdrawal in extreme cases. **Persons with ID, especially girls and women, also often more vulnerable to sexual abuse due to their lack of understanding in what is good and what not.**

Actions to Take :

Providing emotional support (e.g., praise & appreciation)
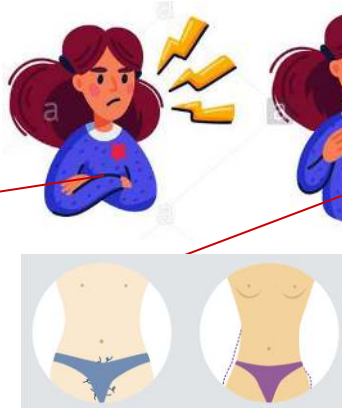
Explain body changes using picture/ doll (implicit content)

Teaching how to maintain personal hygiene, especially on reproductive organs

Explain intimate areas that other people shouldn't touch & differentiate unsafe situation

Notes:
Persons with mild ID tend to have a similar sexual development as their peers (explore, adapt, and control sexual impulse).

BUT persons with moderate or severe to profound ID may be delayed in those development processes or even not being able to control or understand their or someone else's sexual impulse and (in)appropriate actions.
Caregiver's full support is needed.

Personal factors:
Information and
Actions to Take

How does a person with ID manage their emotion?

Intellectual disability (e.g., when having difficulty learning or understanding language) can give a lot of pressure for a person with ID which can cause frustration, anger, and difficulties with managing their emotions. Therefore, a **person with ID might need to have time to escape from the situation at their own pace in order to calm down from stress and anxiety, before receive any advices or moving on.**

Actions to Take :

Act calm & don't demonstrate violence

Sit down to seem **less of a threat**

Give in for the moment; **cooling down**

Provide distraction, using favorite things/ activities

Keep your distance if needed; Don't touch the person **unless he/she is okay with that and already feels comfortable**

Speak calmly about other topics other than the situation that caused the anxiety

Snooker-trick; **talk with a third person** who has no conflict of interest to give the person time to calm down

How to support and develop the self-esteem of a person with ID ?

Low self-esteem and self-blaming for being treated badly happens often and have been a challenge for people with intellectual disability.

Actions to Take :

Enable a person to gather "success experiences" to **increasing self-belief**, by supporting them in exploring their interests, finding a hobby and passion as their strengths

Facilitate **possibility for secondary (non-formal or vocational) education**, e.g., skill training/ practical lessons

Act as a supervisor/ consultant when the person has a question or is experiencing uncertainty

Fani, a person with ID, is playing soccer with friends casually

Doing an activity or passion out of personal interest and not the will of others, is highly suggested.

It can **prevent stress and low self-esteem or low self-belief.**

Note: Persons with ID often notice when being treated differently than others or when people talk behind their back. **Sometimes a person with ID have already internalized the stigma surrounding them.** Address stigma in family and community situations.

Card 15

Personal Factors:
Self Esteem & Abilities

How can religion support a person with ID ?

The higher the level of maternal religiosity, especially in developing countries, **the better the maternal coping mechanism**, depending on the involvement and support of the religious community**.**

Actions to Take :

Religious approach if desired by the person with ID and his/her family (e.g worship, praying, etc.) to get **inner peace & tranquility.**

Religious & praying peer-group for people with intellectual disability and their parents if present in the area to **exchange experiences, feeling & reducing stress.**

Address the stigma of people with ID in and through religious communities.

Seek religious guidance without ruling out medical and psychological advice from the expert.

Note:

Some religious stigmas may seem positive.

But we still have to distinguish stigma from facts! Because stigma has the potential to justify the situation and preventing us to support people with ID and their family properly.

Environmental factors:
Information and
Actions to take

What can we do to prevent abuse ?

People with a disability, such as ID, may face **harassment and discrimination**. They are also vulnerable to sexual violence, abuse and assault. **This may result from** people that **stigmatize** disability or see persons with a disability as an easy pray. It can also be influenced by challenges of a person with ID to **manage certain skills, acquire and understand information, or other common tasks.**

Physical effect (bruises, lacerations, pregnancy, etc)

Psychological effect (e.g., psychological factors leading to physical symptoms, depression, anxiety, low self-esteem, irrational fear)

Behavioral effects (withdrawal, aggressiveness, self-injurious), and difficulty **coping with certain situations**

Actions to Take :

Let experienced fieldworkers Handle and address bullying in inclusive classes.
Involve fieldworkers with limited experiences as well, with extra time to **sharpen the skills** needed.

Role play can be a good way to **teach practical skills in self protection** in a concrete way.

Give a picture about body parts which can't be touched by strangers and depicting all kinds of touch.

Remind them: 1. Your body belongs to you; 2. Keep your clothes on in public; 3. Say no; 4. Get away; 5. Tell someone.

How does family pressure affect a person with ID ?

Some parents may hope that their children can receive and manage high education and pursue a certain career. However, people with intellectual disabilities can have **difficulty pursuing either higher education or the career** their parents have in mind**.**

For the parents of persons with ID, performing academically at the same level as a typically developing child might be important, although it is not always possible, thereby **frustrating both parents and the person with ID.**

Actions to Take :

Set up **parent support groups** to enable them to share their sorrows, experiences, create stress relief. Connect persons to organizations of persons with a disability.

Identify **establishment or practical training programs** where persons with ID can learn daily life skills, vocational skills and self care in a safe and supportive environment that connect to their capability and interests.

Create an **individual (re)habilitation- and education plan**.

Does community stigma affect the life of a person with ID ?

Persons with ID are among **the most socially excluded groups and encounter stigma, prejudice and significant barriers that restrict their human rights.** In addition, a high percentage of the population believe tha**t a disability is a curse from God,** therefore the community may neglect both person with ID and their fieldworkers or caregivers.

The discrimination from community results in exclusion and can cause a person with ID and their fieldworkers/caregivers to be excluded or ignored, **have poor education and being part of the poorest in the community**. Some of identified possible consequences are:

Self-stigma

Reducing self-esteem

Reducing quality of life

Worsen mental health

Affect close relatives. Being teased, abused, or blamed

Actions to Take :

Establish **community awareness,** supporting participation, inclusion and independence

Facilitate community meetings for fieldworkers involving the person with ID and family to achieve public awareness.

Engage the person with ID on **team activities.** This will benefit both the community and person with ID and their caregivers.

The content of these Flashcards was made with the support of:

- Caregivers, teachers & parents of children with intellectual disability from Indonesia
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Colophon

Card 22

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