Flashcards

Intellectual Disability



Preface

Intellectual Disability

- **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.**

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.*

Information about **intellectual disability**	
	Introduction
	Body functions & structures
	Activities & participation
	Personal factors
	Environmental factors
	Colophon

Index

Intellectual Disability

Introduction:

- ❑ Inspirational Stories
- ❑ Why intellectual disability?

Body functions & structures:

- ❑ How does intellectual disability affect body function and structure?
- ❑ Diagnosis
- ❑ Comprehensive check-up

Activities & participation:

- ❑ Daily activity
- ❑ Toileting & hygiene
- ❑ Communication
- ❑ Education
- ❑ Social & intimate relationship
- ❑ Puberty

Personal factors:

- ❑ Stress & emotion
- ❑ Self esteem and abilities
- ❑ Belief and culture

Environmental factors:

- ❑ Risk of abuse & violence
- ❑ Family pressure
- ❑ Community stigma

Colophon:

- ❑ Contributors
- ❑ Contact Information

Card 1

Introduction

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



ABC; Nurina Savitri

Introducing 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 allowed her to win a gold medal in various special Olympic championships!
2. Her name has been written in the Indonesia Record Museum for her musical ability – playing 22 songs for 2 hours nonstop!



Instagram.com/ @ivangunawan

Introducing Windi Setyoningsih, The Famous Fashion Designer!

Her intellectual disability **has never stopped** Windi **from shining** in the fashion design field!

1. She is widely recognised for her outstanding wedding and party dresses and Muslim headscarves (hijabs).
2. One of the well-known designers in Indonesia recognised Windi's abilities and used her designs for his hijab products.

Card 2

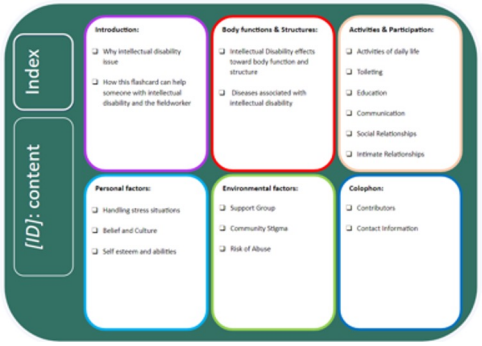
Introduction

Why Intellectual Disability?

Intellectual Disability (ID) is often misunderstood and associated with many other mental illnesses and can be highly stigmatised, which can, in turn, affect the mental health and well-being of the person with ID.

Fieldworkers and caregivers of people with ID are also often impacted by the complexity of the disability and the lack of practical caring solutions for ID in the community. **Know that you are not alone.**

How can this flashcard help?



1. **Go to Index**
2. **Choose the section**
3. **Apply any relevant "Actions to Take" in the journey of caring**

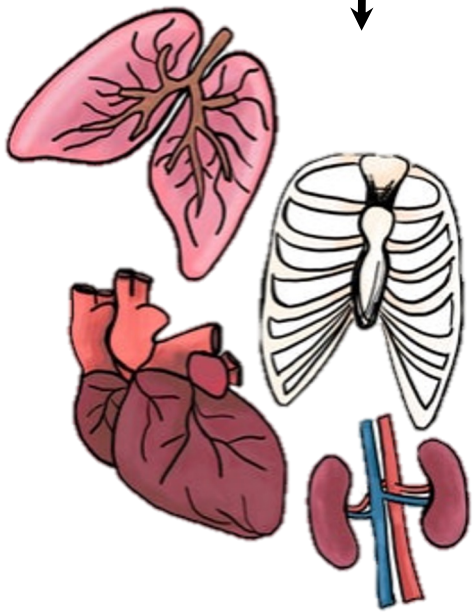
"Be Patient and Consistent"



Let's solve the caring puzzle together with this RehApp chapter!



Body functions and structures:
Information and actions to take



Card 3

Body functions and structures

How does an Intellectual Disability affect body function and structure?

The organ that is most affected is the brain, as it is a **neurodevelopmental disorder** that begins in childhood. People with an intellectual disability will need support for optimal daily participation compared to others of the same age.

The diagnosis of an Intellectual Disability requires limitations in both adaptive skills and intellectual skills:

Adaptive Skills

Social Domains



- Empathy
- Social perspective
- Interpersonal communication

Conceptual Domains



- Math
- Writing
- Language
- Reading

Practical Domains



- Self-management
- Personal care
- Job responsibility
- Task organising

Intellectual Disability

Intellectual Skills

Learning

Problem-Solving



These skills will be affected based on the severity of the ID.

Judgement



Reasoning



Notes: The severity of an ID 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).

Intellectual Disability (possible difficulties or delay in learning skills)



Movement skills



Daily activities (ADL)



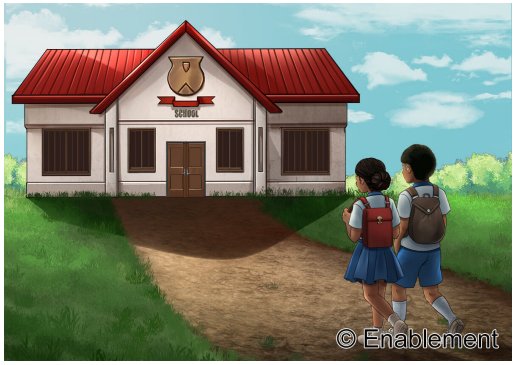
Play



Communication & Speech



Social interaction



Learning & cognitive skills

Card 4

Body functions and structures

Actions to Take :



EARLY DIAGNOSIS IS CRUCIAL

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

Early Comprehensive Medical Check Up



Pediatrician



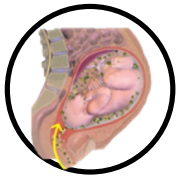
Psychologist

What are the causes of an intellectual disability?

There is a higher chance that underlying diseases are present, and it is important that these are identified early. These can include (but are not limited to):



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 and Participation:

Information and actions to take

Card 5

Activities and participation

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

The ability to fulfill ADLs is **crucial for people with ID's identity and developmental independence.**

Coach caregivers to consider what kind of appropriate support is most likely to help the person with ID become more **independent!**



Actions to Take :





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



Provide a picture agenda with additional information in short, simple sentences. This will help the person with ID remember tasks. When available, use videos and simple-to-use websites to support their learning process.

Card 6

Activities and participation

Toileting

A person with ID may need support in toileting, especially if they did not have sufficient training as a child. A person with an intellectual disability **may need to be reminded when it's time to go to 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.



Actions to Take

Coach the person with ID and/or their caregiver to do the following:



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 toileting to instill discipline of toileting.



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



Praise their achievements.
Repeat the same tasks to make them **understand better.**

Card 7

Activities and participation

Hygiene and self-care

Maintaining personal hygiene can be very difficult for a person with ID if they lack awareness of its importance. Children and youth with disabilities **may need support to follow hygiene rules and routines.**

A person with ID may also struggle to read social cues and know when to take action regarding hygiene issues, such as smelly breath. They may need extra help with personal care, such as brushing their teeth, shaving, combing their hair, and so on.

Actions to Take

Coach the person with ID and/or their caregiver to do the following:



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



Explain things one step at a time with a **visual** example.



Praise small achievements.



Follow the same routines consistently.



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

Card 8

Activities and participation

Communication

Depending on the severity of the intellectual disability, a person with ID can communicate and understand what is being talked about. However, a person with severe ID will often have difficulties communicating clearly, which can lead to misunderstandings. Therefore, it's necessary for adults to communicate properly with people with ID **to make them feel heard and appreciated.**

A person with ID could also have difficulties interpreting social cues and situations. As such, they may struggle to respond to other people appropriately, take appropriate action, and solve problems.

Actions to Take

Coach the caregiver of the person with ID to do the following:



Give 15 minutes of your full attention a day to **make a person with ID feel that their opinions are heard.**



Prepare them on **how to deal with certain situations.**



Practice with the person with ID to teach them to **understand someone's intention a bit better. Give a real scenario.**



Communicate using some pictures to make a person with ID **understand better about the situation.**

Card 9

Activities and participation

Education

Education for people with ID may vary depending on the severity level of their ID. People with a mild intellectual disability might participate in an inclusive school, while people with a moderate or severe level might require 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

Raise awareness of school staff as well as the caregiver on the following:



Providing experts (e.g., psychologists) to assess the **capabilities, needs, and interests** of a person with ID



Adapting and modifying the curriculum or creating **personalised** educational programme to **fulfill their needs**



Making the learning routine **consistent** to help them **memorise** each task better



Providing media and technology that help people with ID learning and finding out about their personal interests

Card 10

Activities and participation

Social relationships

People with ID long for a 'normal' life where they can **make friends** and **engage in community activities**. However, the social environment can create boundaries for them. People with ID are more prone to being bullied or discriminated against.

People with ID often have **little peer contact** because they are told to stay at home by their families. It makes it harder for them to make friends as a result.



Actions to Take



Help and teach the person with ID to **make friends** in the appropriate way by **using social stories and pictures.**



Sensitise school staff and work with them on developing, applying, and evaluating **bullying interventions to create more acceptance in the classroom.**



Explain to the person with ID that **their uniqueness makes them special.**



A buddy system can be used, **linking a student without disability to a person with ID to give them more stability in school and support his/her social life.**

Card 11

Activities and participation

Intimate relationships

People with ID can have intimate relationships, just like everyone else. In fact, **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 about the personal life. Not having their own room.



Social judgment & stigma of people with ID being childlike and asexual.



Poor knowledge of sexual education, low self-esteem, and lack of experience in intimate relationships.

Actions to Take

Coach the caregiver and the family of the person with ID to do the following:



Give private space if possible



Provide a group of friends



Allow personal, intimate relationships and give mental support



Provide sexual education according to his/her age and maturity



Advocate for the sexual needs and rights of a person with ID

Card 12

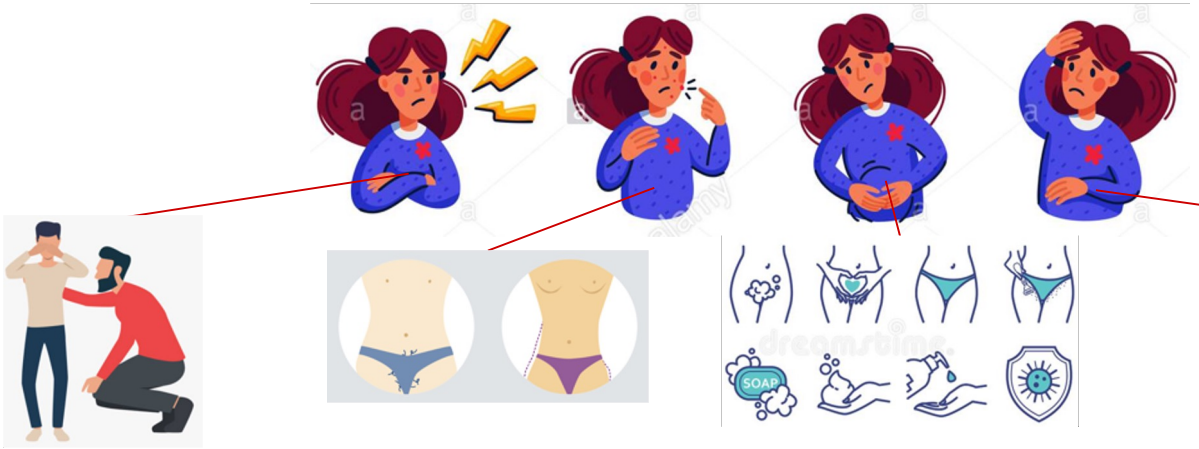
Activities and participation

Puberty

Due to hormonal changes, a person with ID may develop mood problems (anxiety, aggression, and lack of attention) or even depression and social withdrawal in extreme cases. **A person with ID is also more vulnerable to sexual abuse due to their lack of understanding of personal space and intimacy.**

Actions to Take

Coach the caregiver and the family of the person with ID to do the following:



Provide emotional support (e.g., praise & appreciation)

Explain body changes using pictures/ dolls (implicit content)

Teach how to maintain personal hygiene, especially around the reproductive organs

Show intimate areas and explain that other people shouldn't touch them. Identify unsafe situations

Note:

A person with mild ID tends to have a similar sexual development to their peers (explore, adapt, and control sexual impulses).

HOWEVER, a person with moderate or severe to profound ID may be delayed in terms of those development processes, or he/she may not be able to control his/her sexual impulses at all and act inappropriately.

Caregiver's full support may, therefore, be needed.



Personal factors:
Information and
actions to take

Card 14

Personal factors

Stress and emotion

Having an intellectual disability can put a lot of pressure on a person and can cause frustration, anger, and difficulties managing his/her emotions. Therefore, **a person with ID needs time to escape from the situation at their own pace and calm down before receiving any advice or additional stimulus.**

Actions to Take

Coach the caregiver and the family of the person with ID to do the following:



Act calm & don't demonstrate violence



Sit down to appear **less threatening**



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



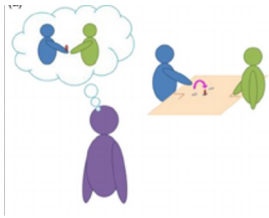
Provide distraction, using favorite things/ activities



Keep distance;
Don't touch him/her **unless the person with ID is already comfortable**



Speak calmly about different topics other than the main problem or his/her behaviour



Snooker-trick; **talk with a third person** who has no conflict of interest

Card 15

Personal factors

Self-esteem and abilities

Low self-esteem and self-blaming for being treated badly can be a problem with some people with an intellectual disability.

Actions to Take

Coach the caregiver and the family of the person with ID to do the following:



Enable the person with ID to gather "success experiences" to **increase their self-esteem** by supporting them in finding a hobby and aspiration, as well as their strengths.



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



Become a confident or coach whom the person with ID can turn to when having a question/ uncertainty. Or find someone who can play that role for them.



Fani, a person with ID, is playing futsal with friends

It is highly suggested that people do an activity or hobby not done by coercion or the will of parents only.

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

Note: People with ID often notice when they are treated differently from others or when people talk behind their backs. Sometimes, **people with ID have already internalised the stigma surrounding them.**

Card 16

Personal factors

Religion

The higher the level of religiosity in (female) caregivers, especially in developing countries, **the better the maternal coping mechanism.**



Actions to Take

Both the caregiver/family and the person with ID can benefit from religion or spirituality. If this is something that is important in the family, keep in mind that:



A religious approach (e.g., worship, praying, etc.) can bring **inner peace & tranquility.**



Religious & praying peer groups can help people with intellectual disability and their caregiver/family exchange experiences and feelings & **reduce stress.**



Religious communities can **stigmatise** intellectual disability. Make sure to address this with the family and community/religious leaders.



Seeking religious guidance should not rule out medical and psychological advice from experts

Note:

Some religious beliefs may seem positive towards disability.

Nevertheless, we still have to distinguish beliefs from actual facts! Stigma has the potential to justify the situation and prevent us from dealing with ID properly.





Environmental factors:

Information and
actions to take





Card 17

Environmental factors

Abuse and violence

People with ID may face **harassment and discrimination**. They are also vulnerable to sexual violence, abuse, and assault. **This may result from difficulties understanding certain skills, information, or other things.**



Physical effects (bruises, lacerations, pregnancy, etc.)



Psychological effects (psychosomatic, depression, anxiety, low self-esteem, irrational fear, etc.)



Behavioural effects (withdrawal, aggressiveness, self-injurious): a person with ID may have **poor coping mechanisms → violent**

Actions to Take

As a fieldworker, these are actions you can take yourself or coach the caregiver and the family of the person with ID in:



Experienced fieldworkers should handle bullying in inclusive classes. **Fieldworkers with limited experience can also be involved**, with extra time to **sharpen the skills** needed.



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



Use pictures of body parts to illustrate which parts shouldn't be touched by strangers and depict various 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.**

Card 18

Environmental factors

Family pressure

Some parents may hope that their children can have a high education and a decent career. However, people with intellectual disabilities can have **difficulty pursuing either of these.**

For the parents of children with ID, performing academically at the same level as a normal child is important, although it is not always possible. This can frustrate **both parents and children with ID. Expectations should be discussed with the family and the person with ID.**

Actions to Take

As a fieldworker you should support in:



Setting **parent support groups** to enable them to share their sorrows and experiences, and create stress relief.



Identifying **practical training programmes** where children with ID can learn daily life skills, vocational skills, and self-care in a safe environment.



Creating an **individual rehabilitation plan**.

Card 19

Environmental factors

Community Stigma

People 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 believes that a disability is a curse from the Gods**. Therefore, the community may neglect both people with ID and their caregivers/family.

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



Self-stigma



Lower self-esteem



Lower quality of life



Poorer mental health



Affecting close relatives. Being teased, abused, or blamed.

Actions to Take

As a fieldworker you should support in:



Raising **community awareness,** supporting people with ID's independence.



Facilitating community meetings and involving people with ID to achieve public awareness.



Engaging people with ID in **team activities.** This will benefit both the community and the person with ID and their caregivers.

Card 20

Colophon

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

- Caregivers, parents and teachers of children with intellectual disability from Indonesia
- Medical and Psychology students-advisors from the Atma Jaya Catholic University Indonesia :
  - Professor Irwanto
  - Weny Pandia
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  - Kevin Surya
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  - Dion Pratama
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- Emanuel Rosío
- Phelix Omondi
- Angelique Kester
- Physiotherapy, Nursing and Social Work students-advisors from Amsterdam University of Applied Sciences:
  - Lennart
  - Natalie
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Card 21

Colophon

This was made possible with the support of:



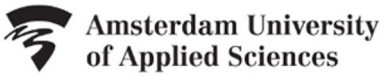










































Card 22

References

When drafting the content of these Flashcards, these resources were particularly helpful:

American Psychiatric Association, American Psychiatric Association. Diagnostic and statistical manual of mental disorders: DSM-5. United States. 2013.

Better Health Channel. (2019). Cognitive disability and sexuality. Betterhealth.Vic.Gov.Au. https://www.betterhealth.vic.gov.au/health/ConditionsAndTreatments/intellectual-disability-and-sexuality#sexuality-education-for-people-with-intellectual-disability

Bunga, B. N., Laure, S. H. A. I., & Kiling, I. Y. (2021). Religiosity and Disability in West Timor: Pray, Access and Peer Empowerment. Journal of Disability & Religion, 1–9. https://doi.org/10.1080/23312521.2021.1906824

Elvén, B. H. (2010). No fighting, no biting, no screaming: How to make behaving positively possible for people with autism and other developmental disabilities. Jessica Kingsley Publishers.

Farlina, M. (2019). Prevention of Sexual Abuse in Children with Mental Disability: A Systematic Literature Review. IJDS Indonesian Journal of Disability Studies, 6(1), 73–83. https://doi.org/10.21776/ub.ijds.2019.006.01.1

Handoyo RT.(2019). A multimethod exploration of stigma towards people with intellectual disability in Indonesia. Doctoral thesis, UCL (University College London). UCL (University College London), p. 1–281.

Handoyo, R., Ali, A., Scior, K., & Hassiotis, A. (2021a). Attitudes of key professionals towards people with intellectual disabilities and their inclusion in society: A qualitative study in an Indonesian context. Transcultural Psychiatry, 58(3), 379–391. https://doi.org/10.1177/1363461520909601

Handoyo, R., Ali, A., Scior, K., & Hassiotis, A. (2021b). A qualitative exploration of stigma experience and inclusion among adults with mild to moderate intellectual disability in an Indonesian context. Journal of Intellectual Disabilities, 1–14. https://doi.org/10.1177/17446295211002349

Kiling-Bunga BN, Ngawas KWA, Kiling IY. Description of prosocial behavior in young children with intellectual disability in East Nusa Tenggara. JPU. 2020;3(1):53–64.

Leffert, J. S., Siperstein, G. N., & Widaman, K. F. (2010). Social perception in children with intellectual disabilities: the interpretation of benign and hostile intentions. *Journal of Intellectual Disability Research*, *54*(2), 168–180. https://doi.org/10.1111/j.1365-2788.2009.01240.x

Masulani-Mwale, C., Mathanga, D., Kauye, F., & Gladstone, M. (2018). Psychosocial interventions for parents of children with intellectual disabilities–A narrative review and implications for low income settings. *Mental Health & Prevention*, *11*, 24–32. https://doi.org/10.1016/j.mhp.2018.05.003

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References

Merianti L, Amelia D, Srywahyuni A. (2020) Stories of mothers with intellectual disability children in West Sumatera, Indonesia. https://doi.org/10.17605/OSF.IO/AESW3

Nakamura, F., & Ooie, K. (2017). A study on mobility improvement for intellectually disabled student commuters. IATSS Research, 41(2), 74–81. https://doi.org/10.1016/j.iatssr.2017.07.002

National Center on Birth Defects and Developmental Disabilities (2021). Facts about intellectual disability in children. Retrived from https://www.cdc.gov/ncbddd/childdevelopment/facts-about-intellectual-disability.html

Patka, M., & McDonald, K. E. (2015). Intellectual disability and faith communities: perspectives of Catholic religious leaders. *Disability & Society*, *30*(8), 1241–1258. https://doi.org/10.1080/09687599.2015.1090953

Sapuan I, Hendarsih S. Hubungan tingkat religiusitas dengan koping ibu yang memiliki anak retardasi mental di SLB Negeri 2 Yogyakarta. STIKES 'Aisyiyah Yogyakarta. 2014.

Sravanti, L., & Arul Jayendra Pradeep V. (2021). *"What, Why, and How" Model of Parent-Mediated Sexuality Education for Children With Intellectual Disability: An Illustrated Account. Journal of Psychosexual Health, 3(2), 117–123.* doi:10.1177/26318318211017685

Sullivan, F., Bowden, K., McKenzie, K., & Quayle, E. (2015). The Close Relationships of People with Intellectual Disabilities: A Qualitative Study. Journal of Applied Research in Intellectual Disabilities, 29(2), 172–184. https://doi.org/10.1111/jar.12168

Tekola B, Kinfe M, Girma F, Hanlon C, Hoekstra RA. Perceptions and experiences of stigma among parents of children with developmental disorders in Ethiopia: A qualitative study. Social Science & Medicine. 2020 Jul 1;256:113034.

Van Splunder JA, Stilma JS, Bernsen RM, Evenhuis HM. Prevalence of visual impairment in adults with intellectual disabilities in the Netherlands: cross-sectional study. Eye. 2006 Sep;20(9):1004-10.

Zacharin, M. R. (2008). *Puberty, Contraception, and Hormonal Management for Young People With Disabilities. Clinical Pediatrics, 48(2), 149–155.* doi:10.1177/0009922808324492

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