

**DEVELOPMENT AND VALIDATION OF
KNOWLEDGE AND ATTITUDE
QUESTIONNAIRE ON INTELLECTUALLY
DISABLED ADOLESCENTS' HEALTH ISSUES
AND ACCESSIBILITY TO PRIMARY
HEALTHCARE SERVICES AMONG PRIMARY
HEALTHCARE PROVIDERS**

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UNIVERSITI SAINS MALAYSIA

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by

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DECLARATION

I, Nur Akmal binti Ismail, declare that the work presented in this thesis is originally mine. The information which has been derived from other sources is clearly indicated in the thesis.



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Signed on 20th December 2023

LIST OF MANUSCRIPTS

List of Manuscripts:

1. Exploring Health Issues of Adolescents with Intellectual Disabilities: A Qualitative Study

Nur Akmal Ismail¹, Surianti Sukeri¹, Azriani Ab Rahman¹, Anis Kausar Ghazali², Mohd Zulkifli Abdul Rahim³, Noran Hashim⁴.

2. Exploring the Accessibility of Primary Healthcare towards Adolescents with Intellectual Disabilities: A Qualitative Study

Nur Akmal Ismail¹, Surianti Sukeri¹, Azriani Ab Rahman¹, Anis Kausar Ghazali², Mohd Zulkifli Abdul Rahim³, Noran Hashim⁴.

3. Development and Validation of Knowledge and Attitude Questionnaire on Health Issues and Accessibility to Primary Healthcare Services of Adolescents with Intellectual Disabilities among Primary Healthcare Providers

Nur Akmal Ismail¹, Azriani Ab Rahman¹, Anis Kausar Ghazali², Surianti Sukeri¹, Mohd Zulkifli Abdul Rahim³, Noran Hashim⁴.

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LIST OF SYMBOLS

Df	Degree of freedom
χ^2	Chi-square
<	Less than
>	More than
=	Equal to
\leq	Less than and equal to
\geq	More than and equal to
%	Percentage

LIST OF ABBREVIATIONS

ADHD	Attention deficit hyperactivity disorder
ASD	Autism spectrum disorder
CBR	Community-based rehabilitation
CFA	Confirmatory factor analysis
CVI	Content Validity Index
DSM	Diagnostic and Statistical Manual
EFA	Exploratory factor analysis
FDC	Family Doctor Concept
FMS	Family Medicine Specialist
FVI	Face Validity Index
ID	Intellectual disability
IRT	Item response theory
KMO	Kaiser Meyer Olkin
MI	Modification Indices
MOH	Ministry of Health
NGO	Non-government organization
OKU	<i>Orang Kurang Upaya</i>
PHC	Primary health clinic
PSDNK	<i>Persatuan Sindrom Down Negeri Kelantan</i>
PWD	Persons with disabilities
RMSEA	Root Mean Square Error of Approximation
SPSS	Statistical Package for The Social Sciences
SRMR	Standardized Root Mean Square Residual
SWD	Social Welfare Department
WHO	World Health Organization

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ABSTRAK

PEMBANGUNAN DAN PENGESAHAN SOAL SELIDIK PENGETAHUAN DAN SIKAP MENGENAI ISU KESIHATAN REMAJA KURANG UPAYA INTELEKTUAL DAN AKSES KEPADA PERKHIDMATAN PENJAGAAN KESIHATAN PRIMER DALAM KALANGAN PETUGAS KESIHATAN PRIMER

Latar belakang: Remaja kurang upaya intelektual menghadapi pelbagai isu kesihatan yang memerlukan perhatian dan pemahaman khusus. Akses kepada perkhidmatan penjagaan kesihatan primer menimbulkan cabaran tambahan bagi mereka. Objektif kajian ini adalah untuk meneroka isu kesihatan remaja kurang upaya intelektual dan akses mereka kepada perkhidmatan penjagaan kesihatan primer dan seterusnya membangunkan soal selidik baharu untuk menilai pengetahuan dan sikap petugas penjagaan kesihatan primer berkenaan kebimbangan tersebut.

Kaedah: Kajian ini dijalankan dalam dua fasa menggunakan pendekatan kaedah campuran. Fasa pertama melibatkan pembangunan soal selidik berdasarkan tinjauan kajian meluas, temu bual mendalam, pengesahan kandungan, pengesahan muka, dan pra-ujian. Temu bual mendalam telah dijalankan dalam kalangan 26 orang responden termasuk 12 penjaga, 10 petugas penjagaan kesihatan primer yang mempunyai pengalaman dalam menguruskan remaja kurang upaya intelektual, dan empat pakar kesihatan dan perubatan dalam pengurusan ketidakupayaan intelektual. Mereka dipilih menggunakan kaedah persampelan bertujuan. Data dianalisis menggunakan analisis tematik. Dapatan kajian kualitatif memaklumkan penjana item. Pengesahan kandungan dilakukan dalam kalangan tujuh pakar dan pengesahan muka dilakukan dalam kalangan 10 petugas penjagaan kesihatan primer di Kelantan. Fasa kedua

melibatkan teori respons item (IRT), analisis faktor penerokaan (EFA) dan analisis faktor pengesahan (CFA) untuk mengukur kesahan dan kebolehpercayaan struktur dalaman soal selidik. Kajian keratan rentas telah dijalankan dalam kalangan 444 petugas penjagaan kesihatan primer untuk menilai IRT, EFA dan CFA. Persampelan berbilang peringkat telah digunakan untuk memilih petugas penjagaan kesihatan daripada 20 klinik kesihatan kerajaan di Kelantan.

Keputusan: Penemuan kualitatif telah mengenal pasti isu kesihatan remaja kurang upaya intelektual seperti keadaan perubatan, keadaan kesihatan mental, ketidakupayaan perkembangan, tingkah laku berisiko tinggi, masalah berkaitan pemakanan, serta isu kesihatan seksual dan reproduktif. Penemuan ini juga telah mengenal pasti cabaran mereka dalam mengakses perkhidmatan penjagaan kesihatan primer mengikut model Levesque iaitu, kebolehdekatan, kebolehterimaan, ketersediaan, kemampuan dan kesesuaian. Keputusan daripada kajian kualitatif dan tinjauan kajian lain telah disepadukan ke dalam pembangunan soal selidik pengetahuan dan sikap yang baharu. Satu soal selidik awal telah dibangunkan dengan 59 item pengetahuan dan 61 item sikap dalam sembilan domain. Berikutan dengan pengesahan kandungan, pengesahan muka, IRT untuk bahagian pengetahuan dan EFA begitu juga CFA untuk bahagian sikap, soal selidik akhir telah menghasilkan 14 item maklumat umum, 38 item pengetahuan, dan 28 item sikap dalam sembilan domain yang sama.

Kesimpulan: Soal selidik baru dalam Bahasa Melayu ini menunjukkan kebolehpercayaan yang kukuh dan psikometrik yang sah untuk menilai pengetahuan petugas penjagaan kesihatan primer tentang isu kesihatan remaja kurang upaya intelektual dan sikap mereka terhadap akses remaja ini kepada perkhidmatan penjagaan kesihatan primer.

ABSTRACT

DEVELOPMENT AND VALIDATION OF KNOWLEDGE AND ATTITUDE QUESTIONNAIRE ON INTELLECTUALLY DISABLED ADOLESCENTS' HEALTH ISSUES AND ACCESSIBILITY TO PRIMARY HEALTHCARE SERVICES AMONG PRIMARY HEALTHCARE PROVIDERS

Background: Adolescents who have intellectual disabilities face distinct health challenges that necessitate specialized care and understanding. Accessing primary healthcare services poses further challenges for this population. The objectives of this study were to explore intellectually disabled adolescents' health issues and their accessibility to primary healthcare services and subsequently develop a new questionnaire to assess primary healthcare providers' knowledge and attitudes regarding those concerns.

Methodology: The study was conducted in two phases using a mixed-method approach. The first phase involved a questionnaire development based on an extensive literature review, in-depth interviews, content validation, face validation, and pretesting. In-depth interviews were conducted among 26 respondents including 12 caregivers, 10 primary healthcare providers who had experience in managing intellectually disabled adolescents, and four health and medical experts in the management of intellectual disabilities. They were selected using purposive sampling method. Data were analyzed using thematic analysis. The qualitative study findings informed item generation. The content validation was performed among seven experts and face validation was conducted among 10 primary healthcare providers in Kelantan. The second phase involved item response theory (IRT), exploratory factor analysis (EFA) and confirmatory factor analysis (CFA) to measure the questionnaire's internal

structure validity and reliability. A cross-sectional study was conducted among 444 primary healthcare providers to assess IRT, EFA and CFA. A multistage sampling was used to select the healthcare providers from 20 government primary health clinics in Kelantan.

Result: The qualitative findings identified intellectually disabled adolescents' health issues such as medical conditions, mental health conditions, developmental disabilities, high-risk behaviours, nutrition-related problems, as well as sexual and reproductive health issues. The findings also identified their challenges in accessing primary healthcare services according to Levesque's model namely, approachability, acceptability, availability, affordability and appropriateness. The findings from qualitative study and literature reviews were integrated into the development of new knowledge and attitude questionnaire. An initial questionnaire was developed with 59 knowledge items and 61 attitude items within nine domains. Following the content validation, face validation, IRT for knowledge section and EFA as well as CFA for attitude section, the final questionnaire has resulted in 14 general information items, 38 knowledge items, and 28 attitude items within the same nine domains.

Conclusion: A new Malay-validated questionnaire demonstrated strong reliability and valid psychometrics for assessing primary healthcare providers' knowledge on health issues of intellectually disabled adolescents and their attitudes towards these adolescents' accessibility to primary healthcare services.

CHAPTER 1

INTRODUCTION

1.1 Background

Adolescence, often referred to as the transitional phase between childhood and adulthood, is undeniably a significant period in one's life. The World Health Organization defines adolescents as those aged 10 to 19 years (Sacks *et al.*, 2003). It is during this transformative stage that individuals are presented with a multitude of health opportunities, paving the way for the establishment of lifelong habits that will shape their overall well-being. The importance of adolescence cannot be overstated, as it encompasses not only physical growth but also emotional, cognitive, and social development (Kuay *et al.*, 2023).

This phase involves navigating remarkable yet challenging transformations, signifying a period of self-discovery, heightened emotional sensitivity, and a spectrum of emotions (Kuay *et al.*, 2023). Additionally, adolescents go through cognitive development, cultivating abstract thinking and the ability to consider multiple perspectives (Singh *et al.*, 2019). In terms of social development, they actively participate in social responsibilities, forming relationships, and exploring their social identity (Onwumere *et al.*, 2021).

In contrast to normal adolescents, those with intellectual disabilities often encounter challenges when attempting to perform typical tasks and their abilities are more limited. Intellectual disability is defined by significant limitations in both intellectual capabilities and adaptive behaviour, encompassing a range of everyday skills (APA, 2013). This includes the conceptual domain (language, literacy, arithmetic, reasoning, knowledge acquisition, and memory), the social domain

(empathy, social judgment, communication skills, the ability to form and maintain friendships), and the practical domain, which involves self-management skills related to personal care, job responsibilities, financial management, leisure activities, and organization of educational and occupational tasks (APA, 2013; Foley *et al.*, 2016; Kedrova and Matantseva, 2016; Shree and Shukla, 2016). Symptoms of this disability manifest during the developmental period, and diagnosis is based on the degree of impairment in adaptive functioning. This disorder is chronic in nature and frequently coexists with other mental conditions such as depression, attention-deficit/hyperactivity disorder, and autism spectrum disorder (APA, 2013). According to the DSM-V, intellectual disability (ID) is also known as intellectual developmental disorder (IDD).

In the past, the term "intellectual disability" was referred to as "mental retardation" or "mental handicap." These terms were often used interchangeably with "learning disabilities", despite the broader scope encompassed by the concept of learning disabilities (APA, 2013; Taggart and Cousins, 2014). Intellectual disability ranges from mild to profound, each requiring different levels of support (APA, 2013).

Mild intellectual disability shows developmental delays but allow for some independence with minimal support and moderate intellectual disability requires more support for self-care and navigation in familiar environments (Patel *et al.*, 2018). Severe intellectual disability involves significant delays and limited communication, often requiring family support or supervised living. Persons with IQ below than 70 are expected to have intellectual disabilities. However, DSM-V emphasizes the need to use both clinical assessment and standardized testing of intelligence when diagnosing intellectual disability, with the severity of impairment based on adaptive functioning

rather than IQ test scores alone (APA, 2013). DSM-V removes IQ test scores from the diagnostic criteria but includes them in the text description of intellectual disability to avoid overstating IQ test scores as the defining aspect of a person's capacity without considering functional levels.

In Malaysia, the term “learning disability” is used by Social Welfare Department (SWD) to categorize and register intellectual disabilities for social welfare purposes (Harun and Shamsuddin, 2014; SWD, 2020). Their operational definition for learning disability is intellectual ability that is not in accordance with their chronological age and those who have profound difficulties in performing their daily livings (SWD, 2020). Global developmental delay, Down syndrome, attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD), intellectual impairment, slow learner, and specific learning disability are all covered in this category (Harun and Shamsuddin, 2014; SWD, 2020).

Worldwide, the prevalence of intellectual disability in general population ranged from 1% to 3% (Liao *et al.*, 2021; Patel *et al.*, 2020). Olusanya *et al.* (2020) found that the global occurrence of intellectual disabilities in adolescents between the ages of 10 and 19 was estimated to be around 6252 cases per 100,000 individuals with 586 per 100 000 population in Southeast Asia, East Asia and Oceania region. In Malaysia, Social Welfare Department (SWD) reported that approximately 34% of individuals with disabilities who were officially registered in 2021 were identified as having learning disabilities (SWD, 2022). Almost half (48%) of those with learning disabilities were children between the ages of 6 and 18. The state of Kelantan contributed to approximately 7.7% of the total learning disabilities reported in Malaysia in 2021 (SWD, 2022). Intellectual disabilities, along with other learning

difficulties, are encompassed within the broader category of learning disabilities (SWD, 2022).

Adolescents who have intellectual disabilities exhibit a higher occurrence of health issues and are more prone to encountering disparities in healthcare compared to their peers without disabilities. These factors greatly influence their overall well-being and their capacity to function effectively (Jansen *et al.*, 2004; Ong *et al.*, 2016; Straetmans *et al.*, 2007). They have limited accessibility to healthcare services including health screenings and health promotion initiatives. Moreover, their health issues often go undiagnosed or unattended (Hanlon *et al.*, 2018). Hence, it is important to address that adolescents who have intellectual disabilities are considered a vulnerable and disadvantaged group when it comes to their health and social care (Doody *et al.*, 2022). Furthermore, identifying and treating health concerns throughout adolescence period provides chances for early intervention and prevention strategies.

Adolescents with intellectual disabilities are more prone to have medical and mental health issues (Reddihough *et al.*, 2021; Sappok *et al.*, 2019). They also struggle with developmental disabilities affecting physical, learning, language, and behavioural aspects (Olusanya *et al.*, 2018; Roden *et al.*, 2020). Cognitive limitations put them at risk for engaging in risky behaviours, including smoking, pornography, and substance abuse (Christensen and Baker, 2020). Nutrition-related issues such as obesity, undernutrition, and abnormal eating behaviours are also common among them (Mayes and Zickgraf, 2019; Sahin and Nogay, 2022). Additionally, their vulnerability makes them more prone to sexual violence and improper sexual behaviours due to a lack of sexual health knowledge (McLay *et al.*, 2015; Roden *et al.*, 2020).

Primary healthcare services are defined as services that adopt a comprehensive approach to health, with the goal of promoting the highest level of health and well-being for all individuals. These services prioritise the needs of individuals across the entire spectrum of health, addressing various aspects of their well-being (WHO, 2023). Ensuring accessibility of primary healthcare services to adolescents with intellectual disabilities is very important. Accessibility is defined as the capacity of healthcare services or systems to meet the population's needs (Davy *et al.*, 2016). Inadequate accessibility in primary care may lead to neglected health issues, contributing to premature mortality in individuals with intellectual disabilities (Weise *et al.*, 2016). Recognizing the importance of accessible primary healthcare is paramount in addressing the healthcare needs of adolescents with intellectual disabilities (Lennox *et al.*, 2015). This recognition can potentially improve their lifestyle behaviours, enhance overall quality of life, and potentially reduce medical costs.

In 2011, the Malaysian Ministry of Health (MOH) undertook the initiative to establish a guideline manual for implementing adolescent health services in primary healthcare facilities. This was done with the aim of effectively addressing the various health concerns that adolescents face within their communities (MOH, 2011b). Then, in 2015, the MOH in conjunction with Majlis Pemulihan Negara introduced a manual for implementing disabled friendly health services for individuals with disabilities nationwide including in the primary healthcare services (MOH, 2015). This manual aims to improve healthcare professionals' understanding and ability to provide comprehensive care for individuals with disabilities in healthcare settings. The manual covered all types of impairments, including hearing, vision, speech, learning, physical, mental, and multiple disabilities.

Other than that, MOH Malaysia has implemented two distinct phases of the disability plan of action. These phases are specifically designed to address and improve the healthcare services provided to persons with disabilities (PWD). These initiatives are aligned with the National Disabled Persons Policy and Action Plan, the Disability Act, and the Convention on the Rights of Persons with Disabilities (MOH, 2015). From the years 1996 to 2010, the initial stage focused on creating various services and programmes specifically designed for individuals with disabilities. Following this, the second stage, spanning from 2011 to 2020, aimed to enhance and reinforce the already established services (MOH, 2015).

1.2 Problem statement

Undeniably with the plentiful of literatures from other countries on the health challenges that individuals with intellectual disabilities encounter as well as their accessibility to healthcare, there is a significant lack of local research in Malaysia that addresses this topic in depth. These issues are important to explore in order to identify gaps in existing healthcare services and inform healthcare providers about the specific needs and barriers faced by individuals with intellectual disabilities, ultimately promoting more inclusive and equitable healthcare practices (McConkey *et al.*, 2020).

The existing evidence highlights the presence of significant health disparities encountered by adolescents who have intellectual disabilities compared to those who do not have disabilities (Jansen *et al.*, 2004; Reddihough *et al.*, 2021; Straetmans *et al.*, 2007). Although health issues among adolescents with intellectual disabilities generally resemble those in typically developing adolescents, it is important to address certain conditions that are more commonly observed among individuals with intellectual disabilities. These individuals often require higher levels of healthcare support compared to the general population. Additionally, it is important to note that

there is a persistent issue regarding the under detection of health problems among this particular group, which ultimately results in neglected health needs (Polanczyk *et al.*, 2015).

The Malaysian government, particularly the MOH recognises the importance of ensuring the rights and needs of disabled persons are met, with the aim of providing them with equitable access to healthcare and optimum care (MOH, 2015). This is demonstrated through the implementation of multiple initiatives aimed at addressing these issues. Despite the implementation of several initiatives, such as the establishment of adolescent health services, plan of action for the healthcare of PWD, and the adoption of a Disability Awareness manual, it is observed that adolescents with intellectual disabilities in Malaysia continue to underutilize primary healthcare services consistently.

The ongoing underutilization can be attributed to the inadequate accessibility to healthcare services for this group of adolescents (Doherty *et al.*, 2020). The contributing factors as reported in prior studies include poor attitude of healthcare providers, lack of training among healthcare providers with regards to intellectual disabilities, lack of sufficient health promotion initiatives, a scarcity of specialised services provided, inadequate availability of disability-friendly facilities, limited health supervision for this group and a recognised deficiency in the quality of care (Ali *et al.*, 2013; Davy *et al.*, 2016; Goins *et al.*, 2005).

It is crucial to address that primary healthcare providers have limited understanding of the unique requirements and challenges faced by adolescents with intellectual disabilities (Doyle *et al.*, 2016). This deficiency in knowledge has the potential to result in the provision of substandard or inappropriate care to this special

group of adolescents. The existence of stigmatization and negative attitudes within the primary healthcare providers contributes to an unwelcoming and discouraging environment for adolescents with intellectual disabilities, possibly dissuading them from seeking essential healthcare (Ali *et al.*, 2013). To our knowledge, there is no available tool for primary healthcare providers to assess their knowledge about the health issues and attitudes towards the accessibility of primary healthcare services for intellectually disabled adolescents in Malaysia.

1.3 Rationale of the study

In this study, a mixed method approach was employed to construct a new questionnaire on health issues of intellectually disabled adolescents and their access to primary healthcare services within local contexts. This study employed a sequential exploratory strategy. The utilisation of qualitative research is important to acquire an in-depth comprehension of the challenges, viewpoints, and experiences encountered by adolescents with intellectual disabilities and their caregivers regarding their health issues and accessibility to primary healthcare services within the local context. The qualitative inquiry offers a deeper exploration of the factors that influence their engagement with healthcare providers and systems. Furthermore, understanding their perspectives and experiences may provide vital insights for establishing successful interventions and policies to enhance healthcare access and delivery for this vulnerable population.

The development of a reliable local tool will enable a comprehensive evaluation of primary healthcare providers' knowledge on intellectually disabled adolescents' health issues as well as their attitude towards accessibility to primary healthcare services for adolescents with intellectual disabilities. The insights derived from this assessment may then be strategically applied to improve the quality of

primary healthcare services, potentially leading to an improvement in the quality of life for adolescents with intellectual disabilities. This specific local instrument may serve as a guide to improve the quality of evidence-based healthcare services for these adolescents by addressing the unique health concerns and enhance accessibility to primary healthcare services tailored for adolescents with intellectual disabilities in Malaysia.

1.4 Research questions

1. What are the health issues among adolescents of intellectual disabilities?
2. What are the challenges faced by adolescents with intellectual disabilities in accessing the primary healthcare services?
3. Is the newly developed questionnaire valid to measure primary healthcare providers' knowledge on intellectually disabled adolescents' health issues as well as their attitude towards accessibility to primary healthcare services for adolescents with intellectual disabilities in Kelantan?

1.5 Research objectives

This part highlights the general and specific objectives of research.

1.5.1 General objective

To explore intellectually disabled adolescents' health issues and their accessibility to primary healthcare services as well as develop and validate new questionnaire assessing knowledge and attitude of primary healthcare providers in Kelantan

1.5.2 Specific objectives

1. To explore health issues of adolescents with intellectual disabilities in Kelantan
2. To explore accessibility of adolescents with intellectual disabilities to primary healthcare services in Kelantan
3. To develop and validate new questionnaire assessing primary healthcare providers' knowledge on intellectually disabled adolescents' health issues and attitude on their accessibility to primary healthcare services in Kelantan.

CHAPTER 2

LITERATURE REVIEW

This chapter presents a review of literature focused on the health issues of adolescents with intellectual disabilities and their access to primary healthcare services. The review incorporates articles in English from both qualitative and quantitative research. Key databases utilized for this research include the Cochrane Library, PubMed, Scopus, and Google Scholar. The literature search involved keywords such as: adolescents with intellectual disabilities, learning disabilities, developmental disabilities, health challenges in adolescents with intellectual disabilities, sexual and mental health concerns, risky behaviours, nutrition, access to healthcare, primary healthcare services for the disabled, adolescent healthcare services, studies on qualitative analysis, and the development, validation, and reliability assessment of questionnaires.

2.1 Health issues of adolescents with intellectual disabilities

Adolescence is a transitional period between childhood and adulthood aged 10 to 19 years. This period is a remarkable and critical stage for creating optimal health. However, even though being perceived as a healthy stage of life for normal adolescents, adolescents with intellectual disabilities suffer more health problems, indicating genetic and biological associations with particular causes of intellectual disabilities and increased exposure to environmental and social risk factors (Hanlon et al., 2018). If the problems go unnoticed and unaddressed, they have the potential to result in premature mortality in the future.

In addition to impacting the overall well-being of intellectually disabled individuals, it is important to note that these health issues can also have a detrimental

effect on their quality of life (May and Kennedy, 2010). Therefore, the necessities for optimal health and sufficient healthcare are separate concerns that ought to be acknowledged and fulfilled. Moreover, other essential elements of well-being including the assurance of sufficient nutrition, stable and safe housing, educational opportunities, the safeguarding of civil rights, alongside with the establishment of political, social, and economic stability are vital for these population's holistic development and integration into society (Evenhuis et al., 2001).

The majority of extensive studies examining health issues in individuals with intellectual disabilities rely on healthcare providers' indirect appraisals of their clients' health status. This approach often leads to an underestimation of the actual prevalence of health problems (Haveman et al., 2010). Aspects such as the limited capacity of people with intellectual disabilities to communicate their symptoms, difficulties encountered by healthcare providers in identifying the signs and symptoms, and limitations in the experience and time of providers to conduct comprehensive evaluations are among the factors that contribute to the above issue (Haveman et al., 2010; Taggart and Cousins, 2014).

There are six main aspects pertaining to health issues in adolescents with intellectual disabilities, namely medical condition, mental health, developmental disabilities, nutritional related health, high-risk behaviours, as well as sexual and reproductive health that frequently addressed and encountered by them.

2.1.1 Medical conditions

Adolescents with intellectual disabilities are more likely to develop a variety of medical issues that are frequently more complicated than those experienced by their non-disabled peers.

Common medical conditions in people with intellectual disabilities including adolescence age group are epilepsy, visual impairment, hearing loss, ear infection, common skin diseases, congenital heart defects (CHDs), respiratory diseases including cold, influenza, pneumonia, aspiration, chronic bronchitis, bronchial asthma, obstructive breathing and obstructive sleep apnea (OSA), endocrine disease such as thyroid disorders specifically hypothyroid disease, metabolic diseases such as diabetes type 1 or type 2 and gastrointestinal diseases such as constipation, gastroesophageal reflux disease (GERD), esophagitis, gastritis, and gastrointestinal cancers (Haveman *et al.*, 2010; Liao *et al.*, 2021; Oeseburg *et al.*, 2010; Straetmans *et al.*, 2007; Van Schrojenstein Lantman-de Valk, 2005; Weise *et al.*, 2016). Oral health issues, injury or trauma are also often seen in adolescents who have intellectual disabilities (Calver *et al.*, 2021; Wilson *et al.*, 2019).

Certain individuals with intellectual disabilities may have health risks related to certain syndromes like fragile X syndrome, Down syndrome, and Prader Willi syndrome (Evenhuis *et al.*, 2001). Individuals with Down syndrome have a higher risk for congenital heart defects and pyloric stenosis at birth. These conditions usually improve over time or may require surgery in infancy or toddler age (Van Schrojenstein Lantman-de Valk, 2005). They also have visual and hearing impairments and hypothyroidism similar to the intellectually disabled people without a specific syndrome. Those with fragile X syndrome often struggle with motor coordination, speech disorders, autistic traits, and attention deficit disorders (Van Schrojenstein Lantman-de Valk, 2005). Those with Prader Willi syndrome typically face hypotonia and feeding issues in infancy, leading to obsessive eating disorders and obesity around age 4 or 5. This obesity can result in early-onset diabetes (Van Schrojenstein Lantman-de Valk, 2005).

Higher prevalence of epilepsy, a neurological condition was reported among those with intellectual disabilities (20% to 30%) compared to the general population (Evenhuis *et al.*, 2001; Van Ool *et al.*, 2016). The occurrence of epilepsy tends to increase in correlation with the severity of the disability (Chapman *et al.*, 2011; Robertson *et al.*, 2015; Van Ool *et al.*, 2016). Individuals who have intellectual disabilities and comorbid epilepsy are potentially susceptible to receiving substandard care for both conditions (Shankar *et al.*, 2018). They are burdened by the complexity of having both illnesses and demand particular considerations.

The contributing factors for gastrointestinal conditions in people with intellectual disabilities such as GERD, esophagitis, gastritis, and gastrointestinal cancers include non-ambulatory, scoliosis, cerebral palsy, the use of anticonvulsant medicines and benzodiazepines, as well as having an IQ below 35 (Holingue *et al.*, 2023; Liao *et al.*, 2021; Sappok *et al.*, 2019). Acute or chronic constipation is more common in this group compared to the general population. It is linked to factors like cerebral palsy, neurological diseases, physical inactivity, unhealthy diet, and use of certain medications such as anticonvulsive medication, proton pump inhibitors and mood stabilizers (Haveman *et al.*, 2010; Holingue *et al.*, 2023; Van Schrojenstein Lantman-de Valk, 2005).

Individuals with intellectual disability are more susceptible to acute respiratory tract infections and chronic respiratory diseases. Colds and influenza were common among school-age students with intellectual disabilities, particularly those with Down syndrome (Liao *et al.*, 2021; Pikora *et al.*, 2014). Muscle weakness and ineffective coughing increase the risk of pneumonia and aspiration. These problems affect musculoskeletal coordination, making it difficult for the individual to clear their

airway while swallowing and breathing (Gentile *et al.*, 2015; Proesmans, 2016). Bronchial asthma is a prevalent chronic condition that affects children and adolescents globally (Hassan Tawfik *et al.*, 2022). Although individuals without and with intellectual disabilities have a similar prevalence of bronchial asthma, the existence of intellectual disabilities may introduce complexities into the treatment and prognosis of bronchial asthma (Davis, 2016; Hassan Tawfik *et al.*, 2022; Morin *et al.*, 2012).

Type 1 diabetes is frequently observed in adolescents with Down syndrome due to the correlation with autoimmune factors (Flygare Wallén *et al.*, 2018). Furthermore, persons with autism spectrum disorder (ASD) are approximately 3.25 times more likely to get Type 2 diabetes compared to people without ASD (Chen *et al.*, 2016). This may be explained mostly by preventable risk factors, including dyslipidemia and obesity, which are prominent within the ASD population (Chen *et al.*, 2016; Flygare Wallén *et al.*, 2018).

Thyroid diseases, particularly hypothyroidism, is frequently observed among adolescents with intellectual impairments when compared to their typically developing peers (Gentile *et al.*, 2015; Liao *et al.*, 2021; Sappok *et al.*, 2019). Individuals diagnosed with Down syndrome and Prader-Willi syndrome have a significantly higher prevalence of hypothyroidism, ranging from 10 to 30% (Gentile *et al.*, 2015; Prasher *et al.*, 2014; Van den Bemd *et al.*, 2022). This condition may lead to additional effects on their physical and mental growth.

Adolescents with intellectual disabilities, particularly Down syndrome, are more prone to ear infections like otitis media (Liao *et al.*, 2021; Pikora *et al.*, 2014). These problems are caused by anatomical variations, immune system deficiencies, and difficulty in communicating pain or distress (Ram and Chinen, 2011). Skin problems

like acne, fungal infections, and psoriasis are common among them due to difficulties in maintaining personal hygiene or sensory sensitivities that cause scratching (Liao *et al.*, 2021; Pikora *et al.*, 2014).

Intellectually disabled individuals with genetic conditions of Down syndrome have a significantly higher prevalence of CHDs, approximately 40% (Liao *et al.*, 2021; Pikora *et al.*, 2014; Santoro *et al.*, 2018). Tetralogy of Fallot, atrioventricular septal defects, atrial septal defects, and ventricular septal defect are the most frequent CHDs seen among those with Down syndrome (Santoro *et al.*, 2018). These cardiac problems have a substantial impact on the well-being, growth, and quality of life of ID adolescents, demanding specialized care and monitoring.

The impact of oral health issues, such as dental caries, gingivitis, and periodontal disease on individuals with intellectual disabilities is quite significant (Haveman *et al.*, 2010; Petrovic *et al.*, 2016; Wilson *et al.*, 2019). Although individuals with intellectual disabilities experience caries at similar rates as the general population, they have a greater occurrence of untreated dental caries (Haveman *et al.*, 2010; Petrovic *et al.*, 2016). Oral health issues can cause discomfort, pain, infection, ruined appearance, and bad breath. Contributing factors include irregular dietary habits, poor oral hygiene practices, dental plaque due to inadequate toothbrushing techniques, and providers' lack of awareness regarding intellectual disabilities, resulting in inadequate attention to oral health needs (Vermaire *et al.*, 2021; Wilson *et al.*, 2019).

Intellectually disabled adolescents are at higher risk of intentional and unintentional injuries (Calver *et al.*, 2021; Shi *et al.*, 2015). Unintentional injuries, such as burns, falls, motor-vehicle accidents, and environmental injuries, frequently

occur when adolescents are driven by their natural curiosity and eagerness to explore the environment surrounding them (Shi *et al.*, 2015). Limited abilities to comprehend or react to dangers make them more susceptible to harm. Self-harm was the leading cause of intentional injury in people with intellectual disabilities (Calver *et al.*, 2021). This finding shows a higher occurrence of mental health disorder and challenging behaviours in this population (Calver *et al.*, 2021). Assault is a common factor for intentional injuries, indicating vulnerability to physical abuse and bullying (White *et al.*, 2018).

2.1.2 Mental health

Mental health and behavioural challenges are more common among adolescents who have intellectual disabilities in comparison to their peers without disabilities. Anxiety disorders, depressive disorders, and conduct disorders are commonly reported conditions among this population (Buckley *et al.*, 2020; Hatton *et al.*, 2018; Pikora *et al.*, 2014; Reardon *et al.*, 2015). Mental health issues are worsened by cognitive functioning, which can cause problems in communication and have negative impacts on social functioning, self-esteem, and interpersonal relationships (Buckley *et al.*, 2020). The poor mental health of these adolescents can be contributed by living in poverty, inadequate nutrition, exposure to bullying and violence, and parental mental health problems (Hatton *et al.*, 2018).

When screening and detection methods are inadequate, there is a higher possibility of mental health problems going undiagnosed and not receiving appropriate treatment (Buckley *et al.*, 2020). The situation can become more complicated when there is a deficiency in training provided to healthcare providers regarding mental health issues related to intellectual disabilities (Scott and Haverkamp, 2014). These

lacking may lead to healthcare providers mistakenly categorise symptoms as pre-existing intellectual disabilities. This situation is usually referred as 'diagnostic overshadowing' (Reardon *et al.*, 2015).

Challenging behaviours exhibited by people with intellectual disabilities, including self-injurious conduct and physical aggression, are linked to mental health problems. However, the link between challenging behaviours and mental health issues are multifaceted (Thakker *et al.*, 2012). Although not all challenging behaviour can be attributed to mental illness, and not all mental illness can be the cause of challenging behaviour, the two conditions may coexist in individuals with intellectual disabilities, especially among those with more severe impairments (Thakker *et al.*, 2012). Challenging behaviours are influenced by interactions between individuals and their surroundings (Ali *et al.*, 2014).

2.1.3 Developmental disabilities

Adolescents who have intellectual disabilities face unique obstacles throughout the developmental course mostly due to limitations in their cognitive ability. They exhibit notable impairments in various cognitive domains, including attention, learning, memory, executive functions, and language skills (Hronis *et al.*, 2017). The influence of attentional abilities on learning and behaviour in adolescents with intellectual disabilities is quite significant. They encounter challenges when it comes to selecting and concentrating on pertinent information while ignoring irrelevant data, allocating cognitive capacity to multiple tasks concurrently, and maintaining to focus for extended periods of time (Hronis *et al.*, 2017; Shree and Shukla, 2016).

The learning and memory capabilities of individuals with intellectual disabilities are lower when compared to their peers without disabilities. They have slower learning rates and difficulties to apply information to new situations. Additionally, they may also have difficulty to identify specific problems or behaviours that facilitate them to learn and remember things (Shree and Shukla, 2016). They may also have speech and language difficulties. Language problems are usually linked to delayed language development rather than unusual language use. They may struggle with practical aspects of language, such as selecting appropriate conversation topics, and deciding when to speak or remain silent (Shree and Shukla, 2016).

Intellectually disabled individuals commonly encounter deficiencies of adaptive skills. Adaptive skills consist of practical, social, and conceptual abilities that are vital for everyday existence. Conceptual abilities consist of capacity to grasp numerical concepts, comprehend financial principles, comprehend and measure time, understand different languages, and exercise autonomy in decision-making. Interpersonal competencies, social responsibility, self-respect, vigilance, social problem-solving, and compliance with regulations are all examples of social skills.

The negative effects of these social skill deficits on adolescents include physical aggression, emotional and friendship difficulties, social isolation, and bullying (Lung *et al.*, 2019; Mazurek *et al.*, 2013). Practical skills include activities of daily living, healthcare management, adherence to schedules, financial management, safety awareness, and job competencies. Individuals with intellectual disabilities face a wide range of challenges on a daily basis, which is demonstrated by the impairment of these adaptive skill domains (Shree and Shukla, 2016).

2.1.4 High-risk behaviours

Smoking, substance abuse, and alcohol consumption have been documented among adolescents with intellectual disabilities, although at a lower prevalence compared to typically developing adolescents (Robertson *et al.*, 2020). The lower prevalence of these risky behaviours among this special group of adolescents is attributed to the fact that many of them may not have yet been exposed to such situations because of increased control by parents and restricted personal freedoms (Christensen and Baker, 2020). They had fewer close friends and spent less of their leisure time with peers. Hence, their limited social interaction could potentially serve as a protecting element against risky behaviours (Robertson *et al.*, 2020). However, the possibility for their engagement in these risky behaviours remains a concern due to their limited understanding of the implications and their susceptibility to peer pressure (Christensen and Baker, 2020).

Adolescents with intellectual disabilities may also engage in accessing and becoming addicted to pornography (Alomiry and Alhwaiti, 2022; Hidayat *et al.*, 2021). Adolescents, in their developmental stage, often display a natural curiosity about their sexual lives. Furthermore, the lack of interaction with peers of the same age frequently hampers them from participating in social activities, sexual exploration, or gaining knowledge about their sexuality (Alomiry and Alhwaiti, 2022). Consequently, they tend to seek information about sex mainly from the internet, leading to involvement in pornography (Hidayat *et al.*, 2021). This is also due to inadequate communication with their parents and teachers regarding sexual issues (Alomiry and Alhwaiti, 2022). Exposure to pornographic materials may lead to inappropriate sexual activity in adolescents with intellectual disabilities (Hidayat *et al.*, 2021).

Adolescents diagnosed with intellectual disability, ADHD, and ASD face an increased vulnerability to bullying in comparison to their typically developing peers (Griffin *et al.*, 2019; Lung *et al.*, 2019). They commonly experience four distinct types of bullying, namely verbal bullying such as mocking and threatening; physical bullying such as beating and slapping; relational bullying like isolating them from a group; and damage the property including taking and destroying their personal belongings (Gladden *et al.*, 2014). Cognitive impairments and difficulties in establishing and sustaining positive peer relationships are frequently identified as the main contributors to an individual's susceptibility to bullying (Lung *et al.*, 2019). As a result, the occurrence of depression, anxiety, and low self-esteem, associated with bullying is significantly higher among adolescents who have intellectual disabilities (Griffin *et al.*, 2019).

2.1.5 Nutritional related health

Intellectually disabled individuals are comparatively prone to chronic diet-related health issues such as overweight, obesity, diabetes and growth retardation (Gast *et al.*, 2022). The prevalence of obesity is considerably higher among individuals diagnosed with mild to moderate intellectual disabilities. In contrast, individuals with severe to profound intellectual disabilities exhibit a relatively high prevalence of underweight (Hsieh *et al.*, 2014; Kolset, 2020).

The development of obesity among individuals with intellectual disabilities, including adolescents is correlated with physical inactivity, lack of comprehensible health promotion pertaining to the healthy eating habits, practising unhealthy food choices such as consuming high amounts of sugary foods and drinking soda, taking medications that may contribute to weight gain, and being diagnosed with Down

syndrome (Gast *et al.*, 2022; Haveman *et al.*, 2010; Hsieh *et al.*, 2014). Obesity may lead to a substantial health threat, as it increases the risk of developing conditions like diabetes at younger age, heart disease, hyperlipidaemia and hypertension (Hakime Nogay, 2013; Haveman *et al.*, 2010; Van Schrojenstein Lantman-de Valk, 2005).

Undernutrition among children and adolescents with intellectual disabilities may occur as a consequence of insufficient consumption of nutritious foods, which can be attributed to their reliance on others for feeding and food preparation (Mohamed *et al.*, 2021). Other risk factors include frequent infections, various health issues, restricted access to healthcare, food insecurity, and poor socioeconomic status (Mohamed *et al.*, 2021).

Abnormal eating behaviours are commonly observed in the adolescent with intellectual disability especially among ASD. These behaviours include ingestion of non-food items (pica), pocketed food, preference for specific types of food or picky eater, food refusal and heightened sensitivity to various textures (Gentile *et al.*, 2015; Sturmey *et al.*, 2016). Nutritional related problems may also correlate with difficulties related to eating and swallowing among those with cerebral palsy (Kolset, 2020).

2.1.6 Sexual and reproductive health

Adolescents who have intellectual disabilities encounter unique challenges in relation to their sexual and reproductive health. The challenges mentioned include lack availability of comprehensive sexuality education, difficulties in effectively communicating about sexuality, and an increased susceptibility to sexual abuse (Baines *et al.*, 2018; Roden *et al.*, 2020). They have comparatively lower levels of sexual and reproductive knowledge in comparison to their counterparts in the general population although their physical and sexual development are identical to those of

typically developing adolescents (Baines *et al.*, 2018). Insufficient understanding of sexual education has the potential to lead to inappropriate sexual behaviours, such as engaging in public masturbation, initiating sexual intercourse at a young age and practising unsafe sexual activities (Borawska-Charko *et al.*, 2017; Palfiova *et al.*, 2016). It may result in sexual implications such as sexually transmitted infections (STIs) and teenage pregnancy (Baines *et al.*, 2018; Roden *et al.*, 2020; Van Schroyen Lantman-de Valk, 2005).

Despite the recent implementation of comprehensive sexual education in school and healthcare systems, it remains inadequate in addressing the needs of children and adolescents with intellectual disabilities, especially those who have more severe cognitive impairments (Roden *et al.*, 2020). In Malaysia, Reproductive and Social Health Education (PEERS) which focuses on sexual education is designed and incorporated into the Health Education course curriculum for primary and secondary school children (Razali *et al.*, 2017). However, this syllabus primarily caters to the needs of normal children and adolescents only.

In addition, the MOH Malaysia had also created the 'Live Life Stay Safe' module in 2009 with the purpose of educating disabled children and adolescents and providing parents, educators and healthcare providers with information on reproductive health (MOH, 2009). This module was designed to accommodate individuals with disabilities in general, but not to adolescents with intellectual disabilities specifically. Besides, teachers and parents frequently express their feelings of unease and inadequate knowledge to communicate about sexual and reproductive health with their students and children (Roden *et al.*, 2020).

Sexual abuse is characterised by non-consensual sexual conduct, when individuals use tactics such as physical force, bribery, coercion, threats, or exploitation of vulnerable victims who lack the capacity to provide permission due to factors such as age, immaturity, or intellectual limitations (Graham, 1996). The examples are rape, inappropriate touch, sexual harassment, exploitation, and grooming. The increased susceptibility of adolescents with intellectual disabilities to experiencing sexual abuse compared to normal population may be attributed to their limited understanding of sexuality, reliance on others and limited social interactions (Smit *et al.*, 2019). As a result, they may experience depression, anxiety, social isolation and self-harm (Smit *et al.*, 2019).

2.2 Primary healthcare services in Malaysia

Primary healthcare is defined by WHO as a holistic approach to health aims to ensure the highest level of health and well-being for everyone by focusing on people's needs across the continuum of health. This includes health promotion, disease prevention, treatment, rehabilitation, and palliative care, all provided as close as possible to individuals' daily environment (WHO, 2023). Primary healthcare encompasses three essential components: integrated health services, multi-sectoral policies, and active involvement of individuals, families, and communities to promote social participation and self-care in matters of health (WHO, 2023). Primary healthcare is widely regarded as a comprehensive and equitable strategy that effectively promotes individuals' physical and mental health, while also fostering social well-being. It is recognised for its cost-effectiveness and efficiency in delivering healthcare services (WHO, 2023).