# Perceptions Toward Healthcare and Dental Care Services among Parents and Caretakers of People with Intellectual Disability (PWID)—A Questionnaire Study

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54

**INTRODUCTION** The government heavily subsidizes Malaysia's

Dublic healthcare system through taxation, with patients paying minimal costs to obtain treatment for their medical needs.<sup>[1]</sup> Furthermore, persons with special needs who have a "disability card" issued by the

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Aim and Objective: In Malaysia, there was lack of local evidence on the perception of parents/caretakers of people with intellectual disabilities (PWID) about healthcare. Thus, this study aims to assess the perceptions toward healthcare services of parents or caretakers for PWID. Materials and Methods: Online survey using Google Forms was conducted on parents/caretakers of PWID who attended the special care dentistry clinic and special community centers in Kuantan, Pahang. A questionnaire was developed for data collection. Cronbach alpha was conducted to measure the reliability. Content and face validation was performed to establish the validity. Data entry and analysis were done using IBM statistical package for social sciences (SPSS) version 24. This study only involved univariate (descriptive) data analysis in which categorical data were summarized in actual numbers and percentages. Results: The respondents' perceptions toward healthcare access and services were reasonably good; about 50% disagreed and strongly disagreed on having difficulty accessing healthcare facilities. 65% and 55% of parents/caretakers brought PWID for regular health and dental checkups. The majority agreed and strongly agreed (about 73%) that healthcare staff gave equal services and good support and showed positive attitudes toward PWID under their care. Insufficient healthcare information and below-par communication skills remained the main barriers faced by the parents/caretakers of PWID. About 13% of the respondents reported experiencing discrimination in receiving health and dental services for PWID under their care. The Cronbach alpha scores for sections 2 and 4 were 0.892 and 0.681, respectively. Conclusion: Most of the respondents felt that Malaysia's healthcare services for PWID were fairly good. However, it was intriguing to find that some still experienced discrimination. This shows that education about intellectual disability is salient for healthcare workers and should be embedded in the current curriculum.

**Keywords:** *Perception, healthcare services, dental care services, intellectual disability (PWID), parents, caretakers* 

Malaysian Welfare Ministry are excused from paying any of these expenses. This is because some persons

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with special needs have financial problems as they cannot work, and their family members have to look after them. The Malaysia Disability Act 2008 stated that people with a disability should have equal access to healthcare as those who do not have disabilities.<sup>[2]</sup>

A study done in Malaysia in 2015 among children with disabilities found that most healthcare services for them were unmet.<sup>[3]</sup> The healthcare services that are highly needed yet highly unmet include dental, psychology, speech therapy, and diet advice.<sup>[3]</sup>

People with intellectual disabilities (PWID) may need help from other people to access healthcare facilities, as they lack social skills and fear embarrassment or trauma from their experience or might as well have a fear of receiving healthcare treatment.<sup>[4-6]</sup> Parents of children with intellectual disabilities only brought their children to the clinic if they noticed that they could not perform activities of daily living (ADL) and developed aggressive behavior.<sup>[4]</sup> Late presentation and detection from the parents might affect the benefits of early therapeutic interventions such as training in self-help skills and remedial teaching.<sup>[4]</sup>

Besides, due to impaired communication skills, PWID may encounter problems seeking treatment for themselves.<sup>[5,6]</sup> This resulted in mismanagement and incorrect diagnosis by the clinician.<sup>[6]</sup> Some research reported that PWID received poor attitudes from the clinicians, including how they spoke to the patient and the substandard treatment.<sup>[6,7]</sup> Thus, PWID prefer to avoid seeing general practitioners.<sup>[6]</sup>

Apart from the above factors, the perception of the parents of children with intellectual disabilities toward healthcare service providers also plays a major role in deciding which healthcare will treat their children.<sup>[8]</sup> A meta-narrative study showed that a parent with a negative experience with healthcare services had poor perceptions toward healthcare service providers.<sup>[8]</sup> The examples of negative experiences were poor pain management toward their children, inadequate information shared by the healthcare providers, and failure to involve parents in decision-making.<sup>[8]</sup> Thus, parents of children with intellectual disabilities were found to be more satisfied when they brought their children to the specialist center than general practice.<sup>[9]</sup> Other factors such as inadequately trained staff, lack of assessment tools, and poor communication between the family and the service providers also contributed to the parents' preferences.<sup>[10,11]</sup> However, the main reasons for the parents not bringing their children with intellectual disabilities to healthcare facilities were unaware of the

existence of services, financial problems, and difficulties in bringing their children because of their behavior.<sup>[11]</sup>

Parents with Down syndrome were inclined to bring their children to specialist care even though they lived afar.<sup>[12]</sup> This was because they saved more time in getting faster results from investigations by the specialists and obtained multiple health services in one place, including dental, medical treatment, and physiotherapy or occupational therapy.<sup>[12]</sup> On top of this, adequate knowledge regarding their children's health and positive support from the healthcare providers were vital points for the parents, which subsequently affected the children's treatment.<sup>[12]</sup> Providing the best services is essential for their children and the parents as they are at high risk of mental health problems due to psychological stress and societal pressure.<sup>[12]</sup>

According to a systematic analysis, most parents of children with autism in Western countries were initially dissatisfied with health services due to a lack of treatment alternatives and support from healthcare practitioners, as well as high costs and lack of transparency.<sup>[13]</sup> As a result, parents are unmotivated to continue their children's treatment.<sup>[13]</sup> In Malaysia, very little is known regarding PWID parents' or caregivers' perception of healthcare services. Hence, it is critical to explore this issue to improve healthcare services for PWID.

### MATERIALS AND METHODS

### STUDY DESIGN, POPULATION AND SETTING

This cross-sectional study was done using a selfadministered online questionnaire collected from October 2021 to March 2022. A purposive sampling method was used to recruit parents and caretakers of PWID attending the Special Care Dentistry clinic in our university hospital and from five special community centers in the Kuantan district. We extracted participants' phone numbers from the university hospital from their medical/dental records. Meanwhile, for those from five special community centers, we first contacted the supervisor of each center using the contact number obtained from the State's Social Welfare Department. The supervisors of these special community centers were contacted and explained about this study. After getting their consent, we asked for their help to distribute the Google Form through the WhatsApp application to all the parents and caretakers of PWID attending their center. Data collection was done via an online survey whereby the parents and caretakers of PWID were invited to fill out the online questionnaire through a Google Form.

#### **INCLUSION AND EXCLUSION CRITERIA**

The inclusion criteria were parents and caretakers of PWID aged 18 years and above who can understand the Malay or English language. Those with learning or intellectual disability were excluded from this study.

#### SAMPLE SIZE CALCULATION

The sample size was calculated using Kish's formula with an 80% confidence interval and a 5% margin error. From the literature review, the total population of PWID in Pahang state was 94913. Since no previous study determined the perception among PWID, the P = 0.50 was used to cater for maximum variation. Therefore, we estimated the minimum sample size required to be around 141. After considering the 30% nonresponse rate, the final sample size required was 183.

#### STUDY INSTRUMENT

This study used a newly developed self-administered questionnaire. We constructed the questionnaire based on existing literature on this topic.<sup>[3,7,14]</sup> The new question naire was created because no validated questionnaires from previous studies fit our research objectives. This is mainly because this is the first quantitative study looking into perceptions of healthcare services among parents and caretakers of PWID, particularly in Malaysia. The newly developed questionnaire consists of five sections: (1) sociodemographic profile, (2) perception toward healthcare and dental care access, (3) health and dental attendance patterns, (4) perceptions toward healthcare and dental care services, and (5) barriers to healthcare and dental care services for PWID. Two sections that assess their perception (sections 2 and 4) used a 5-point Likert scale ranging from strongly disagree to agree strongly. Cronbach alpha was conducted to measure the reliability of the newly developed questionnaire, especially for sections 2 and 4 that used the Likert scale. The Cronbach alpha for section 2 was 0.892, which shows that it is highly reliable. The Cronbach alpha for section 4 was 0.681, which shows that the section is reliable.

Meanwhile, the other three sections used multiplechoice answer questions. A total of 36 questions were distributed on five screens (pages). The duration to complete the questionnaire was estimated at around 10 minutes. Content and face validation was performed to improve the questionnaire's adequacy, accuracy, and appropriateness. Content validation was done by three experts who frequently deal with PWID (medical and dental). Face validation was done among 20 respondents to ensure that the questionnaire was relevant and appropriate. These 20 participants tested the Google Form version of the questionnaire before conducting the actual study to ensure its reliability, accuracy, and appropriateness and to avoid any technical error. To ensure participants completed all the questions in the Google Form, we set each question as compulsory to be answered before they were allowed to move on to the next question. The participants were allowed to change their answers as long as they did not submit the form.

#### STATISTICAL ANALYSIS

Data entry and analysis were done using IBM statistical package for social sciences (SPSS) version 24. Data checking and cleaning were done before analysis. Categorical data were summarized in actual numbers and percentages. This study only involved univariate (descriptive) data analysis.

### **E**THICAL CONSIDERATION

This study was approved by the Kulliyyah of Medicine and IIUM Research Ethics Committee (IREC) with ID no. IREC 2021-063. Participation in this study was entirely voluntary. All participants who agreed to participate in the survey signed a written consent form attached to the Google Form. Detailed information about the study was given to participants inside the participant information sheet attached in the Google Form. This information includes the purpose of the study, the expected duration to complete the survey, the data storage procedure (including its period and the person who has access to it which are the investigators involved in this study only), and the detail of the investigator whom participants can contact for any clarity. Those who completed the form were given MYR20 as a token of appreciation.

### **R**ESULTS

A total of 220 parents and caretakers of PWID were invited to fill up the Google Form questionnaire. Out of this, 189 completed the form making the response rate 86%. Table 1 shows the sociodemographic profile of the respondents. Most of the respondents were parents of PWID (74.5%). More than one-third (39.2%) of PWID were diagnosed with autism, followed by Down syndrome and cerebral palsy. Although most of the respondents work as professionals and nonprofessionals, with 34.9% and 24.9%, respectively, about 40% were either unemployed or retired. This was noticeable in the monthly income of the respondents, the majority of them were in the B40 group, which referred to those with household income among the bottom 40% population in the country.<sup>[15]</sup> Most respondents were full-time carers for PWID under their care.

Table 2 illustrates the perceptions of parents and caretakers of PWID toward healthcare access. At least

56

Table 1: Sociodemographic profile of respondents			
Variables $(n = 189)$	n (%)		
Relationship with PWID			
Parent	141 (74.6)		
Siblings	15 (7.9)		
Relatives	7 (3.8)		
Carers (nonfamily members)	5 (2.6)		
Others	21 (11.1)		
Gender			
Male	40 (21.2)		
Female	149 (78.8)		
Age (mean $\pm$ SD)	43.96 (±12.1)		
Race			
Malaysia	171 (90.5)		
Chinese	12 (6.3)		
Indian	1 (0.6)		
Others	5 (2.6)		
Diagnosis of PWID under your care			
Down syndrome	53 (28.0)		
Cerebral Palsy	19 (10.0)		
Autism	74 (39.2)		
Unknown	43 (22.8)		
Taking care of the PWID full time			
Yes	130 (68.8)		
No (please specify your role)	59 (31.2)		
Special education class	14 (23.7)		
Community center for people with special	26 (44.1)		
needs			
Housemaid	3 (5.1)		
Others	16 (27.1)		
Occupation			
Professional	66 (34.9)		
Nonprofessional	47 (24.9)		
Unemployed	61 (32.3)		
Retiree	15 (7.9)		
Monthly income <sup>[15]</sup>			
B40 ( <rm4,850)< td=""><td>155 (82.0)</td></rm4,850)<>	155 (82.0)		
M40 (RM4,850 < <i>x</i> < RM10,960)	30 (15.9)		
T20 (>RM10,960)	4 (2.1)		
Educational level			
Primary	7 (3.7)		
Secondary	82 (43.4)		
Tertiary	100 (52.9)		

more than one-fifth of the respondents reported having difficulty with the current healthcare access (agree and strongly agree). More than one-third of respondents agree and strongly agree that they have difficulty accessing health and dental care for PWID under their care (32.2% and 33.9%).

Table 3 shows the healthcare attendance of PWID. Just slightly more than half of the respondents reported that PWID under their care has a medical follow-up.

Table 3: Healthcare and dental care attended	lance
Variables	n (%)
Child/adult with ID has medical follow-up	
Yes	106 (56.1)
No	83 (43.9)
Child/adult with ID has dental follow-up	
Yes	73 (38.6)
No	116 (61.4)
Frequency of child/adult with ID care for medical	
checkups	
Twice a year/6 monthly	98 (51.9)
Once a year	25 (13.2)
Once in 2 years	12 (6.3)
Once in 5 years	5 (2.6)
Once in 10 years	5 (2.6)
Never	44 (23.3)
Medical check up patient attendance	
Regular	123 (65.1)
Irregular	22 (11.6)
Never	44 (23.3)
Frequency of child/adult with ID care for dental	
checkups	
Twice a year/6 monthly	68 (36.0)
Once a year	36 (19.0)
Once in 2 years	17 (9.0)
Once in 5 years	5 (2.6)
Once in 10 years	3 (1.6)
Never	60 (31.7)
Dental check up patient attendance	
Regular	104 (55)
Irregular	25 (13.2)
Never	60 (31.7)

Table 2: Perceptions toward healthcare and dental care access for PWID					
Variables	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
	n (%)	<b>n</b> (%)	n (%)	n (%)	n (%)
Difficult to get the healthcare access for PWID under my care	$\frac{38}{25} (20.1)$	57 (30.2)	33 (17.5)	36 (19.0)	25 (13.2)
Difficult to get dental care access for PWID under my care	33 (18.3) 50 (26.5)	52 (27.5)	38 (20.1)	38 (20.1)	26 (13.8)
Difficult to access the medical building facility	50 (26.5)	47 (24.9)	41 (21.7)	22 (11.6)	29 (15.3)
Difficult to access the dental building facility	47 (24.9)	46 (24.3)	53 (28.0)	23 (12.2)	20 (10.6)
Difficult to get information about the health needs of PWID	28 (14.8)	64 (33.9)	45 (23.8)	29 (15.3)	23 (12.2)
under your care	2((12.9))				
Difficult to get dental information for the oral healthcare for	26 (13.8)	62 (32.8)	56 (29.6)	21 (11.1)	24 (12.7)
PWID under your care					

Table 4: Perception toward healthcare and dental care services					
	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
	<b>n</b> (%)	n (%)	<b>n</b> (%)	n (%)	n (%)
Equal service from medical doctors	2 (1.1)	7 (3.7)	29 (15.3)	75 (39.7)	76 (40.2)
Equal service from dentist	4 (2.1)	7 (3.7)	38 (20.1)	64 (33.9)	76 (40.2)
Medical healthcare staff show positive attitudes toward child	1 (0.5)	1 (0.5)	37 (19.6)	75 (39.7)	75 (39.7)
Dental healthcare staff show positive attitudes toward child	1 (0.5)	5 (2.6)	41 (21.7)	42 (22.2)	100 (52.9)
Good support from medical staff for the healthcare of your child/PWID	2 (1.1)	3 (1.6)	33 (17.5)	73 (38.6)	78 (41.3)
Good support from dental staff for the oral care of child/ PWID	1 (0.5)	5 (2.6)	48 (25.4)	63 (33.3)	72 (38.1)
Medical staffs communicate well toward carer and child/ PWID	1 (0.5)	2 (1.1)	27 (14.3)	75 (39.7)	84 (44.4)
Dental staffs communicate well toward carer and child/PWID	1 (0.5)	7 (3.7)	40 (21.2)	68 (36.0)	73 (38.6)
Child/PWID feels uncomfortable in the healthcare facility	49 (25.9)	59 (31.2)	41 (21.7)	26 (13.8)	14 (7.4)
Child/PWID feels uncomfortable in the dental facility	49 (25.9)	49 (25.9)	53 (28.0)	23 (12.2)	15 (7.9)
Experienced element of discrimination in receiving health service for PWID	70 (37.0)	50 (26.5)	45 (23.8)	15 (7.9)	9 (4.8)
Experienced element of discrimination in receiving dental service for PWID	59 (31.2)	52 (27.5)	54 (28.6)	13 (6.9)	11 (5.8)
Health services in Malaysia are OKU friendly	4 (2.10)	10 (5.3)	56 (29.6)	65 (34.3)	54 (28.6)
Dental services in Malaysia are OKU friendly	5 (2.6)	11 (5.8)	64 (33.3)	59 (31.2)	51 (27.0)

 Table 5: Barriers to healthcare and dental care services for

 PWID

Variables	Yes <i>n</i> (%)	No n (%)
Poor communication skills among	46 (24.3)	143 (75.7)
healthcare providers		
Difficulty in healthcare access	40 (21.2)	149 (78.8)
Healthcare facilities, not PWID friendly	28 (14.8)	161 (85.2)
Inequality of treatment given	2 (1.1)	187 (98.9)
Lack of healthcare information given	53 (28.0)	136 (72.0)
Others, please state	1 (0.5)	188 (99.5)

Respondents can choose more than one answer

However, a majority (61%) reported that PWID under their care does not have a dental follow-up. Most of them (65.1%) bring PWID under their care for medical checkups at least once a year. Meanwhile, only slightly more than half (55%) bring PWID under their care for dental follow-up on a yearly basis.

Table 4 shows the quality of care perceived by parents/ caretakers of PWID. Most respondents, more than 70%, perceived that healthcare staff (medical and dental) give equal services and good support and show positive attitudes toward PWID under their care. However, about 20% of them perceived that PWID under their care felt uncomfortable in healthcare facilities. About 13% of the respondents reported experiencing discrimination in receiving health and dental services for PWID under their care.

Table 5 illustrates the barriers faced by parents and caretakers of PWID. About 28% reported they lack healthcare information given by the healthcare staff.

This was followed by poor communication skills (24.3%), difficulty in accessing healthcare facilities (21.2%), and healthcare facilities are not PWID friendly (14.8%). Only 1.1% reported experiencing inequality of service by healthcare staff.

### DISCUSSION

Our result [Table 1] shows that most (82%) participants were in the B40 group. This referred to those with household income among the bottom 40% population in the country.<sup>[15]</sup> Furthermore, most respondents were full-time carers for PWID under their care, restricting their opportunity to work and gain income. The result is consistent with a systematic review which reported that the prevalence of PWID was higher in low-income countries.<sup>[16]</sup> In addition, a large-scale cohort study found a significant association between low socioeconomic status with poorer health for their children (aged 10 years and below).<sup>[17]</sup> The impact of low family income on PWID may affect their healthcare. In Malaysia, the number of registered persons with disabilities (PWD) at the Department of Social Welfare in 2017 was 3258. Out of this, 34.8% was in the category of PWID.[18]

About one-fifth of the respondents did not know the diagnosis of PWID under their care [Table 1]. Intellectual disability normally begins in childhood and is characterized by significant limitations in intellectual functioning and adaptive behavior.<sup>[5]</sup> However, in normal circumstances, parents might notice their children's condition late before bringing them to the hospital for further examination and investigation.<sup>[19]</sup> In Malaysia, the common diagnoses for psychiatric clinic patients were neurodevelopmental disorders, including attention deficit hyperactivity disorder (ADHD), autism spectrum disorder, and intellectual disability.<sup>[20]</sup> Other than that, the intellectual disabilities may be due to depressive disorder, anxiety disorders, and Schizophrenia.<sup>[20]</sup> Thus, this brings us to why some parents do not know the diagnosis of their children with intellectual disabilities is.<sup>[20]</sup>

Questions regarding access to health and dental care are not just about access to the building but the availability of the services themselves [Table 2]. In Malaysia, we have domiciliary health and dental care where medical and dental professionals come to some care homes/for those who are bed-bound/homebound. Furthermore, some rural areas have difficulty accessing health/dental care. In the present study, about a third of parents and caretakers of PWID reported difficulty in accessing both healthcare and dental care [Table 2]. Although the PWID have the same opportunity to access hospital in western countries, the problem remains the same: communication problems, lack of facilities, lack of trained staff, and failure to make a reasonable adjustment for the patient.<sup>[21]</sup> In another study done in the United Kingdom (UK), there were reported cases of PWID where they cannot get healthcare access due to social status and language barriers.<sup>[21]</sup>

According to Malaysia Disabilities Act 2008, people with disabilities have equal access to healthcare services.<sup>[22]</sup> However, the findings from the present study are in accordance with another local study done in Penang where PWID reported having problems in getting their needs.<sup>[3]</sup> Examples of the burdensome healthcare needs were getting hearing aids, speech therapy, dental therapist, and nutritional advice.<sup>[3]</sup> This happens due to several reasons, such as transportation factors, inflexibility, appointment time, cost factors, lack of promotion from services, and unavailability of services in a rural area.<sup>[3,23]</sup>

In terms of suggestions for improvements, more promotion of service availability should be done so that parents or caretakers of PWID will be able to get the help they need.<sup>[3]</sup> In addition, skilled professionals and doctors should be available in rural areas to make it easy for everyone to access.<sup>[3]</sup> The healthcare system should also be more flexible in appointment times, as many parents have reported taking time off work to send their children to the doctor.<sup>[23]</sup>

Almost a third of PWID never attended the dental clinic in this study. However, most of the parents/

caretakers brought PWID for at least a yearly review for both medical and dental [Table 3]. PWID lacked self-care, causing them to depend on others, such as their parents or caretakers.<sup>[12]</sup> The situation could be worse if the parents or caretakers are inexperienced such as during the first childhood, or did not have awareness regarding intellectual disabilities.<sup>[12]</sup> A study done in the UK, showed PWID living in community care settings were more likely to get a medical or dental checkup.<sup>[24]</sup> Besides, there was a Model that was brought up in the USA, which instead of focusing on specialist special needs at hospital based, it was better to create a community based with all the services provided for disabled people.<sup>[24,25]</sup>

In Malaysia, some parents and caretakers of PWID did not have the effort to bring PWID to the hospital for a medical and dental checkup as they were problem-oriented healthcare attendants, as found in a local study.<sup>[26]</sup> However, it was also difficult for them because of other locality factors, appointment time, and no reminder from the hospital, making them forget about their children's appointments.<sup>[23]</sup> Thus, instead of focusing on treatment for PWID at hospital based, Malaysia is still a long way to go toward deinstitutionalization, where the PWID patient can have their basic medical and dental checkup at community psychiatric services.<sup>[27]</sup> This movement will slowly but surely encourage parents or caretakers of PWID to seek medical and dental care.

This study found that most respondents were satisfied with the quality of healthcare services for PWID under their care [Table 4]. On the contrary, a systematic review found that only 12% of patients met a good quality of services, while 88% failed to meet their needs.[25] The main reasons for this were improper diagnosis by hospital staff, failure to address the patient's complaints, lack of experience managing patients with aggressive behavior, and inadequate treatment planning.<sup>[25]</sup> Furthermore, bad attitudes from personnel were evident, with some refusing to treat the patient after learning that they had intellectual disabilities.<sup>[25]</sup> In the United States, the cost is also part of the main barriers faced by families with PWID under their care.<sup>[28]</sup> Moreover, as everyone has the same opportunity to obtain healthcare services, there were no differences between a PWID and another person in terms of waiting a long time for treatment. In addition, poor communication skills of the healthcare workers (HCW) and failure to consider the PWID's condition with the appointment time were also the reasons contributing to the low percentage of satisfaction.[7,9,25]

However, our study also noted that PWID experienced discrimination while receiving health and dental care. Compared with western countries, there was a lack of evidence regarding discrimination toward PWID from healthcare staff and doctors in Malaysia.<sup>[29]</sup> Hence, the finding of this study should remind us that discrimination toward PWID is still happening in healthcare and dental care settings even after many years of the existence of the Malaysia Disability Act. Effort from every level of the healthcare system must be strengthened continuously to achieve zero discrimination for PWID.

The three main barriers to the current healthcare and dental services were inadequate healthcare information for PWID, poor communication by the HCW, and difficulty accessing healthcare [Table 5]. This corroborates with previous studies in western countries and a systematic review<sup>[9,10,25,28]</sup> in Malaysia. However, there was evidence where PWID could not fulfil their need in healthcare,<sup>[3]</sup> the evidence of PWID being discriminated against by the doctor or receiving bad attitudes from the staff are still scarce.

In Malaysia, community psychiatric departments continuously help PWID improve their lifestyle.<sup>[27]</sup> Malaysia is still behind in terms of systems, with most caretakers not receiving any reminder notifications for their children with intellectual disabilities, hospital appointments not being flexible for PWID, and the doctor or staff treating their children changing frequently, rendering treatment become ineffective.<sup>[23]</sup>

To the best of our knowledge, this is the first study in Malaysia exploring the perceptions toward healthcare and dental care services among parents and caretakers of PWID. As for the limitation of this study, first, it was conducted in Kuantan and may not represent the whole Malaysian parents and caretakers of PWID (thus affecting the generalizability of our result). Second, even though the authors had prepared free-typing under the barriers theme, respondents who said they had encountered prejudice did not specify what kind of discrimination they had experienced. As a result, a longitudinal qualitative study on this topic is needed for future research and the betterment of healthcare and dental care services in Malaysia for PWID.

### **CONCLUSION**

In summary, this study signifies that the perceptions toward healthcare and dental services in Malaysia among parents and caretakers of PWID are reasonably good for most of them, albeit there was still discrimination and/or discomfort for some PWID. A minority of the respondents admitted did not bring PWID under their care for annual checkups. Education on intellectual disability must be embedded in the curriculum for healthcare faculties to prepare them with knowledge and skills to cater for PWID in the future. Campaigns about awareness of intellectual disability should be emphasized in social media. The evidence gained from this study can be utilized to improvise healthcare services for their comfort and accessibility.

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### CONFLICTS OF INTEREST

There are no conflicts of interest.

### **AUTHORS CONTRIBUTIONS**

Not applicable.

**E**THICAL POLICY AND INSTITUTIONAL REVIEW BOARD STATEMENT Not applicable.

#### **PATIENT DECLARATION OF CONSENT**

Not applicable.

#### **DATA AVAILABILITY STATEMENT**

Not applicable.

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60

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61