

## **THE GLOBAL PREVALENCE AND DIAGNOSIS OF AUTISM SPECTRUM DISORDER (ASD) AMONG YOUNG CHILDREN**

\*Aminah Bee Binti Mohd Kassim<sup>1</sup>, Noor Hassline Binti Mohamed<sup>2</sup>

<sup>1</sup>Family Health Development Division  
Ministry of Health Malaysia

<sup>2</sup>Faculty of Psychology and Education  
University Malaysia Sabah

\*Corresponding author's e-mail: aminahbee@moh.gov.my

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**Abstract:** Autism Spectrum Disorder (ASD) refers to a group of developmental disorders. Although the global prevalence of ASD is reported to be between 3-6 children per 1000, there is difficulty in comparing the prevalence of ASD across countries because of the variation in methodology, age group of population and the sample size studied. The prevalence of ASD shows an increasing trend and factors attributing to the rise in prevalence include the increase in awareness on the signs and symptoms of ASD, the increase in access to services, the changes in the definition of autism over time and the broadening of the diagnostic criteria. Among the administrative factors also linked to the increase in prevalence were changed in reporting practices and availability of records. Before 1990's diagnosis of ASD was more often after the entrance to the school. Currently, there are diagnostic tools available and the diagnosis can be made among toddlers. However, for those on the milder end of the spectrum with average or above-average language and cognitive abilities, the diagnosis is still made after school entry. Early detection, diagnosis, and intervention are important in promoting better long-term outcomes and as such screening programs need to be in place. Sustainability of the program requires training of primary care providers, the use of specially designed tools for screening and protocols for referral, and a multidisciplinary diagnostic team. This paper shares the Malaysian experience in implementing a screening program since 2011 and the outcomes of the screening program for ASD in primary care.

**Keywords:** Global Prevalence, Diagnosis & Autism Spectrum Disorder

## **SCREENING AND DIAGNOSIS OF AUTISM SPECTRUM DISORDER**

### **Definition of Autism Spectrum Disorder (ASD)**

Autism Spectrum Disorder (ASD) is the name for a group of developmental disorders. As in its name “spectrum” refers to a wide range of symptoms, skills, and levels of disability. to Diagnostic and Statistical Manual of Mental Disorders: Fifth Edition (DSM-5) (2013) individual with ASD is characterized by the following symptoms: i) persistent deficits in social communication and social interaction across multiple contexts, ii) restricted, repetitive patterns of behaviour, interests, or activities, iii) symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities) and iv) symptoms together limit and impair everyday functioning.

Autism Disorder or Classical Autism was described in Diagnostic and Statistical Manual of Mental Disorders: Fourth Edition (1994) also known as DSM-IV, must fulfill the following criteria: i) impairment in social interaction, ii) impairments in communication and restricted, repetitive, or stereotyped patterns of behavior, interests, or activities. Autism Disorder (AD) in the DSM-IV is under the umbrella condition known as Pervasive Developmental Disorder (PDD) which has been replaced with the term Autism Spectrum Disorder under the Fifth Edition. Thus, Autism Disorder is a subset of the Autism Spectrum Disorder.

### **Changes in Defining Autism**

There has been a substantial change in the way autism has been defined and diagnosed. From history, autism first case was identified by Leo Kenner in 1943 where he described children who seemed socially isolated and withdrawn as ‘infantile autism’. Using Kenner’s description of autism, in 1966 it was estimated 1 in 2500 children had autism. However, at this point the definition and prevalence of autism only detected children more severe features and missed those with subtle features (Wing, 1993).

The way autism was defined changed in the 1980s when infantile autism was included in the Diagnostic and Statistical Manual of Mental Disorder Third Edition under the class of conditions called pervasive developmental disorder (PDD). According to DSM III, to garner a diagnosis, a child

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needed to meet 8 of 16 criteria, rather than all 6 of the previous items. In 1987 a revised version of DSM III included the expansion of the criteria to allow a diagnosis even if symptoms became apparent after 30 months of age (Wing, 1993). These changes may have caused the condition's prevalence to increase above 1 in 1,400 in comparison to the prevalence in 1966.

Then, in 1991, the U.S. Department of Education ruled that a diagnosis of autism as one of educational disability which qualifies children with autism for special education services (Pennington, Cullinan, & Southern, 2014). This may have encouraged families to get a diagnosis of autism for their child. This could account for the rise in numbers of students with autism in a school setting from 15,580 in 1992 to 406,957 in 2011, a 26-fold rise in two decades. However, it was found that the revised version of DSM-III appeared to over-diagnose individuals with a greater cognitive disability while under-diagnosing those with a higher IQ range. Thus in 1994 DSM-IV was published to balance sensitivity and specificity across IQ range and age. DSM IV also included new disorders under the PDD condition namely childhood disintegrative disorder, Rett's syndrome, Asperger's syndrome and also PDD-NOS category (Volkmar & Reichow, 2013).

In 2013, DSM-5 was published to enable a better description of autism spectrum disorder and replacing the condition of pervasive developmental disorder (PDD). Rett's syndrome was no longer regarded as autism spectrum disorder after the discovery of a gene that linked with the disorder. Thus, in DSM V it was excluded as a part of ASD diagnosis. DSM V combined the social and communication symptoms as one single category, includes the restricted behaviors consistent with Kenner's characteristic of autism with the addition of sensory sensitivity symptom which was a lack in DSM IV (Volkmar & Reichow, 2013).

Volkmar & Reichow (2013) concluded that although changes made in DSM-5 were praiseworthy however there were some setbacks. DSM-5 is more specific in diagnosing ASD compared to DSM-IV however; it is less sensitive in detecting certain individuals that met criteria for PDD NOS in DSM IV resulting in them not to be diagnosed as ASD. Studies comparing the use of DSM-IV ASD and the DSM-5 ASD have reported that about 9–54% of DSM-IV ASD cases do not qualify for the DSM-5 ASD (Tsai,

2014). Recent research has criticized the DSM-5 and shows that the DSM-5 under-identifies children with ASD, particularly children at the mild end of the spectrum. The study also suggests the DSM-5 be rectified by requiring one less social communication and interaction symptom for a diagnosis (Mayes, Calhoun, Murray, Pearl, Black, & Tierney, 2014). The definition of ASD has changed over time and the defining of ASD is still an on-going process.

### **Prevalence of Autism Spectrum Disorder (ASD) And Autism Disorder (AD)**

Global estimates Autism Spectrum Disorder is said to be between 3-6 children per 1,000 and it was found that males are four times more affected than females (Elsabbagh, et al., 2012). Prevalence of ASD (DSM-5) and Pervasive Developmental Disorder or PDD (DSM IV) are considered together as both are umbrella conditions for autism. Prevalence of PDD / ASD based on a review of 60 studies had a wide range from 0.21 to 26.4 per 1000 and a median rate of 6.8 per 1000. In the same study, a review of 72 epidemiological studies on the prevalence of AD also reported a wide range from 0.07 to 2.2 per 1000. The median rate reported was 1.5 per 1000 (Tsai, 2014). Prevalence in developing countries is lower compared to that of the more developed nations (Uwaezuoke, 2015). Studies on autism in the Western Pacific Region report varying prevalence rates ranging from 0.28 to 9.4 per 1,000. The only available study in South East Asia, namely Indonesia estimates the rate at 1.17 per 1,000 (Elsabbagh, et al., 2012).

### **Comparison of Prevalence Across Countries**

Comparing prevalence rates across countries is difficult and not accurate as there is too much variation in methodology, and assessment tools used, as well as variability in the age groups studied and size of the population studied (Tsai, 2014). Earlier studies appear to suggest that the greatest influence is due to methodological variables (Wing, 1993). For example, the prevalence rate by the CDC in the United States reports a prevalence of 2.24% or 22 per 1000 among children aged 8 years old used information from school and health records (Christensen, et al., 2016). A study in Canada on the local prevalence of ASD reported a prevalence of 10.6 per 1000 among children 5 to 17 years using school board records within a region (Dudley & Zwicker, 2016). A South Korean population-based study among children 7 to 12 years used standardized questionnaire

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followed by a standardized diagnostic procedure reported a prevalence of 26.6 per 1000 (Kim, et al., 2011).

Age of child studied plays an important part because severe cases of ASD are more apparent at an earlier age however the less severe cases only become obvious as a child begins to go to school. In 2016, ASD prevalence estimates in the US found that 4-year-old ASD prevalence was 13.4 per 1000, which was 30% lower than 8-year-old ASD prevalence of 22 per 1000 (Christensen, et al., 2016). A Swedish study in 2011 showed the prevalence of diagnosed ASD was 4 per 1000 among children 0–5 years, four times lower than the prevalence among children 6–12 years reported as 17.4 per 1000 (Idring, et al., 2015). The availability of records is also another factor contributing to variation in prevalence. A study on 58,467 4-year-old children in the US found that sites with access to both education and health records recorded higher rates compared to sites with only health records (Christensen, et al., 2016). The lack of standardized methodology in studying prevalence makes it difficult to compare across countries.

### **Increasing Prevalence of ASD**

The estimates of ASD have increased over the past several decades. Is there a real increase or an apparent increase? A review of 60 studies on ASD/PDD showed that there is an increase in prevalence. When the year 2009 was used as the point of comparison, the median rate of PDD/ASD from 2000 to 2009 was 6.35 per 1,000 whilst the rate for the years 2010 to 2014 was 8.0 per 10,000 (Tsai, 2014). In the same study, a comparison was carried out for Autism Disorder. When the year 2000 was used as the point of comparison, the median rate of AD from 1966 to 2000 was 11.9 per 10,000 compared to the year 2001 to 2013 where it was reported as 28.4 per 10,000 showing an increase of more than double the prevalence rate (Tsai, 2014). Studies have been conducted to identify the cause of this increase. Among the factors attributed to the increase in prevalence is the increase in awareness of the signs and symptoms of ASD, the increase in access to services and the broadening of the diagnostic criteria (Elsabbagh, et al., 2012) (Dudley & Zwicker, 2016) (Idring, et al., 2015).

There were also other reasons linked to administrative reasons such as a study in Denmark that identified the cause for the increase in prevalence was related to a change in reporting practices (Hansen, Schendel, & Parner, 2015). The US National Health Interview Survey on

developmental disabilities comparing data from 2011 and 2014 attributed its increase to the changes in the order of questions in the survey questionnaire and a new approach to asking about autism spectrum disorder (Zablotsky et. al, 2015). As the survey was self-reported in nature, parents in the earlier survey may have reported a child as having other developmental disorders instead of autism.

A population survey in Sweden showed that the prevalence of the autism (based on symptoms) has remained stable over a period of 10 years however the official prevalence for registered, clinically diagnosed, autism spectrum disorder had increased substantially over the same period of time, thereby attributing the increase in prevalence to administrative changes (Lundström et al., 2015). Although the reported prevalence in developing countries is lower compared to that of the more developed nations (Uwaezuoke, 2015), report of increasing trends in prevalence is also seen in Asia where ASD was 0.19 per 1000 before 1980 and in the 2010 report the prevalence is quoted as 1.48 per 1000 (Sun & Allison, 2010). The increasing trend in developing countries is attributed to increasing knowledge among health professionals and the community. A study in Pakistan among general practitioners reported that GPs who were younger. In short, there are multiple reasons for the increase in prevalence estimates and one major factor is that the definitions of autism have changed over time which also consistent with finding from Wing (1993).

### **Diagnosis of Autism and Autism Spectrum**

Until the 1990s it was rare for children to receive a diagnosis of autism until the age of 3 or 4 years. Today many children are now first identified in toddlerhood, although others, in particular, those with average or above-average language and cognitive abilities, are not diagnosed until school age or older (Manning et.al, 2011). Making a diagnosis of autism spectrum disorder (ASD) is difficult since there is no medical test to diagnose the disorders. The diagnosis of ASD is made either by using criteria from the Diagnostic and Statistical Manual of Mental Disorders DSM-IV-TR (2000) and DSM-5 (2013) or 10th-Revision of International Classification of Diseases (ICD-10). Health care providers should take into consideration cultural and socioeconomic factors that may affect assessment ASD (MOH, Clinical Practice Guidelines; Management of Autism Spectrum Disorder in Children and Adolescents, 2014).

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The ICD and DSM categorical system classifications have led to the development of the Autism Diagnostic Interview-Revised (ADI-R) and the Diagnostic Interview for Social and Communication Disorders (DISCO). Other ASD-diagnostic instruments that can be used to facilitate assessment are the Autism Diagnostic Observation Schedule (ADOS) and the Childhood Autism Rating Scale (CARS). Both ADI-R and DISCO are used as a tool to interview parents or caregivers. The ADI-R is a detailed parent interview. It is used for the diagnostic purpose for anyone with a mental age of at least 18 months. The interview measures behavior in the areas of reciprocal social interaction, communication, and language, as well as patterns of behavior. DISCO on the other hand is detailed but semi-structured and used to identify the impairment of social interaction, social communication and social imagination together with the associated repetitive behaviour, and all other features that may be found in ASD (MOH, Clinical Practice Guidelines; Management of Autism Spectrum Disorder in Children and Adolescents, 2014).

Both ADOS and CARS are assessment tools used by trained health professionals. A CAR is a 15-item behavior observation rating scale to identify and differentiate children with ASD from typically developing children or others with developmental disabilities. ADOS is a semi-structured assessment of communication, social interaction and play (or imaginative use of materials) for individuals suspected of having ASD. The ADOS consists of four modules, each of which is appropriate for children and adults with different developmental and language levels, ranging from nonverbal to verbally-fluent (MOH, Clinical Practice Guidelines; Management of Autism Spectrum Disorder in Children and Adolescents, 2014).

The ADOS and ADI-R are considered “gold standard” assessment measures in the evaluation of autism spectrum disorders. Diagnostic assessments can also evaluate the presence of other developmental, behavioral, emotional, and attention deficit disorders (Mayes et.al, 2014). In diagnosing ASD, professionals look for delays or abnormal functioning in at least one of the following areas, with onset before age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

## **EARLY DETECTION AND SCREENING**

### **Early Detection for Better Outcomes**

Early detection and intervention are important in promoting better long-term outcomes for children with ASD (Clark et. al, 2018; Pijl et. al, 2017). A study on school-age outcomes of children who received an early before 3 years of age and later diagnosis of ASD found that the cognitive and behavioral outcomes of children diagnosed early were better. The children who received early diagnosis had early access to intervention, demonstrated better verbal and overall cognition at school age, were more likely to attend mainstream school and required less ongoing support compared to children who were diagnosed after the age of 3 years than children diagnosed later. Early diagnosis is important as it promotes more positive outcomes at school age due to increased opportunity for Early Intervention (Clark et. al, 2018).

American Academy of Paediatrics and the American Academy of Neurology and Child Neurology Society recommend that pediatric primary care providers incorporate standardized developmental screenings within the developmental surveillance during well-child care visits. The American Academy of Paediatrics recommends that pediatricians screen children for autism at 18 months of age (American Academy of Pediatrics, 2001).

### **Screening for Autism**

Both screening and surveillance of autism are important. Screening is the prospective identification of unrecognized disorder by the application of specific tests or examinations. Surveillance refers to the ongoing and systematic collection of data relevant to the identification of a disorder over time by an integrated health system. Screening and surveillance are related activities involved in the detection of impairments with a view to prevention disability (Charman & Gotham, 2013).

In choosing a screening tool both sensitivity and specificity of the tool needs to be high; sensitivity in order that the screen misses few cases of the disorder and avoid falsely reassuring parents and professionals; specificity in order that only a few cases without the disorder are screen positive and thereby avoiding falsely alarming parents and costly referral for in-depth assessment (Charman & Gotham, 2013). It has been estimated



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that acceptable sensitivity and specificity for developmental screening tests are 70% to 80%, and the use of screening instruments in combination with asking parents about their concerns improves the efficiency of an instrument (Glascoe, 1999).

There are many screening tools available both general or ‘broadband’ developmental screening tools and specific tools for screening for ASD. Some examples of general screening tools are Child Behaviour Checklist, Infant-toddler checklist and Parents’ Evaluation of Developmental Status. Some of the specific tools for screening for ASD are Checklist for Autism in Toddlers, Modified Checklist for Autism in Toddlers, Modified Checklist for Autism in Toddlers Revised with Follow-up, the Social Responsiveness Scale and the Autism Spectrum Screening Questionnaire (MOH, Clinical Practice Guidelines; Management of Autism Spectrum Disorder in Children and Adolescents, 2014).

Three systematic reviews (SRs) found that Checklist for Autism in Toddler (CHAT), Modified Checklist for Autism in Toddlers (M-CHAT) and Social Communication Questionnaire (SCQ) performed better in the screening of young children for ASD. A study in nine Arab countries showed sensitivity 86%, the specificity 80% and positive predictive value 88% was very similar to a study in 2001 (Seif Eldin, et al., 2008). The sensitivity and specificity of MCHAT in recent studies are lower (MOH, Clinical Practice Guidelines; Management of Autism Spectrum Disorder in Children and Adolescents, 2014). However, screening can be a useful adjunct to ongoing parent-practitioner surveillance. M-CHAT is recommended for use at 18 months to assist with early identification of ASD, and 24 months, to identify those toddlers who have regression. (MOH, Clinical Practice Guidelines; Management of Autism Spectrum Disorder in Children and Adolescents, 2014)

For older children above 4 years, Social Communication Questionnaire (SCQ) i.e. a parent-rated questionnaire is suitable. It evaluates the social interaction, communication, language and stereotypic behaviors for possible autism or other ASD. SCQ was better in detecting ASD in individuals over seven years of age (sensitivity of 86% to 90% and specificity of 78% to 86%) compared to children aged 2 to 3 years old (sensitivity 47% to 54% and specificity 89% to 92%). To ensure the success of the screening, early detection, and intervention program, there

is a need for continued investment in the early detection of autism spectrum disorder. The odds of being referred before 3 years of age were higher in children with autism spectrum disorder than in children with another condition during the program, however, this was not sustained once the program ended (Pijl et. al, 2017). There needs to be continuity in (a) training of primary care providers to recognize early signs of autism, (b) use of a specially designed referral protocol and screening tool/questionnaire and (c) formation of a multidisciplinary diagnostic team.

## **AUTISM SCREENING AND EARLY DETECTION IN MALAYSIA**

### **Prevalence of ASD in Malaysia**

The first study that reported the prevalence of autism in Malaysia was a small-scale feasibility study on the use of M-CHAT involving 4,767 toddlers in 5 districts in 2005. The M-CHAT failure rate in this study was reported as 0.6%. All children who failed M-CHAT were assessed by Paediatric psychiatrist and confirmed using DSMIV. The autism prevalence rate was reported as 1.6 per 1,000 (MOH, Prosiding Mesyuarat Membincangkan Hasil Kajian Saringan dan Pengendalian Masalah Autisme, 2006). In addition to the 1.6 per 1000 children diagnosed with autism, from the cases that failed M-CHAT, another 1.6 per 1000 were diagnosed with other developmental disorders and mainly focused on communication issues.

The more recent study in Malaysia, i.e. the National Health Morbidity Survey 2016, included a total of 5846 children aged 18 months to 3 years in the study. This survey done 10 years later using M-CHAT reported a failure rate of 1.6% and this is more than double compared to the study in 2005 (National Health and Morbidity Survey 2016: Maternal and Child Health (MCH): Volume II: Maternal and Child Health Findings, 2016). Using the 2005 findings and the Compounding Annual Growth Rate (CAGR) formula, the estimated prevalence rate of autism for 2016 is 1.875 per 1,000. However, with the changes in diagnostic criteria and broadening of ASD definition, the estimate for ASD in Malaysia could be much higher.

### **The Screening Program for Autism in Malaysia**

The idea to implement a screening program for autism was mooted in 2004 administrative data available at that time showed that the majority (80%) of the cases diagnosed with autism we identified after the entrance to preschool onwards i.e. between the ages of 4 to 12 years. It was hoped that implementing a routine screening program during the well-child clinic sessions would improve the detection of cases before the entrance to preschool. Following the feasibility study in 2005, the M-CHAT was incorporated into the home-based Child Health Record Book, to ensure children are screened at 18 months and 3 years. The use of the book began in 2008 and by 2012 all children attending health clinics have been supplied with the book. The Malaysian CPG for management of Autism also recommends screening at 24 months which will be carried out throughout the country. Therefore, all children attending clinics will be screened at 18 months, 2 and 3 years.



Figure 1: The 0-6 Year’s Old Child Health Record Book (Bahagian Pembangunan Kesihatan Keluarga, 2015)

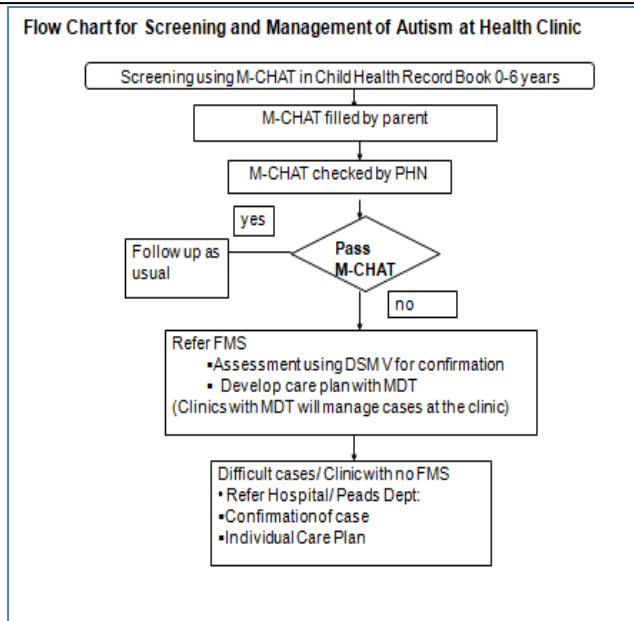


Figure 2: Flow Chart for Screening and Management Used in Study (MOH, 2006)

Not all children who fail the checklist will meet the criteria for a diagnosis on the autism spectrum disorder (ASD). Health staffs have been informed that regardless of the screening results, any child suspected of ASD at any age by the family or other care providers need to be referred for evaluation. In the public health clinic setting, when a child fails the M-CHAT, he or she will be referred to Family Medicine Specialist for further assessment and diagnosis using DSMIV. Clinics that have Multidisciplinary Team (MDT) management sessions will manage cases at the health clinics. Where necessary or in clinics with no MDT, the child will be referred to the hospital for confirmation of diagnosis and intervention.

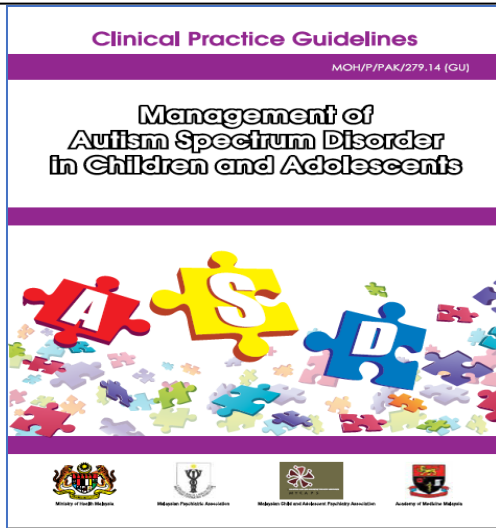


Figure 3: The MOH, CPG of ASD in Children and Adolescents (MOH, 2014)



Figure 4: Poster Used in Awareness Programs (Infosihat, 2003)

### **Diagnosis of ASD**

During the early stages of the program in 2005, DSM IV was used for diagnosis. However, from 2015 onwards, DSM-5 has been in use. In the DSM-5, there is a consolidation of autistic disorder, Asperger Syndrome, and pervasive developmental disorder into ASD. Rather than being distinct disorders, symptoms of these disorders represent a single continuum of mild to severe impairments in the two domains of social communication and restrictive repetitive behaviors. The Ministry of Health developed the Clinical Practice Guidelines; Management of Autism Spectrum Disorder in Children and Adolescents in 2014 to assist clinicians in the implementation of the services.

### **OUTCOME OF THE SCREENING PROGRAM IN MALAYSIA**

Sustainability is an issue. Holzer et al. (2006) investigated the long-term effects of an early detection program where follow up of program was done after 2 years. A 2-step approach in screening was carried out where the program contained the following aspects: (a) familiarizing primary care providers with early developmental problems and (b) informing pediatricians and general health practitioners about a screening tool (Checklist for Autism in Toddlers-CHAT). A failed CHAT would lead the pediatrician to refer for a diagnostic assessment. With the program, the mean age at diagnosis decreased by 1.5 years, but this effect was not sustained after the program ended. These findings emphasize the importance of a maintenance strategy (Holzer, et al., 2006).

The screening program in Malaysia has been in place nationwide for more than 5 years. There has been a steady improvement in the number of cases detected and over the years the cases have been detected earlier. In 2004 only 20% of cases we detected before the age of 4 years, however, data shows that in 2015, 63% of the cases were detected before the age of 4 years. Early detection allows for early intervention and better outcomes.

Table 1: Numbers and Percentage of Children Less Than 12 Years  
Diagnosed with Autism

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Age	2004	2011	2012	2013	2014	2015
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<b>&lt; 4-year-old</b>	39(20%)	46(40%)	68(40%)	83(49%)	123(52%)	186(63%)
<b>4 – 12-year-old</b>	148(80%)	71(60%)	102(60%)	87(51%)	113(48%)	111(37%)
<b>Total Autism (18 months - 12 year)</b>	187	117	170	170	236	297

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*Source: Family Health Development Division, MOH (2017)*

Having a screening program seems to have improved the detection of Autism. In addition to the screening program, the improvement to the detection of ASD can be attributed to increased public awareness about autism.

## **DISCUSSION**

Screening and diagnosis are important in ensuring the child with autism are identified correctly and referred for appropriate interventions. One of the challenges to start a program is the need to have evidence of its magnitude. To acquire evidence requires resources.

### **Prevalence Rates**

The prevalence of ASD globally has increased over the years and especially so over the past two decades. Studies show that the rise can be attributed to many reasons but the major factors include an increase in awareness among the public and health professionals, the availability of screening program and diagnostic tools and intervention services.

This trend is also seen in Malaysia where the prevalence of autism among children below 4 years was found to be 1.6 per 1000 in 2005 and is estimated to be close to 1.9 per 1000 in 2016.

Caution must be applied when comparing the prevalence rates across countries because of the differences in methods used to conduct the studies, age group and size of the population studied and the definition of autism used in the different studies. The rate quoted for the prevalence of autism in the United States is 1 in 68 children or 15 per 1000. This rate cannot be used to compare with the lower prevalence rate quoted for Malaysia because of the differences in study methodology. The rate quoted

in the US is among children aged 8 years versus below 4 years for Malaysia.

### **Definition of Autism**

The definition of autism has also evolved from the classical infantile autism to the now broader term Autism Spectrum Disorder. The prevalence rates will also vary depending on the definition used in the study. The rate of 1 in 68 children is that of ASD i.e. inclusive of the milder end of the spectrum. The rate quoted for Malaysia is based on DSMIV classification and is only for Autism Disorder and does not include the milder forms of the autism spectrum. The differences due to different definitions were mentioned earlier in this paper, where the median prevalence rate of PDD / ASD is quoted as 6.8 per 1000 compared to the lower median rate of Autism Disorder at 1.5 per 1000 (Tsai, 2014). The changing of definitions affects the provision of health, educational and welfare services to children with the condition. When the definition is too broad, resources for service provision becomes stretched. However, a narrower definition will cause children on the mild spectrum to be missed and not be eligible for services.

### **Screening and Diagnosis: Sustainability**

Better outcomes are predicted if early identification of children with autism and intensive, early intervention during the toddler and preschool years are available. Two processes are required for the execution namely; 1) routine developmental surveillance and screening specifically for autism to be performed on all children to first identify those at risk for any type of atypical development, and to identify those specifically at risk for autism; and 2) to diagnose and evaluate autism, to differentiate autism from other developmental disorders (Filipek, et al., 2000). Studies have shown that rates of early identification and referral for diagnosis decrease after the study period is over. Improving primary care screening, skills, and knowledge may improve the timing of diagnosis, initiation of treatment, quality of care, and outcomes for children with ASD (Carbone et. al, 2016).

Malaysia Ministry of Health has instituted the screening program for autism through its routine child health services by incorporating the M-CHAT into the home-based Child Health Record Book. To ensure the sustainability of the screening program, training for both nurses and



doctors are conducted regularly. Data on screening is monitored 3 monthlies at the national level and during the earlier stages of the program; it was taken up as a key performance indicator and monitored closely. A monitoring mechanism has been put in place where records are audited by nursing supervisors to ensure nurses in the front line are aware of autism and the screening tool is utilize appropriately. Much effort and resources have been put into ensuring the sustainability of the program.

## **CONCLUSION**

Although awareness of autism has been around for more than 70 years, it is still relatively new and newer knowledge is being unearthed with more research on this condition. Malaysia has come a long way over the past decade as an interest in autism and the need to develop screening services only began in 2005. More research needs to be conducted locally in Malaysia to ensure the availability of local data for better planning of health services and intervention programs for children with autism. It is important that all children regardless of the severity of ASD receive assistance.

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