

Assessment and Diagnosis of Autism Spectrum Disorder in Hanoi, Vietnam

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Abstract For individuals with autism spectrum disorder (ASD), early and accurate diagnosis enables early intervention, which leads to improved quality of life. The diagnostic label of ASD has only been recognized in Vietnam since 2000 and the number of children who have been diagnosed has increased dramatically. However, there is limited understanding about the condition. This article aims to describe the current assessment and diagnostic practices in Hanoi, Vietnam, a low resource setting. Data for this article came from in-depth interviews with parents of children with ASD and service providers, and observation at health clinics and early intervention centers that provide ASD assessment during field work from July 2011 to May 2012. This study reveals that although there is some improvement in assessment services, parents still face a number of challenges in accessing quality assessment and diagnosis of ASD in Vietnam. These include rushed and perfunctory assessment; a lack of clinical guidelines for assessment; limited communication among health professionals in assessment teams, and between professionals and parents of children with ASD. Public awareness-raising of the signs of autism, capacity building for professionals, development of practical and contextual appropriate

assessment protocols are needed to enhance the accessibility and quality of assessment services.

Keywords Autism Spectrum Disorder · Assessment · Diagnosis · LMIC

Introduction

Comprehensive assessment and accurate diagnosis of autism spectrum disorder (ASD) are crucial to understanding and supporting children to access appropriate interventions, and thereby improve long-term outcomes (Perry et al. 2002; Shattuck and Grosse 2007). Due to the absence of biomarkers, diagnosis of ASD depends upon professionals' clinical judgment of the behavioral presentation of individuals and taking an accurate developmental history from the parent. Professionals are aided by diagnostic guides such as the Diagnostic and Statistical Manual of Mental Disorders (DSM)-IV (or DSM-5 since its release in May 2013) and the International Classification of Diseases (ICD)-10.

There is increasing consensus among professionals about what constitutes best practice for comprehensive assessment (NICE 2011; Shattuck and Grosse 2007; Taylor et al. 2016; Wilkinson 2010). Best practice ASD screening, diagnosis and assessment consists of early recognition (screening) and then referral to a multidisciplinary diagnostic assessment team, who will undertake review of a child's developmental history (such as communication, social and play skills); integration of information from multiple sources (parent, childcare teacher); clinical assessment through interaction with and observation of the children, and use of standardized developmental or cognitive tests, physical examination and assessment of other co-existing conditions (NICE 2011; Wilkinson 2010). Scholars highlight the importance of

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respecting parents' concerns and providing them with timely and supportive feedback (Wilkinson 2010). Best practice ASD assessment post diagnosis also provides information on a child's strengths and difficulties (Taylor et al. 2016).

However, in reality the assessment and diagnosis of this condition continues to present numerous challenges even in high-resource countries (Taylor et al. 2016; Wilkinson 2010). These include: the application of diagnostic criteria through observation; the use of standardized diagnostic checklists, and other assessment tools; and implementation of various assessment procedures (Goldstein and Ozonoff 2009). In addition, the capacity of service providers and service systems, and care-management policies relating to the diagnostic labels, influence the diagnosis (Filipek et al. 1999; Shattuck and Grosse 2007; Taylor et al. 2016) and contribute to inconsistent diagnostic assessment and interpretation.

The diagnostic label of ASD has only been used since the late 1990s and early 2000s at major children's hospitals in Vietnam (CLAN 2010). At the National Hospital of Pediatrics (NHP—based in Hanoi), the first case diagnosed with autism was reported around 1997–1998 (personal communication with a doctor at NHP, 5 of January, 2012). The number of children who have been diagnosed with autism or as having signs of autism at the NHP increased to 450, 1792, and 1968 in 2008, 2010 and 2011 respectively (Khoa tâm thần 2012; Minh 2011). The hospital receives about 6000 children attending for diagnosis and treatment annually (Vu 2009). At the same time, the Children's Hospital 1 (one of the two biggest pediatric hospitals in Ho Chi Minh City) admitted the first two cases of ASD in 2003 and by 2009 the hospital diagnosed and managed more than 800 cases (CLAN 2010; Pham 2010). Nevertheless, the number of diagnosed cases is believed to represent only a minority of probable cases (Brown 2009; Vu 2009).

There is limited understanding about the condition in Vietnam and no nationally recognized ASD diagnostic process or set of guidelines. Drawing on data that forms part of a larger qualitative study undertaken in Hanoi from July 2011 to May 2012 that sought to understand the social construction of ASD in Vietnam (Ha 2014), this article describes (1) current practices in the assessment and diagnosis of ASD in Hanoi, Vietnam and (2) discusses challenges of accessing accurate diagnosis. This contributes to our understanding of ASD assessment and diagnostic processes in low and middle-income countries (LMIC).

Method

Participants

A total of 27 parents (21 mothers and 6 fathers) participated in in-depth interviews. The parents' ages ranged from 28 to

56 years. Most of the parents were in their 30s and 40s. They were all Kinh, the ethnic majority in Vietnam, accounting for 86% nationwide, and 98.7% in Hanoi (GSO 2010). One parent was Christian, and all the others were either Buddhists or did not declare a religion. Most had university education or higher. Their educational backgrounds were therefore much higher than the general population of Hanoi.

In addition to 27 parents participating in-depth interviews, 125 other parents also completed an online survey. This online survey with parents of children with ASD in Hanoi was carried out over 1 month from mid-August to mid-September 2012 using <https://www.surveymonkey.com> to gather a broader sample of responses to supplement and verify patterns observed through other qualitative research techniques. Table 1 presents demographic characteristics of parents of children with ASD who participated in the in-depth interviews and the online survey.

Seventeen key informants were invited to take part in in-depth interviews. They included: four managers at three intervention centers and one school having special classes for children with disabilities; four professionals participating in assessment, diagnosis and intervention; four educators in special classes for children with disability, and at parent-run schools for children with ASD; three policy makers in different sectors, including health, education and social welfare; one international occupational therapist (OT) who had 1 year experience working on ASD in Vietnam; and one representative of a non-government organization (NGO) working to support families with children with intellectual disabilities. Among them, 5 were men and 12 were women.

The first author conducted observations of diagnostic and assessment procedures at four clinics and early intervention centers: one public pediatric hospital (where most parents in Hanoi take their children for ASD assessment), one university based centre, and two private early intervention centers.

Procedure

Parents of children with ASD participating in in-depth interviews were recruited through various means: most of them were recruited through the 'Hanoi Club' of parents of children with ASD, and some of them through the observations at clinics, and through snowballing techniques. Regarding recruitment for online survey, advertisement of the survey was circulated widely in two websites of parents of children with ASD in Hanoi (tretuky.com and vui-cungcon.com), Facebook and email lists. In addition, leaflets of the survey were printed and distributed at a number of clinics for children with ASD. During 1 month, this survey received a total of 203 responses; however, only 125

Table 1 Background of parents who participated in study

Background information	In-depth interview (<i>N</i> = 27)	Online survey (<i>N</i> = 125)	
	Number (<i>n</i>)	Number (<i>n</i>)	Percentage (%)
Sex			
Male	6	30	24
Female	21	95	76
Religion			
Buddhist or no religion	26	118	94.4
Catholic and others	1	7	5.6
Marital status			
Single	0	2	1.6
Married	26	118	94.4
Separated or divorced	1	4	3.2
Widowed	0	1	0.8
Highest level of education			
Secondary school or lower	0	2	1.6
High school	2	11	8.8
College	3	19	15.2
University or higher	22	93	74.4
Employment			
Full-time	21	101	80.8
Part-time	1	12	9.6
Not working	4	12	9.6
Family income per month (VND) (20,000 VND = 1 USD)			
Less than 3,000,000		9	7.2
3,000,000–5,000,000		35	28.0
6,000,000–10,000,000		36	28.8
11,000,000–20,000,000		27	21.6
More than 20,000,000		12	9.6
Don't want to answer		6	4.8
Number of children having ASD			
1	27	123	98.4
2	0	2	1.6

questionnaires were completed fully and included in the analysis. Seventy eight other questionnaires were excluded for analysis because the respondents either did not finish their questionnaires or missed a significant number of questions.

The observations lasted from 3 to 5 days duration at each clinic or intervention site. Observations at clinics helped authors understand the services available, the procedure of diagnosis, the communications and interactions between service providers and parents and children, and concerns regarding assessment and interventions. In three clinics, with permission from service providers and clinic managers, the first author conducted interviews or group discussions with care-givers. Three in-depth interview with mothers, and three group discussions (with a total of 13 parents,

5 grandparents and one nanny) were carried out in these clinics.

Data Analyses

We used a combination of techniques to analyze data in this study. Quantitative data (online survey with parents) were analyzed using SPSS 16. For textual data, we used qualitative data analytic methods utilizing an interactive thematic analysis approach which involves an iterative process moving between collecting and interpreting data and the identification of comparative themes across the data (Liamputtong and Ezzy 2005). Textual data included in-depth interviews, group and individual meetings, observation notes, and field notes.

All interview audio files were transcribed verbatim. The first author read through three transcripts, conducted open coding, and developed a codebook. These transcripts were translated into English and two co-authors individually conducted open coding. Then the team worked together to compare codes, and revise the codebook. All interview transcripts, observation notes, and field notes then were coded. Besides analyzing data by themes, we also analyzed data by case and tried to interpret how narratives were communicated in certain ways. The NVivo 10 software (QSR 2013) was used for analysis and management qualitative data. Data from online survey with parents were analyzed by SPSS 16 to provide some supplementary descriptive data. Descriptive analysis was conducted to provide data on characteristics of participants. *T*-tests were employed to compare means between groups. Triangulation (multiple sources of information and methods) was emphasized to enhance the rigor of analysis and interpretation process. Findings from this study are presented below thematically, integrating the findings from the various methods.

Ethics

This study was approved by the Human Research Ethics Committees of The University of Queensland and of a local research organization in Hanoi. All participants participated voluntarily and provided written informed consent. All names in this paper are pseudonyms.

Results

This study revealed a number of different themes and findings pertinent to the diagnosis and assessment of ASD. These have been grouped within the following headings: recognition of early signs and referral; diagnostic labels of ASD; length of assessment; assessment procedure; assessment team; communication between professionals and parents; and concerns about over diagnosis. Each of these themes is described below, with direct quotes from transcripts provided as illustrations of each theme. In addition, where appropriate, data from the online survey are presented with the in-depth interview and observation data to supplement these themes.

Recognition and Referral

Awareness of early signs or what are sometimes called ‘red flags’ for ASD is crucial for early identification of children who are at risk with ASD. Parents of children with ASD in Hanoi say that they experience a number of concerns in terms of communication, behavior and socialization of their

children, but *chậm nói* (speech delay/language delay) is the most common concern that causes them to seek assessment. The majority of interviewed parents reported that they sought help when they saw that their child could not speak or could speak only one or two words by the age of two, or three, or when their child used to speak and then lost their speaking ability. Health providers also stated that *chậm nói* is the top reason that parents present their child for assessment.

When my child was two (years old), I found he had some signs that differed to other kids. These differences are he did not babble to call mom and dad, did not ask for toys, and his eyes did not have good attention. He did not respond when I called him. At that time, people said it would be OK, he was just slow. When he was three, I thought he was totally not normal, he could not speak, so I took him to hospital... (Linh, 37 years old, father of 10-year-old boy).

Other concerns noted by parents in this study include children who do not respond to their names, have poor eye contact, prefer to be alone, have tantrums, strange behaviors or have eating or sleeping disorders. However, many of the parents in this study reported that they often overlooked these signs because they did not have knowledge and experience, or they were persuaded by other people that they did not need to worry about these signs. Later on, when they learned more about ASD after their child’s diagnosis, parents recalled that their child already had these issues and they were concerned about these, but did not seek help from professionals.

Almost all participants reported that they brought children directly to assessment clinics when they had developmental concerns without referral from health professionals. This is because there is no routine developmental surveillance for children within the health system in Vietnam. The limited understanding about developmental disorders in general and ASD in particular by health professionals, also prevented referral for ASD screening or diagnosis. Some parents recalled that they took their children to specific pediatricians; however, the pediatrician either did not acknowledge the child’s problem, or acknowledged the parents’ concerns but did not make any referral for further assessment. For example, one mother said:

My daughter had terrible eating and feeding problems. She ate very little and everything needed to be very fine [...] I am still terrified when I think back about her eating problems. I took her to health clinics, and invited a doctor specialized in nutrition to my home several times. They prescribed some medicine, and advised me on nutrition only. [...] I also had a very close relationship with a pediatrician. She took care of

my daughter whenever she had health problems such as fever, coughing. When my daughter was 25 months, I was so worried about her, I read some articles and thought she might have autism, so I talked with the pediatrician, and she told me I had too much imagination (Mai, 37 years old, mother of 10-year-old girl).

Results from the online survey of 125 parents showed that parents began to be concerned about their children from 6 months of age at the earliest to latest time of 6 years and 3 months. On average, parents in this study began to be concerned about their children at the age of 1 year and 11 months. The length of time between when parents are first concerned to when they seek assessment varies. In stories of parents with older children, they often waited from months to 2 years before seeking assessment and diagnosis. Data from the online survey showed that 41% of parents took their children for assessment immediately. The longest waiting time indicated was 2 years. In general, parents waited 3 months from when they started to have concerns to when they sought out specific assessment.

With more information on ASD in the Vietnamese media, and greater awareness about ASD among both parents and service providers, parents are starting to worry about their child and seek assessment earlier. Health provider key informants reported that children are taken to hospital for assessment at younger ages now than they were in the past. Further analysis of the online survey data suggests this is the case. A comparison between groups of children who are 5 years old and younger and groups of children who are older than 5 years old show the younger children are more likely to have triggered concern in their parents earlier, been sent for assessment and diagnosis earlier, as well as have shorter time gaps between being concerned and assessed. The following Table 2 shows comparative results between two groups.

Diagnostic Labels

A number of varying diagnostic labels are given to children with ASD in Hanoi. These include 'Tự kỷ' (Autism), '(có) dấu hiệu tự kỷ'/'có nét tự kỷ' ((has) signs of autism), 'theo dõi tự kỷ' (follow up autism), 'tự kỷ chức năng cao' (high functioning autism), Asperger, and PDD (pervasive developmental disorder). Service providers explained that they give the diagnosis of tự kỷ (autism) for children who meet clinical criteria for childhood autism, and tend to give this diagnostic label to children who are over 3 years old. The diagnosis of 'theo dõi tự kỷ' (follow up autism) and '(có) dấu hiệu tự kỷ'/'có nét tự kỷ' ((has) signs of autism), are given to young children (less than 3 years old), or those who might not meet the full criteria for autism. However, in

Table 2 Comparison of means between two groups of children: 5 years and younger, and older than 5 years old

Group child's age	≤5 y.o	>5 y.o	Total
Dependent variables	(n = 72)	(n = 50)	(n = 122)
Age of child when parent has first concern			
Mean (years)	1.78*	2.1	1.9
Std.Deviation (SD) (years)	0.50	0.84	0.68
Age of child when child was first assessed			
Mean (years)	1.96***	2.47	2.17
SD (years)	0.50	0.80	0.69
Age of child when child was diagnosed ASD			
Mean (years)	2.09***	2.77	2.37
SD (years)	0.49	1.05	0.84
Gap between age of child when parent has first concern, and age of child when assessed			
Mean (years)	0.18**	0.37	0.26
SD (years)	0.26	0.46	0.37
Gap between age of child when assessed and age of child when diagnosed			
Mean (years)	0.13	0.33	0.21
SD (years)	0.29	0.92	0.64

* p value of difference between groups <0.05 ; ** p value <0.01 ; *** p value <0.001

practice, many children under 3 years old are also given the diagnosis of tự kỷ. For example, among 15 children enrolling in an intervention program in the public hospital in the 1st week of January 2012, 12 children who were less than 36 months of age had the diagnosis of tự kỷ. Statistics at clinics count all of these diagnostic labels as tự kỷ.

Tự kỷ (autism), dấu hiệu tự kỷ (signs of autism), and theo dõi tự kỷ (follow up autism) are the most common diagnostic labels given to children with ASD in Hanoi. Data from the online survey with 125 parents showed that only 35% of children received the diagnosis of tự kỷ at first. The two diagnostic labels of dấu hiệu tự kỷ (signs of autism), and theo dõi tự kỷ (follow up autism) were given for 55% of children in Hanoi. Figure 1 demonstrates the distribution of diagnostic labels that children with ASD were given (from parents' responses to questions in the online survey).

Length of Assessment

The length of assessment varied amongst facilities at which observations occurred. At the public hospital, each child was seen by doctors and psychologists for approximately 40 min to 1 h altogether. The time for assessment was longer in some other facilities, ranging from 1 to 2 h. Children were often given a diagnosis immediately after one short assessment. One facility requested children participate in 10 sessions of intervention (fully paid for by parents) before providing a diagnosis. However, they were also

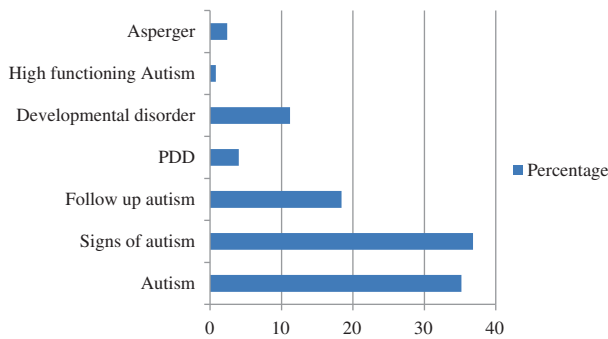


Fig. 1 Diagnostic labels used in Hanoi as reported by parents ($N = 125$)

provided an initial conclusion with diagnostic labels such as *tư kỹ* (autism) being used at the end of the first assessment.

During in-depth interviews, parents and professionals at the public hospital mentioned lack of time as the top reason that they were concerned about inaccurate diagnosis. The public hospital is always overcrowded because it receives children not only from Hanoi, but also from other provinces, and no appointment is required. Doctors reported seeing around 30–40 children per day and psychologists reported seeing an average of 20–30 children per day. Observations undertaken confirmed that doctors often have only 15–20 min to interview a parent and observe the child at the same time. Psychologists had a little bit longer, from 20–30 min. In most cases children do not have enough time to settle and become familiar with the examiners (a task that is typically very difficult for a child with ASD). Some of them cried, objected and were uncooperative with examiners. These behaviors challenged health professionals conducting observations of children. One psychologist reported:

In Vietnam, the diagnosis is not very accurate because of time constraints; we might have 33 patients or more for assessment a day. In my opinion, it is acceptable to have an accuracy rate at approximately 70%. (Binh, Psychologist).

In other facilities, service providers have more assessment time because they have fewer clients. However, parents were concerned about the quality of assessment at private centers due to the capacity of service providers and the lack of government monitoring of service quality.

Assessment Procedure and Instruments

As Filipek et al. (1999) described and other scholars supported, rigorous assessment of ASD includes two levels: level 1—screening (developmental screening, and autism screening); and level 2—diagnosis and evaluation for intervention (NICE 2011; Volkmar et al. 2014). Each level

requires specific instruments and tests. Some examples of various screening instruments at level 1 include: the Denver Developmental Screening Test (DDST—Frankenburg and Dodds 1967), or the Ages and Stages Questionnaires® (ASQ®—Squires et al. 1999) for developmental screening, and Modified Checklist for Autism in Toddlers (M-CHAT™ Robins et al. 2001) for autism screening (Filipek et al. 1999). At level 2, diagnostic instruments recommended include diagnostic parental interviews such as the Gilliam Autism Rating Scale (GARS—Gilliam 1995) and the Autism Diagnostic Interview-Revised (ADI-R—Lord et al. 1994), and diagnostic observation tools, for example, the Childhood Autism Rating Scale (CARS—Schopler et al. 1980, 1988) and the Autism Diagnostic Observation Schedule-Generic (ADOS-G Lord et al. 2000). Once a diagnosis has been made, more comprehensive assessments of speech, language, social and adaptive skills are used to identify target areas for intervention.

In Hanoi, although the DSM-IV and ICD-10 are the primary guidelines used by medical doctors to make a diagnosis of ASD, there are no government or consensus guidelines regarding which assessment procedures and tools should be used. Each facility uses different procedures and assessment instruments, and there is incorrect application of assessment tools for screening and diagnosis.

In the observed public hospital, appropriate tool use was observed with professionals using the DDST (Frankenburg and Dodds 1967) and Bayley Scales of Infant Development (BSID) (Bayley 1993) to identify if children are developmentally delayed, the M-CHAT (Robins et al. 2001) for screening for risk/likelihood of autism, and DSM-IV as a guideline for clinical criteria of diagnosis of ASD. The CARS (Schopler et al. 1988) was used to examine the level of severity of autism. However, in one private early intervention center the M-CHAT (a screening tool) and GARS II (Gilliam 1995) were used for diagnostic purposes. Another private early intervention center reported that they used the M-CHAT, BSID, and were planning to use the GARS II for assessment if the child was already known to have ASD. These assessments would typically be used for screening, developmental assessment and checking the likelihood of ASD rather than for diagnosis or intervention planning.

It was frequently observed that instruments for screening and diagnosis for ASD were combined in one assessment. This questions the validity of test results as well as the clarity of assessment procedure and purposes. One health provider talked about the assessment procedure and use of assessment tests at her hospital:

The doctor will ask parents and observe children first. The doctors use DSM-IV for diagnosis. Then the doctors might refer the child to the test room. For those who the doctors are already sure [of autism] by

DSM-IV, the children will be asked to do a CARS test in order to identify the severity. Denver (DDST) and Bayley (BSID) are also used to test for children with ASD to identify the delay of intellect and psychology. For those who are not sure we use M-CHAT for screening. There are no guidelines from the Ministry of Health. (Binh, psychologist).

There is sometimes misinterpretation of the purpose of test use to support a diagnosis of ASD. Although the M-CHAT™ (Robins et al. 2001) is a screening checklist for ASD rather than a diagnostic test, and the DDST (Frankenburg and Dodds 1967) and Bayley (Bayley 1993) are developmental assessments (screening and comprehensive respectively), these tests are misused in both diagnostic practice and research in Vietnam. For example, one study summarized the prevalence of ASD in one province in Vietnam based on the results of M-CHAT only (Giang et al. 2010b). The first author also witnessed that some children were given an ASD diagnosis by professionals using only developmental screening tests. The following was what a psychologist told the mother of 27-month-old boy after half an hour assessment including parents' interview, brief observation, and administering the DDST:

After asking you and doing the Denver test [with him], [I see], he has lot of problems. He is not delayed only, but has autistic behaviors [the psychologist wrote down in chart 'theo dõi tự kỷ' (follow up autism)].

Licensing is one of the challenges for service providers in Vietnam to use 'gold standard' instruments for ASD diagnosis assessment. Health providers at public hospitals stated that they knew some other recommended assessment instruments such as ADOS (Lord et al. 2000) and ADI-R (Lord et al. 1994); however, their hospital has not yet used these gold standard tests due to lack of licensing and training.

In addition, instruments/tools for assessment of children with ASD have been often translated from foreign language materials and most of them have not yet been fully culturally adapted. According to service providers, the M-CHAT (Robins et al. 2001), CARS (Schopler et al. 1988), GARS II (Gilliam 1995), and other tools have been translated (in full or in part at local clinics) but not validated for Vietnamese children because of resource limitations. Many of these translations have not been undertaken following standard forward/back translation processes, rather they have been locally translated by health professionals on the ground at particular clinics.

In this study, some parents expressed concern that sometimes they did not fully understand the meaning of the questions asked nor did they understand some of the fixed

response options (common in checklists and tool such as CARS and GARS II). They stated that service providers did not provide adequate instructions for them to assist them to respond to these tests. Therefore, sometimes they were not sure if they had answered the questions correctly, and consequently wondered about the validity of these tests.

I think I made some mistakes when I filled in the form, since I could not distinguish clearly between options. I asked the psychologist some unclear questions, and he told me that the test was translated so it might be confusing (Thanh, mother, 38 years old, accountant).

Observations at clinics revealed some potential biases when using tools that had not been adapted appropriately for Vietnamese children. For example, the Vietnamese language has some differences to English. Vietnamese pronouns are extremely complicated since they reflect gender, age and kinship relationships. Many single words in English may be two or more words in Vietnamese, hence items on the tools were ambiguously interpreted. In addition, Vietnamese people tend not to talk to their small children when they are taking care of them, hence questions about communication may not reflect cultural norms and expectations appropriately. Child raising practices also affect the development of children. Vietnamese people value the weight of children; thus, people, especially in urban areas, often try to feed their children as much as they can. In many urban families more than one family member is involved in the process of feeding children: one may feed the child and the other(s) may dance, sing or do something to distract children so they can swallow food. Family members also often do things for children; for example, dressing or putting shoes on for children at ages when Western children are expected to be independent. Hence, developmental assessment tools that are translated but not culturally adapted to reflect cultural norms for Vietnamese children may provide inaccurate results.

Multidisciplinary Team Assessment and Professionals' Capacity

In Hanoi, multidisciplinary teams comprising relevant health and educational professionals (Ozonoff et al. 2005; Wilkinson 2010) are not yet available. Assessment for ASD diagnosis in Hanoi typically involves two professionals, usually a medical doctor and psychologist/s, or psychologist/s and special education specialists. Professionals often conduct assessments separately rather than observe and assess children together. The discussion between professionals during assessment is limited. A doctor explained:

I make the assessment and diagnosis and send the result to the psychologist. We do not form a group and assess (the patient) together. In Vietnam, patients could not wait for a long time, e.g. 6 months, in order to have an assessment. It is wasteful to wait like this; the patients miss time for an intervention. In addition, health facilities at provincial and district levels cannot diagnose (autism), so all patients come here, and this results in us being overloaded (Hương, pediatrician).

According to key informants working within health and education sectors, there is no educational institute in Vietnam providing formal training (with degrees) in occupational therapy and speech therapy, two professions that are frequently involved in multidisciplinary assessment in western countries. One educational institute provides a 3-month training course in occupational therapy, and there are also a couple of short training courses in speech therapy. Psychologists and education specialists are currently the main professionals carrying out developmental assessments.

The capacity of service providers is a concern as it impacts directly on the quality of diagnostic processes in ASD. Very few key health providers in this field have learned about ASD, assessment tools and intervention approaches from overseas study tours, short training courses abroad and foreign materials. ASD has recently been integrated into the medical curricula of a few universities in Hanoi. However, this training provides basic knowledge only. Nevertheless, providers who have had limited training in autism, still provide affirmative conclusion/diagnosis for parents. For example, one psychologist reported that she did not receive adequate training on child development, and had limited knowledge about ASD, but she confidently provided diagnoses such as ‘*theo dõi tật kỷ*’ (follow up autism), or ‘*tật kỷ*’ (autism) during her assessments. A number of service providers also erroneously viewed this condition as a disease or temporary condition, which children could grow out of or could ‘fade away’ with intervention. The lack of comprehensive understanding about ASD as a lifelong condition by service providers may contribute to the tendency to over diagnose ASD.

Communication between Service Providers and Parents

Service providers and parents often had limited communication during assessments. During the observations of assessments at clinics, the first author found that parents were frequently asked a series of leading questions. This raised doubts as to whether parents actually understood the questions asked by the professionals. The lack of clarification and probing for more information did not provide opportunities to really understand the context to seek examples and better know the child and his/her responses. It

was often difficult to see how service providers gained sufficient information to assess the children accurately in such a short time.

Some parents expressed their dissatisfaction with the way service providers asked questions when undertaking a diagnostic interview, observation, and when drawing diagnostic conclusions. For example, one mother said:

I came there and I found that they are overbearing. As you observed at the examination room, the doctor asked questions, but in the leading direction. For example, the doctor asked my daughter if she knows how to brush her teeth, or when my daughter could not finish her song, the doctor said this was a delay. In my understanding, other kids are similar [might not finish the whole song in front of a stranger], but the doctor insisted that they meant she had the disease [autism]. She also imposed other things. I told her but it seems the doctor did not listen to me [...] (Thanh, 38 years old, accountant, mother of 3-year old girl).

In addition, providing parents with a report which summarizes the assessment process, outcomes and the diagnostic formulation is recognized as a best practice in ASD assessment (Keen and Rodger 2012). In the current study, the authors found that service providers often wrote briefly about the history of the child, criteria for the diagnosis, and the diagnosis and treatment into the *sổ y bạ* (child’s medical notebook). Information in the notebooks was not very detailed, and did not have much information on the strengths and difficulties of children (except some criteria for diagnosis). This makes it difficult for evaluating any change at the next assessment either by the same professionals or by other professionals. Health providers also talked with parents about their child’s diagnosis, and some offered suggestions for intervention. However, parents suggested that service providers did not spend sufficient time discussing the diagnosis or encouraging parents to ask questions about the diagnosis and next steps.

Assessment for Other Pediatric Medical Conditions

Children in Hanoi are not often routinely referred for audiological assessment nor medical and neurological evaluation to exclude other genetic and metabolic disorders. In the public hospital where observations took place only some children were sent for audiological evaluation, and some were referred for electroencephalogram (EEG). Most children were assessed and diagnosed after less than an hour of assessment with a pediatrician and / or psychologist only. In one early intervention center, all children were required to do an EEG to identify the presence of epilepsy. The center did not conduct any other medical or

neurological evaluations. A center at one university had its own audiological assessment room. Only a few children are required to undertake this assessment, since this center emphasizes developmental assessment for intervention rather than medical, audiological or other diagnostic assessments.

Concern About Over-Diagnosis

While misdiagnosis was an issue in the late 1990s and early 2000s in Vietnam, over-diagnosis has now become one of the greatest concerns of parents and some professionals. In a workshop on autism entitled ‘Autism disease among children’ organized at the Children’s Hospital I at Ho Chi Minh City in 2008, Huong and Cong (2008) reported on a study of 20 children between two and 7 years old diagnosed with autism at clinics in Hanoi. After follow-up assessment 6 months later and at three different settings using DSM-IV and ICD-10, they found only two of the initial 20 children had long-term and stable symptoms of autism. Six other children were ambiguous ‘cases’ involving autism, mental retardation and ADHD. The remaining children improved and would not be diagnosed as having autism. One foreign occupational therapist working 1 year in Hanoi in an early intervention center for children with ASD expressed her concern:

I think in Vietnam people know autism rather than other developmental disorders, therefore lots of children go away with the label of autism though they may have other development disorders. From my experience, I see many children coming to the center for specific language disorders. There are many types of language disorder, but people doing assessments do not know these disorders. They know about autism, so they use autism as a diagnosis for many children with speech problems only.

Some service providers also explained that they preferred giving an affirmative diagnosis for borderline cases. Firstly, they believed that as service providers, who are more knowledgeable than parents, they are expected to give some ‘diagnostic label’ for children when parents have concerns. Secondly, they think that interventions for children with ASD are good for any children with general developmental delays. Furthermore, the competition between private early intervention centers as well as economic factors (parents pay for all intervention fees at private early interventions) may contribute to the tendency to give affirmative diagnoses of ASD in Hanoi especially if the diagnosis is provided at a private center where ASD interventions take place, ensuring an automatic referral feeding into clinic revenue.

Discussion

Even in high income settings such as the US, Australia, and the UK, the application of best practices for assessing ASD represents a challenge for health services (Goldstein and Ozonoff 2009; Taylor et al. 2016). This study outlines the difficulties in applying the same standards in Vietnam as an LMIC where the health resources, expertise and support services for ASD are still very limited. It raises questions as to the feasibility of the use of these best practice standards in LMIC. This study suggests that in LMIC countries such as Vietnam health service providers are forced to adopt a pragmatic response in order to try to meet the needs of children and parents seeking assessment and diagnosis, even if this may be problematic and result in overdiagnosis or misdiagnosis. In this paper we have detailed the realities faced by service providers and the consequences for children and parents seeking diagnosis and assessment.

There have been some improvements in assessment and diagnosis of ASD in Hanoi, Vietnam over last two decades. Caregivers in Hanoi recognize problems in their children and send them for assessment earlier. More children have been given a diagnosis which helps parents know how to support their children. Finally as described elsewhere (Ha et al. 2014), there are now a number of parent-run and private intervention centers serving children with ASD in Hanoi, although there are too few and they remain accessible to only a minority of wealthier families.

This study has some limitations. It was conducted only in Hanoi, where economic, infrastructural and service conditions are better than most of other areas hence it is limited in its generalizability across Vietnam. We also had difficulty in recruiting men, parents from lower socio-economic backgrounds and parents whose children did not access any services. The qualitative findings may reflect the opinions of those most comfortable to talk to the researcher or those most motivated to participate in the research. Nevertheless, a major contribution of this article is that it provides a detailed exploration of the assessment and diagnosis procedures for ASD in Vietnam. It demonstrates the difficulties in assessment and diagnosis of ASD in a low resource setting. This highlights concerns that many children with ASD in LMIC remain undetected and untreated and may be provided with inaccurate diagnoses (Wallace et al. 2012).

As noted, there is no in routine health and development screening for young infants and children in Vietnam, leading to a lack of early identification of ASD. Our study found that once a problem is suspected by parents, these children are not assessed by a well-qualified team of multi-disciplinary professionals. Consensus or national clinical guidelines for ASD diagnosis and assessment are not yet available. Professionals at different service facilities use different assessment tools and children are assessed and

given a diagnosis in a rushed and perfunctory manner. Assessment tools used from Western countries have not yet been validated and culturally adapted for Vietnam, and sometimes are used inappropriately. The communication between health providers and parents needs to improve in order to respect parents' concerns, explore and provide adequate information and support for the children and their parents.

Providing a quick diagnosis of ASD for children is controversial. On the one hand, it motivates parents and professionals to act earlier for children with ASD. On the other hand, the quick and often inaccurate labeling of children brings potential adverse social and educational consequences for the children. With the ASD label, the children will frequently experience stigma and discrimination (Ha et al. 2014), and are also at risk of having limited opportunities to maximize their capacities. This highlights the need for careful assessment and accurate diagnosis before giving the diagnostic label to children and their families.

This study suggests that greater effort is needed to improve the accessibility and quality of assessment and diagnosis for ASD. Some actions are not expensive, for example, raising public awareness of the signs of autism, innovations to make screening tools widely available for caregivers, integrating screening in health checkups to improve early identification. Researchers, professionals, caregivers of children with ASD and policy makers need to work together to develop alternative procedures and protocols for assessment, taking into account the contexts common to LMIC. The government should develop a clear national diagnostic pathway/process and agreed upon tools to be used. In addition, capacity building for health providers is needed to enhance their knowledge, attitudes and skills in order to take an accurate medical history of a child from caregivers, carry out assessments using standardized instruments, conduct physical assessments, collaborate with professionals from different disciplines and communicate effectively with caregivers. Furthermore, it is necessary to have more research to understand assessment and diagnostic services in other countries with similar social and economic conditions, to validate and culturally adapt tools, and pilot different models to improve the accessibility and quality of screening and diagnostic assessment services.

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Compliance with Ethical Standards

Conflict of interest The authors declare no competing interests.

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