

Characteristics of Agencies Providing Support Services for Children with Autism Spectrum Disorders in Vietnam

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Abstract—As in virtually all countries, in Vietnam there has been a general trend towards apparent increased rates of Autism Spectrum Disorder (ASD). To address the needs of families and children with ASD, many agencies providing support services have been opened throughout Vietnam over the last two decades. Although agencies in general appear to strive to provide good quality service, the actual quality of operations is unknown. The present article collected and analyzed secondary data from 68 agencies across Vietnam from different information sources, using the nine criteria published by Tran, Weiss, and Pham (in press) [1] and Nguyen, Hoang, Nguyen, Pham, and Tran (2017) [2] to evaluate agency quality. Results of this review suggest that a significant number of centers do not have appropriate legal status, are not following basic ethical standards, are using non-evidence based intervention methods, and are unclear in regards to the intervention procedures or intervention plans they use. Although the current study has a number of limitations, it provides important initial information regarding the current status of ASD services in Vietnam.

Index Terms—Agencies, autism spectrum disorders, intervention, services, operating standards treatment, Vietnam

I. INTRODUCTION

Autism Spectrum Disorder (ASD) is believed to be increasing in most if not all countries across the world, including in Vietnam [3], [4]. The estimated ASD rate in Vietnam ranges from 0.5 - 1% [5]. Although this disorder almost always has a major impact on the lives of the individuals and families it affects, in Vietnam it has not been formally accepted as a form of disability in all relevant policy domains; i.e., it is recognized as an official disability within the health-care system but not within the educational or social service systems [2], [6], [7]. Families, especially parents, often struggle to raise and educate their children with ASD. To fulfil this need, numerous centers, classes, schools, and businesses in Vietnam providing evaluation and intervention services for ASD have been opened over the past 20 years [2].

Since services for ASD are relatively new and are not yet controlled by law, regulation and / or government authority, agencies have developed their own operating standards, or lack thereof [2]. For instance, although never directly stating what specific approaches are used, many agencies report using an eclectic approach including both behavioral interventions and special education, although centers also sometimes report use of very specific methods such as

music therapy or speech therapy; all centers claim to “treat” or “intervene” with the child with ASD [8]. The actual operations of the Vietnamese agencies in this field are currently unknown, however.

Although there has not been a comprehensive review of the agencies’ operations and services, there have been several single publications that have reviewed individual centers’ operations [1], [2]. A research review is necessary to obtain an overall picture of the current status, and can serve as a necessary step to conduct empirical study on the operations of the centers. Most importantly, this paper serves as a base for policy makers, providing basic information regarding these agencies, and what are the important policy issues that need to be addressed.

The question the present research seeks to answer is, according to published materials including research papers, conference proceedings, news, and websites, in what manner are the ASD intervention agencies in Vietnam operating? This is the first study in Vietnam on this topic using this method, and will establish fundamentals for more advanced research. It will contribute to practice in Vietnam by providing the field of ASD centers with ideas and directions to develop and improve their services. Parents can be more aware of what type of services they should select or avoid for their children with ASD. Finally, policy makers can use this review as a reference for their policy decisions for families and individuals affected by ASD.

II. LITERATURE REVIEW

A. Services Operations for Families and Children with ASD across the World

This next section reviews literature regarding the services operations and operating standards and guidelines for services for children with ASD across the globe. In general, policy systems for ASD in developed countries are well established [9]-[12]. For instance, in the United States, all 50 states have guidelines for standards of education, training and practice for different types of services and professionals [13]-[15]. These guidelines apply to early assessment and intervention services for children with ASD, as well as to training and practice of specific professionals such as special educators and social workers.

Mauch, Pfefferle, Booker, Pustell, and Levin (2011) published a report on state services for individuals with ASD, looking at services in all states in the United States, assessing policy and system administration, services targeted, care system development issues, standards, and quality. They reviewed innovative programs such as the “new school” model or intervention models for young adult with ASD. In 2013, Massachusetts Department of Public

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Health released guidelines for early intervention operational standards to describe requirements for community early intervention programs that are used as criteria for ongoing monitoring, contract performance review and early intervention program certification. These guidelines are based on core values of: respect, individualization, family-centeredness, community, team collaboration, and life-long learning [14]. The Ohio Department of Education in 2014 released its operating standards for the education of children with disabilities that listed different critical aspects of services, such as maintaining confidentiality, procedural safeguards, evaluations, individualized education program (IEP), and delivery of services [16]. L&M Policy Research (2014) conducted a comprehensive review of all states in the United States describing the type of services provided for families as well as individuals affected by ASD [15].

Other highly developed countries such as Singapore, Australia, Canada, United Kingdom, and others have developed and published clear policy and services guidelines [10], [17], [18]. The Department for Education in United Kingdom (2015), for instance, published guidelines for residential special schools regarding minimum standards. This document contains a statement of national standards to safeguard and promote the welfare of children with ASD receiving services at residential special schools.

In some other parts of the world, especially in developing countries, however, the policy and services for families and children with ASD are very limited [1], [19]. Samadi and McConkey (2011) found that in general families in low-and middle-income countries (LMIC) who have a child with ASD have limited access to professional support services. For example, in a health-care report by UNICEF Cambodia, ASD was not mentioned at all [20]. In Indonesia, there are no specific resources for children with autism, such as special schools or therapy centers provided by the Indonesian government [21]. According to Zheng (2015), with rapid economic development and increasing awareness of the importance of early childhood intervention (ECI), China is re-examining its social and educational practices for young children with disabilities. The current policies and laws related to ECI are rarely implemented in China, however, and ECI faces immense problems and needs improvement for policies and practices in China to better support children, families, and service providers [22].

In developed countries such as the United States, evaluations and diagnosis of ASD are generally conducted in a clear manner with clear procedures [17], [23]. “gold standard” evaluation tools are used, such as the ADOS (Autism Diagnostic Observation Schedule) or ADI-R (Autism Diagnostic Interview-Revised) in combination with other standardized measures including intellectual and adaptive behavior tests [23]-[25]. After evaluation, families are provided with thorough consultations for their children’s problems and solutions [26]. In many developing countries, in contrast, such procedures are not well established. For instance, in a study assessing factors in Africa related to age of first receipt of services for children with ASD, Bakare & Munir (2011) found a number of factors underlying delayed receipt of services, including limited knowledge and awareness about ASD by service providers, inappropriate help-seeking behaviors on the part of the families, and

inadequate healthcare facilities and healthcare personnel with basic knowledge regarding ASD [27].

In most countries, evidence-based practice (EBP) is considered the ultimate standard for all intervention [28], [29], [30]. EBP is considered a relatively “light” but more realistic form of service for supporting families and children with ASD, relative to evidence-base intervention (EBI) [31]. In high income countries, there have been a number of studies assessing the effectiveness of early ASD intervention models constructed on EBP research evidence [32]-[34]. Studies also have examined the competence of practitioners in high income countries to implement these procedures with children with ASD and their family [17], [35].

However, in many settings the EBP principle often is not followed. For instance, a study by Twyman (2015) of classroom teachers in the United States found that the three most frequently used interventions could not be considered EBP for students with ASD. Further, two of these interventions actually had evidence suggesting the treatments were potentially iatrogenic for some students with ASD [36]. A study by Stahmer, Collings, and Palinkas (2005) examined provider self-reports of the use of interventions in community settings. The authors found that providers reported the use of both evidence-based and non-evidence-based techniques, and that they often combined and modified these EBI techniques. Few providers had a clear understanding of evidence-based practice, and all providers reported concerns about adequate training [37].

Various methods can be used to reduce these service provision problems. First, clinicians need to have an adequate level of education and degree which may be, for instance, a Master’s degree in an appropriate major (e.g., psychology; special education) [38]. They should pass an examination for licensing, and be required to attend continuing education to update skills and knowledge [39]. In 2017, the New York State of Department of Health (United States) published a clinical practice guideline to ensure that “early intervention programs provide consistent, high-quality, cost-effective, and appropriate services that result in measurable outcomes for eligible children and their families” [40]. Such clinical practice guidelines are tools to increase the likelihood that children with disabilities receive early intervention services that are consistent with scientific evidence. A guideline for special educators published by Council for Exceptional Children in United States in 2009 suggested that certain issues, such as “preparation of special educators”, “continuing learning and career ladders”, “assuring ethical professional practice”, “assuring quality professional services” were essential to ensure the service quality for children with ASD [41].

B. Services operations for families and children with ASD in Vietnam

Until now, there has been no formal comprehensive review assessing and analyzing secondary data from different ASD agencies in Vietnam. However, there have been a number of research reports exploring individual aspects of ASD assessment and intervention in Vietnam published as journal articles, conference proceedings, and law/policy documents. Although a number of efforts have been made, Vietnam does not have official recognition for ASD as a

disability [1], [2]. The Vietnamese medical system uses ICD-10 (International Classification of Diseases-Tenth Edition) and hence ASD is recognized as a disease and children may receive diagnoses and intervention at hospitals. However, services at hospitals can only serve a limited number of children for a limited time [42]. Services within the education system are essential for children with ASD, but in the Vietnamese education and social security systems there is no official recognition of ASD as a disability [2]. According to studies by Tran et al. (2015), and Vu, Whittaker and Rodger (2017) evaluations for ASD in Vietnam remain limited in their quality, especially at hospitals [8], [43]. For instance, in ASD evaluations, a study by Tran and Vu (2011) found that ASD evaluations were very short (sometimes 10-20 minutes), and lacked careful considerations of different aspects of developmental and family situations as well as post-assessment consultation with the families [44]. Tran et al. (2015) found that there were no official established procedures for evaluations at ASD early intervention agencies. Most recently, a study by Vu et al. (2017) indicated that although there has been some improvement in assessment services, parents still face a number of challenges in accessing quality assessment and diagnosis of ASD in Vietnam, including rushed and perfunctory assessment; a lack of clinical guidelines for assessment; and limited communication among health professionals in assessment teams, and between professionals and parents of children with ASD.

In regards to intervention, there have been a number of research studies in Vietnam examining application of different treatment programs and approaches, such as Applied Behavior Analysis (ABA) [45]; Treatment and Education of Autistic and Communication Related Handicapped Children (TEACCH) [46]; Early Start Denver Model (ESDM) [47], occupational therapy [48]; and music therapy [49]. Studies have examined the effectiveness of intervention programs in Vietnam, such as community intervention [50], inclusive intervention model at preschools [51], social skills training models [52], [53]. However, most intervention studies in Vietnam have been methodologically weak, using case studies or intervention studies without random assignment or a control group. Given these limitations, it is not surprisingly most studies have reported that the interventions were effective; the validity of these results is quite limited, however. Further, some potentially iatrogenic services such as acupuncture, hyperbaric oxygen therapy, and stem-cell therapy are provided at large and prestigious hospitals and governmental agencies.

In Vietnam, at present is no oversight of ASD services. Literally any individual or agency can provide whatever services they want, without any government oversight [1], [2]. To move the ASD service field in a more scientific and socially responsible direction, Tran et al. (in press) and Nguyen *et al.* (2017) proposed a 9-standards guideline for agencies providing services for ASD in Vietnam, presented in Fig. 1.

(1) Legality	• Is the agency formally registered under a governmental organization?
(2) Ethics	• Does the agency report basic ethical guidelines for services, such as not showing children's and parents' faces on social media without permission?
(3) Human resources	• Appropriateness of training and experience of personnel working for the agency.
(4) Intervention approaches	• Does the agency adapt and use EBP guidelines?
(5) Service procedures	• Does the agency have acceptable procedures for intake and evaluation to treatment and referral?
(6) Intervention plan	• Does the agency develop an intervention plan, versus provide services without an explicit plan?
(7) Periodic staff support	• Does the agency hold regular (weekly, monthly and yearly) meetings, trainings, etc. ?
(8) Facilities	• Is the agency's physical environment minimally acceptable?
(9) Recommended standards	• Does the agency promote professional networking, having professional evaluation services, well-equipped facilities, new and extra activities for children?

Fig. 1. 9 standards guideline for agencies providing services for ASD in Vietnam.

Comparing to developed nations where law, policies, and standards for ASD services are clearly stated and established, Vietnam lacks fundamental policy documents and governmental oversight in this area. While EBP are encouraged all over the world, this approach is still not recognized and used as principle for practice in Vietnam [8]. Moreover, research studies in Vietnam tend to be non-programmatic and often low-quality (e.g., involving non-blind assessment). Vietnam needs much more high-quality research in this field. Hence, an overview of agencies in

Vietnam providing ASD services may help clarify the current situation, and identify key questions for research

III. METHODOLOGY

The present study is a part of a larger project that aims to provide data for the establishment of policy for operating standards for ASD services in Vietnam. After establishing initial criteria, these standards were used to describe agencies in Vietnam that provide ASD services. The current

study used secondary data, public information available from research papers, flyers, brochures, websites, etc. To maximize coverage, several different search methods were used including: (1) an Internet search using terms such as “dịch vụ” (service) “cơ sở” (agency/site), “trung tâm” (center), “hoạt động” (operation), “làm việc” (working), “can thiệp” (intervention), “điều trị” (treatment), “hỗ trợ” (support) with “tự kỷ” (autism) or “rối loạn phổ tự kỷ” “autism spectrum disorder”; (2) manual review of multiple print Vietnamese journals (e.g., Journal of Psychology, Journal of Education, Journal of Social Sciences and Humanities), proceedings from conferences on ASD, developmental disorders, inclusive education, and special education; (3) a search of governmental law documents of policy statements in print and online. To increase coverage, authors emailed their network of professionals including university faculty, clinicians, researchers, and agency directors. A total of 106 agencies providing ASD services were identified, with 68 being included in the study, and 38 excluded due to a lack of available information.

After obtaining information regarding the 68 agencies, each agency was rated regarding each of nine guideline categories listed in Figure 1, including (1) Legality; (2) Ethics; (3) Human resources; (4) Intervention approach; (5) Service procedures; (6) Intervention plan; (7) Periodic staff support; (8) Facilities; (9) Recommended. These standards were established by Tran et al. (in press), and Nguyen et al. (2017). Each piece of information was coded into one of four categories (1) Appropriate; (2) Partially appropriate; (3) Inappropriate; (4) No information. “Appropriate” means the agency mentions the information in their materials and fits the criteria; for instance, their legal status. “Partially appropriate” means the criteria is partially met; for instance, in regards to human resources, most staff have adequate academic background and degree, but some may not. “Inappropriate” means the criteria is not met, for instance the agency reports using “coin rubbing” (a non-EBP) to treat ASD. “No information” means the criteria was not mentioned in the materials. Data were coded by a research assistant, with 20% randomly selected to recode for inter-rater reliability, which was 0.83.

IV. FINDINGS

Initial analyses showed that the 68 agencies were from 19 (of 63) provinces that cover the breadth of Vietnam. In general, the agencies were relatively new, with average number of years of operation about seven. The oldest agency opened in 1990 and the most recent 2017, when this study was conducted. Only three research papers regarding about the agencies were found, all of which reported intervention models of the agency. The remainder of information (95.6%) was obtained from agency websites.

TABLE I: BASIC DESCRIPTIONS OF THE 68 AGENCIES

Number of agencies included in research	68
Number of cities/provinces that agencies are located	19
Year starting service (opening)	1990 – 2017 (<i>M</i> =2011; <i>SD</i> =6.9)
Type of information source	
- Research paper	3 (4.4%)

- Conference proceedings	0 (0%)
- Flyers/brochure	0 (0%)
- Website	65 (95.6%)
Type of agency	
- Private company / business	5 (7.4%)
- Center (an agency officially listed under a national Association)	44 (64.7%)
- Hospital	5 (7.4%)
- School (usually kindergarten, elementary schools, officially registered with the government as a “school”)	11 (16.2%)
- Class (a small group of children receiving services, not registered as kindergarten or pre-school)	2 (2.9%)

Most of the agencies (64.7%) described themselves as “centers”, although not all “centers” were formally registered under a governmental organization (a requirement to be officially considered a “Center” in Vietnam). The next most frequent type of agency was schools, 16.2%. Most agencies did not present information for all nine criteria. The average percentage for “No information” was 35%. More than half of agencies had some form of appropriate registration for the legality, for example under the local People’s Committee, Department of Education, or some scientific or professional associations. A small number (5.9%) did not have any legal status. More than half of agencies reported appropriate ethics status, such as respecting families and children, and doing what is best for society, children and families.

TABLE II: SUMMARY OF THE AGENCIES’ CHARACTERISTICS REGARDING THE 9 CRITERIA

Evaluation criteria	Appropriate (%)	Partially appropriate (%)	Inappropriate (%)	No information (%)
1. Legality	55.9	0.0	5.9	38.2
2. Ethics	51.5	0.0	16.2	32.4
3. Human resources	8.8	60.3	17.6	13.2
4. Intervention approach	27.9	29.4	17.6	25.0
5. Intervention procedure	5.9	25.0	19.1	50.0
6. Intervention plan	5.9	4.4	22.1	67.6
7. Periodic activities	4.4	44.1	16.2	35.3
8. Facilities	10.4	40.3	16.4	32.8
9. Recommended	7.4	55.9	16.2	20.6
Percentage mean	19.79	28.82	16.37	35.01

However, 16.2% did show children’s faces and personal information of the child and family without statement of permission, a violation of basic ethical standards. Most agencies had “partially appropriate” staff in terms of education and academic background, although 17.6% hired staff without a minimum bachelor’s degree, or degrees that were not in psychoeducation, or health care. In regards to the intervention approach (where EBP is considered “appropriate”), only 27.9% agencies met this criteria. The rest used a mix of EBP and non-EBP such as acupuncture, hyperbaric oxygen, stem-cell therapy and coin rubbing. Few agencies reported appropriate procedures for intervention, used an intervention plan, periodic activities, facilities and

recommended criteria. About half of agencies had mixed activities, facilities and recommended standards, which means they partially met the standards of organizing activities of the agency, standards of facility or physical environment, and recommended standards.

V. DISCUSSION

This is the first study that has examined the characteristics of ASD services in Vietnam using secondary data. The nine criteria presented in Tran et al. (in press) and Nguyen et al. (2017) have provided a reasonably comprehensive overview of operations of these agencies. Probably the most noteworthy finding is that slightly less than 30% of agencies met full criteria for providing EBP services to their clients. And in fact, this may be a significant over-estimate, for four reasons. First, this assumes that the services that are reported to be provided actually are provided and second, that they are implemented correctly. Third, the agencies reviewed in this study are likely the best agencies among hundreds or even thousands of formal and informal agencies in Vietnam, since they invested in introducing their agencies in different ways (writing papers about the models at their agency, or creating websites, etc.). And fourth, approximately 1/3 of agencies identified had no publically available information, and these agencies likely have less developed standards since they had not bothered to provide public information. Hence, the overall service quality in Vietnam likely is even lower than reported here. Among these agencies, many of them do not indicate essential components of effective services such as having clear procedures, intervention plans and activities to support staff development. Obtaining appropriate physical facilities can be a problem in Vietnam in the major cities such as Hanoi and HCMC, with very dense population and increasing rent fees. Regarding treatments provided by agencies, although most of interventions reported to be used EBP or mixed-EBP methods, there were 17.6% non-EBP methods reported used. There are likely not only are of no value for the child but also waste the time and money of the family, and opportunities for development of the child, and these some of these treatments may be potentially harmful. In addition, the ultimate failure of these treatments may undermine families' confidence in the education and health care systems.

There are several limitations to this study that should be mentioned. First, although we used all available methods for searching for information, as noted above there likely are many agencies that were missed, and these are probably less developed agencies. Second, and most importantly, all data were ultimately from the agencies themselves, rather than objective evaluations. Hence the accuracy of the data is unclear and they may over-estimate the actual quality of agencies, since it might be expected that agencies would try to appear the best in their agency introduction, to attract more clients, etc. Finally, on the other hand, agencies could have standards that were not published on their websites (e.g., ethical guidelines that agency staff are expected to follow but that are not publicized).

VI. CONCLUSION

By reviewing the information presented by agencies providing support services for children with ASD in Vietnam using the nine guideline criteria, this paper has helped to clarify somewhat the publically-presented agency characteristics. Although some positive points were identified, such as most agencies having appropriate legal status and stated minimal ethical guidelines, significant problems were identified. Many agencies have staff without adequate degree and academic backgrounds, and have limited agency activities and facilities. Most importantly, a number of agencies provide non-EBP treatment for children with ASD that potentially could be harmful to the children.

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